Renal Palliative/Supportive Care in Developing Countries

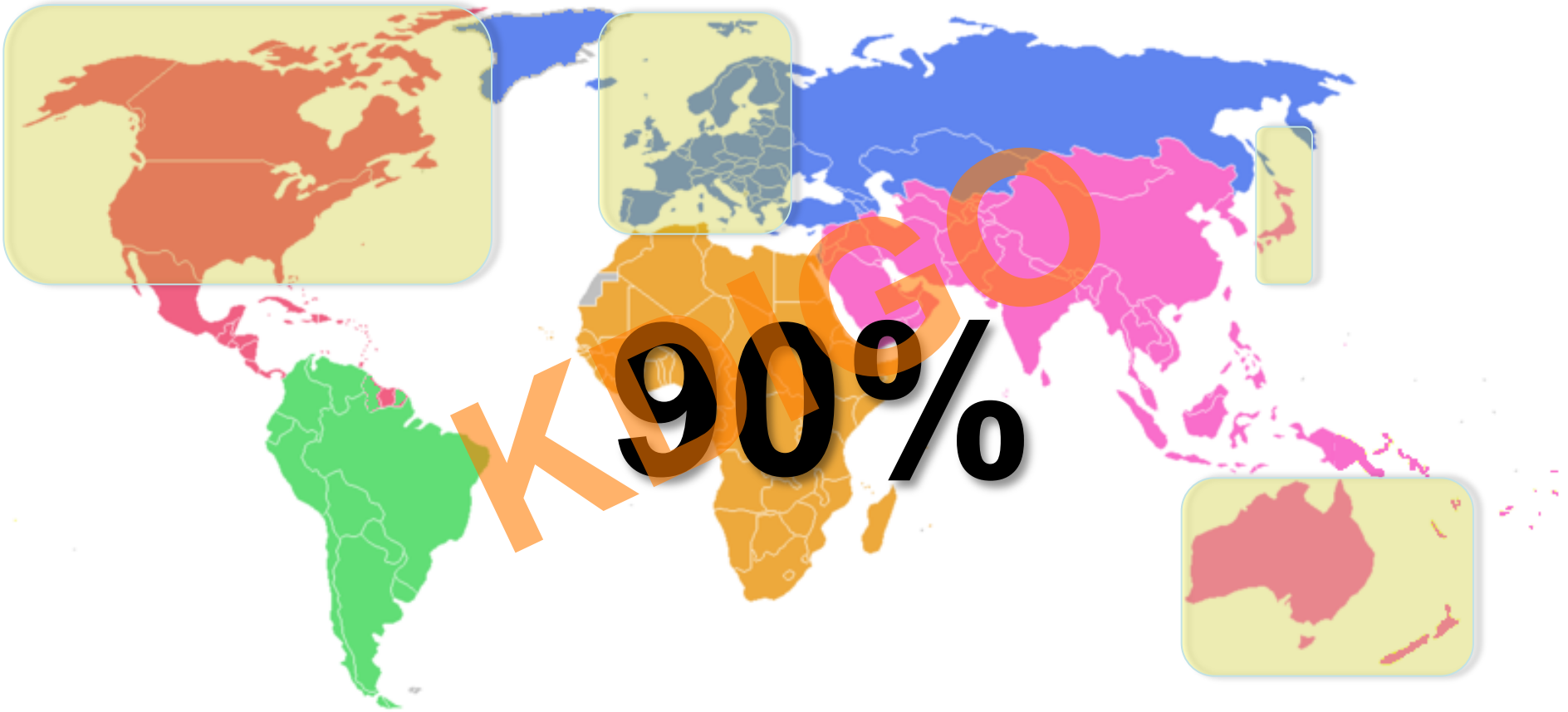
–

India Perspective

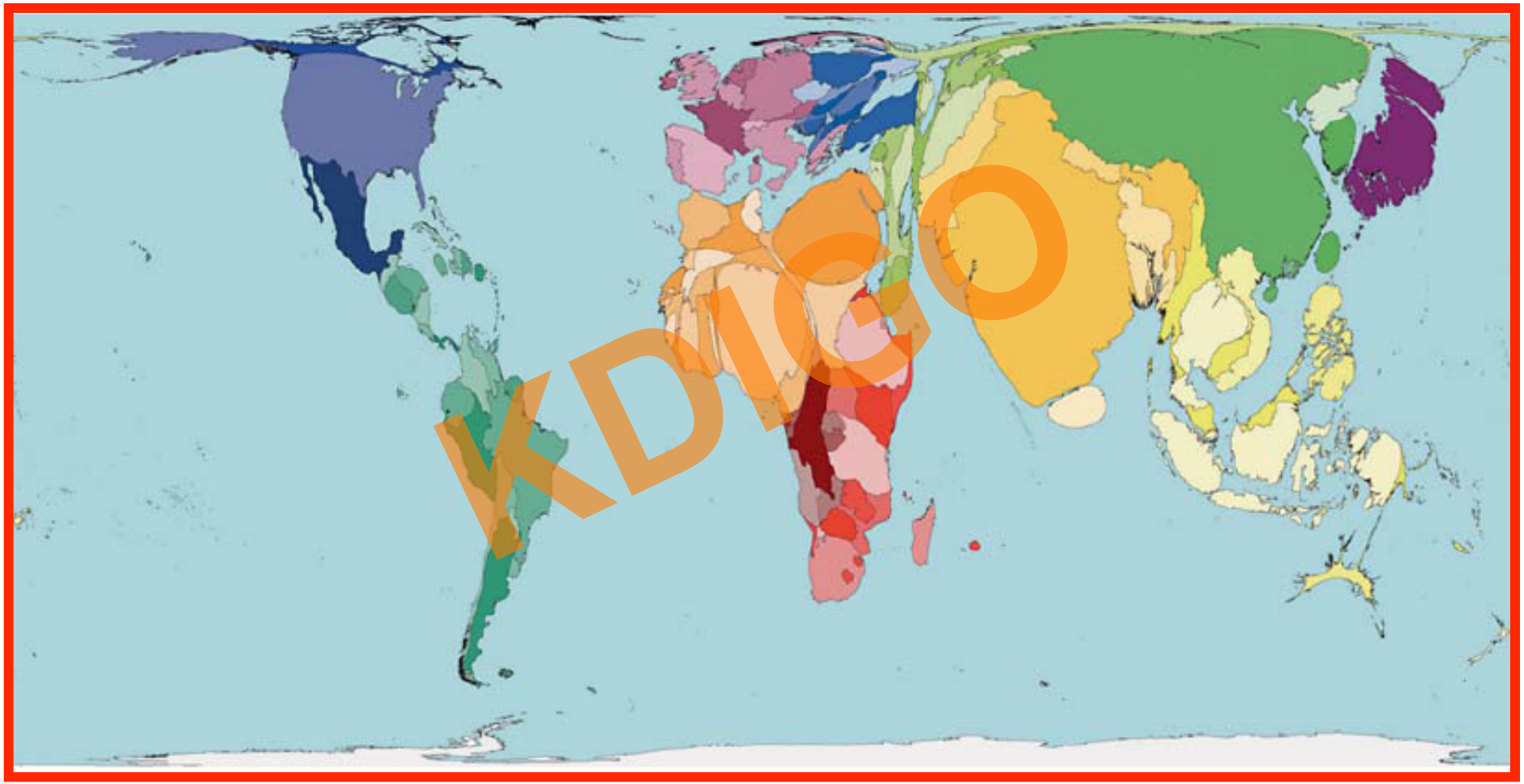
Disclosure of Interests

None

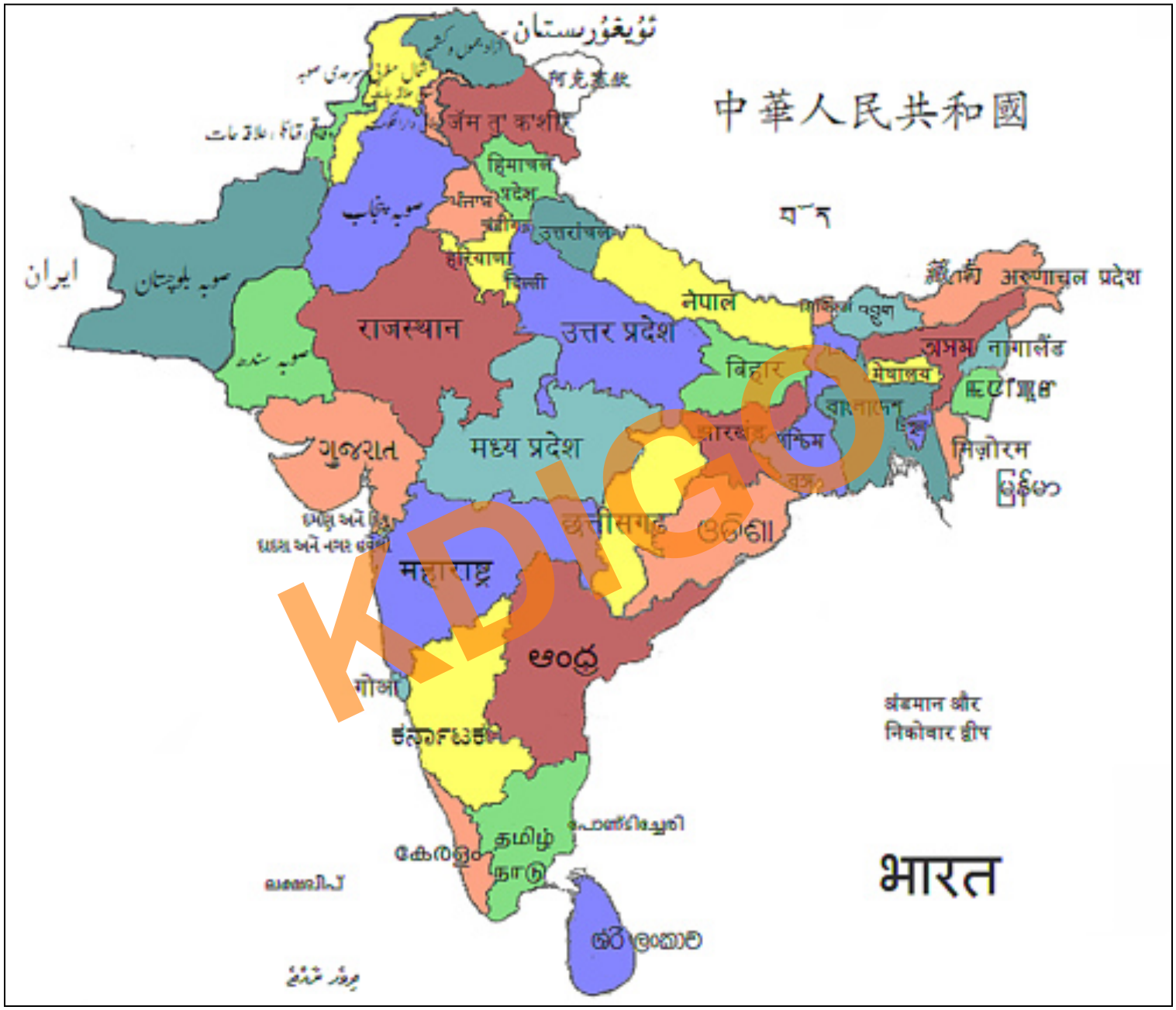
Worldwide Dialysis Population



Burden of CKD mortality relative to country size



Nugent, et al. Nephron Clin Pract , 2011

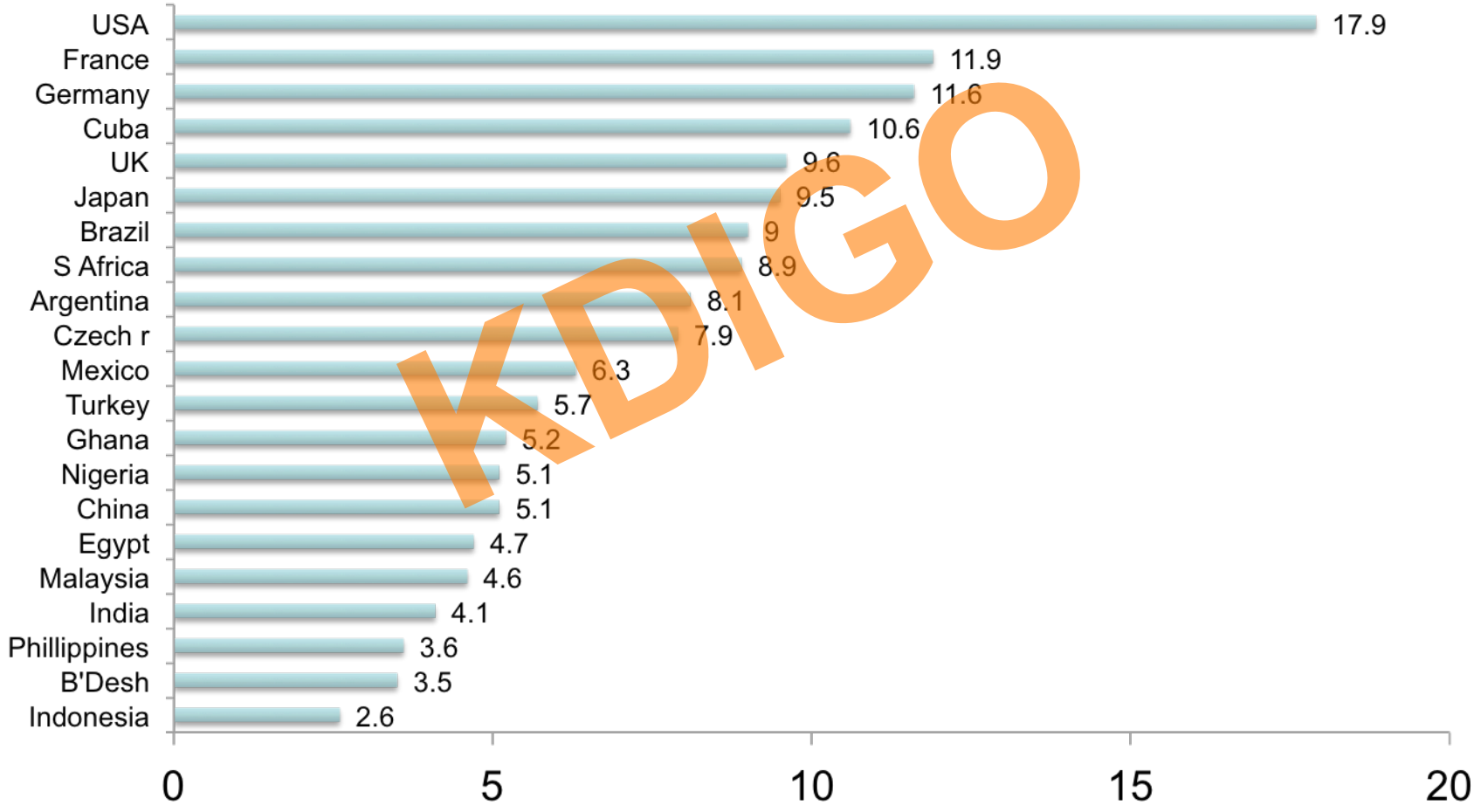

ایران
中華人民共和國
नेपाल
राजस्थान
उत्तर प्रदेश
बिहार
मध्य प्रदेश
महाराष्ट्र
भारत
अंडमान और
निकोबार द्वीप

Economic Development Indicators

	Pop (bns)	Rural (%)	Pop growth (%)	Lit. (%)	Life expect. (yrs)	Per capita GNI (USD)
High income	1		0.7		78.3	39,473
Developing	5.4		1.3		65.2	1,964
India	1.24	69	1.4	63	67	1,420
Pakistan	0.17	64	1.8	55	66	1,120
Bangla Desh	0.15	72	1.2	57	70	780
Sri Lanka	0.02	85	1.0	91	78	2,580

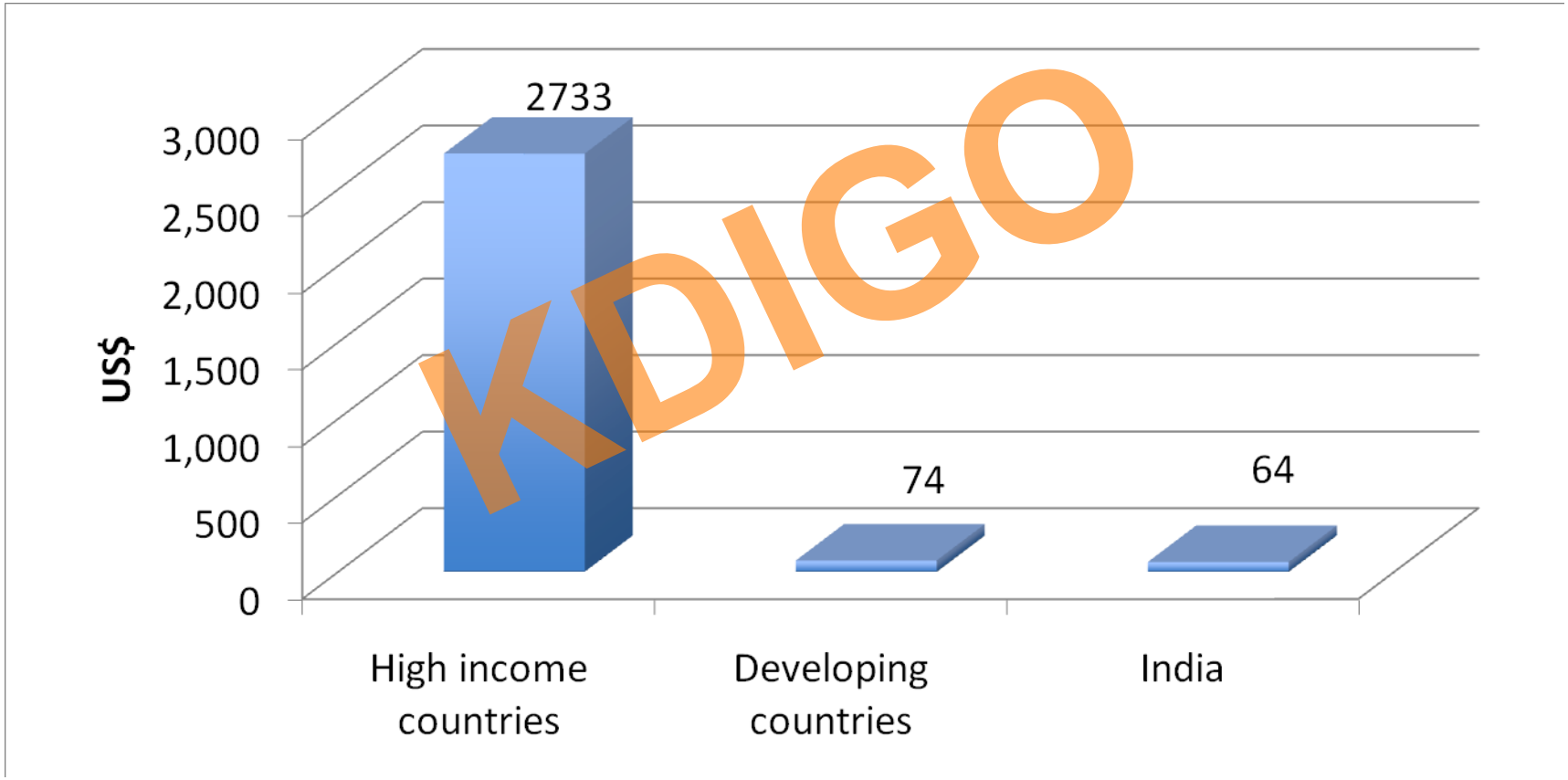
Source: *World Development Indicators database*, May 2013

Percent GDP spent on healthcare (2010)



Source: http://data.worldbank.org/

Average annual govt expenditure per year for health care, 1995-1999



Socioeconomic status and values of key health determinants

Parameter	Poor	Middle class	Affluent
Poor	Did you have enough?	Did you like it?	Was it presented well?
