KDIGO Controversies Conference on Supportive Care

Sara Davison & Gregorio T. Obrador
Conference Co-Chairs

Controversies Conferences

2013

SUPPORTIVE CARE

- Conference on palliative care and the needs of patients when dialysis is not an option
- Co-chairs: Sara Davison, Canada & Gregorio Obrador, Mexico
- Date: December 5-8, Mexico City, Mexico
- In collaboration with the International Society of Nephrology (ISN) and Fundación Mexicana del Riñón A.C. (FMR)

Supportive Care Conference

Steering Committee

- **Sara N. Davison, *Canada*** — **Conference Co-Chair**
- **Gregorio Obrador, *Mexico*** — **Conference Co-Chair**
- Michael J. Germain, *United States*
- Alvin “Woody” Moss, *United States*
- Donal O'Donoghue, *United Kingdom*
- Sarala Naicker, *South Africa*
- Fliss Murtagh, *United Kingdom*
- Edwina Brown, *United Kingdom*
- Vivekanand Jha, *India*

Supportive Care Conference Participants

Hilary Bekker, *UK*
Frank Brennan, *Australia*
Mohammed Benghanem Gharbi, *Morocco*
Aine Burns, *UK*
Katharine Cheung, *USA*
Sara Combs, *USA*
Cécile Couchoud, *France*
Juan J. Dapueto, *Uruguay*
Andem Effiong, *USA*
Ken Farrington, *UK*
Fredric Finkelstein, *USA*
Guillermo Garcia Garcia, Mexico
Brenda Hemmelgarn, *Canada*
Jean Holley, *USA*
Kitty Jager, *Netherlands*
Vanita Jassal, *Canada*
Kamyar Kalantar-Zadeh, *USA*
Holly M. Koncicki, *USA*
Peter Kotanko, *USA*
Adeera Levin, *Canada*
Hannah McLoughlin, *UK*
Rafique Moosa, *South Africa*
Olivier Moranne, *France*
Rachael Morton, *Australia*
Mohan M. Rajapurkar, MD, *India*
Jane O. Schell, MD, *USA*
Stephen Seliger, MD, MS, *USA*
Manjula Kurella Tamura, *USA*
Bjorg Thorsteinsdottir, *USA*
Kriang Tungsanga, *Thailand*
Mark Unruh, MD, MS, *USA*
Tushar Vachharajani, *USA*
Katie Vinen, *UK*
Christoph Wanner, MD, *Germany*
Ming-Hui Zhao, MD, PhD, *China*
Carlos Zuniga, *Chile*

Mexican Kidney Foundation

- The Mexican Kidney Foundation is a non-profit organization established in 2004

- Its mission is to improve the lives of people with kidney disease in Mexico by promoting prevention, facilitating access to high quality treatment and advancing knowledge of kidney disease through research

