



**WEBINAR TRANSCRIPTION:
ETHICS OF HEALTH RESOURCES ALLOCATION
IN THE PUBLICLY FINANCED HEALTH CARE
SYSTEM IN BRAZIL**

Presentation by Dr. Fabio Ferri-de-Barros, November 2015

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ETHICS OF HEALTH RESOURCES ALLOCATION IN THE PUBLICLY FINANCED HEALTH CARE SYSTEM IN BRAZIL

November 30, 2015

Webinar by **Dr. Ferri-De-Barros**, Associate member of the Alberta Children's Hospital Research Institute.

In this webinar **Dr. Ferri-De-Barros** presents us the findings of different studies and his own thesis about priority setting and the overall reach ethics have on the allocation of public resources in Brazil's health care system.

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PRIORITY SETTING FOR HEALTH RESOURCE ALLOCATION IN BRAZIL: A SCOPING REVIEW AND ETHICAL ANALYSIS

INTRODUCTION

(Min 02:25)

I am a surgeon, and that is what I do most of the time. The way I am using the concept of ethics of priority setting is by applying its principles in my clinical practice, as well as in my health services research program. I have been seeing excellent results with that approach, particularly when engaging with different stakeholders who are allocating resources, or who are affected by the allocation of health resources.

Disclosures

- **No financial conflicts of interest**
- **Self funded research**
- **Personal experience as a surgeon in Brazil**
 - **Motivated this research**
 - **Unique perspective for analysis**

DISCLOSURES

(Min 03:20)

I have no conflicts of interests to declare. My lens for the analysis and data collection is that of a surgeon, who worked in Brazil and who faced real world issues of priority setting, which motivated my research. This provided a very unique perspective to my analysis.

Introduction-Rationale

- **Improvement in primary health care (SUS-1988)**
- **Persistent unmet needs and health inequities**
 - The SUS falls short of the intent
 - *(Universality, Integrality and Equity)*
- **Public/Private mix**
- **Fair priority setting: Core health policy challenge in Brazil**

(CONASS, 2009, pg. 51; Paim et al., 2011; Ferri-de-Barros et al., 2012)

(should be provided in an equitable manner). In Brazil there is a public/private mix, which is the mode of financing and delivery health care. Particularly in the setting of the public/private mix, fair priority setting is absolutely critical and is, in my opinion, the main health policy challenge in Brazil at the moment. We establish through supportive forms of the policy and provide a national coordinates approach to an appropriate use of medicines. So Figure 1 is a pictorial representation of the policy and shows the inter connections of the policy. We see that the quality use of medicine and healthy consumers are in the center of the policy and it persists across the policy.

INTRODUCTION-RATIONALE

(Min 03:55)

The publicly financed health care system in Brazil was implemented in the late 80s, the 'Sistema Único de Saúde' (SUS), and since its implementation there have been substantial improvements in primary healthcare. However, the system still falls short of its intent. The three core principles of SUS are universality (health care provided to all), integrality (complete package of service), and equity

Ethics of Priority Setting: Critical in LMIC

- **Scarce resources: Who dies, who lives?**
 - Justice and fairness (Daniels & Sabin, 2008) A4R
- **A4R Leading framework (empirically applied)**
 - Case study in Tanzania (scaling up antiretroviral treatment)
 - Case of "Seguro Popular" Mexico (González-Pier et al., 2006)
 - **Widely accepted by relevant stakeholders**
(WHO, 2006 in Daniels & Sabin, 2008 pg. 202)

ETHICS OF PRIORITY SETTING: CRITICAL IN LMIC ETHICS OF PRIORITY SETTING: CRITICAL IN LMIC

(Min 05:20)

In low and middle income countries (LMIC) ethics of priority setting is very important, because typically scarce or limited resources mean that most of the time decisions for allocating health resources imply choosing who dies or who lives based on the allocation of resources. In the small island 'Ilhabela', where I practiced and where I was inspired to do my work on ethics of resource allocation, I was frequently faced with the decision of either trying to surgically reconstruct a leg of someone who had a car or a motorbike accident, if we had access to health resources such as transferring this patient to a tertiary care center in São Paulo, or whether we could not transfer this patient and an amputation of this leg would be done instead. This was very difficult to deal with on a daily basis. Typically this is what happens in low and middle income countries every day, on the front line where

people are dying or living, getting their legs reconstructed or amputated, just based on the allocation of resources. Therefore, justice and fairness is absolutely critical to make sure that resources are allocated not based on who screams louder or who has more power or influence, but based on a system that accounts for what the health care system has to offer as a whole. Accountability for Reasonableness (A4R) is a leading framework for justice and fairness and for guiding decision making in priority setting. This framework has been broadly applied empirically in diverse case studies in LMIC. It is widely accepted by relevant stakeholders including the WHO, as Daniel & Sabin showed in their publication. All these references are in my thesis work.

