

# Palliative and Supportive Care in Latin-America

Juan J. Dapuerto



# Disclosure of Interests

Juan José Dapuetto, MD. PhD

- Professor of Medical Psychology. Director of the Clinic Department of Medicine, Hospital de Clínicas. Facultad de Medicina, Universidad de la República
- Co-chair Quality of Life and Palliative Care Committee of the Latin-American Society of Nephrology and Hypertension SLANH.
- Private practice in psychiatry and psychotherapy.
- No conflicts of interest to disclose.



# Questions to be addressed

1. Current state of Palliative care for the cancer and and/or other chronic diseases in your region.
2. Is Palliative care a local and “grass roots” system of care or is it used only in central regional care (tertiary hospitals or health care systems)?
3. Is Palliative widely available?
4. Is cost to the patient a major barrier to Palliative care?
5. Is the Government (either central, regional, local) playing a role in providing or directing Palliative care?
6. Ethnic and religious barriers to Palliative care that are particular to your region.
7. Other barriers to Palliative care that are particular to your region.

# Some facts about the continent

- Population : 581.400.000
- Population growth 2000-2011: 1,1%
- Proportion of urban population: 79.3%
- Life expectancy at birth: 74 years (2010)
- Proportion of older than 65 years: 7%
- Analfabetism: 9 % in males and 10% in females

\* World Bank <http://www.worldbank.org>

\* United Nations Development Program [www.undp.org](http://www.undp.org)