Sustainability

IPADE

INSTITUTO PANAMERICANO DE ALTA DIRECCIÓN DE EMPRESA
UNIVERSIDAD PANAMERICANA

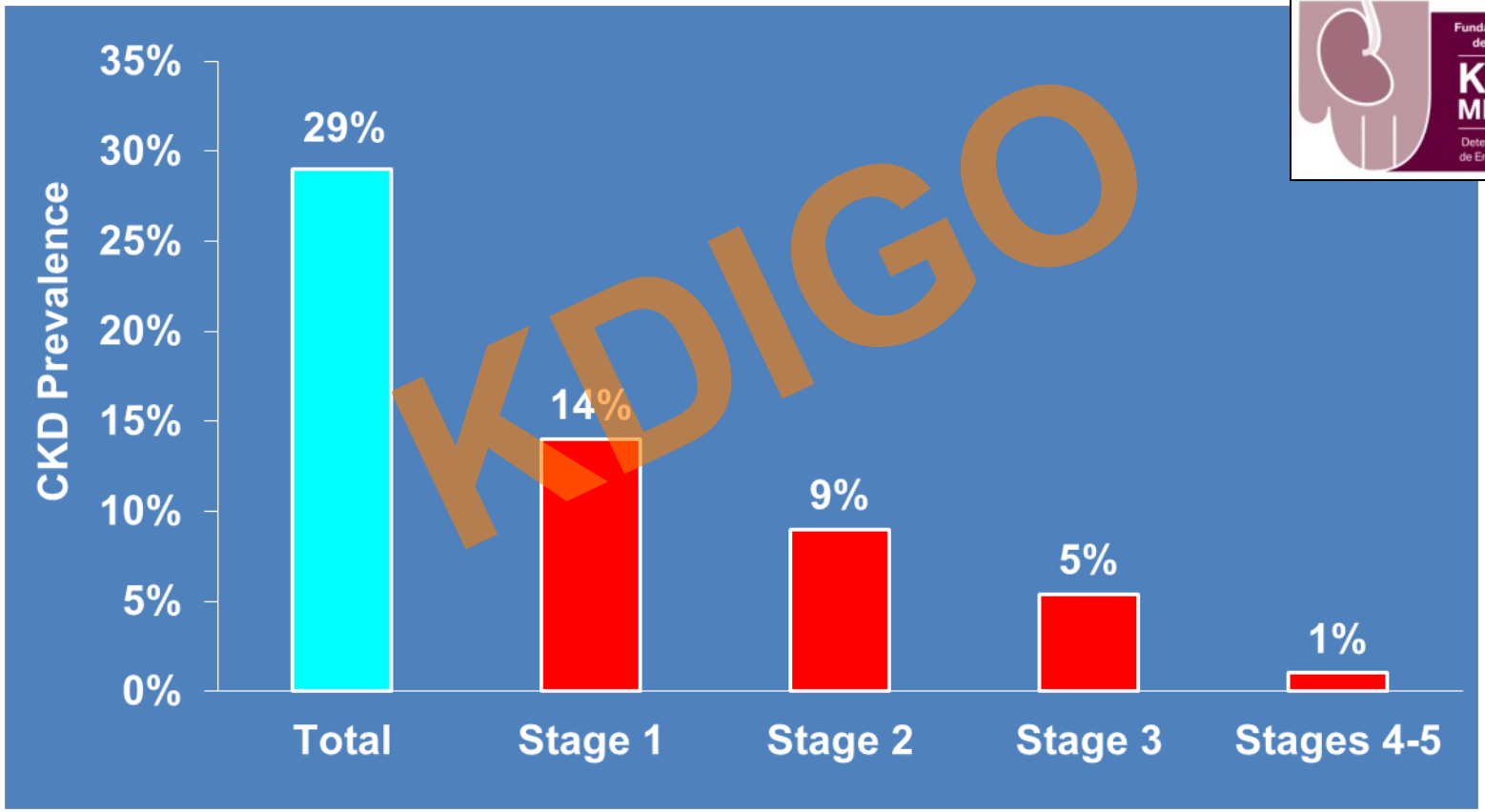
EPS 12 C 02
Septiembre, 2012

FUNDACIÓN MEXICANA DEL RIÑÓN, A.C.
¿ES POSIBLE DIRIGIR UNA OSC COMO EMPRESA?