Accountability for Reasonableness (A4R)

- 1.Relevance**
- 2.Publicity**
- 3.Appeals**
- 4.Enforcement**
- 5.Empowerment** (Gibson et al, 2005a)

A4R (Daniels & Sabin, 1997)

ACCOUNTABILITY FOR REASONABLENESS (A4R)

(Min 08:18)

The accountability for reasonableness framework has originally four core principles. Decisions should be based on reasons that are relevant, and these reasons should be publicly communicated to all stakeholders involved in, or affected by, these decisions. There should be a mechanism to appeal or to revert decisions based on further reasoning and leadership to ensure that the first three conditions are met. The empowerment condition has been suggested by Jennifer Gibson et al. to be added to A4R as an important fifth condition. It entails that all decision makers should be empowered to participate in a similar manner. I also found this absolutely critical in the decision-making setting in Brazil, and I will get back to that in the next few slides.

Methods

Aim
To synthesize current knowledge about ethics of rationing health care resources in Brazil.

Conceptual Framework
Describe, Evaluate and Improve (Martin & Singer, 2003):

Objectives:

- I. To describe priority setting (scoping review)**
(Arksey & O'Malley, 2005; Levac et al., 2010)
- II. To evaluate priority setting (ethical analysis A4R + E)**
(Daniels & Sabin, 1997; Gibson et al, 2005a; Gibson et al, 2011)
- III. To improve priority setting**
(Recommendations based on I & II)

METHODS

(Min 09:40)

In our research we try to synthesize the current knowledge of ethics of rationing health care resources in Brazil with a scoping review approach. Based on the synthesis we then analyzed the process according to the modified A4R framework.

The main objectives of our work were to: 1) describe priority setting with the scoping review, 2) to evaluate priority setting according to the A4R framework, augmented with

the empowerment condition, and then 3) to provide some recommendations for improving priority setting based on the findings from objective 1 and 2. The conceptual framework of our study was to describe, evaluate and improve the framework, originally described by Martin & Singer in 2003. Douglas Martin was my initial supervisor for this work, and also helped me with my initial thinking process regarding my methods.

METHODS

(OBJECTIVE I)

(Min 11:10)

Scoping studies are a critical step for evidence-informed health policy. For those of you who are familiar with clinical research, scoping studies are to health policy makers what systematic literature reviews are for clinicians. It is not without its limitations and potential gaps, however, for this particular study and topic it was the only reasonable method with the resources and time constraints that I had to complete this research. It is particularly relevant when one is trying to map a very complex topic such as ethics of health resources allocation in the publicly financed system in Brazil, and also very helpful to define research gaps.

Methods (Objective I)

- **Narrative synthesis: Scoping studies**

- **Critical step for evidence-informed health policy making**

- (Lomas, 2005; Mays et al., 2005; Arksey & O'Malley, 2005)

- **Map a complex topic, define research gaps**

- (CIHR, NIHR in Levac et al., 2010)

Validity and Sampling

- **Explicit search strategy**
 - **Two independent reviewers (Native speakers)**
-
- **Documents and Legislations**
 - **Interest groups reports**
 - **Brazilian studies on ethics of resource allocation**
-
- **Thematic analysis performed independently**
 - **Results tabulated**
 - **Themes synthesized by consensus**

(Mays et al., 2005; Levac et al., 2010)

documents and legislation, which were available to us. We relied on interest groups reports of broad stakeholder groups and we searched for all Brazilian studies on ethics of health resource allocation. The thematic analysis was performed independently by the two native speakers, Mauricio and myself. The results were tabulated for further analysis and the themes were synthesized independently initially, and then further by consensus.

VALIDITY AND SAMPLING

(Min 12:12)

In terms of validity, which is one of the main concerns with this method, we had used an explicit search strategy, which is nicely described in the thesis PDF document that you have received. The analysis was done by two independent reviewers who are native speakers of Portuguese. Mauricio B. Ferri helped me quite a bit with the analysis. He himself did similar research on a different topic. We reviewed all the

Data extraction sheet

3 most recent National Health Conferences

Conference	Dates/phases	Central theme	Sub themes
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Brazilian Studies on Ethics of priority setting

Study	Subject	Objectives	Methods	Conclusions
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DATA EXTRACTION SHEET

(Min 13:24)

We had a data extraction sheet, which looked like the one shown on this page. We reviewed the documents from the three most recent National Health Conferences (CNS), which is the main forum for making health policy decisions, and which are held every four years in the publicly financed system in Brazil. We also tabulated the Brazilian studies on ethics of priority setting as shown on the slide.

Results-Objective I (Describe)

- **7 policy documents (Ministry of Health)**
 - National Health Conferences (CNS)
(By laws and reports of 3 most recent CNS)
- **3 Reports (interest groups)**
 - World Bank Report (2007)
 - CONASS report (2009)
 - Lancet Brazil Working Group (2011)
- **11 Studies on Ethics of PS in Brazil**

RESULTS-OBJECTIVE 1 (DESCRIBE)

(Min 14:00)

We found seven core policy documents, that were included for our analysis on the Ministry of Health website. Those were mainly documents from the National Health Conferences. We found the bylaws and the reports of the three most recent National Health Conferences, which were included for analysis. We found only three reports by interest groups: the World Bank report (2007), the CONASS report (2009) and a very substantial review from the Lancet Brazil working group (2011). We also discovered eleven studies on ethics of priority setting (PS) in Brazil.

The National Health Conferences are typically organized by three main levels: the municipal level, the state level and the federal level. They are supposed to include participants from the general public, the health care providers and also from decision makers. This distribution is supposed to be fairly strict. It is actually legislated and should be enforced by legislation, however it is not. I will get back to that in the results section.