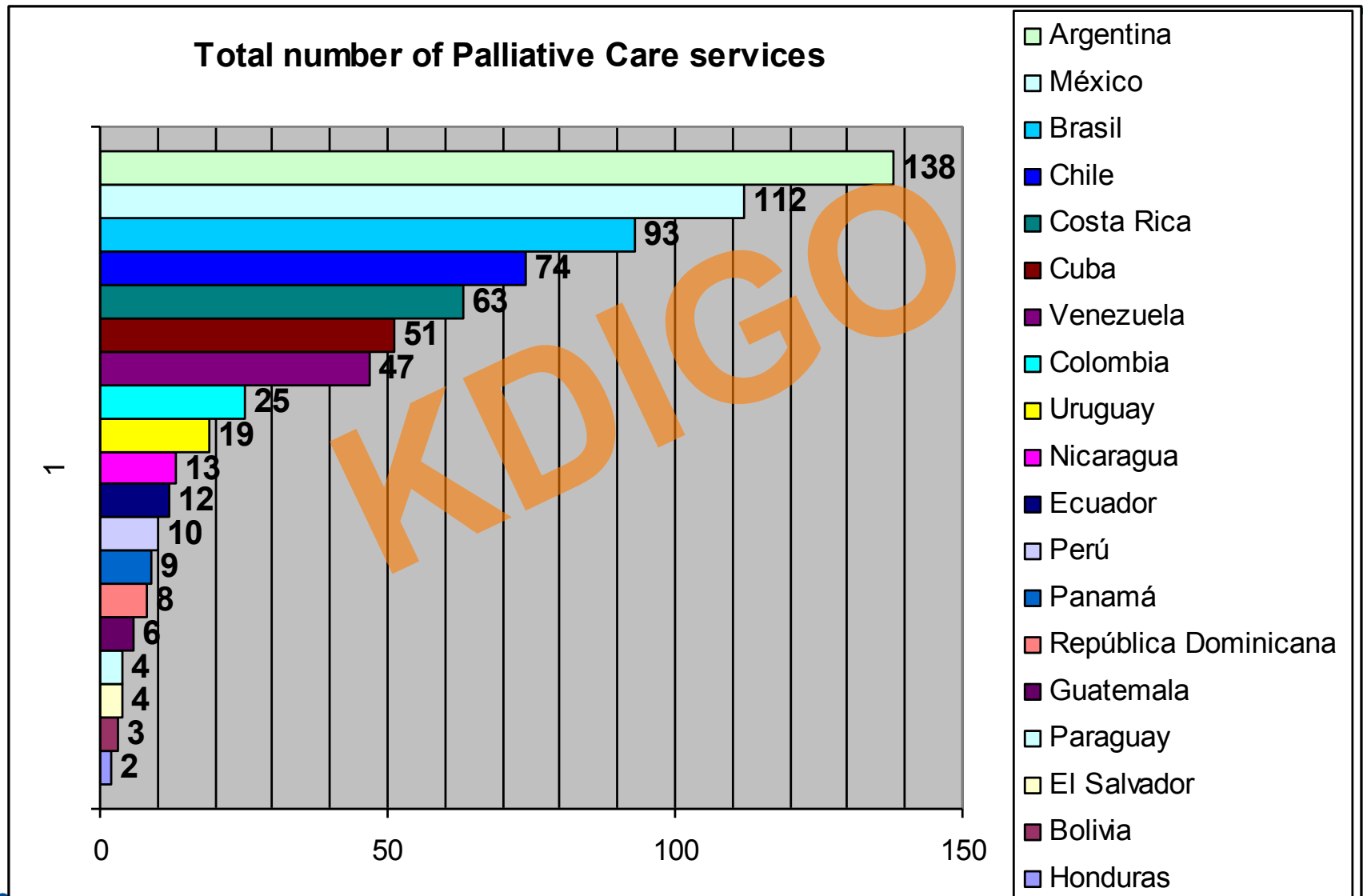


## *Atlas de Cuidados Paliativos en Latinoamérica.*

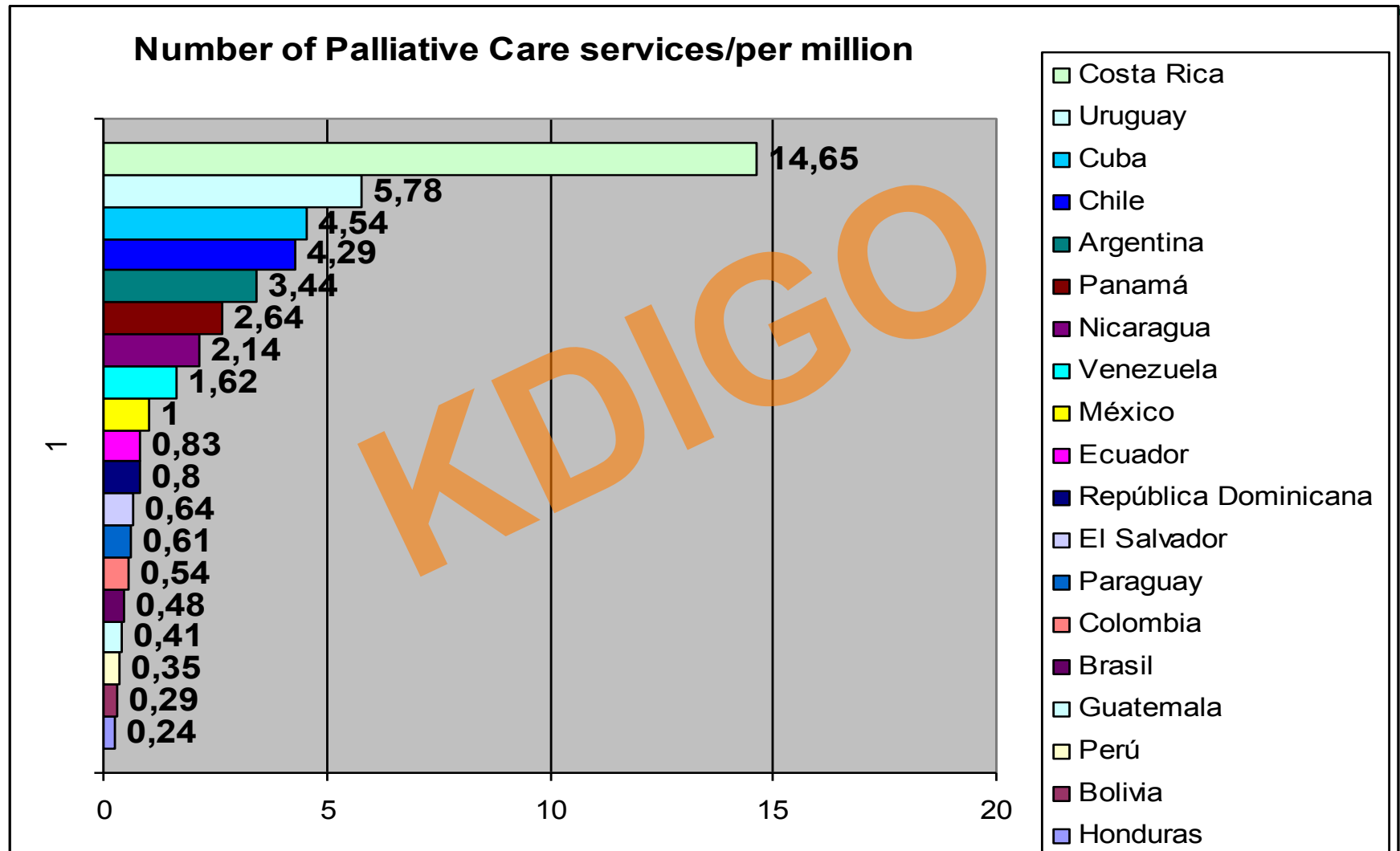
Pastrana T, De Lima L,  
Centeno C, Wenk R,  
Eisenclas J, Monti C,  
Rocafort J, on behalf of the  
Asociación Latinoamericana  
de Cuidados Paliativos  
(ALCP).

Houston, IAHPC Press, 2012.

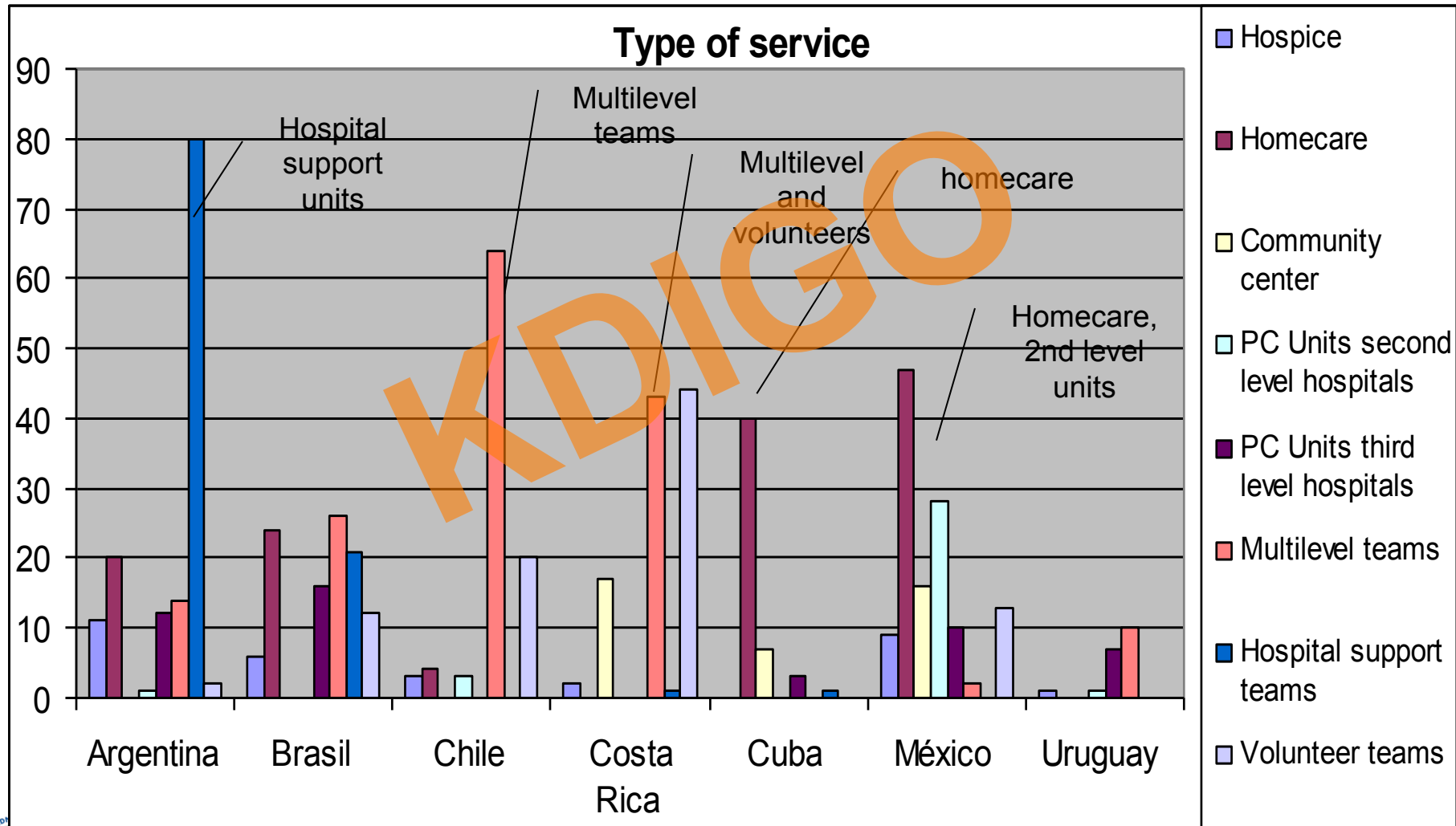
# Current state of Palliative Care for the cancer or other chronic diseases in your region.