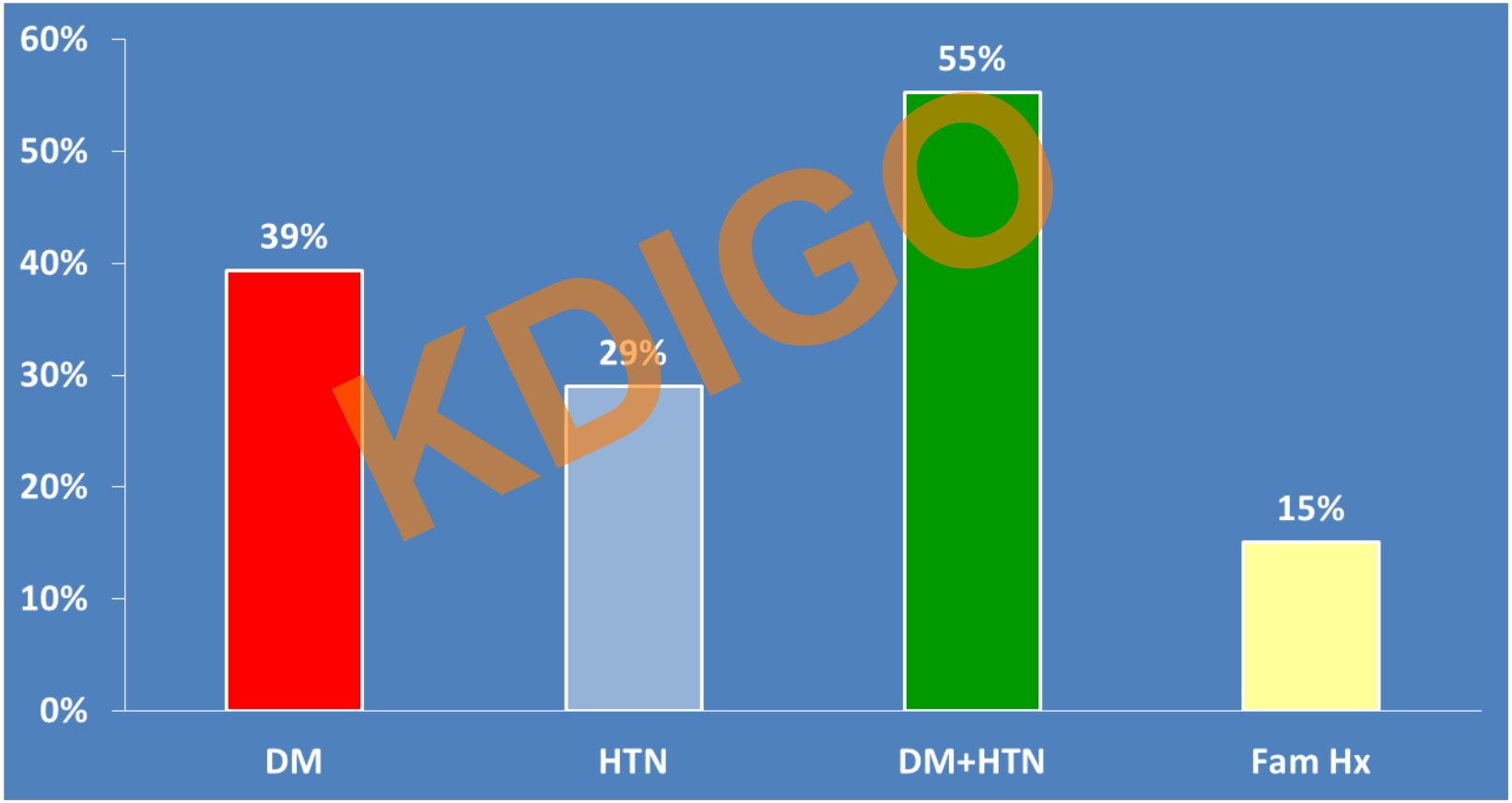
Activities

Patient Information Center (COI)	>12,500 patients served >62,500 have benefited
Dialysis program	>1,860 patients served >93,600 PD bags distributed >1,032 dialysis sessions
Way to transplant program	>85 children transplanted
Medications support program	>2,250 Epo >500 iron >2,875 immunosupressive agents
World Kidney Day	>50 million people
Research award	5 awards