National Health Conferences (CNS)

Participants

- 50% members of the **public**
- 25% elected representatives of **health professionals**
- 25% elected representatives of **managers**

Every 4 years, Municipal, State and National levels

Health Policy report sent to the higher level

Health Policies are voted at the federal level

state level report which is sent to the national level. Finally, the health policies are voted at the federal level.

CNS Themes and Sub-themes

Conference	Dates	Central Theme	Sub themes
12 th CNS	Municipal	Health: A legal right and state duty	Right to health
	State	The health that we have and the	Social security
	National	SUS that we want	Participatory management

NATIONAL HEALTH CONFERENCES (CNS)

(Min 16:08)

The National Health Conferences include 50% members of the public, 25% elected representatives of health professionals, and 25% elected representatives of managers. They are held every four years at municipal, state and national level and at every level health policy reports are performed and sent to the higher level. The municipal reports are sent to the state level. Then the state level will provide a

CNS THEMES AND SUB-THEMES

(Min 16:50)

The main themes and sub themes of the conferences are such as shown in the example of the 12th CNS by the municipal, state and national level. The core theme of the CNS was 'Health as a legal right and a state duty and the health that we have and the SUS that we want'.

The sub themes were right to health, social security and participatory management.

Studies on Ethics of priority setting in Brazil

Study	Subject	Objectives	Design	Conclusions
Fortes & Zoboli, 2002	Ethics of resource allocation micro-level	Analyze ethical dilemmas in micro allocation decisions	Individual interviews of 395 random citizens	Deontological and utilitarian values, 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

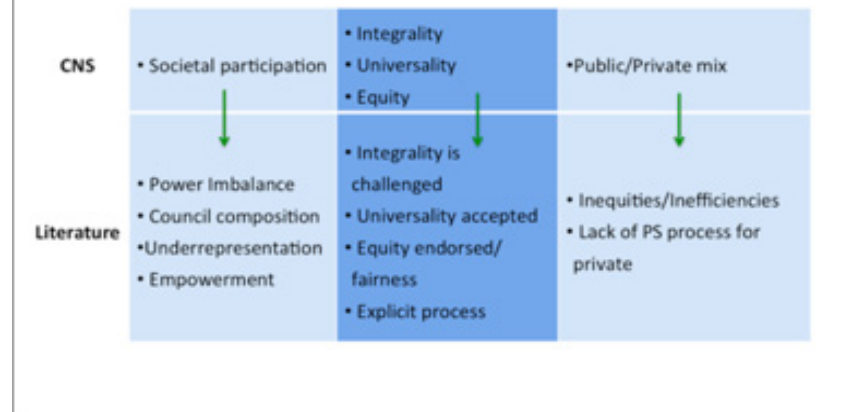
allocation came from Dr. Fortes. Unfortunately, he is no longer working on this topic. He was the vice dean at the School of Public Health at the University of São Paulo. He is also a pediatrician. You will see in the thesis, that most of the literature on this topic in Brazil was produced by Dr. Fortes. There is also interesting papers from Wendhausen (2006), which I will come back to. If I remember correctly, Wendhausen is a nurse from the south of Brazil and she did very interesting work, particularly looking at empowerment.

STUDIES ON ETHICS OF PRIORITY SETTING IN BRAZIL

(Min 17:24)

The slide shows examples of the tabulated results. In the thesis you will find the complete table with all the documents, which were included in the analysis. This is an example of how this data was collected for analysis and of the studies gathered. Most of the literature on ethics of resource

Thematic Analysis



THEMATIC ANALYSIS

(Min 18:42)

When we looked at the thematic analysis we tried to look at the main themes of the documents from the government and the health authorities (Ministry of Health), and then look at the literature for answers to these main topics.

As an example, one of the core themes of the CNS was societal participation. The answers that myself and Mauricio found regarding that theme in the literature, was that there is a market power imbalance. The council composition does not meet the requirements set for it by the legislation that guide the CNS. There is a strong underrepresentation of different stakeholder groups. This is something that was shown in our first publication, which was published in the journal 'Acta Bioethica 2009'. In addition, there is a need for empowerment of participants to make it a fair game. There is a strong imbalance in the decision-making processes.

The other interesting finding was that a recurrent theme in the CNS is the recreation of the principles of integrality, universality and equity. However, the principle of integrality is challenged, and it has been challenged not only in the Brazilian literature on ethics of priority setting but throughout the literature on the topic of priority setting. No healthcare

system on the planet is capable of financing everything to everybody. Clearly the principle of integrality has been challenged throughout the literature.

Generally speaking, the universality principal is widely accepted, as health care should be provided to everybody. The equity principle is also endorsed in the literature, as well as the sub-concept of fairness within equity. The need for an explicit process has also been outlined in the literature.

Another recurrent theme from the CNS was the public/private mix. The literature shows that the public/private mix generates or facilitates inequities and inefficiencies. That is very clear from the literature on ethics of priority setting in Brazil, which is very short unfortunately. I found that in the broad literature of ethics of health resource allocation and the public-private mix, there is no question that this mix creates inequities and inefficiencies. Some health services researchers and experts would argue that the mix also facilitates other things, but as always in healthcare or any allocation decision, there are pros and cons to the public/private mix. It certainly creates equities and efficiencies. The lack of a formal priority setting process for the private system is clearly outlined in the literature.