# Current state of Palliative Care for the cancer or other chronic diseases in your region (2)



Is palliative care a local & “grass roots” system of care or is it used only in central regional care (tertiary hospitals or health care systems)?





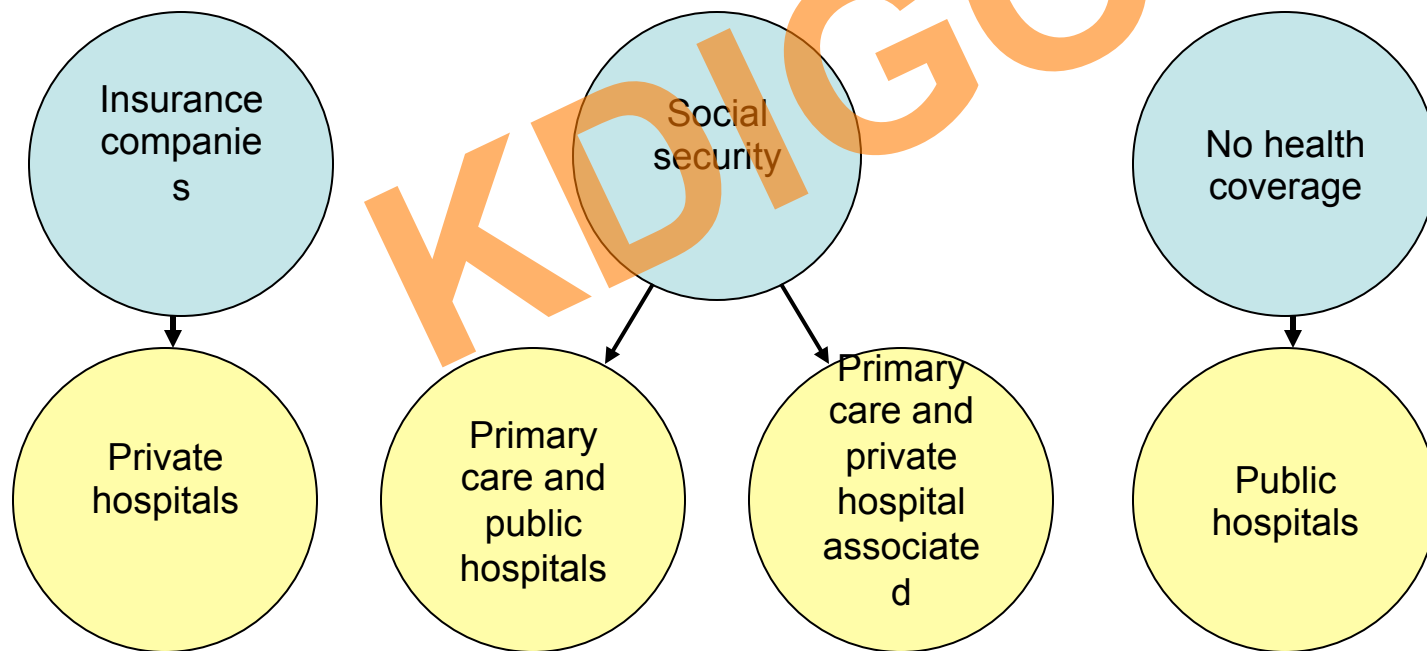
# Is palliative care widely available?

The common rule is diversity and disparity  
(inequality)

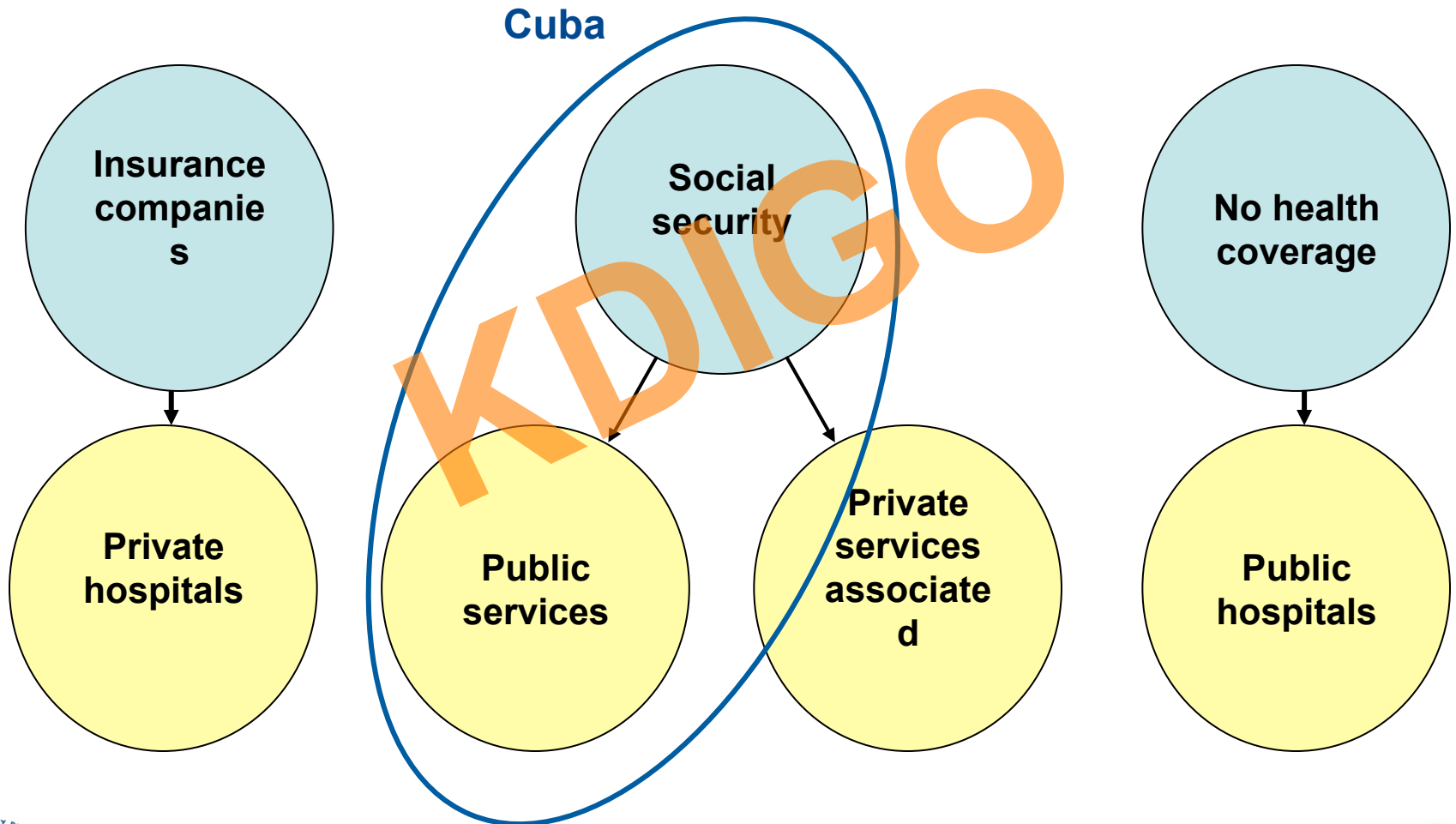
- Costs and type of health coverage
- City vs rural areas
- Isolated regions
- Historical and cultural diversity

# Is cost to the patient a major barrier to palliative care?

- It will greatly depend on the national (or even regional) health system.

