Palliative and Supportive Care in Latin-America

Juan J. Dapueto
Disclosure of Interests

Juan José Dapueto, 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

Atlas de Cuidados Paliativos en Latinoamérica.


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

Total number of Palliative Care services

- Argentina
- México
- Brasil
- Chile
- Costa Rica
- Cuba
- Venezuela
- Colombia
- Ecuador
- Perú
- Panamá
- República Dominicana
- Guatemala
- Paraguay
- Paraguay
- El Salvador
- Bolivia
- Bolivia
- Honduras
Current state of Palliative Care for the cancer or other chronic diseases in your region (2)

Number of Palliative Care services/per million

Country: Costa Rica

- 14.65

Country: Uruguay

- 5.78

Country: Cuba

- 4.54

Country: Chile

- 4.29

Country: Argentina

- 3.44

Country: Panamá

- 2.64

Country: Nicaragua

- 2.14

Country: Venezuela

- 1.62

Country: México

- 1.00

Country: Ecuador

- 0.83

Country: República Dominicana

- 0.80

Country: El Salvador

- 0.64

Country: Paraguay

- 0.61

Country: Colombia

- 0.54

Country: Brasil

- 0.48

Country: Guatemala

- 0.41

Country: Perú

- 0.35

Country: Bolivia

- 0.29

Country: Honduras

- 0.24
Is palliative care a local & “grass roots” system of care or is it used only in central regional care (tertiary hospitals or healthcare systems)?

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<th>Country</th>
<th>Hospice</th>
<th>Homecare</th>
<th>Community center</th>
<th>PC Units second level hospitals</th>
<th>PC Units third level hospitals</th>
<th>Multilevel teams</th>
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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.

- Insurance companies
- Social security
- No health coverage

- Private hospitals
- Primary care and public hospitals
- Primary care and private hospital associated
- Public hospitals
Examples of health systems and coverage

- **Insurance companies**
  - Private hospitals
- **Social security**
  - Public services
  - Private services associated
- **No health coverage**
  - Public hospitals

*Cuba*
Examples of health systems and coverage

Argentina, Brasil, Chile, Uruguay

- Insurance companies
  - Private hospitals
  - Public services
- Social security
- Private services associated
- No health coverage
  - Public hospitals
Examples of health systems and coverage

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

- Insurance companies
- Social security
- Private services associated
- Public services
- Private hospitals
- Public hospitals
- No health coverage
Benefits and Palliative Care services may differ within a same country

- National Health System: Brazil, Colombia, Costa Rica, Cuba, Uruguay, Venezuela
  - Better accessibility, 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 these 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
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 a 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 Santisima Concepción.

- No relevant disclosures.
How Does Limited Availability of RRT in Latin America Impact on EoL Care?

RENAL REPLACEMENT THERAPY IN LATIN AMERICA
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RRT Modalities in Latin America (2010)

62% HD
21.2% DP
16.8% TR

660 PMP
RRT Modalities in Latin America (2010)

LATINOAMERICA
Nicaragua
Guatemala
Paraguay
Bolivia
Rep Dominicana
Honduras
Cuba
Perú
Costa Rica
Ecuador
Venezuela
Panamá
Colombia *
El Salvador
Brasil
Argentina
México
Uruguay
Chile
Puerto Rico

PACIENTES PMP

HD
DP
TR

660 PMP

x = 513 PMP

Supportive Care Controversies Conference | December 6-8, 2013 | Mexico City, Mexico
Latin America RRT Prevalence - 2010

Number of Nephrologists

[Graph showing the number of nephrologists in various Latin American countries as of 2010, with highlighted countries in green and orange.]
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.
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%)
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.
Curso Latinoamericano de Cuidados Paliativos en Nefrología y Diálisis

2010

2012

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.
- Disturbios sexual en pacientes con EBC.
- 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:
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Fono : 56 - 2- 341 34 39
schnfro@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

Sociedad Uruguaya de Nefrología

2010

SLANH

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.
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 Committee.
Latin America Society of Nephrology and Hypertension (SLANH).