Marcela is asking whether there is a difference in the views on integrality between the public health professionals and managers. Probably, but I could not find anything in the literature since it is not very robust and only a limited number of papers have been published on this topic. Therefore, this issue has not been formally addressed in the literature at least the last time I reviewed it. I remind you that my systemic review of the literature was done in 2013, two years ago. For this presentation I did only a quick scan of the automatic feed that I receive from the initial review that I did. I did not get any new publications and I think it is fair to assume that there are no significant new publications on the topic. Yet, I believe that there is a difference regarding the views on integrality between the public health professionals and managers because the CNS remain the same since SUS was implemented in the late 80s.

Objective 2-Ethical Analysis Extended A4R

Evaluation Checklist (Gibson et al., 2011)

1.Relevance

2.Publicity

3.Appeals

4.Enforcement

5.Empowerment (Gibson et al, 2005a)

A4R (Daniels & Sabin, 1997)

OBJECTIVE 2 - ETHICAL ANALYSIS EXTENDED A4R

(Min 24:23)

The ethical analysis with the extended A4R framework was done according to the evaluation checklist suggested by Gibson et al in 2011. This reference is also available to you within the PDF document of my thesis. I will go over the main findings step by step.

Objective II-Ethical analysis

Relevance:

Criteria (decision based on reasons?)

- ✓ Voted guidelines (Municipal and State levels)
- ✓ Voted policies (National level) guide allocation decisions

- **Implicit priority setting**

(Fortes, 2008; Ferri-de-Barros et al., 2009)

"To expand oral health coverage" (voted policy)

Outcome: CAD\$ 1,000,000,000 to expanding oral health

To what extent?? Integrity principle

OBJECTIVE II - ETHICAL ANALYSIS

RELEVANCE

(Min 24:53)

Regarding the relevance condition, we looked at the good practices that we observed throughout the process with our analysis. One of the main questions when we go to the checklist is: what are the criteria on how to assess relevance of decision-making? Are the decisions based on reasons? There are guidelines, which are voted at the municipal and

state levels, and the policies are voted at the national level. These voted policies and guidelines are supposed to guide allocation decisions. Therefore there is a criteria, however the priority setting occurs implicitly because even though the decisions are based on the guidelines and policies, the policies are too broad. For example one of the voted policies that I found in one of the documents for analysis disclosed the plan for allocating resources included allocating 1 billion Canadian dollars to expand oral health coverage (I converted this to Canadian dollars because I defended my thesis in Canada, yet if I remember correctly it was 9 billion Brazilian reais (BRL)). If you look at that policy, which was a voted policy, the question is to what extent this expansion was carried out. One has to understand that when you are allocating any kind of resources there is an opportunity cost. For any decision you make to allocation resources to expand one service, some other service will loose. The winners and losers in that game and in that process are not disclosed. We do not know why the government or the Ministry of Health decided to expand oral health coverage, and we do not know why a certain quantity was allocated to oral health coverage and not to pediatric surgery, for example. Is it fair to think, that we will start giving braces to every kid in Brazil, and perhaps provide dental implants for everybody in Brazil, while there are kids who are waiting eight years to get scoliosis surgery and if they do not get the surgery they may die as a

result of it? If that information was disclosed and available to everybody, would everybody agree that allocating money to do dental implants would be more important than allocating money to save patients' lives? That sort of reasoning is not available and is not explicit for discussion. That is why the relevance condition is partially met at best in this process.

Objective II-Ethical analysis

Relevance:

Data (decision based on reasons?)

- ✓ Policy 7, guideline 2 (pg.21) 14th CNS
- ✓ Improve decision making based on data

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".

OBJECTIVE II - ETHICAL ANALYSIS

RELEVANCE

(Min 28:30)

Another question talking about relevance is data: are the decisions based on good data? According to the policy 7 guideline 2 of the 14th CNS document, one of the recommendations was to improve decision-making based on data. The managers agreed that this is needed, that there is a gap and a need to improve capacity for decisions based on data or evidence based health policy making. This was also noted by a study done by the World Bank, led by La Forgia & Couttolenc in 2007. One of their main findings, when they analyzed the publicly financed system in Brazil, was that the planning for allocating health resources is conducted mainly as a formal exercise to comply with the legal requirements, rather than as an instrument to implement policy as a basis for resource allocation. I found that to be very true during my five years of working experience in the north coast of São Paulo, in Ilhabela and São Sebastião. Even though a lot of data was collected, that data, for most cases, just set there and there was nothing really that could be done based on it. Decision typically depended on the local politics and

were rather based on the general principal of priority setting, known as the “squeaky wheel gets the grease”, so whoever screams louder would get the resources for their program. This is a general rule, but it is not true not for every decision, and not across the board. Yet, that appears to be a tendency also in my analysis shown on the further slides. The data shown in my analysis was according to the review going back to the data that I collected. We found one paper from La Forgia & Couttolenc that suggested that there is a lack of decision-making based on data because the quality of the data is fairly poor.