Education	Valued but abstract	Crucial for success and making money	Necessary for making and keeping connections
Destiny	Fate	Choices	*Noblesse oblige*
Worldview	Local	National	International
Language	For survival	For negotiation	About networking
Importance of time	Present	Future	Tradition
Decision	For the moment, survival-based	For future ramifications	On basis of tradition and decorum

Payne, 2003

Healthcare Delivery System

- Three-tier system (Public, Charitable, Private)
- Primary Health Centers (PHC)
  - 2 doctors for 25,000 population
  - medical care free, limited medications
  - patients must travel to PHC
  - travel from remote villages means loss of day's wages
- Investigations can be done only in Intermediate care hospitals
- Specialist care available in hospitals located in major cities
- Increasing number of private "For-profit" hospitals.

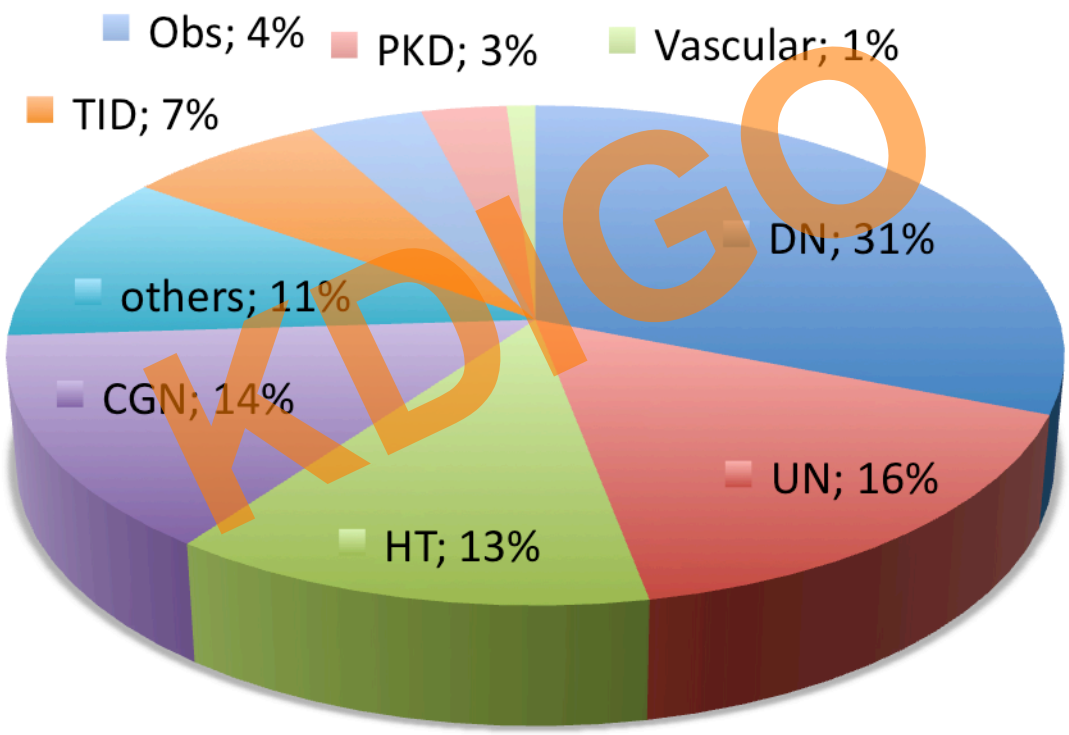
ESRD incidence in India

	2006	2007	2008
Number of new cases	84	81	91
Incidence (per million population)	147	142	160
Sex ratio (M:F)	1.4:1	1.6:1	1.2:1
Mean age (years)	49.5	50.4	49.6
Patients with diabetic nephropathy	39 (47)	41 (51)	40 (44)
Patients referred in stage V	19 (22)	14 (17)	17 (19)
Number with arteriovenous fistula as the initial dialysis access	8 (9)	11 (14)	12 (13)

All figures in parentheses denote percentages.