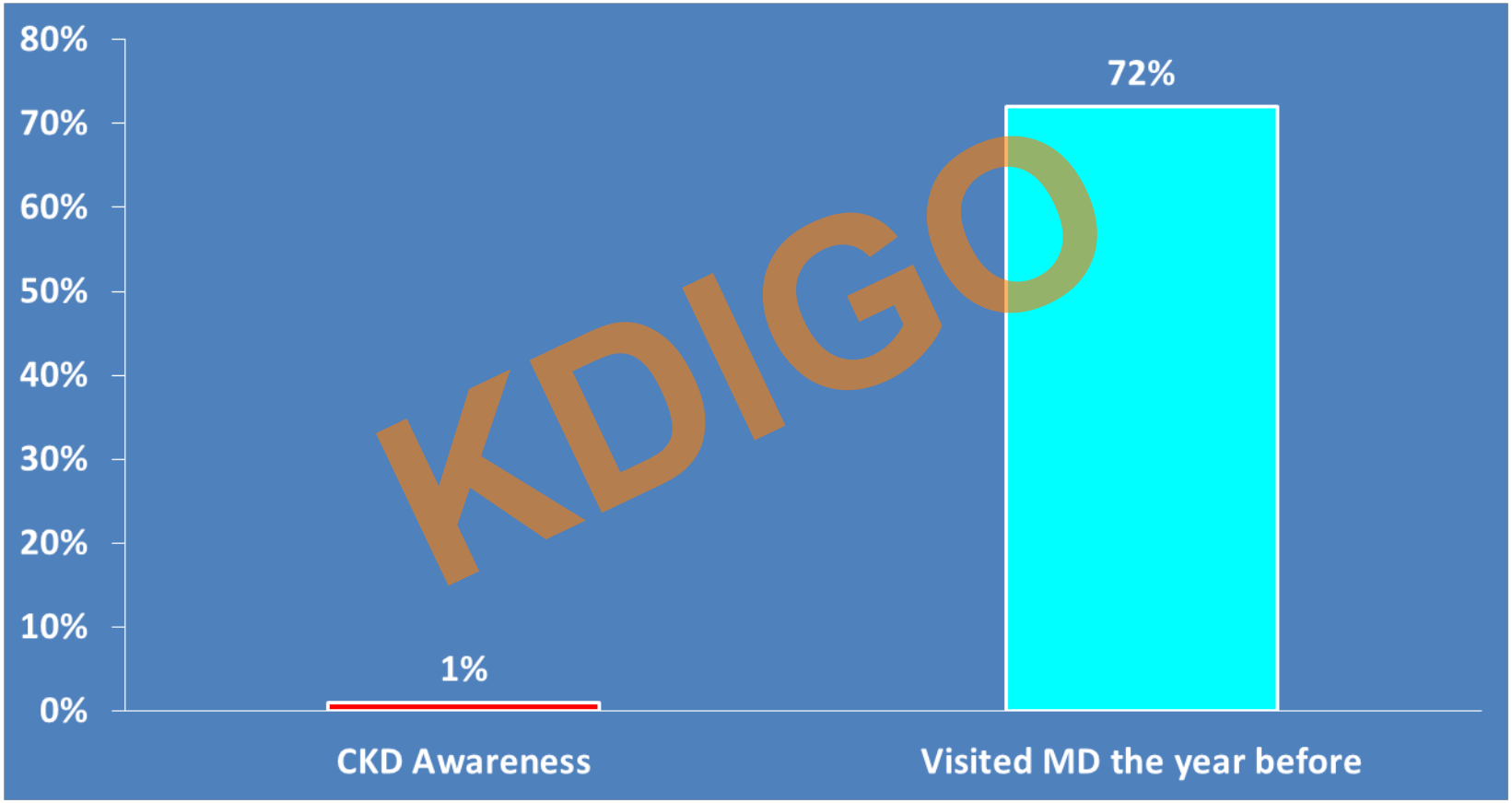
CKD Prevalence



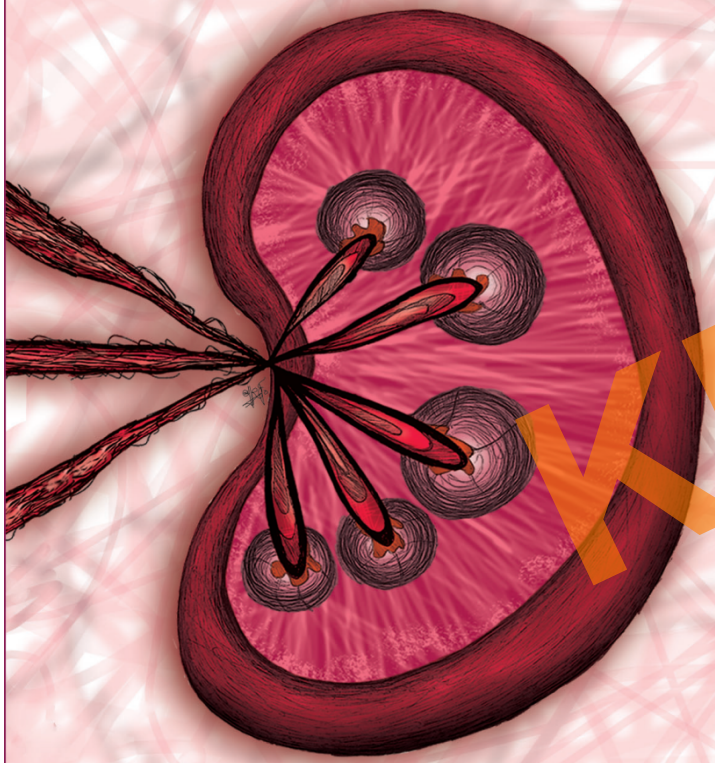
CKD Prevalence by Risk Factor



CKD Awareness



Guías Latinoamericanas de Práctica Clínica Sobre la Prevención, Diagnóstico y Tratamiento de los Estadios 1-5 de la Enfermedad Renal Crónica



KDIGO

SLANH
SOCIEDAD LATINOAMERICANA DE NEFROLOGÍA E HIPERTENSIÓN

FMR®
Fundación Mexicana del Riñón A.C.

2013 Clinical Practice Conferences

VI Reunión de la Asociación Nacional de Nefrólogos de México, A.C.

"Daño Renal Agudo: Un Problema de Salud Global"

En colaboración con la Universidad de Alberta, Edmonton, Canadá, la Sociedad Española de Nefrología Instituto Mexicano de Investigaciones Nefrológicas (IMIN), el Comité de Salud Renal en Poblaciones en Desventaja de la ISN-GO, ISN-GO Latinoamérica, la Sociedad Latinoamericana de Nefrología e Hipertensión (SLANH) y la Asociación Mexicana de Especialistas en Nutrición Renal (AMENUR).