Objective II-Ethical analysis

Publicity

Transparency-Context, aim, scope and criteria

- ✓ Guiding themes communicated to the public
- ✓ Voted guidelines communicated to the public
- ✓ Voted policies communicated to the public

**Reasons for allocation decisions
not communicated to the public**

Decisions justifiable based on integrity principle

OBJECTIVE II - ETHICAL ANALYSIS

PUBLICITY

(Min 31:45)

Looking at the condition of “publicity”, which is another condition of the A4R framework, one of the checklist questions by Gibson addresses the aim, scope and criteria of the transparency context. We found that the guiding themes for all the CNSs are communicated to the public. The guidelines as well as the policies are voted for, however, the main flaw is that the reasons are not communicated to the public. That is the main catch, because any allocation for health recourse allocation in a publicly financed system can be publicly justified just based on the integrality principle. There are over 400 policies and even though this appears to be a very democratic process because it involves participation and the voice of the voting by many different interest groups, there are problems with that. For example one of the recent public policies at the federal level to recruit thousands of foreign trained physicians to Brazil. This was something that was highly criticized by different stakeholders in Brazil, including the National Medical Council. However, this policy and the amount of money spent

on this policy is, generally speaking, just a firewall based on the integrality principle. It is based on one of the policies voted that suggests expanding the family health program. Since it was decided by a vote it makes it legitimate, however, the reasons behind it and the mechanisms and budget for each specific policy, are not disclosed to the public.

Therefore the federal government has room to do whatever it wants with the budget, since their decisions would be justified based on the voted policies in the CNS. This is a major problem and flaw when you look at fairness and legitimacy of the CNS in Brazil.

Objective II-Ethical analysis

Appeals

- ✓ Voting with broad participation
- ✓ "SGEP" perfecting participation
(CONASS, 2009 pg.51)

No formal appeal mechanism

Are allocation decisions aligned with voted policies?

OBJECTIVE II - ETHICAL ANALYSIS

APPEALS

(Min 35:02)

Looking at the appeals condition the good practices includes voting with broad participation. There is broad participation from multiple stakeholder groups and there is a group that is supposed to be in charge of perfecting participation according to the CONASS report 2009. However, there is no formal appeal mechanism described after the policies are voted with a majority. According to Accountability for Reasonableness, if there are new reasons or new rationales for changing allocation decisions, there should be a mechanism to go back and review decisions. For example, if I had a group of stakeholders demonstrate to the Ministry of Health that there are kids dying because they are not getting scoliosis surgery in a fair manner in the publicly financed system in Brazil, and at the same time the government spend 9 billion BRL for oral health, I would argue that it is more reasonable to allocate more funds to save children's lives as opposed to expanding dental health. If all stakeholders involved in that argument could review it and agree that that argument is reasonable, such an allocation decision should

be revised and there should be a mechanism to enforce and implement policy change.

However, we do not even know what the reasons for allocation decisions are and if they are aligned with the voted policies. In terms of meeting the appeals condition of the A4R, for sure the process falls short of meeting this condition.

OBJECTIVE II - ETHICAL ANALYSIS

ENFORCEMENT/ LEADERSHIP

(Min 37:25)

When looking at the enforcement and leadership condition, the interesting things or good practices include the fact that well structured leadership exists, which is very important because the system is ready for change. There is research to be done. Researchers as myself, and people like you who are interested in this topic, could research more about this. This is great since when you look at most publicly financed systems across the globe, very few systems have a well structured leadership and format as Brazil does with the publicly financed system. I do not want to sound too critic about the publicly financed system in Brazil because it has enabled major health changes in Brazil, such as universal vaccination coverage or the family health program, which has been great. However, this analysis for sure shows some criticism. It is about how we can make the system better and how to allocate the resources in a more fair and accountable manner so the health care dollars can be effective in helping

Objective II-Ethical analysis

Enforcement/Leadership

- ✓ Well structured leadership
- ✓ Legislated framework for leadership
- ✓ Improved public participation with SUS

Commitment to ethical practices? (CONASS, 2009, pg.39)

Lack of enforcement of legislated principles

(Wendhausen, 2007; Martins et al.,2008)

more people or at least the process can be a little bit more just and fair. Going back to the analysis, the well-structured leadership is, for sure, a positive side or good practice of this process. The legislated framework for leadership is very important because there is always something to be enforced once the capacity for enforcement is there. There has been improved public participation with the public healthcare system gradually since the very first CNS.

According to the CONASS report of 2009, the only problem is that there is no real commitment to the ethical practices, which only exist in theory. It looks good on paper but it is not necessarily occurring in the real world processes. One of the main problems, which were clearly demonstrated in Wendenhausen's empirical studies, is the lack of enforcement of legislated principals. This is something I noted myself during my initial empirical studies. This project was supposed to be a PHD thesis. I had completed all my PHD course work at the University of Toronto, and when I went to Brazil to complete my empirical data collection, there was a new government and a new group of health managers in the region where I was supposed to collect my empirical data.

Unfortunately, I could not get the health care managers to participate in the data collection. Therefore, I had to convert this into a theoretical and scoping review research. However,

I did some pilot data collection with different municipal health councils and one of the main issues that I have encountered was the lack of enforcement. The Secretary of Health, for example, is much more empowered as other municipal health council members. Most of the municipal health council members would also work in the publicly financed system in the regions. They would feel trapped to voice their opinions as their jobs could be jeopardized if they had divergent opinions as compared to the lead managers in the municipal health council. For sure there is a lack of enforcement of legislated principles not only according to the review but also according to my brief personal experience with the system.