Modi G and Jha V, Kidney Int 2011

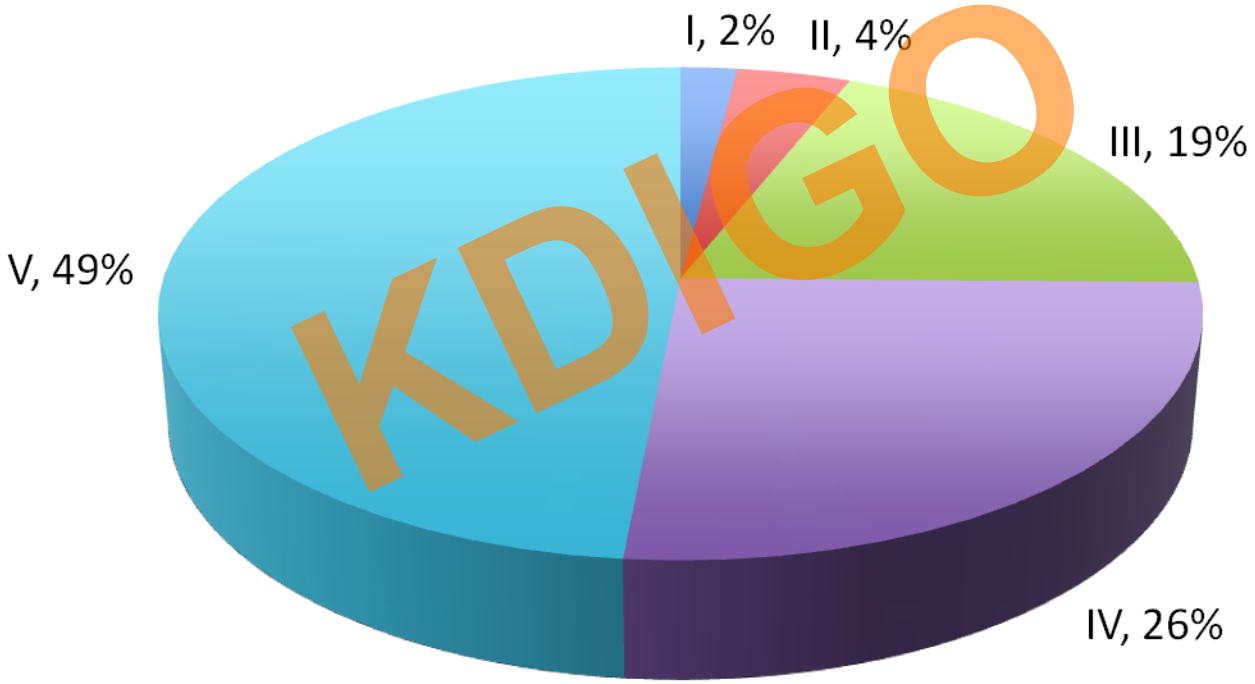
Causes of CKD in India



Rajapurkar et al, BMC Nephrol 2012

n=45,748, 2004-2009

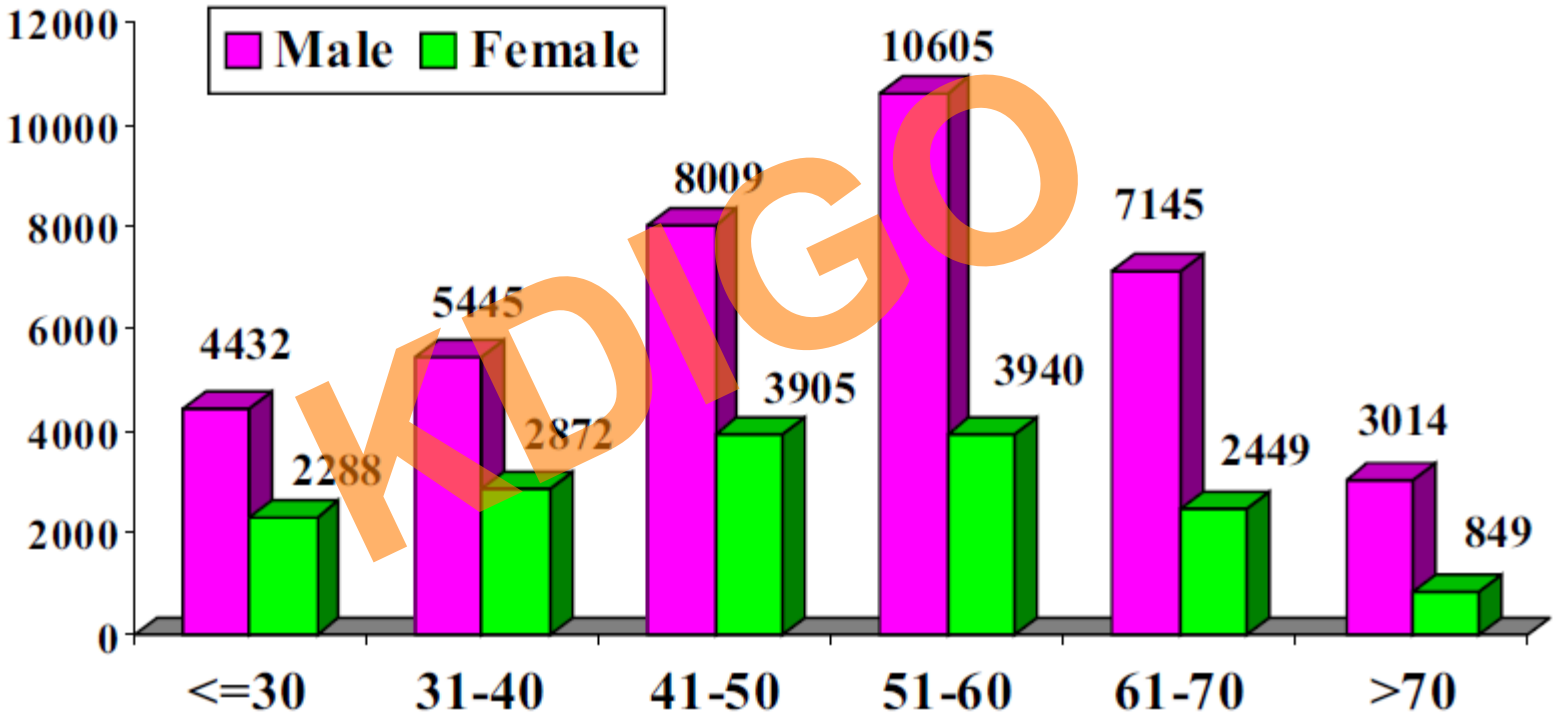
CKD stages at presentation



n=45,748

Source: Indian CKD Registry

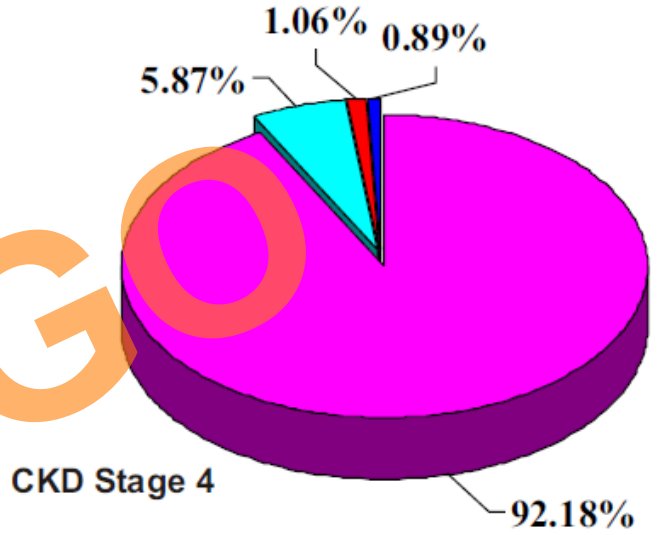
Age and gender distribution



- Males : 38650 / 54953 (70.3% Males)
  Mean age 50.8 14.6 years
- Females : 16303 / 54953 (29.7% Females)
  Mean age 48.3 14.4 years
- Overall : Mean age 50.1 14.6 years ; Age Range (19,98) years

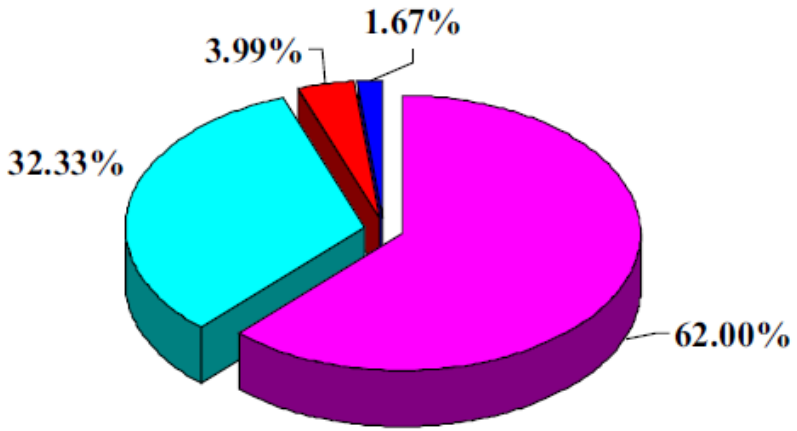
CKD management

Current Management	No's	%
Conservative + Palliative	42451	77.25
Dialysis – MHD	10060	18.31
Dialysis – CAPD	1329	2.42
Renal Transplantation	1113	2.02
TOTAL	54953	100.0



CKD Stage 4

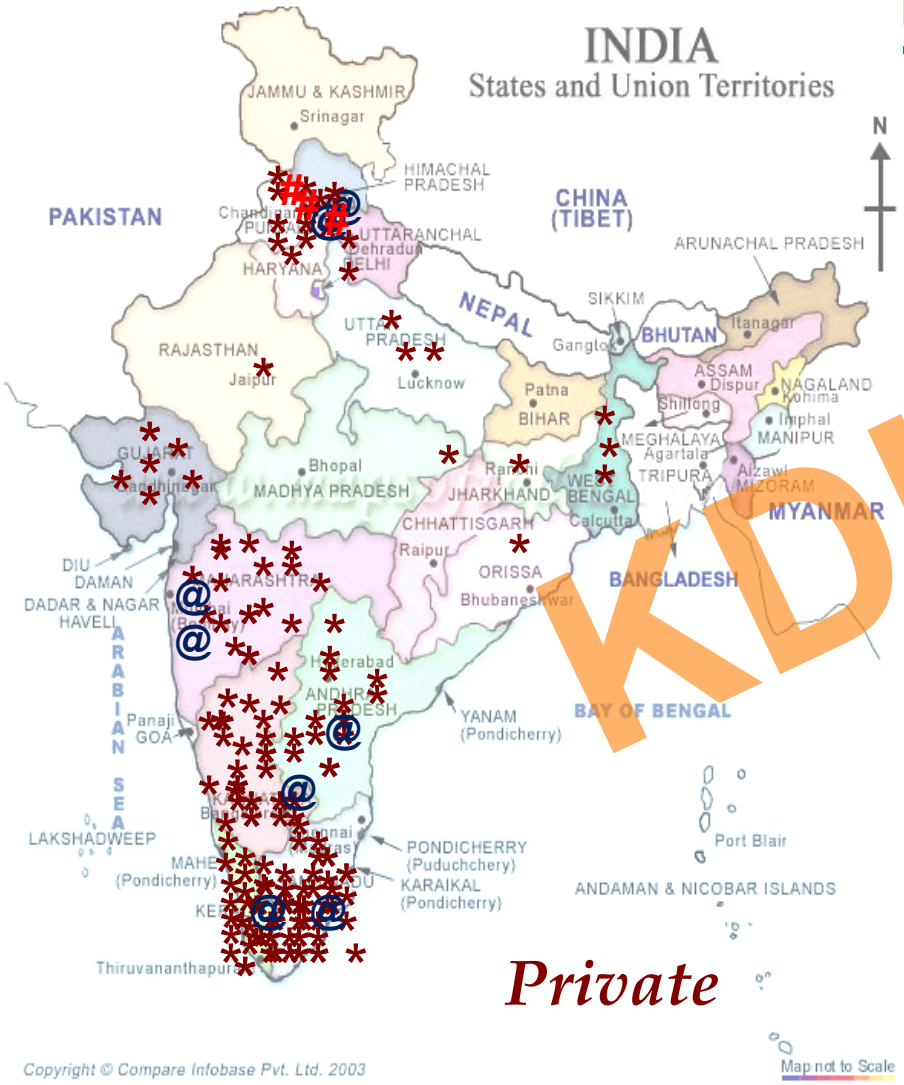
15266 (62.0%) / 24621 among Stage V were not receiving any form of renal replacement at the time of reporting