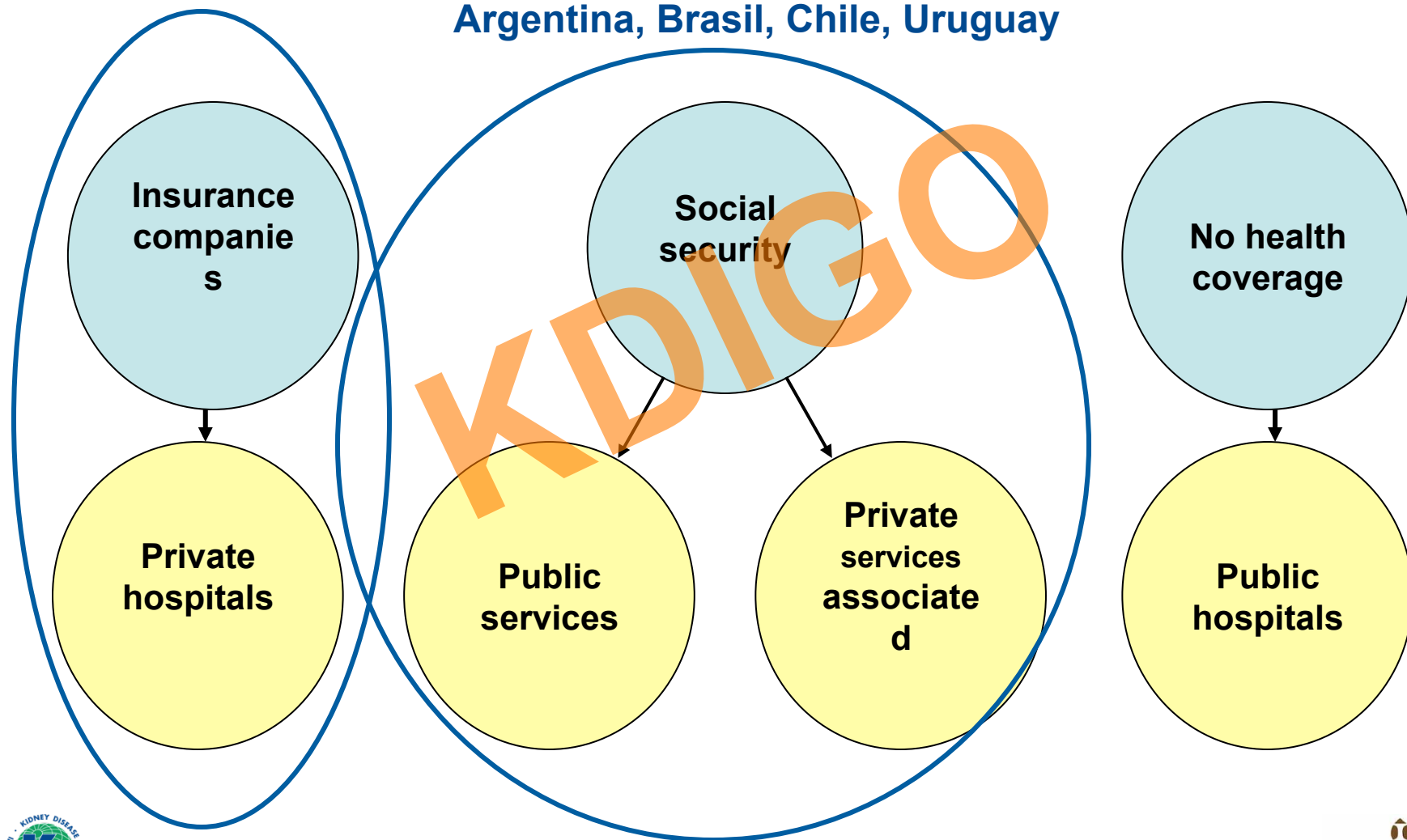


# Examples of health systems and coverage



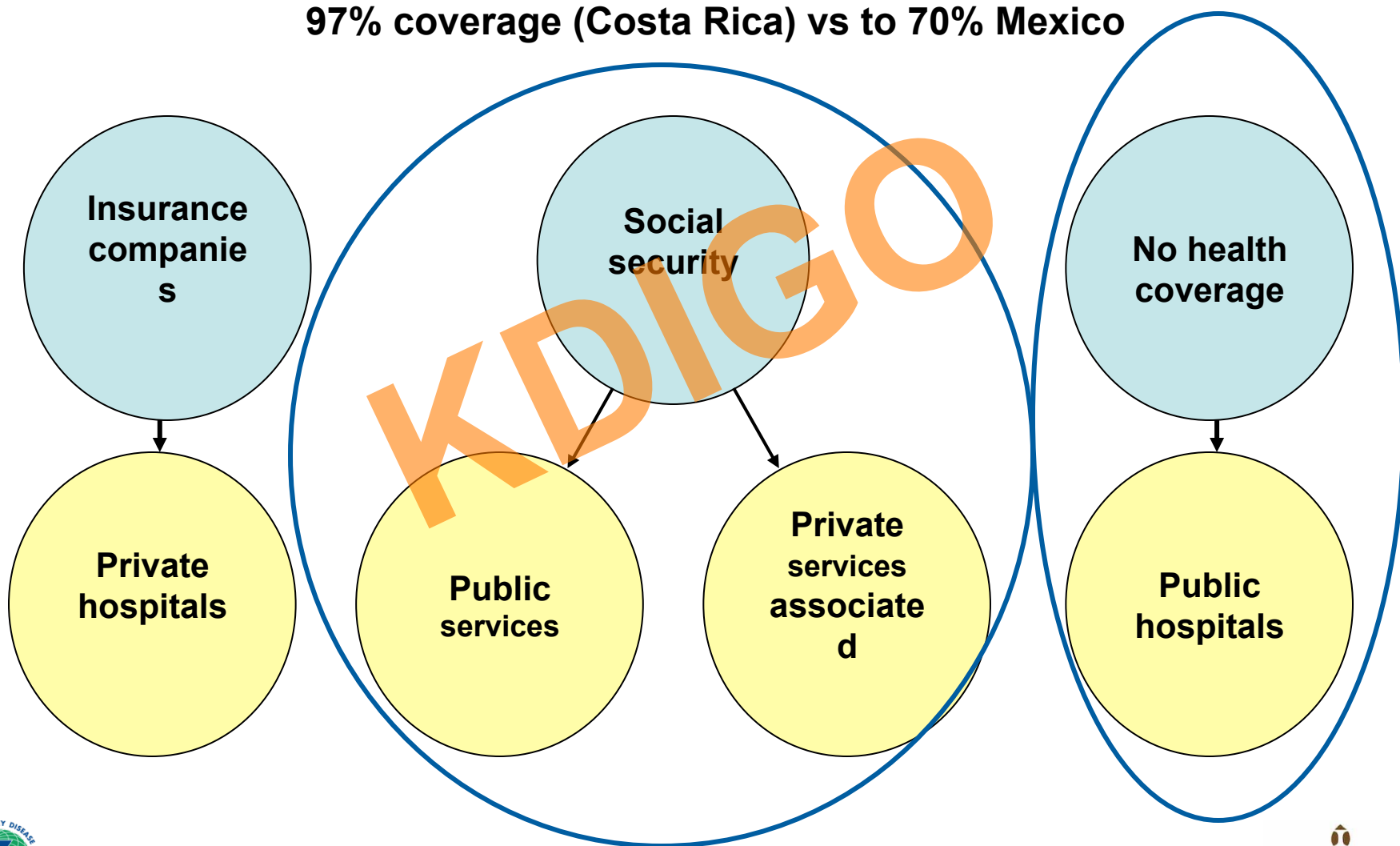
# Examples of health systems and coverage