Objective II-Ethical analysis

Empowerment (Gibson et al, 2005a)

- **Power imbalance among diverse categories of voting participants (knowledge, hierarchical bias, authority)**
(Wendhausen, 2006; CONASS, 2009, pg.39)
- **Gap between managers/conferences/councils** (CONASS, 2009 pg.51)
- **Numeric distribution of voting participants does not follow what is prescribed by law** (Wendhausen, 2006)
- **Inequitable voting power in diverse geographic regions**
(Ferri-de-Barros, Howard & Martin, 2009)

OBJECTIVE II - ETHICAL ANALYSIS

EMPOWERMENT

(Min 42:40)

Looking at the empowerment condition suggested by Gibson et al, there is a power imbalance among diverse categories of voting participants based on a lack of knowledge and a hierarchical bias, as I described to you before. For example, participants being threatened and being afraid of losing their jobs if they have different opinions, and also based on authority. This is clearly outlined in Wendenhausen's research and also in the CONASS report 2009. It is also clearly shown in the CONASS report 2009, that there is a gap between managers, conferences, and councils. In addition, the numeric distribution of voting participants does not follow what is prescribed by law. This is also clearly reported in the literature and it is also my personal experience in the region where I worked. According to our publication of 2009, there is an inequitable voting power in different geographic regions. That is very interesting because if you look at the north-east of Brazil, the way the number of participants in the CNSs is according to the number of the population in the different regions of Brazil. However, for example in the north-east of

Brazil most of the population relies on the publicly financed system, whereas in the south-east of Brazil there is a much larger proportion of people who have access to the privately financed health care. However, voting members from the north-east of Brazil would be outnumbered and outvoted by participants from the south-east just because there are more participants from the south east in the CNS. This represents inequitable voting power. The decisions based on voting will always represent a challenge to the concept of equity if you look at regional discrepancies of health indicators in the different regions of Brazil. Obviously the population from the north-east would benefit from expanded health resources.

Good Practices

- **Broad Social Participation (SUS)**
- **Well defined leadership for the CNS**
- **Voting process at all levels, SGEP**
- **Policies approved during the 14th CNS**
 - **Mitigate power imbalances in decision-making**
 - **Improve capacity to generate data**

GOOD PRACTICES

(Min 45:50)

In summary, in terms of good practices, there is broad social participation for the publicly financed system but not for the privately financed system. That is a completely different issue. There is also a well-defined leadership for the CNS. In addition, there is a voting process at all levels (municipal, state and federal level). There have been policies approved during the most recent CNS and these policies are aimed at tackling some of the issues such as mitigating power imbalances in decision-making and improving capacity for evidence based policy making.

Opportunities for Improvement

- **Legislation is not enforced** (Wendhausen, 2006);
- **Poor planning capacity (rationales)?** (La Forgia & Couttolenc, 2007)
- **Rationales are not publicly available. No appeal-Integrity** (Ferri-de-Barros et al., 2009; 2012)
- **Marked power imbalance** (Wendhausen, 2006; CONASS, 2009; Ferri-de-Barros et al., 2009)
- **Lack of public participation in PS for the private** (Ferri-de-Barros et al., 2009; Paim et al., 2011; Ferri-de-Barros et al., 2012).

OPPORTUNITIES FOR IMPROVEMENT

(Min 46:40)

The main opportunities for improvement are enforcement of the legislation, improving planning capacity, meaning that planning of allocating decisions should be based on strong rationales, making rationales publicly available, and making sure that the appeal mechanism is enforced. Another opportunity for improvement is to make sure that the principle of integrality is revised because it is not feasible, and utopic, to say the least, that any publicly financed health care system will be able to provide everything to everybody. The issue of power imbalance we have already talked about. Another main issue is the lack of public participation in priority setting for the privately financed system. This is a huge issue because the influential people, who could drive change and have the power to drive change in allocation decisions for the publicly financed system, typically don't use the publicly financed system. They use the privately financed system and are therefore self excluded from the decision making process in the public system. There is no mechanism for participation in the privately financed system that is enforced or even legislated. The structure that exists for planning and for voting in the publicly financed system does not exist for the privately

financed system, or is in the very early stages of thinking with some stakeholder groups in Brazil, starting to make the argument for building structures for public participation. However, this is far from being robust and from being implemented.


There is for sure a lack of empirical studies about priority setting in Brazil. The literature is very scarce. There are some reviews looking at priority setting in lower and middle income countries and these reviews do not include any core studies of Brazil. I found this lack of studies in my review and this was confirmed by the studies that I quote on the slide.

Discussion

- **First knowledge synthesis on the topic**
- **Lack of empirical studies about PS in Brazil**
 - Youngkong et al. (2009) "Systematic review" PS LMIC
 - Mitton et al. (2009) Scoping review on Public participation

Thesis research:

- **Contributes to the call for action** (Victoria et al., 2011)
- **Fills a gap in the international PS literature**
WHO acknowledge Brazilian CNS model
(The World Health Report, 2008, pg. 110, in CONASS, 2009, pg. 50)



I believe that our research contributes to the call for action by Victoria et al, a paper published by the Lancet group about the publicly financed system in Brazil. For those of you who are interested in the public system in Brazil this is a very good reference for understanding how the system works. More research in ethics of priority setting is likely to improve the process and fairness of health resource allocation in Brazil, if the critical mass of stakeholders is involved and aware of the issues regarding the current model of decision-making.