CKD Stage 5

CKD Registry of India (n=54953)
(Indian Society of Nephrology)

Distribution of facilities



Private

Govt

Initiation of dialysis

- First dialysis when hyperkalemia, acidosis, encephalopathy or fluid overload
- Often treated by acute PD using rigid catheter
- Dialysis time reduced to accommodate more patients
- Frequency decided by complications, finances
- Death from complications of underdialysis

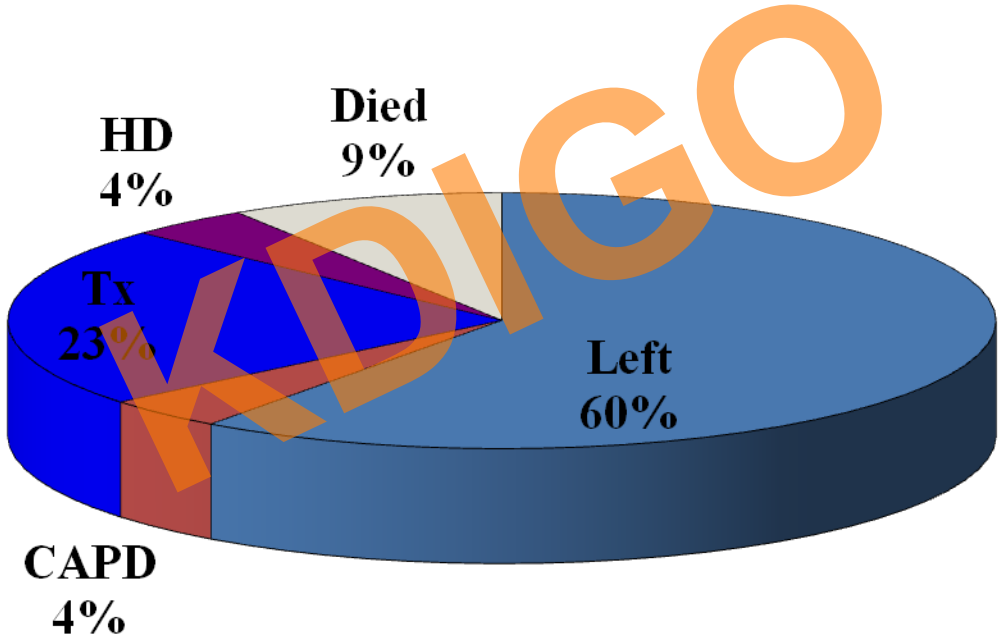
No. of HD Sessions/week

1 Session	30%
2 Sessions	50%
3 Sessions	20%

Hours of Dialysis/week

< 9 hours	85%
9 – 10 hours	10%
10-12 hours	5%

Outcomes on HD

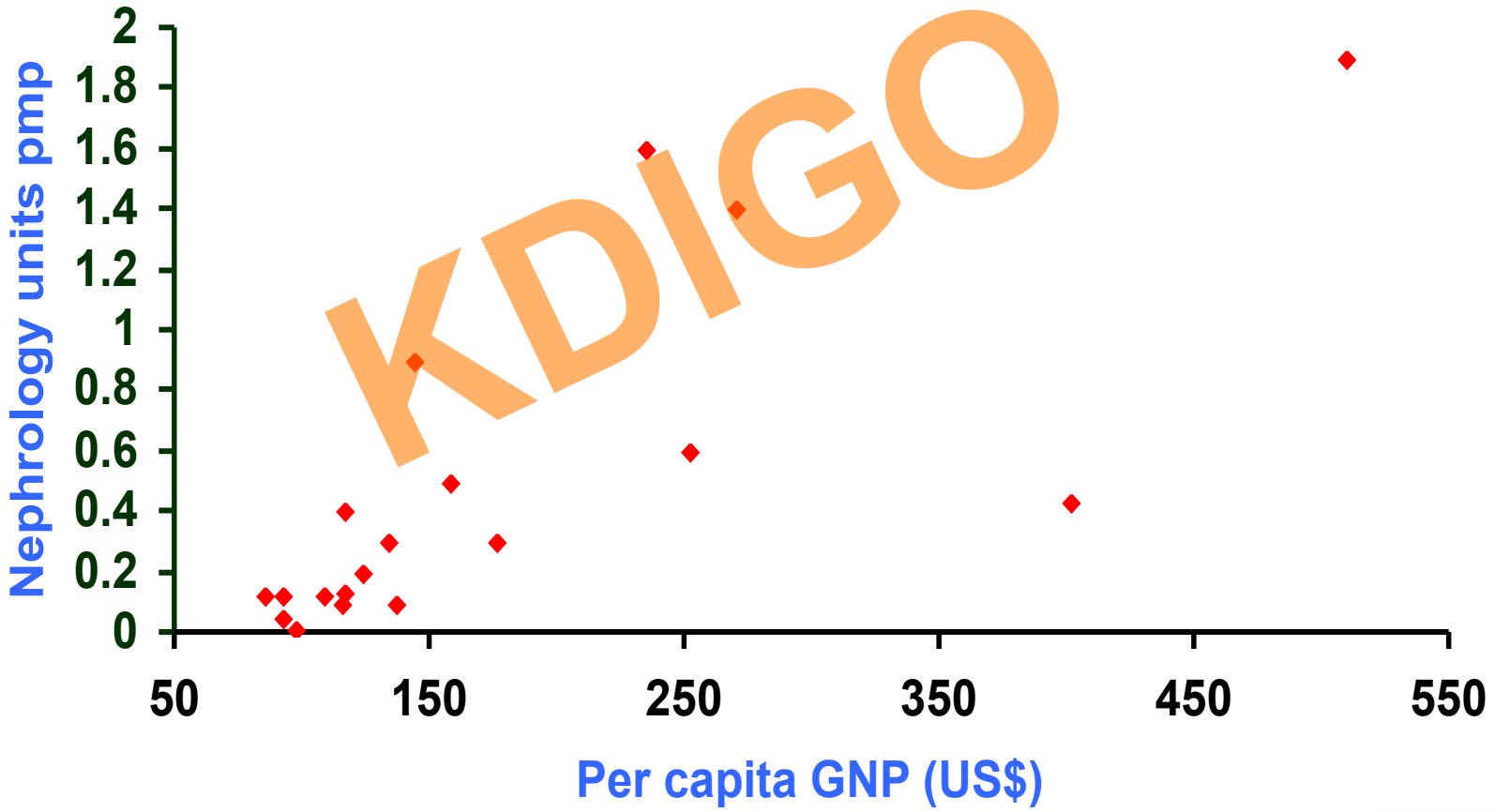


Rao M, et al, Nephrol Dial Transplant, 1998

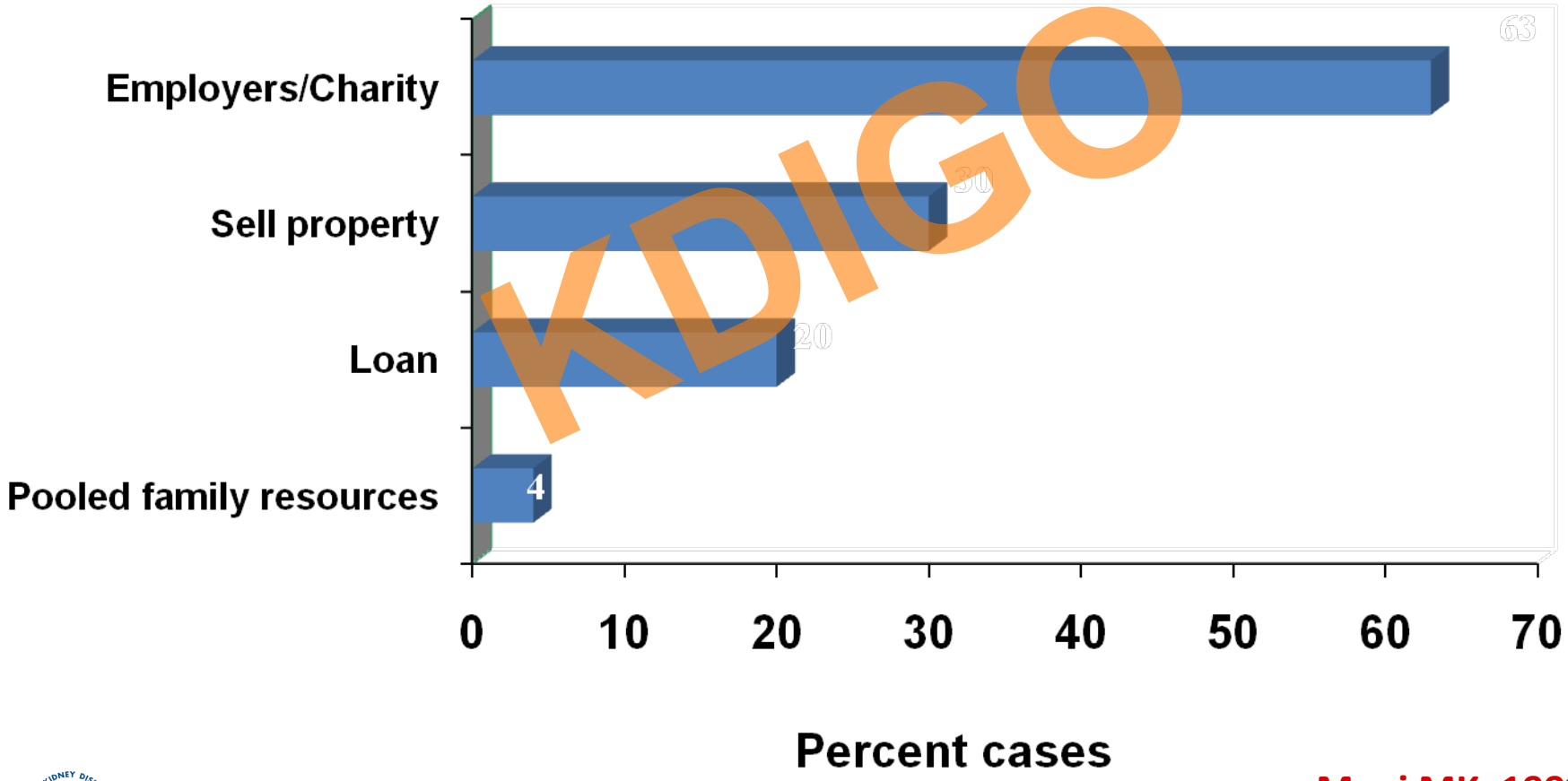
Issues in access and quality of RRT

- Certain sections of population have limited access
  - Females
  - Extremes of age
- Geographic disparity major concern
- High degree of variability in dialysis delivery
  - Frequency of dialysis
  - Infection control measures