## Argentina, Brasil, Chile, Uruguay



# Examples of health systems and coverage

97% coverage (Costa Rica) vs to 70% Mexico



## Benefits and Palliative Care services may differ within a same country

- National Health System: Brazil, Colombia, Costa Rica, Cuba, Uruguay, Venezuela
  - Better accesibility, consistency and standardisation of benefits and health services
- National laws, state regulations: Argentina
  - Benefits greatly differ among health providers
- Absence of national laws

# How does the treatment of Palliative care of CKD patients differ from the cancer population?

- Most of palliative care programs arise from the National Cancer Programs
  - Oncologists and mental health professionals
- In some countries patients with chronic conditions other than cancer are not eligible for PC
- Extended programs “ad-hoc”
- Some countries have global access to PC

## Ethnic and religious barriers to Palliative care that are particular to our region.

- There are cultural, ethnic and religious differences across countries that may significantly impact on sensitive issues like doctor- patient communication, family enrollment in treatment, decisions at the end of life, advanced directives, sedation.
- To study the impact of this factors is a relevant issue for future research



## Other barriers to Palliative care that are particular to our region.

- Legislation on opioids and restrictions in the access to pain treatment

KDIGO

# State of the art of the research in Palliative care in Latin America?

- Most of the studies on PC in Latin America describe programs, strategies, advances and limitations
- There is lack of validated instruments to assess specific symptoms, symptom burden, global function and quality of life
- This is even more relevant in the case of pediatric palliative care
- There are only a few clinical trials in PC (5 years)

# Renal Palliative/Supportive Care in Latin America



**Carlos Zuniga**

**Palliative Care Committee  
Latin-American Society of Nephrology  
and Hypertension (SLANH)**



# Disclosure of Interests

## **Carlos Zuniga San Martín, MD, FACP**

- President Chilean Society of Nephrology
- Co-chair Palliative Care Committee of the Latin-American Society of Nephrology and Hypertension (SLANH).
- Member of ISN Latin America Committee.
- Professor of Internal Medicine and Nephrology. School of Medicine. Catholic University of Santísima Concepción.
- **No relevant disclosures.**

# How Does Limited Availability of RRT in Latin America Impact on EoL Care ?

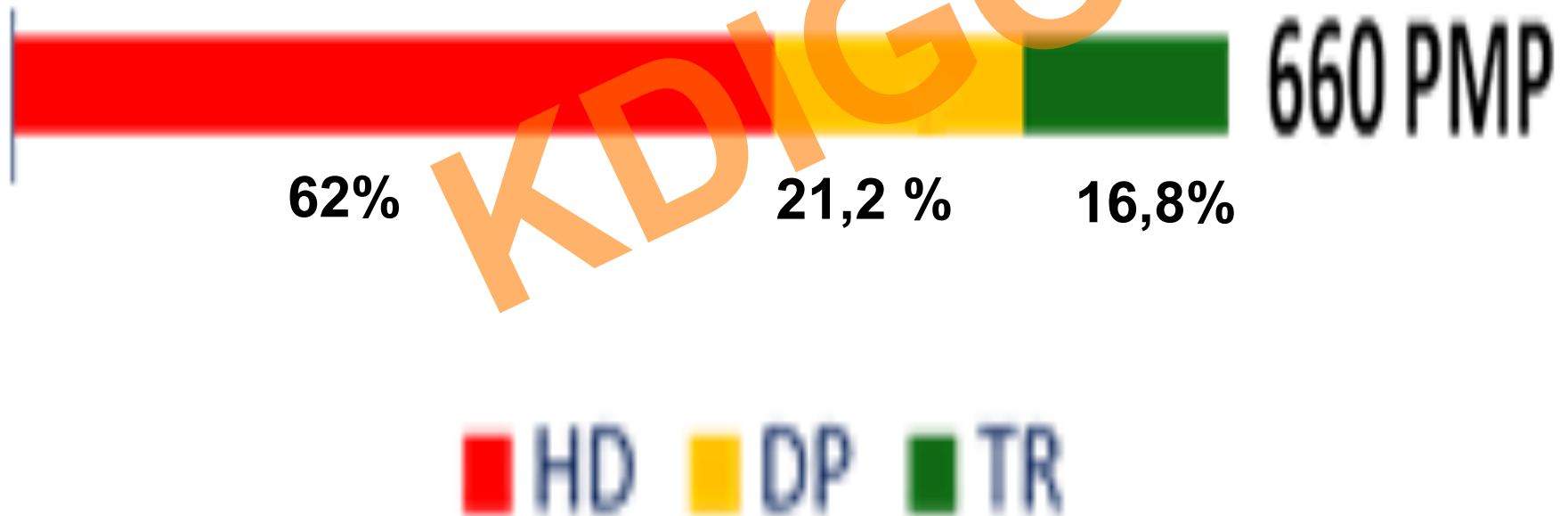
## RENAL REPLACEMENT THERAPY IN LATIN AMERICA