Our thesis research also fills a gap in the international literature on priority setting because the publicly financed system in Brazil and the CNS model has been acknowledged by the WHO and other stakeholders as a substantial model. It is one of the largest publicly financed health care systems in the world depending on how you account for size or structure. For sure other countries can learn a lot of lessons looking at the Brazilian model.

DISCUSSION

(Min 49:22)

I suppose this is the first knowledge synthesis of ethics of health resource allocation in Brazil. I assume this is why we get the opportunity to talk about this topic to such a knowledgeable group like the IDB.

Limitations

- **Scoping review (Depth/Breadth)**
 - Complex topic
 - Macro level Priority Setting
- **Lack of empirical data (“real world process”)**
 - Qualitative interviews- Portraying (?)
(Kapiriri et al., 2007)
 - Participant observation- Subjective, Sampling (?)
(Wendhausen, 2006)

LIMITATIONS

(Min 52:23)

For sure the findings of our research have limitations. If you look at a scoping review as a method it is very hard to find a balance between depth and breadth, what to collect, what to analyze and to explore.

However, this seems to be a reasonable method especially because we are dealing with a very complex topic and very

limited data to collect. Since there is very limited data, the scoping review method is not too cumbersome when looking at the breadth, because there is not a lot to be included in the review, especially looking at the macro level priority setting, which is the scope of our research.

There is a lack of empirical data, since I could not collect the data as initially planned for my PHD thesis, even though I had the agreement from the municipal health council members from three different health jurisdictions or regions in Brazil to participate in my research. I also led three voluntary mission trips where we provided surgeries free of charge in different regions of Brazil, so I could get their buy-in. I had the empirical research laid out and planned, however the timing was unfortunately poorly executed, which was beyond my control. When the newly elected government took over, the new leadership did not agree to go ahead with my data collection. Having said all that in the disclosures, there are issues as well with the empirical data. The qualitative interviews, which are traditionally the method for collecting empirical data about decision-making, have the limitation of maybe portraying the results.

For example, if I was to interview the managers they would most likely not assume that there is a power imbalance. They would probably state that they are very democratic about

their processes. This is an example of portraying which is for sure a limitation of qualitative interviews.

Participant observation, which is another form of collection empirical data, for example in the Wendhausen study, is limited to the sample size, how you sample and achieve the thematic saturation that you would like to see. There is a little bit of subjectiveness as well to the number of participants.

For sure there are limitations when using the scoping review methods and there are limitations to the empirical data and the different methods of collecting empirical data. In the ideal world and if I had more time I would suggest to people interested in this sort of research in Brazil the next step would be to collect empirical data and to connect it to my findings and update the scoping review that I have performed.

Reflexive Account

- **Improvement of process-improved outcomes**
 - Primary health/social determinants of health
 - Unmet needs of surgical care
 - Greater challenge
- **Health services research (community level)**
 - Elucidate reasons for inequity of outcomes
 - Empowerment
 - Capacity building

REFLEXIVE ACCOUNT

(Min 57:07)

On the reflexive account, which is not necessarily based on the hard data, that is not that hard anyways, but rather the data that I have collected, for sure there have been improvements. The health outcomes and health indicators have improved as well as the social determinants of health with the implementations of basic public health measures such as sanitation, vaccines, preventable diseases, and basic maternal health. However, when we look at needs of surgical care

and hospital based care, which are more expensive commodities in any health care system, these are a particular challenge in a publicly financed system with a tight budget, like the underfunded Brazilian publicly financed system. A lasting improvement would be a very big challenge in this context. The basic public health changes and improvements within the implementation of the publicly financed system are the 'low-hanging fruit'. The complex care, for example, to mitigate the burden of injury in Brazil or in any low and middle income country, for sure requires improvements of the processes in health resource allocation. More health services research is clearly needed at the community level so that different interest groups and managers can elucidate the reasons for inequity of outcomes. How come legs are amputated in a community hospital, which is only two hours away from a tertiary hospital where legs can be reconstructed? How come that operating on a femoral leg fracture of an old lady, which is a very common problem in orthopedics, takes four hours, requires blood transfusion and the mortality rate can be up to 50 percent in a small community hospital, whereas in São Paulo in the right clinic this procedure can be done in 45 minutes with a complication rate of less than 10 percent? These sort of questions need to be studied, answered and addressed by health care managers and by local researchers.

Empowerment is for sure needed. As an orthopedic surgeon I made this argument in the region where I worked and I made managers and other people aware of the limitations and the issues that I have mentioned just looking at the orthopedic and injury problems. However, I had absolutely no empowerment. People would not listen to the arguments because of their own political agendas or different priorities for allocating resources, which were not disclosed to the public. There is a need for capacity building so that that data can be collected and at least taken into account. This is critical and very important as a next step.