GNP and dialysis availability in India

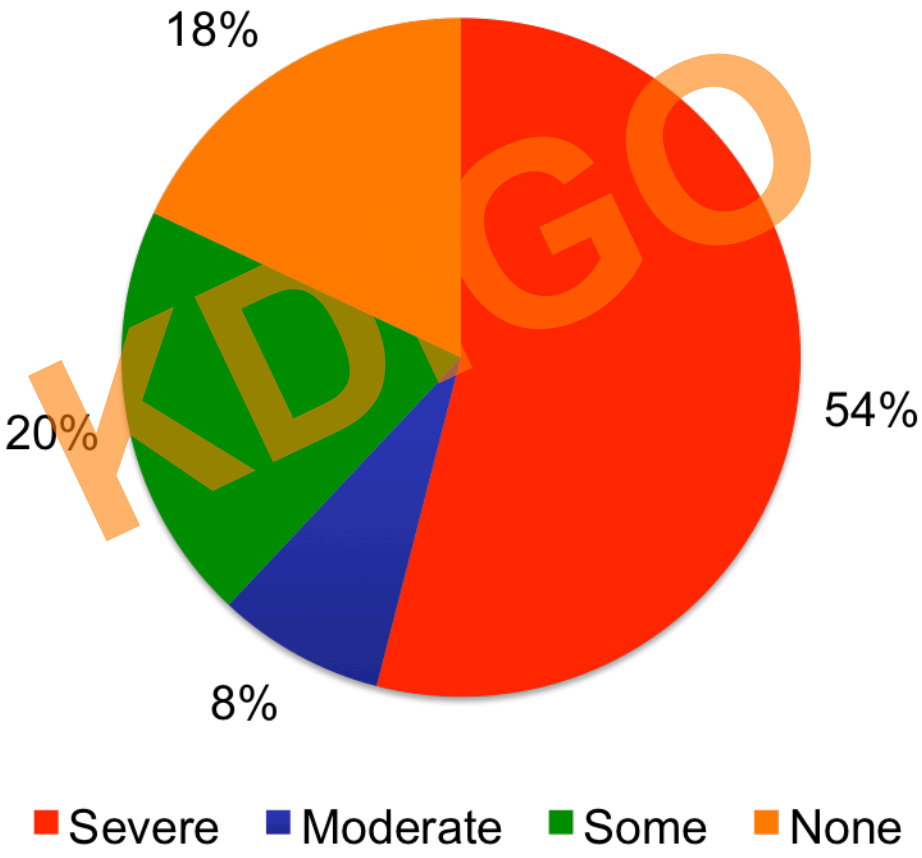


Meeting ESRD Treatment costs



Mani MK, 1998

Catastrophic healthcare expenditure associated with RRT



Ramachandran and Jha, PLoS One, 2013

News In Print Copy Formate - Windows Internet Explorer

http://nation.com.pk/pakistan-news-newspaper-daily-english-online/print/Regional/08-Sep-2008/Financial-constraints-lead-to-closure-of-35-dialysis-centres

The Nation on Web

The Nation

Financial constraints lead to closure of 35 dialysis centres

September 8, 2008

KARACHI (APP) - Pakistan with 224 dialysis centres and 988 dialysis machines in 61 of its cities witnesses a constant surge in the number of diabetic patients with end stage renal failure.

The Fourth Dialysis Registry of Pakistan 2007-2008, released by the Kidney Foundation here Friday shows that the number of End Stage Renal Diabetics (ESRD) grew from 4393, in 2006-2007, to 6127 in 2007-2008.

This was in a scenario where number of dialysis centres supported by the community decreased from 20.08 % in 2006 to 12.94 % in 2007- 2008.

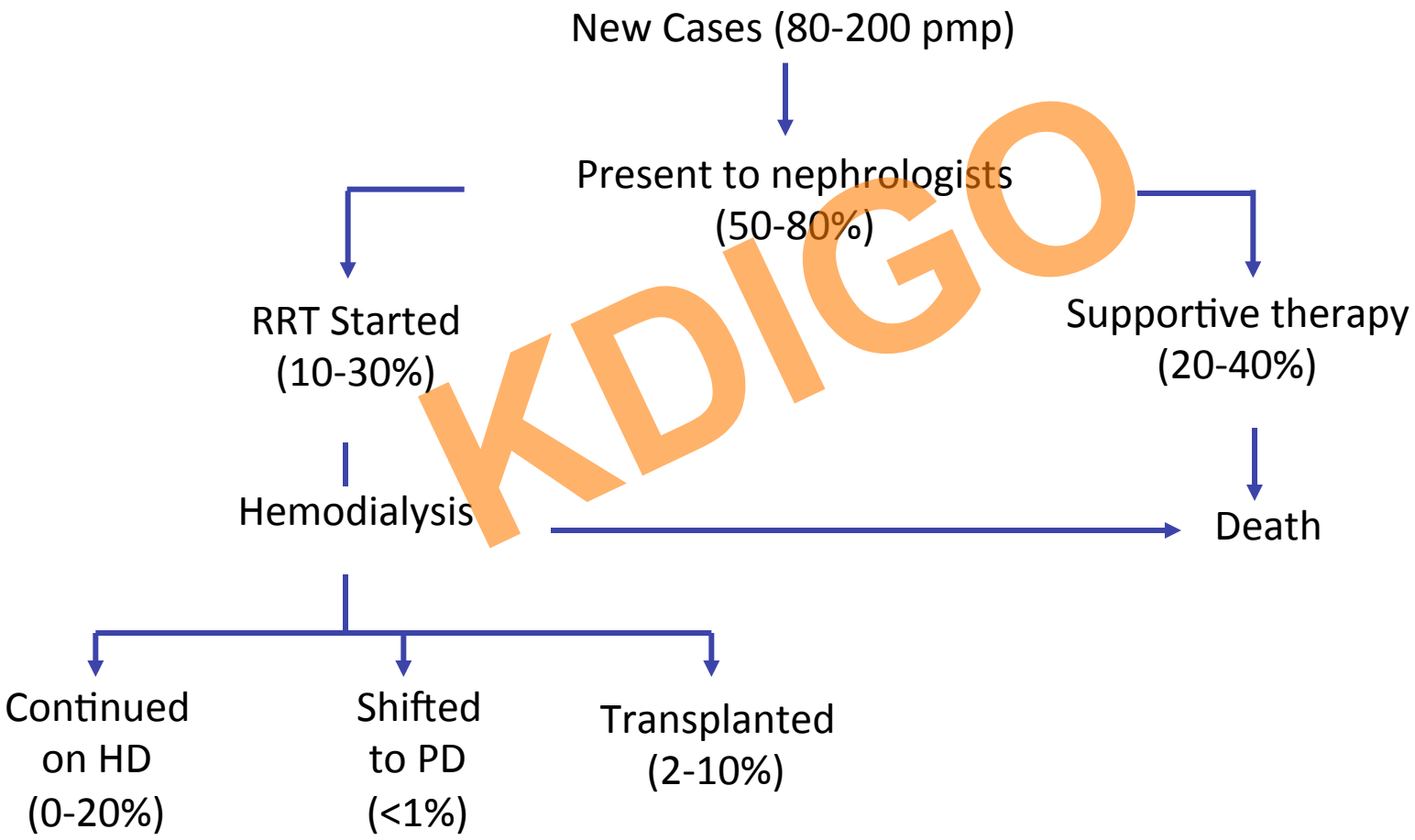
Twenty-one of the 224 dialysis centres were rendered non-functional due to administrative and financial constraints, 17 of the centres did not share the data while another 14 were closed down, due to un-disclosed reasons, in 2007-2008.

It was in the same year that 23 new dialysis centres were established in the country, none in Pakistan Occupied Kashmir. 11 of these were government-funded, four were semi- government, eight in private sector while none were supported by the philanthropists.

The 195 dialysis centres, operational during 2007-2008, were supervised by a total number of 343 doctors and 553 technicians against an acute shortage of dieticians, coming to mere 365 (20.57%) and 66 social workers for 175

Internet | Protected Mode: On 150%

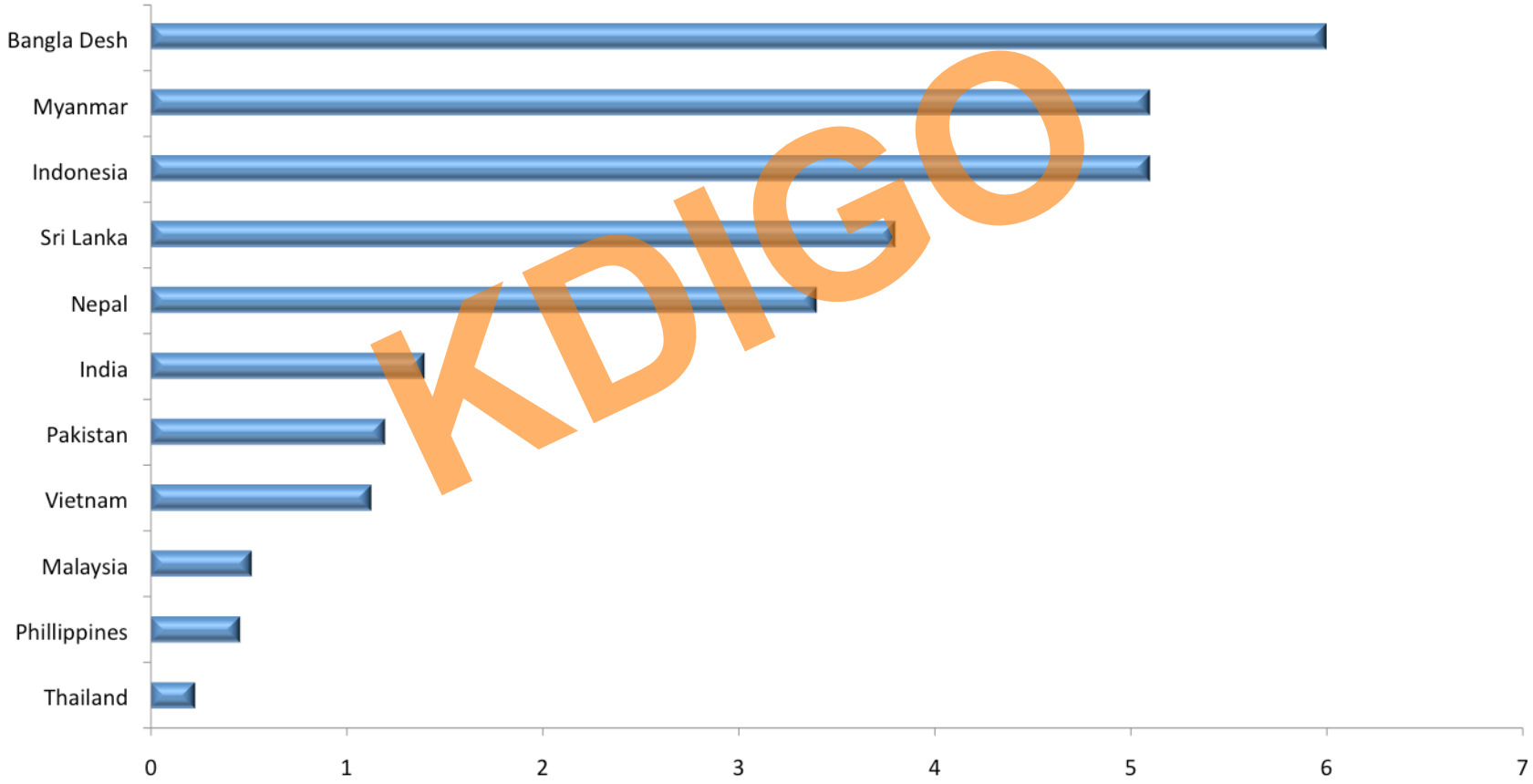
Fate of ESRD patients



The impact of transitions

- Better education, consciousness of human rights, democratic environment
- Increasing middle class, booming private sector, market forces
  - Increasing demand for better care
  - Labor force distortions for production/ distribution of HCWs
- Financial crisis, depreciation of currencies
  - Increased cost of imported drugs/supplies