<b>COUNTRY</b>	<b>POPULATION (mill-2010)</b>	<b>GGP-PER CAP- (USD)</b>	<b>Nephrologist/PMP</b>	<b>RRT PREVALENCE PATIENTS/ PMP</b>	<b>PUBLICATIONS PMP-SCI 2012</b>
<b>Nicaragua</b>	5.822	1243	2.9	40	0.34
<b>Honduras</b>	8.046	2226	1.7	191	---
<b>Bolivia</b>	10.426	2421	2.3	148	0.1
<b>Guatemala</b>	15.362	3178	2.2	165	0.07
<b>Paraguay</b>	6.46	3635	5.9	114	0.77
<b>El Salvador</b>	6.194	3702	5.3	529	0.48
<b>Ecuador</b>	14.307	4569	7.4	344	---
<b>R. Dominicana</b>	9.379	5530	9	163	---
<b>Cuba</b>	11.241	6000	31.8	298	1.24
<b>Perú</b>	29.462	6009	10.2	291	0.27
<b>Colombia</b>	46.115	7067	5.8	461	0.41
<b>Panamá</b>	3.406	8590	7.9	410	0.29
<b>Costa Rica</b>	4.564	8676	4.8	315	1.75
<b>México</b>	112.337	10064	5.5	965	1.63
<b>Venezuela</b>	27.15	10810	18.5	452	3.2
<b>Argentina</b>	41.138	10941	33.4	752	7.07
<b>Brasil</b>	190.733	12594	18.4	586	3.95
<b>Uruguay</b>	3.357	13866	53	908	12.21
<b>Chile</b>	17.196	14394	7.7	1091	5.06
<b>Puerto Rico</b>	3.726		26	1270	4.3