Objective III- Recommendations

- 1) Integrity** (Fortes, 2009; 2010b; CONASS, 2009; Ferri-de-Barros et al., 2012)
- 2) Build capacity for planning** (La Forgia & Couttolenc, 2007)
- 3) Empowerment** (Wendhausen, 2006; 2007; Martins et al., 2008)
- 4) Develop explicit rationales/appeals** (Ferri-de-Barros et al., 2009)
- 5) Participation of the private system** (Martins et al., 2008)

OBJECTIVE III - RECOMMENDATIONS

(Min 01:01:26)

The full list of recommendations is available in the PDF document. The brief summary based on our review suggests to: 1) examine the principle of integrality, 2) build capacity for planning, 3) empower different participants so the participation in the process can be leveled (leveling the playing field), 4) develop explicit rationales and appeals mechanisms, so that these mechanisms can be effective because if we do not know the rationales it is very hard to appeal decisions, and 5) there is a strong need to create structure and mechanisms for participation for decision making for the privately financed system.

FUTURE CHALLENGES

(Min 01:02:58)

A future challenge is to translate the knowledge we acquired from this review. When I went back to Brazil to talk to key players and decision makers at the state level, they as well as my professors, told me that this is very interesting research, however, it is very unlikely to be implemented in Brazil in the short term because there is a very strong political barrier to be explicit about resources. Other challenges include to engage stakeholders to accept the recommended changes, and to complete empirical research as I mentioned previously due to the lack of interest from researchers to conduct this type of research, and of interest groups to be the research subjects.

Future Challenges

- Knowledge translation (consultation)
- Stakeholder engagement
- Empirical research

QUESTIONS

(Min 01:04:45)

Regarding the lack of enforcement, and the limitations in planning, is it possible that some decisions are taken lightly or without a clear rationale because there are low expectations regarding fulfillment or implicit priority setting related to barriers of access?

Perhaps. It is very difficult to know because there is an unclear rationale. Therefore, we do not know how the money is spent. There is no information available publicly on how resources are allocated. We do not know how many health care dollars are going to different programs in Brazil. I know for example that there is an issue with financing pediatric orthopedic surgery. There are a lot of children with permanent sequel which could be preventable if they had access to surgical care which is available in Brazil.

There is no lack of professionals to deliver the medical care these children need but there is a lack of funding. If I would like to know from the government if these kids are not getting care because this money is spent elsewhere and because if this money was not spent elsewhere there would be an even greater burden on disease in another area.

The health care managers cannot provide me with the rational saying that your program is under-financed because other programs are more important than your program. Therefore, I am allocating 10 to program A and 1 to program B. We do not know what that proportion is and we do not know the rationale for that mix of allocation of funding. I think that generally speaking, there is a low expectation regarding fulfillment. I believe that every program in Brazil feels that it is underfunded because one of the main issues in the publicly financed system is that it is strongly underfunded. That is a separated discussion, but with the amount of taxes and money that is collected to fund public health in Brazil it is impossible to provide everything to everybody. There are scarce resources. The example that really strikes me as being unreasonable is how can it be that 9 billion BRL are spent on oral care if there are kids dying from trauma, from preventable causes. It does not seem reasonable to me. It is a very complex problem.

How to balance the power imbalance among stakeholders, meaning the health system users?

The main users or people who rely on the publicly financed system are the people who have no voice in Brazil, because they are not educated enough to understand how the system works, how taxes are distributed and how the system is

financed. The people who could actually drive change and participate and have a stronger voice, do not usually care much about the publicly financed system because they have their health care needs met in the privately financed system, including the president of Brazil. If you look at all the high level politicians in Brazil, they all have their health care needs met in the most expensive privately financed hospitals in São Paulo. It will be very hard to make the publicly financed system work if people who can drive change do not depend, or do not rely on that system. It is not a problem in their backyard but in someone else's backyard. The reason why the publicly financed system is great in Canada, in my opinion, is because everybody depends on it. If it was not working well, everybody would suffer. Therefore, people who can drive change actually care about the system. They have a very strong voice to hold managers accountable to their decision to satisfy the different health care needs.

How do priority-setting stakeholders, like CONITEC, interact with the National Health Conference participants and influence decision processes?

I do not know for sure. That was not part of our analysis. However, any influence is based on lobbying, the process and on the number of voting participants. All the decision-making processes based on round table discussions at the different levels (municipal, state and federal levels), include a

voting at the end of the day. In my understanding the louder your interest group is, the stronger its voice is to influence other decision makers or voting members the more likely your ideas and priorities will be taken into account and voted for. If you have a small number of voting representatives, which is the case of the northeastern region of Brazil, it will be less likely that your priorities are voted for as policies. At the end of the CNS there are over four hundred policies voted and approved. The problem is that any decision by any group cannot be justified because the actual decision to allocate a certain amount of dollars to a certain program comes from the Ministry of Health, or from the local decisions makers based on the budget they have.

Something that appears as a recurrent issue in the papers that I have found, and from my personal experience in the north coast of São Paulo, the municipal sector of health decides how to fund orthopedic programs, versus the dengue programs, versus the family health program, according to what they think is more important. There is no explicit reasoning behind their decision-making. For example, nobody knows how the decision is taken whether to increase capacity at the municipal hospitals to deal with trauma, versus expanding capacity at the regional level, so that patients with trauma at the municipal level could be transferred to the regional hospitals. However, from my experience talking

to different decision makers these decisions are based on politics. Depending on who is in the state government and the municipal government and depending on what will bring more votes, a regional or a municipal hospital will be opened. Even if there was a strong argument from an epidemiological point of view, the decision makers would not necessarily take into account the data so that the decisions could be based on that data.