Population (millions) per nephrologist

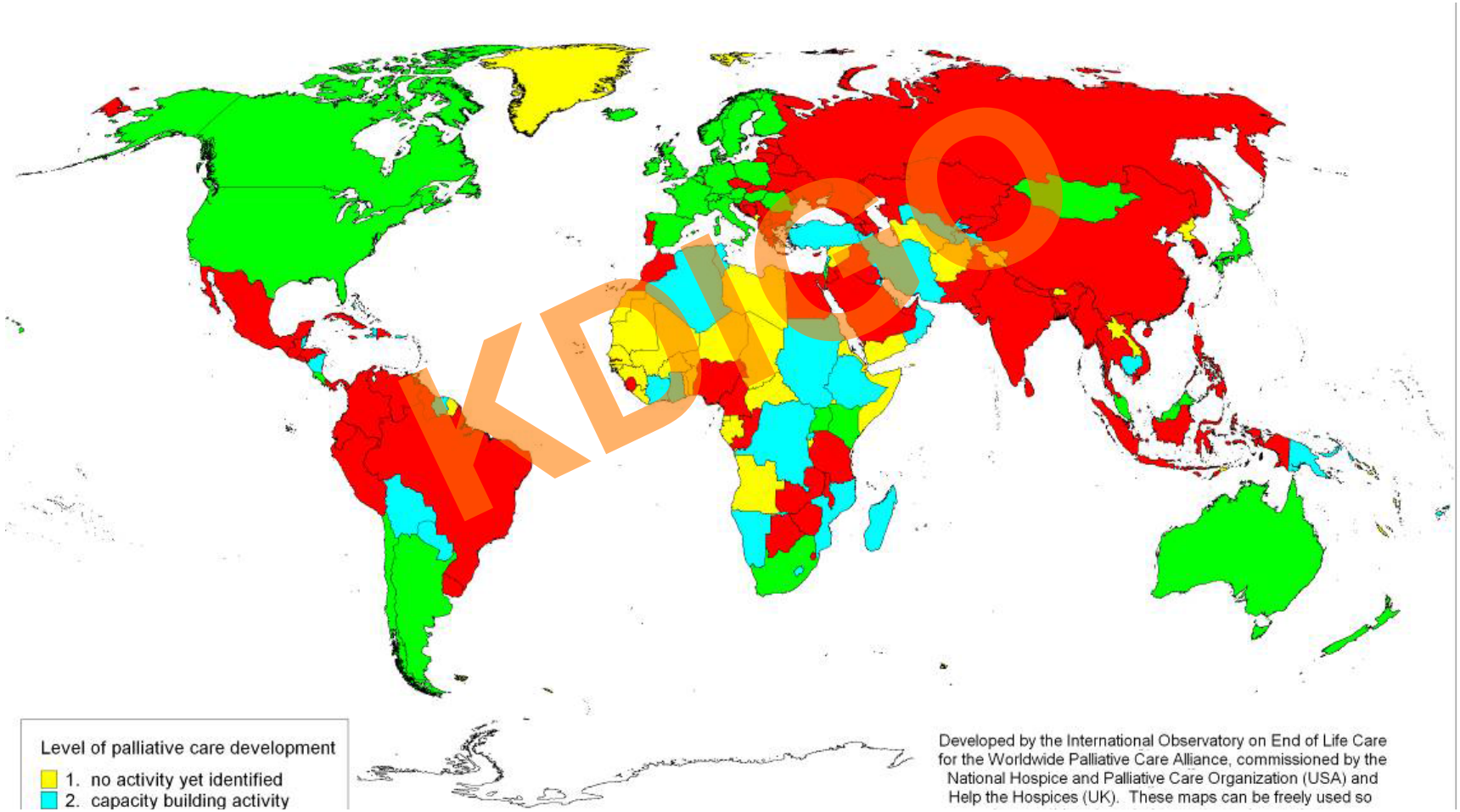


Jha, Semin Nephrol 2009

Supportive care in India

Levels of Palliative Care

Wright et al. International Observatory on End of Life Care 2006



Ratio of palliative care services to population (x1000)

Current status

- No national policy
- 138 organizations in 16 states/UTs
- Concentrated in large cities and cancer centers
- Exception : Kerala
  - Institute of Palliative Medicine
  - Trivandrum Institute of Palliative Sciences
- Limitations in drug availability
- Research
  - Indian Association of Palliative Care
  - Indian Journal of Palliative Care

Legal provision

- Indian Law Commission: Medical treatment on terminally ill patients (for protection of patients and medical practitioners), 2006
  - Adult patient's right to self determination and right to refuse treatment binding on doctors if based on informed choice
  - State's interest in protecting life "not absolute"
  - Refusal to accept medical treatment does not amount to "attempt to commit suicide"
  - Endorsement by physician does not constitute "abetment to suicide"
  - Applying invasive therapy conterary to patient wishes might constitute "unlawful battery"

Proposed reforms

- Clear definitions of competence, informed decision and best interests
- Recognizes patient's Right to refuse treatment
- Informed decision by competent patient binding on the doctor
- Recommends constitution of panel of experts to authorize withdrawal and withholding of life support decisions
- The physician will consult the family but their views are not binding on him/her
- *Advance directives, and legal powers of attorney to be deemed invalid for decision-making as it may "create complications"*
- Provides for Court declarations: Family/physician/hospital can move court on the question of lawfulness of withdrawal of life support. This is viewed as an "enabling", as opposed to mandatory, provision
- Recognizes patients' right to receive palliative care
- Directs Medical Council of India to formulate guidelines on EOLC

Barriers to delivery of supportive care in India

- Poverty
- Scarcity of medical resources
- Low nutrition and health indices, low literacy rates
- Cultural attitudes, fear of "cultural" invasion
- Importance of religion in customs and rituals around death
- Reliance on *unorthodox* medical systems, hope for cure
- Lack of advocacy groups
- Thrust on "curative" medicine, adverse effect of pharma sponsored CMEs
- Lack of supportive care education and training

Steinhauser et al J Royal Soc Med 2000
Chaturvedi J Med Ethics 2008

KDIGO Survey on Supportive Care for ESRD in LMIC

No of responders: 137

Countries represented: 44 (41 LMIC)


ARCTIC OCEAN
Greenland
Svalbard (Nor.)
ARCTIC OCEAN
United States of America
Canada
Iceland
Norway
Sweden
Finland
Russia
United Kingdom
Denmark
Neth.
Ireland
Estonia
Latvia
Ger.
Ukraine
Kazakhstan
Mongolia
France
Italy
Spain
Portugal
ATLANTIC OCEAN
United States of America
Kyrgyzstan
Tajikistan
China
Japan
Korea
Greece
Tunisia
Lebanon
Syria
Iraq
Iran
Nepal
Bhutan
Kuwait
Algeria
Libya
Israel
Jordan
Saudi Arabia
Laos
PACIFIC OCEAN
Western Sahara
Mauritania
Mali
Niger
Chad
Eritrea
Oman
Yemen
Djibouti
Bangl.
Honduras
Guatemala
Nicaragua
Costa Rica
Panama
Ecuador
Ven.
Guyana
French Guiana
Suriname
Guinea-Bissau
Sierra Leone
Liberia
Cote d' Ivoire
Togo
Gabon
C.A.R.
Dem. Rep of Congo
Rep. of the Congo
Ethiopia
Somalia
Uganda
Kenya
Sri Lanka
Cambodia
Philippines
Indonesia
Papua New Guinea
Solomon Islands
Fiji
INDIAN OCEAN
Brazil
Paraguay
Chile
Argentina
Uruguay
Angola
Zambia
Namibia
Zimbabwe
Botswana
Mozambique
Madagascar
Swaziland
Lesotho
South Africa
ATLANTIC OCEAN
Australia
New Zealand

Responder characteristics

Age (years)	No of responders
31-40	22
41-50	46
51-60	46
>60	23

Responder characteristics

Clinical work	No of responders
Adult nephrologists	126
Adult internists	4
Pediatric nephrologists	5
General pediatrician	1
Others	1

Responder characteristics

No of CKD patients per month	No of responders
≤ 20	10
21-40	17
41-60	16
61-80	12
>80	82

Govt policy for dialysis

Response	Number
Yes, in the whole country	26
Yes, in some parts	7
No	7
Not sure	4
No response	0

Funding for dialysis

- **In your country, are there public healthcare funding systems that support the cost of dialysis?**

Yes, in the whole country	26
Yes, in some parts	9
No	6
Not sure	3
No response	0

Funding for dialysis

- **In your country, are there private healthcare funding systems that support the cost of dialysis?**

Yes	32
No	6
Not sure	6

Population coverage

What percentage of the population has cost coverage for dialysis by public/private health funding or insurance system?

0-20%	43
21-40%	9
41-60%	4
61-80%	13
>80%	57

Dialysis availability

What percentage of the population cannot get or withdraw dialysis due to lack of finances?

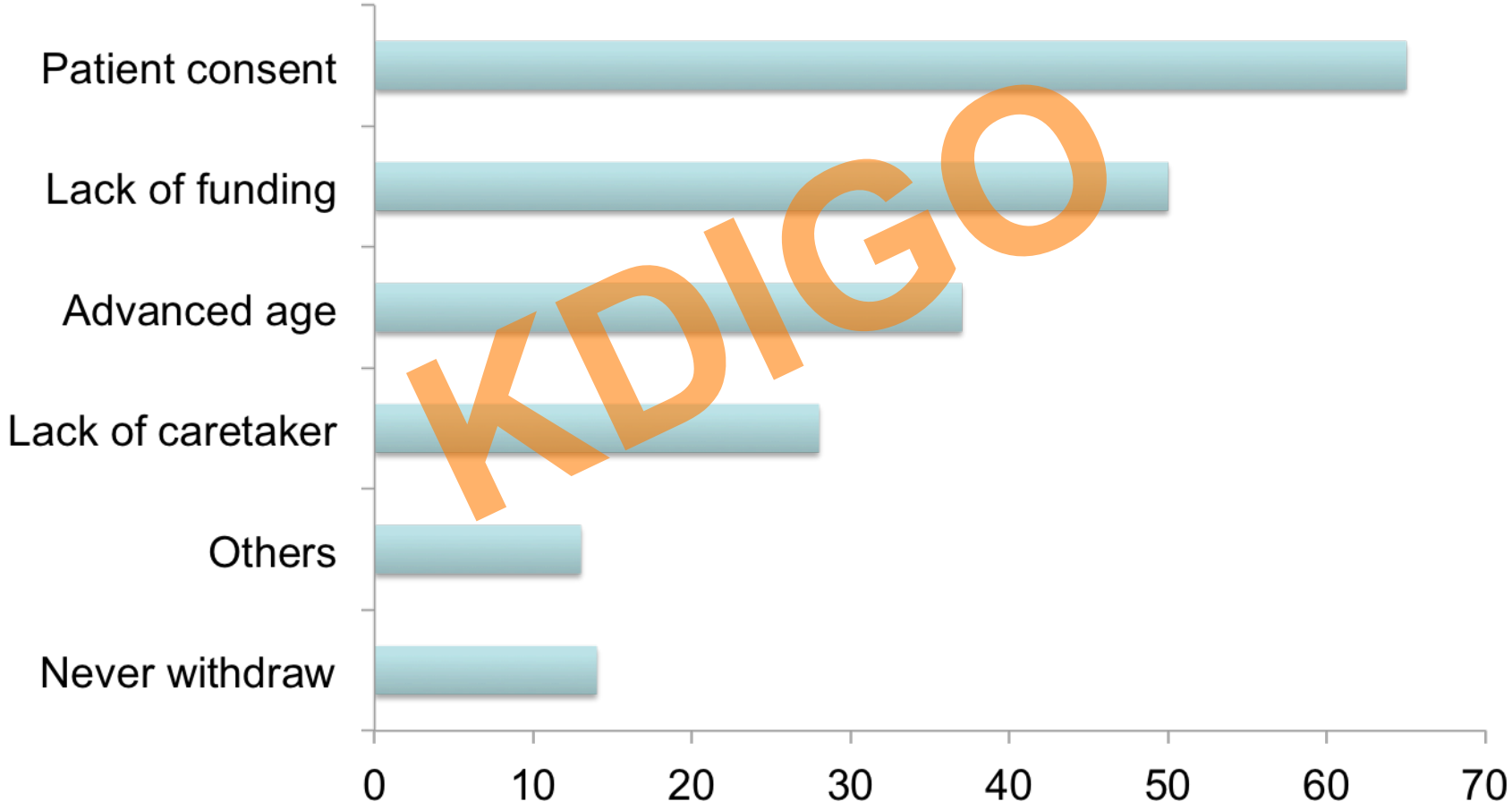
	Cannot get	Withdraw
≤ 10%	65	70
11-30%	9	13
31-50%	7	4
51-80%	11	5
>80%	8	7