# RRT Modalities in Latin America (2010)

LATINOAMERICA



62%

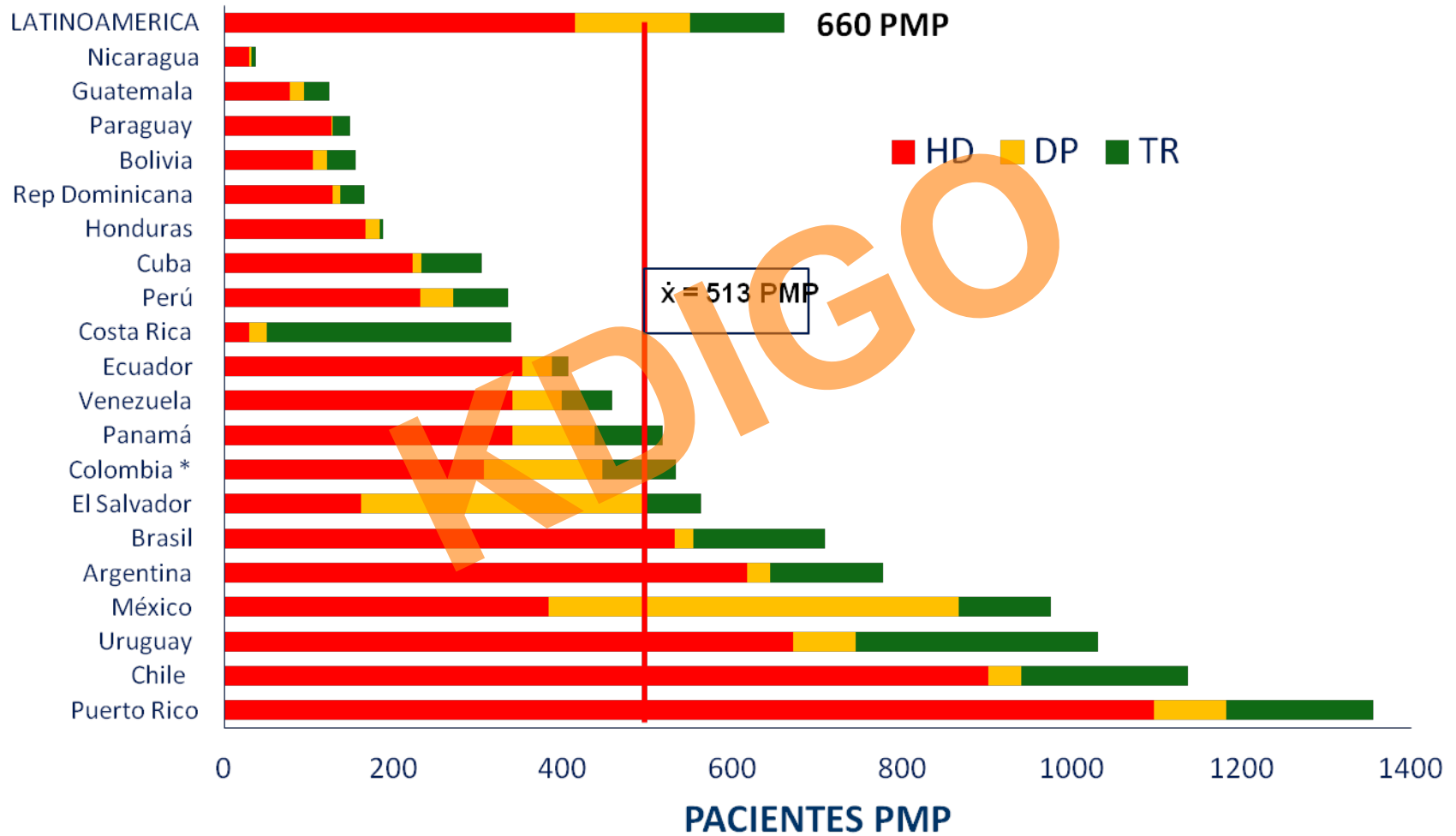
21,2 %

16,8%

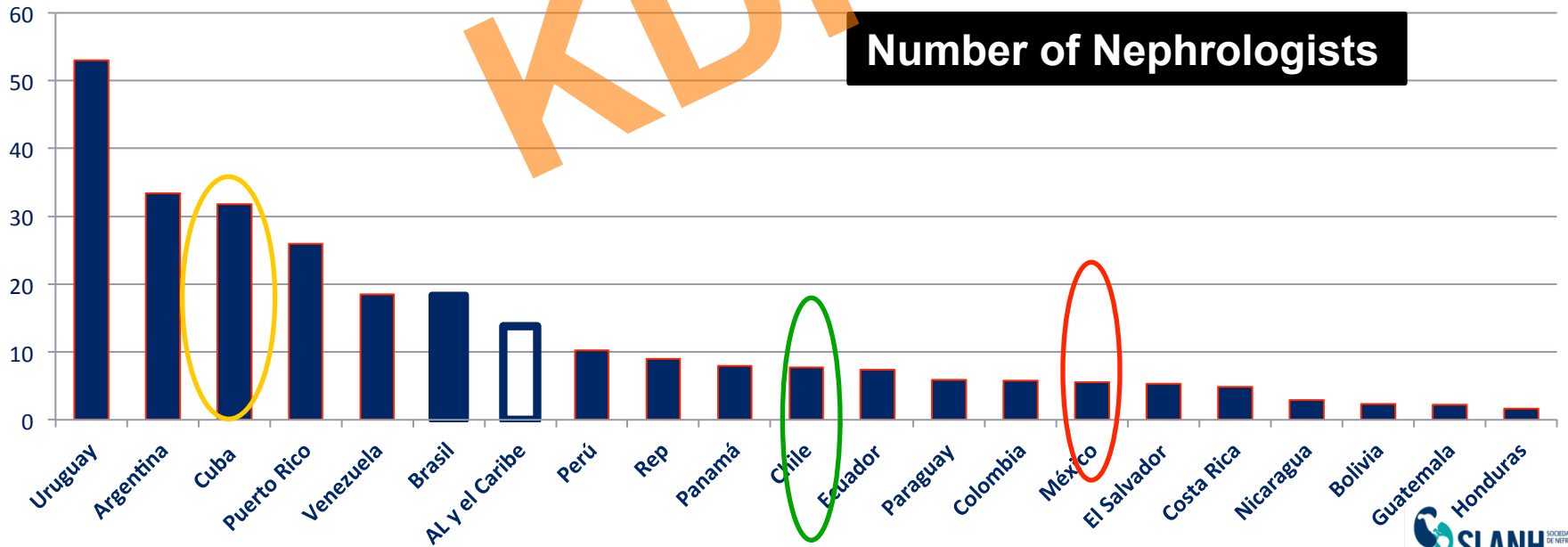
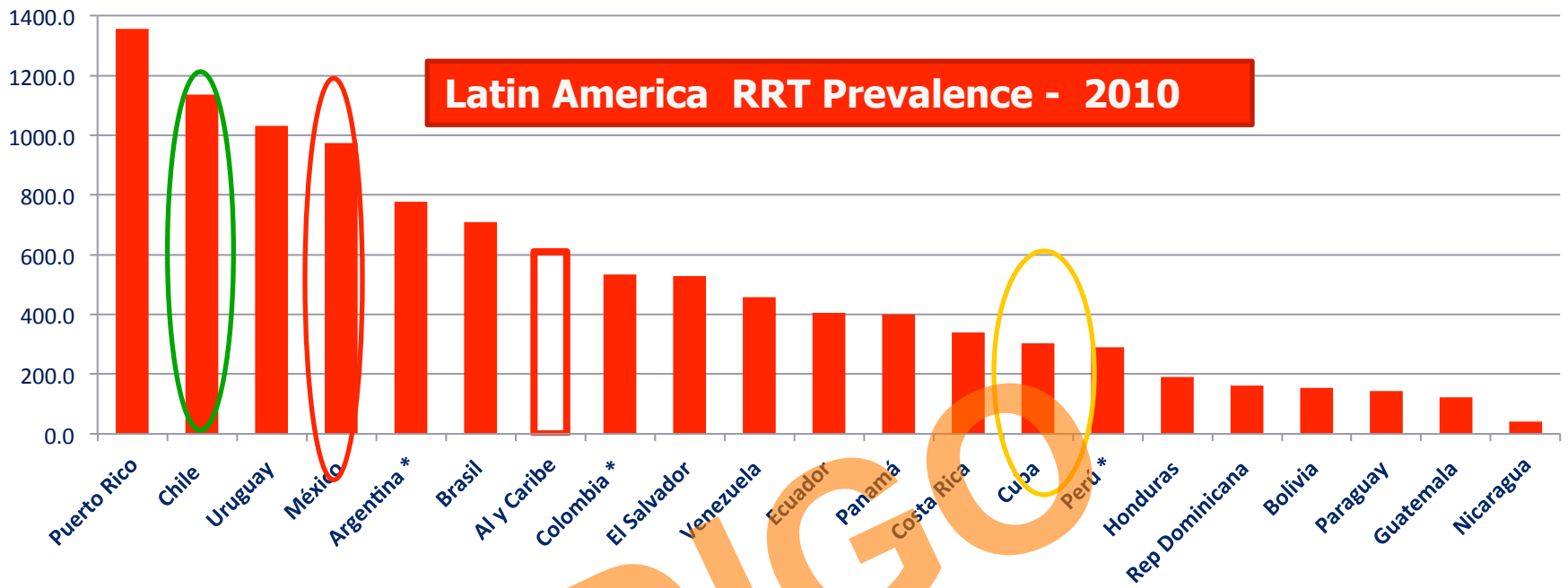
660 PMP

■ HD ■ DP ■ TR

# RRT Modalities in Latin America (2010)







# How Does Treatment with Palliative Care of ESRD Patients Differ from that of Cancer Patients?

- ❖ Palliative care for ESRD patients is not available in many Latin American countries, and is very limited for cancer patients.
- ❖ Although it varies from country to country, a Latin American ESRD patient has a high probability of dying with uremic symptoms while waiting for RRT.
- ❖ Supportive/Palliative care should be an essential form of care for these patients.
- ❖ Supportive/palliative care is an additional option for ESRD patients but it **does not** replace RRT.

# 2013 On-line Survey on the Status of Supportive/Palliative Care in Latin America

**TOTAL COUNTRIES IN SLANH: 20**

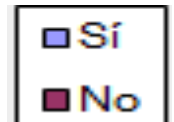
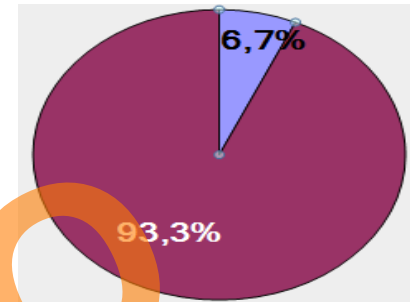
Survey Responders: 15 countries (75%)

No Responders: 4 countries (25%)

# Survey Results

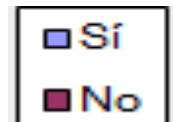
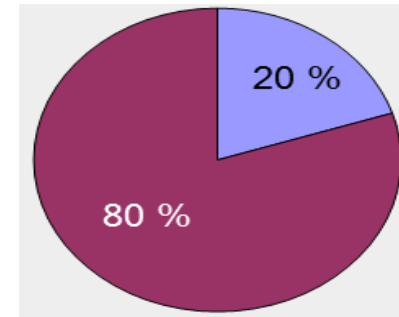
Do you have access to national supportive/ palliative care programs for CKD patients?