Dialysis availability

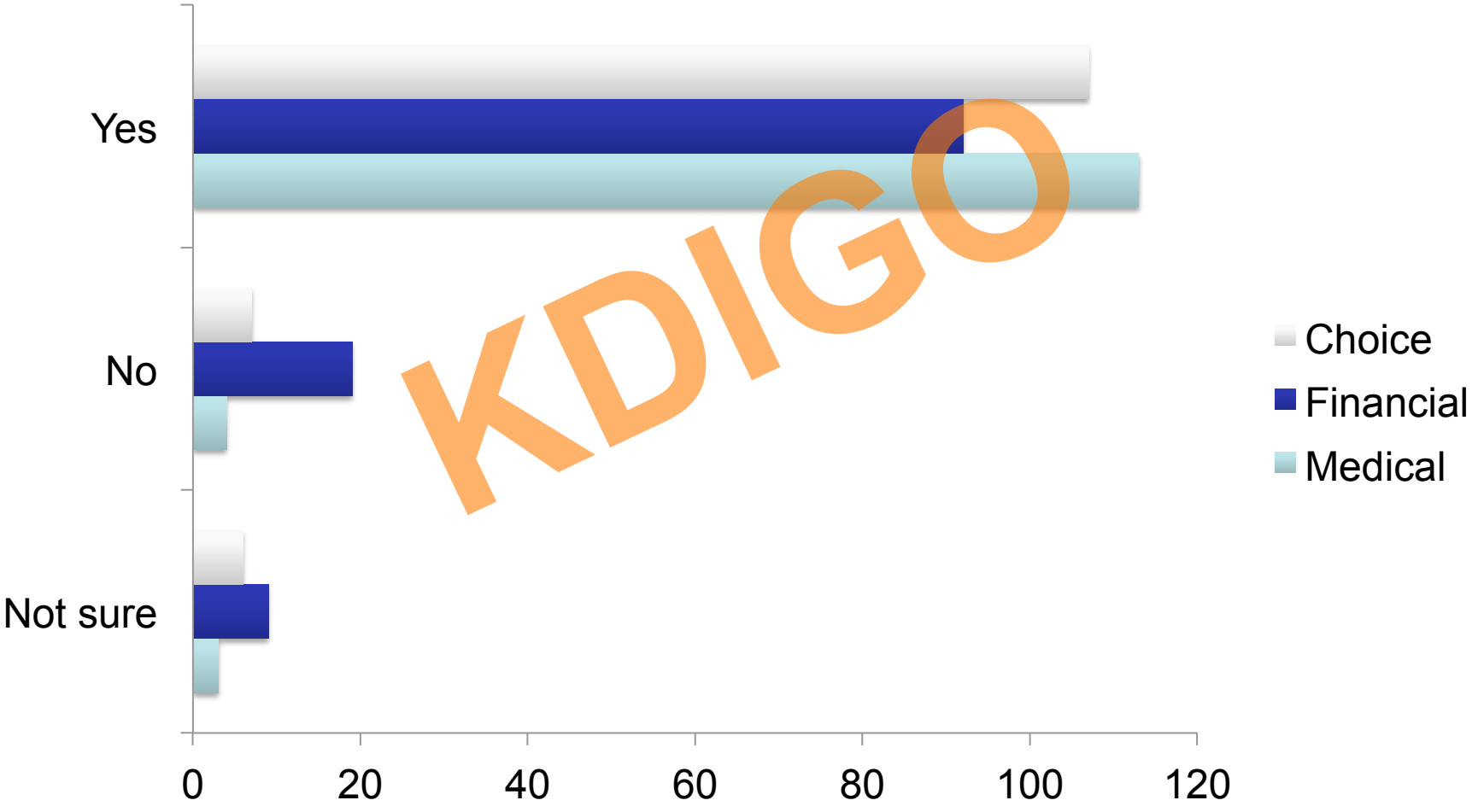
What percentage of the population cannot get or withdraw dialysis due to lack of caretaker at home?

	Cannot get	Withdraw
≤ 10%	81	86
11-30%	14	10
31-50%	5	4
51-80%	0	0
>80%	0	0

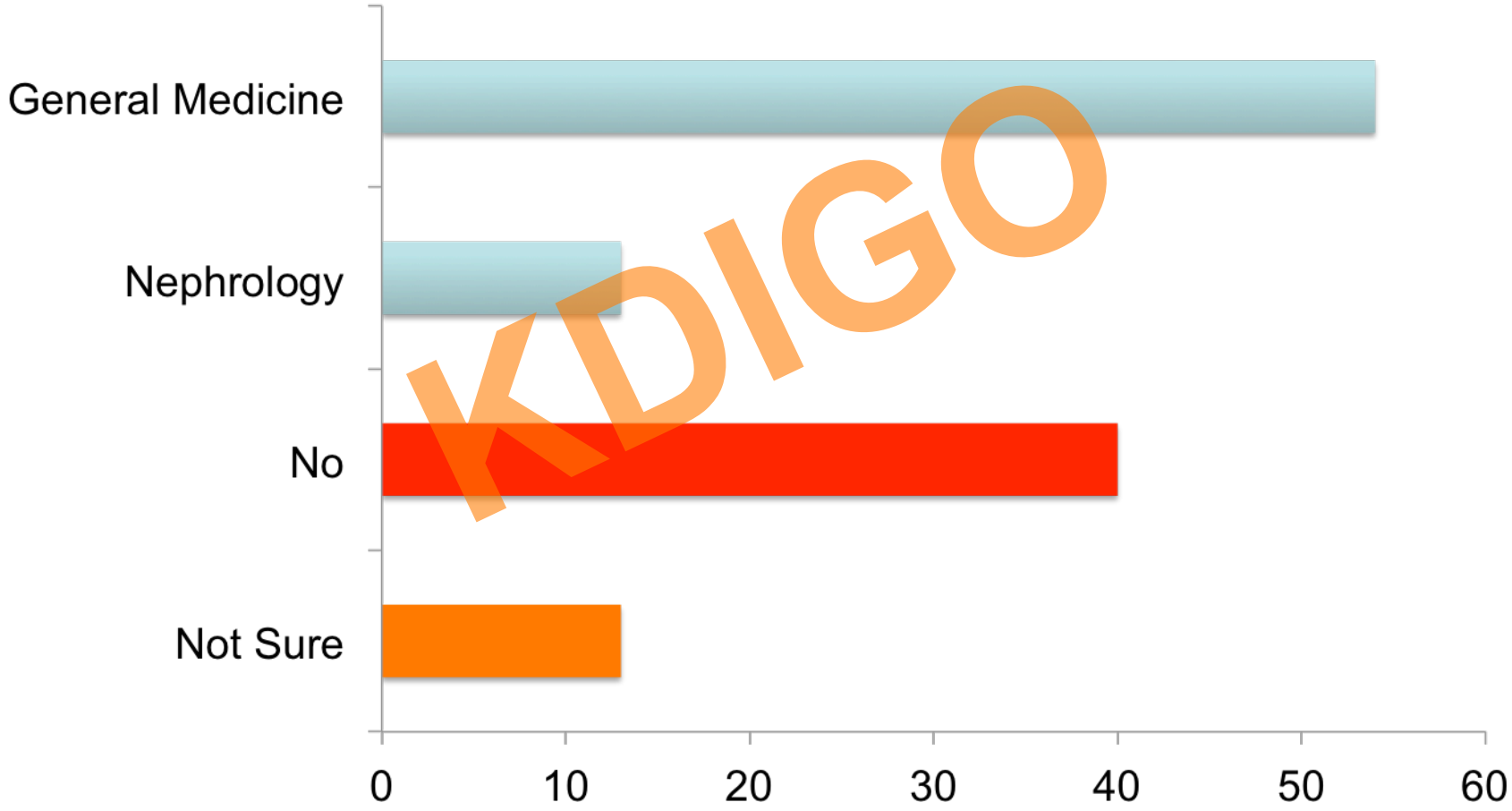
Witholding or withdrawal of dialysis



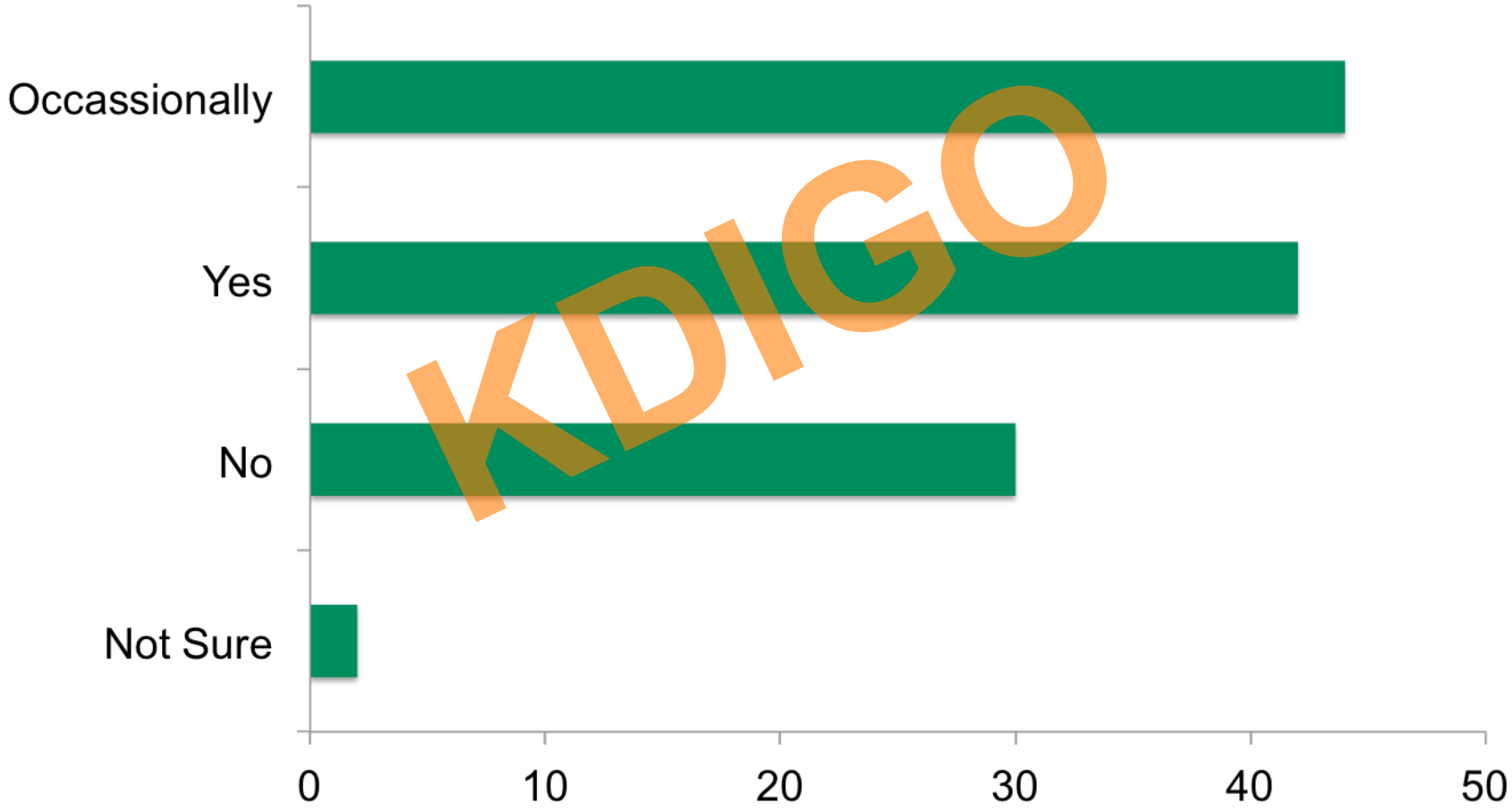
Should supportive care be available to patients who do not receive/withdraw from dialysis?