Countries : YES 1 NO 14



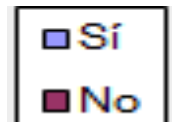
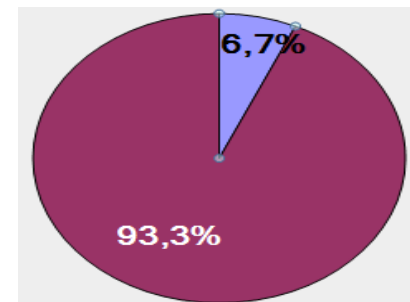
Does your Nephrology Society have a committee or work group dedicated to palliative care, quality of life and ethical issues in clinical practice ?

Countries : YES 3 NO 12



Do you have pain management guidelines for dialysis patients?

Countries : YES 1 NO 14



# Survey Results

Is there a guideline with recommendations to address ethical issues in dialysis patients?	YES	0	NO	15 (100%)
Are there programs available to train medical teams in supportive/palliative care for patients with CKD?.	YES	3 (20%)	NO	12 (80%)
Are nephrology fellows being trained in supportive-palliative care for patients with CKD?.	YES	4 (26,7%)	NO	11 (73,3%)
Is it mandatory for patients to sign an informed consent before starting chronic dialysis ? .	YES	10 (66,7)	NO	5 (33,3%)

KDIGO



# What is the Status of Research on Renal Palliative Care in Latin America?

- ❖ Both quantitative and qualitative research data on renal supportive/palliative care in Latin America are **scarce**
- ❖ There is an urgent need for collaborative studies to generate national and regional data on renal palliative/supportive care.
- ❖ After needs are assessed, interventions to improve the quality of life of patients with CKD/ESRD could be implemented

# What is the Status of Research on Renal Palliative Care in Latin America?

Despite that research is scant, several educational programs have been developed in some Latin American countries

KDIGO

# EDUCATIONAL PROGRAMS

2010

**PRIM R** Curso Latinoamericano de Cuidados Paliativos en Nefrología y Diálisis

5 y 6 de Agosto de 2010  
Santiago - Chile

XVI CONGRESO  
**SLANH**  
Cartagena de Indias 2012

2012

**2º** Curso Latinoamericano de Calidad de Vida y Cuidados Paliativos en Diálisis

**Expositores:**  
 Dr. Juan José Dapuerto (Uruguay)  
 Dr. Matías Najun (Argentina)  
 Dr. Giovanni FM Strippoli (Italia)  
 Dr. Jaime Godoy (Chile)  
 Dr. Andrés Valdivieso (Chile)  
 Dr. Jorge Vega (Chile)  
 Dr. Emilio Röessler (Chile)  
 Dra. Mónica Galanti (Chile)  
 Dr. Aquiles Jara (Chile)  
 Dra. Jacqueline Pefaur (Chile)

**Directores:**  
 Dr. Carlos Zuñiga  
 Dr. Hans Müller

**Organiza:**  
 Sociedad Chilena de Nefrología  
 Comité Cuidados Paliativos

**Patrocinan:**  
 (Logos of various medical and educational organizations)

**Contenidos del curso:**

- Principios básicos de la Medicina Paliativa.
- Evaluación y Tratamiento del dolor en diálisis.
  - Trastornos del sueño y su manejo en la insuficiencia renal crónica.
- Disfunción sexual en pacientes con ERC.
  - Alteración óseo-mineral en la ERC y su impacto en la calidad de vida.
  - Desafíos éticos en Nefrología y diálisis.
- Diagnóstico y tratamiento de la Depresión en diálisis.
  - Terapia nutricional y calidad de vida en diálisis.
    - Comunicación Médico - Paciente en el proceso de morir y el duelo.
  - Calidad de Vida y Cuidados paliativos en Nefrología Pediátrica.
- El valor del Trabajo Interdisciplinario en diálisis.
  - Instrumentos para medir Calidad de vida en Nefrología.
  - Beneficios y limitaciones de la actividad física en pacientes renales.
  - Bases para implementar Programas de Cuidados Paliativos en diálisis.

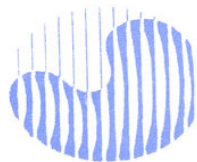
**Información e Inscripciones:**  
 Sociedad Chilena de Nefrología  
 Fono : 56 - 2- 341 34 39  
 schnefro@gmail.com  
 www.nefro.cl

**19 / 20 Julio - 2012**  
**Santiago - Chile**  
 Centro de Eventos • Club Manquehue  
 Av. Vitacura 5841, Comuna de Vitacura

NEPHROLOGY AND DIALYSIS PALLIATIVE CARE SYMPOSIUM APRIL 2012



# Nephrological Societies' Committees on Renal Supportive/Palliative Care



SOCIEDAD CHILENA DE NEFROLOGIA

2004



Sociedad Argentina  
De Nefrología

2009

KDIGO



Sociedad Uruguaya  
de Nefrología

2010



**SLANH** SOCIEDAD LATINOAMERICANA  
DE NEFROLOGÍA E HIPERTENSIÓN  
LATIN AMERICAN SOCIETY OF  
NEPHROLOGY AND HYPERTENSION

2012



# Research Suggestions

- ❖ Assess symptom prevalence in CKD/ESRD patients in different Latin American countries.
- ❖ Promote multicenter collaborative studies to identify priorities for the provision of care and medications (particularly availability of opioids).
- ❖ Enhance international research collaboration to advance knowledge and implementation of CKD/ESRD supportive/palliative care programs in Latin American and other developing countries.

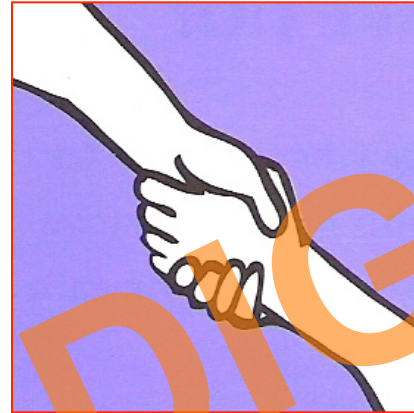
# Other Recommendations

- ❖ Promote initiatives to develop/adapt clinical practice guidelines on renal supportive/palliative care that are sensitive to local needs, culture and legislation
- ❖ Incorporate renal supportive/palliative care into professional training programs
- ❖ Urge governments to integrate palliative care into all levels of the healthcare system and independent of the kind of disease
- ❖ Consider developing a Renal Supportive/Palliative Care Committee in The International Society of Nephrology

# Conclusions

- ❖ ESRD priorities in Latin American countries have focused on providing universal access to RRT
- ❖ There are no reports of governmental programs addressing supportive/palliative care as part of the integral management of CKD/ESRD patients
- ❖ Educational programs on supportive/palliative care for CKD/ESRD patients are increasingly being offered at national or regional scientific meetings
- ❖ Some nephrological societies have renal supportive/palliative care committees

*... Thank you very much...*



***Dr Carlos Zúñiga S.M.**  
Palliative Care Committe.  
Latin America Society of Nephrology  
and Hypertension (SLANH).*