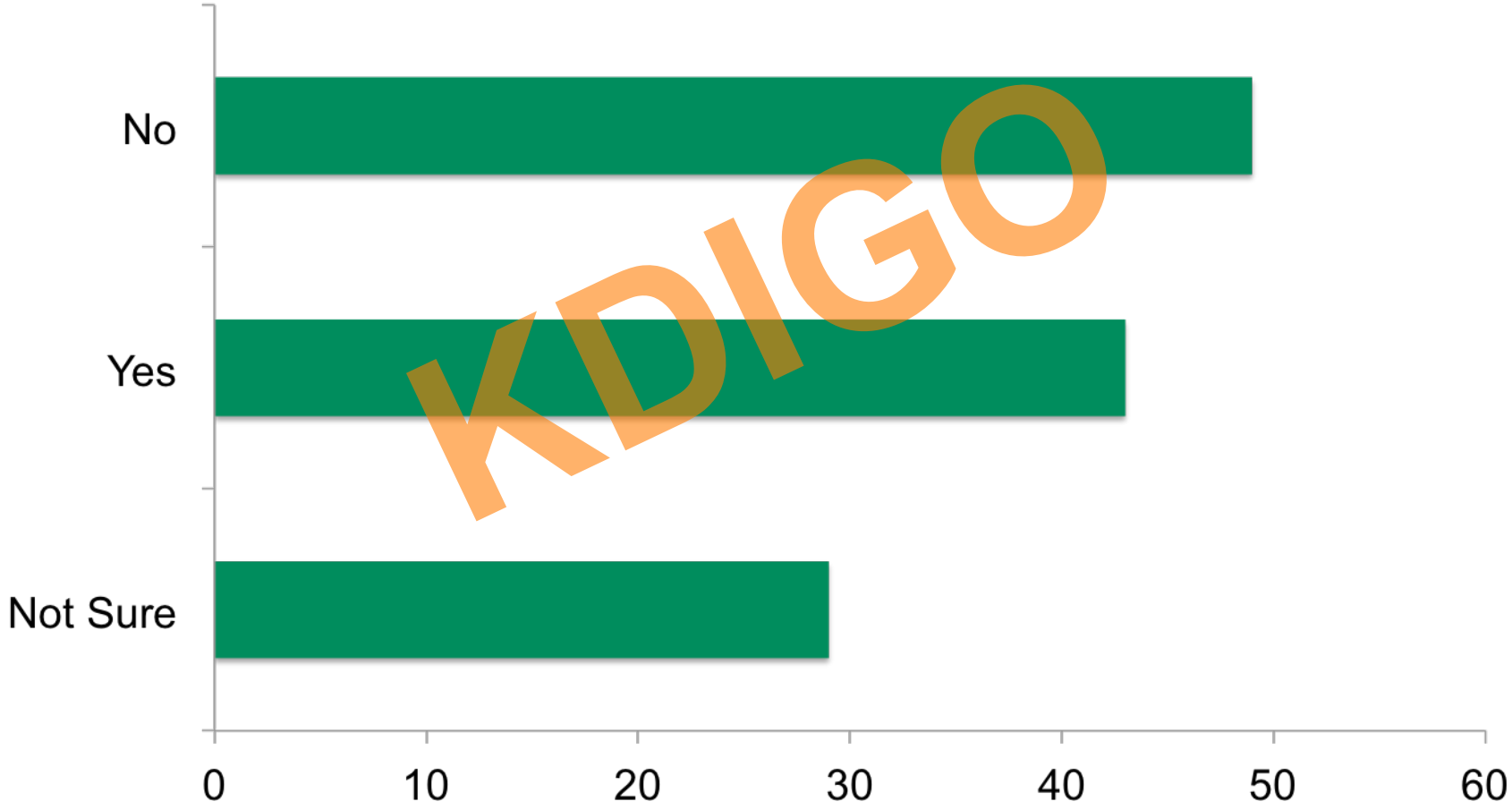
Supportive care education



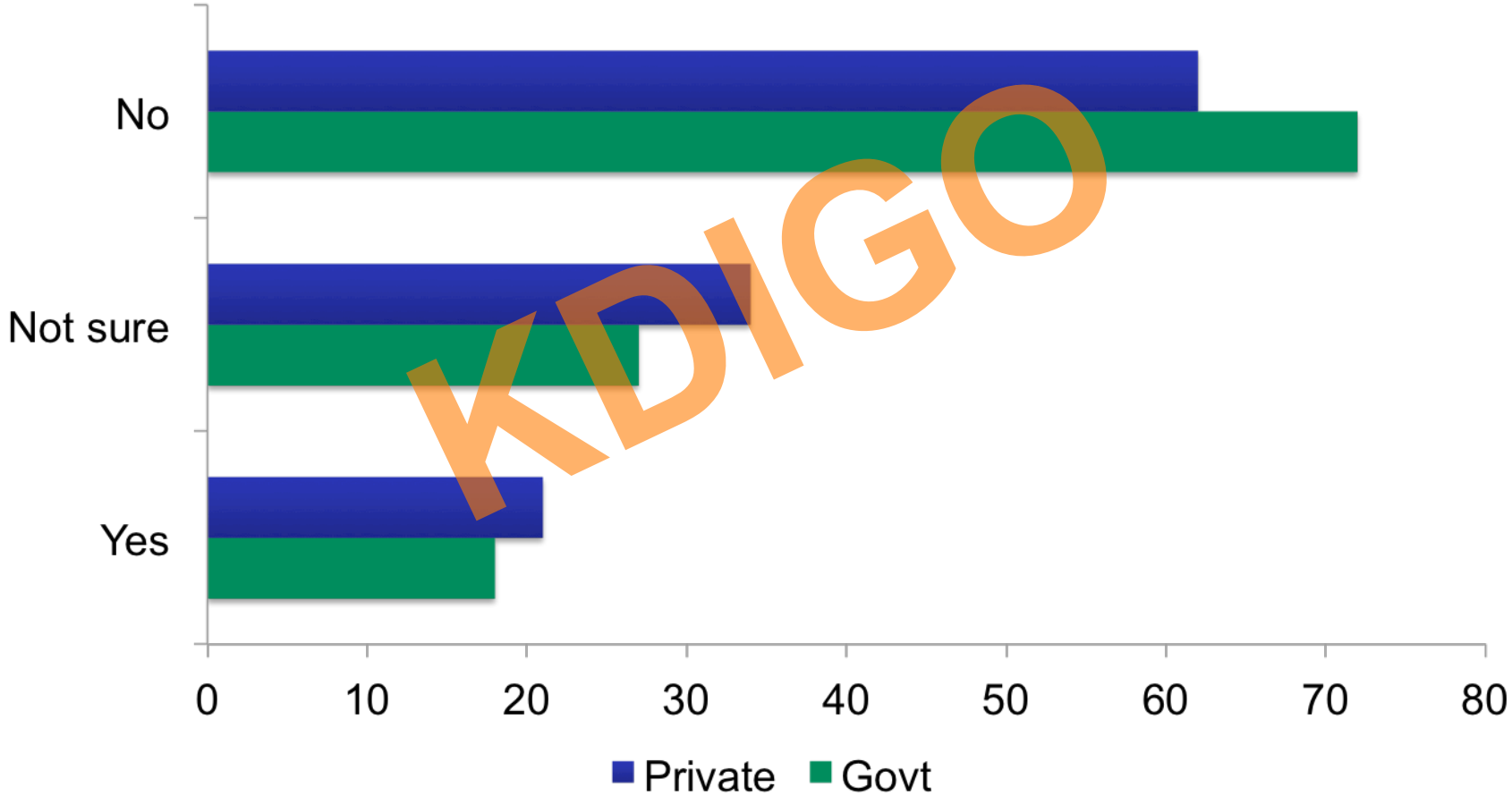
Do you actually discuss dialysis withdrawal when you deem it to be futile?



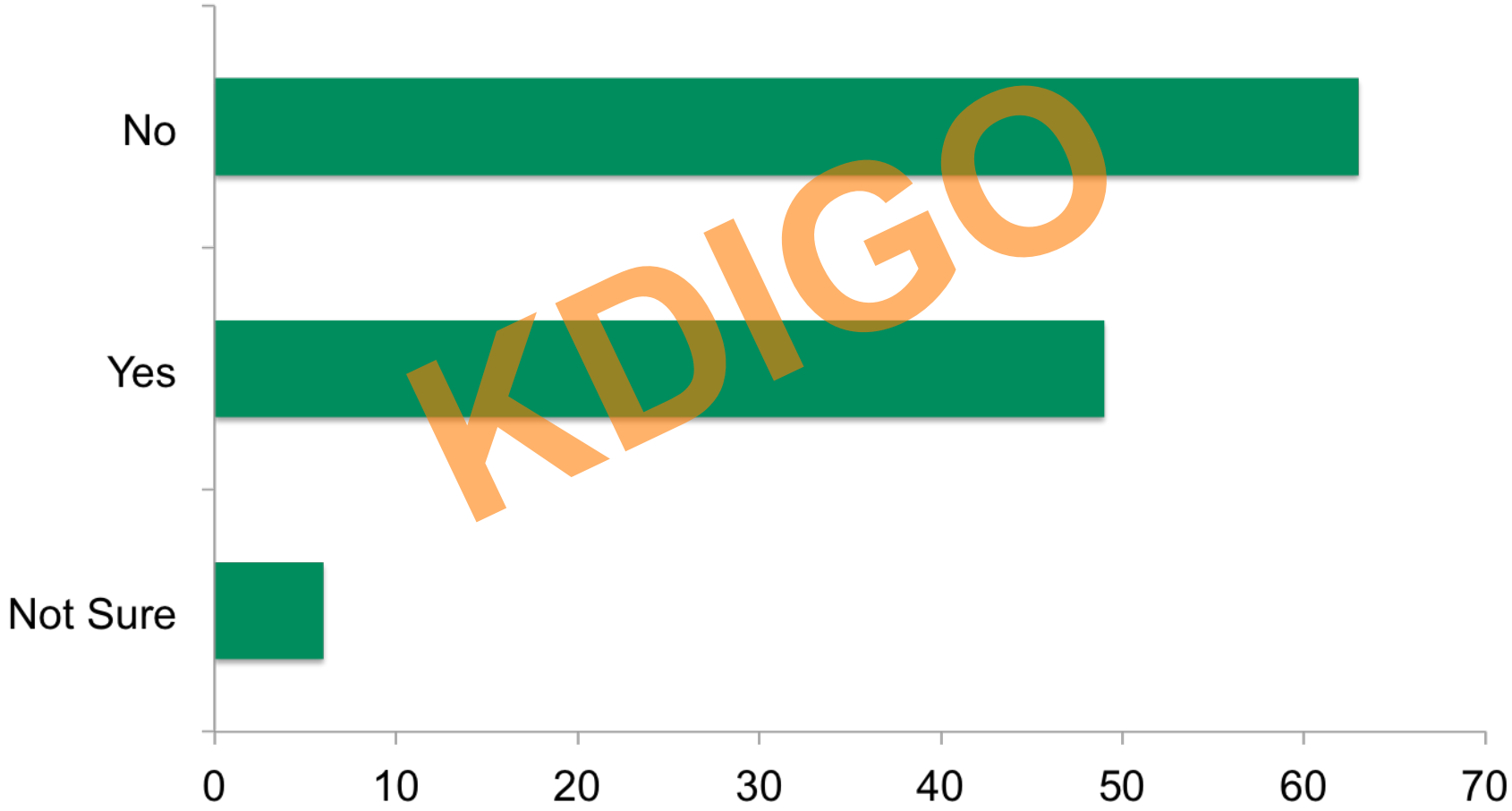
Is government or private reimbursement available for palliative care to ANY group of patients (for example terminal cancer) in your country?



Do your ESRD patients have access to government or private reimbursement for supportive care?



Does your hospital have an End-of-life Care Team?



Do you think palliative care is a luxury that cannot be afforded by countries that do not have the means to provide needed curative or preventive interventions?