20-23 de Marzo, 2013
Hotel Riu Plaza ,
Guadalajara, Jal, México

Dirigido a: Nefrólogos, Internistas, Cardiólogos, Medicina Crítica, Médicos Generales y Familiares, Enfermeras, Especialistas en Nutrición y Estudiantes de Ciencias de la Salud.

Idioma: Español e Inglés (habrá traducción simultánea)

Se otorgarán premios a los mejores 3 trabajos libres (carteles) presentados.

Guadalajara, Mexico

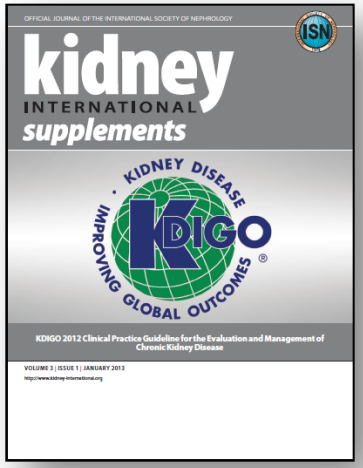
March 22, 2013

Approximately 250 local nephrologists, nurses, dieticians and GPs attended

Presentations on KDIGO Global Initiatives and AKI, Anemia and CKD Guidelines

2013 Clinical Practice Conferences

- Update on KDIGO CKD Guidelines
- Attended by physicians and nurses from several Latin American countries



Future KDIGO Conferences

- **IMIN meeting (November, 2013, Cancun, Mexico)**
  - KDIGO lipid guidelines (C. Wanner)
  - KDIGO anemia guidelines (G. Obrador)
  - KDIGO transplant guidelines (J. Alberu)

- **2014 SLANH meeting (Santiago, Chile)**
  - Program is being planned

FMR's Mission

To improve the lives of people with kidney disease in Mexico by promoting prevention, facilitating access to high quality treatment **including supportive care** and advancing knowledge of kidney disease through research.

Dissemination of Supportive Care

- **Pre-congress course on renal supportive care**
  - IMIN, Mexico City, June, 2014
- **KDIGO clinical conference**
  - SLANH congress, Santiago, Chile, August 2014
- **Renal supportive care course**
  - National Institutes of Medical Sciences and Cardiology & Universidad Panamericana School of Medicine, Mexico City

Acknowledgements

ANCORA
Agente de Seguros y de Fianzas, S.A. de C.V.

KDIGO

AMGEN®

Sara Davison
Conference Co-Chair

Sara Davison
Disclosure of Interests

Consultancy

Otsuka: 2013

- Pain assessment tool development

Purdue: 2013

- RCT (analgesic) protocol development

Global Epidemiology of CKD

Tremendous growth in CKD continues

- Driven by high burden of diabetes, hypertension, and vascular disease
- Increase in age, comorbidity, and functional impairment (both high and LMIC)
  - US: ~57% increase in the # of incident octogenarians and nonagenarians between 1996-2003
- Most rapid increases are occurring in low and middle income countries
- Care gaps are highly prevalent in CKD
  - Biggest gaps observed in the poorest patients
  - Unmet needs

Patient Perspectives in Clinical & Research Priorities

- **A relative lack of randomized trials that address nephrology**
- **Most of the large mortality trials in nephrology have been null**
  - Suggests we should be considering other clinically relevant outcomes (in addition to mortality)
- **Patients' priorities in care are rarely considered when setting clinical and research agendas**
  - Patient-centred care?
  - What little we know is that they often have different perspectives about which outcomes matter most

Top 10 Research Priorities: Canadian Advanced CKD Patients

1. Best way to **enhance communication** between HCP & patients to maximize patient participation in decision-making? Different **modalities of dialysis**, facilitate **self-management**.
2. The **impact of dialysis modalities on QOL, mortality and patient acceptability**, and are there specific patient factors that make one modality better for some patients with kidney failure than others
3. Effective treatment(s) of **itch**
4. Strategies to increase kidney transplantation
5. The **psychological and social impact** of kidney failure on patients, their family, and other caregivers, and how to reduced
6. Best ways to promote heart health, including management of blood pressure
7. Impact of **dietary restrictions** (sodium, potassium, phosphate) separately, and when taken in combination, on important outcomes including QOL
8. Best ways to manage **symptoms** including poor energy, nausea, cramping, and restless legs
9. Causes and effective treatment(s) of **depression**
10. Best vascular access

Andreas Laupacis
Brenda Hemmelgarn
CANN.NET

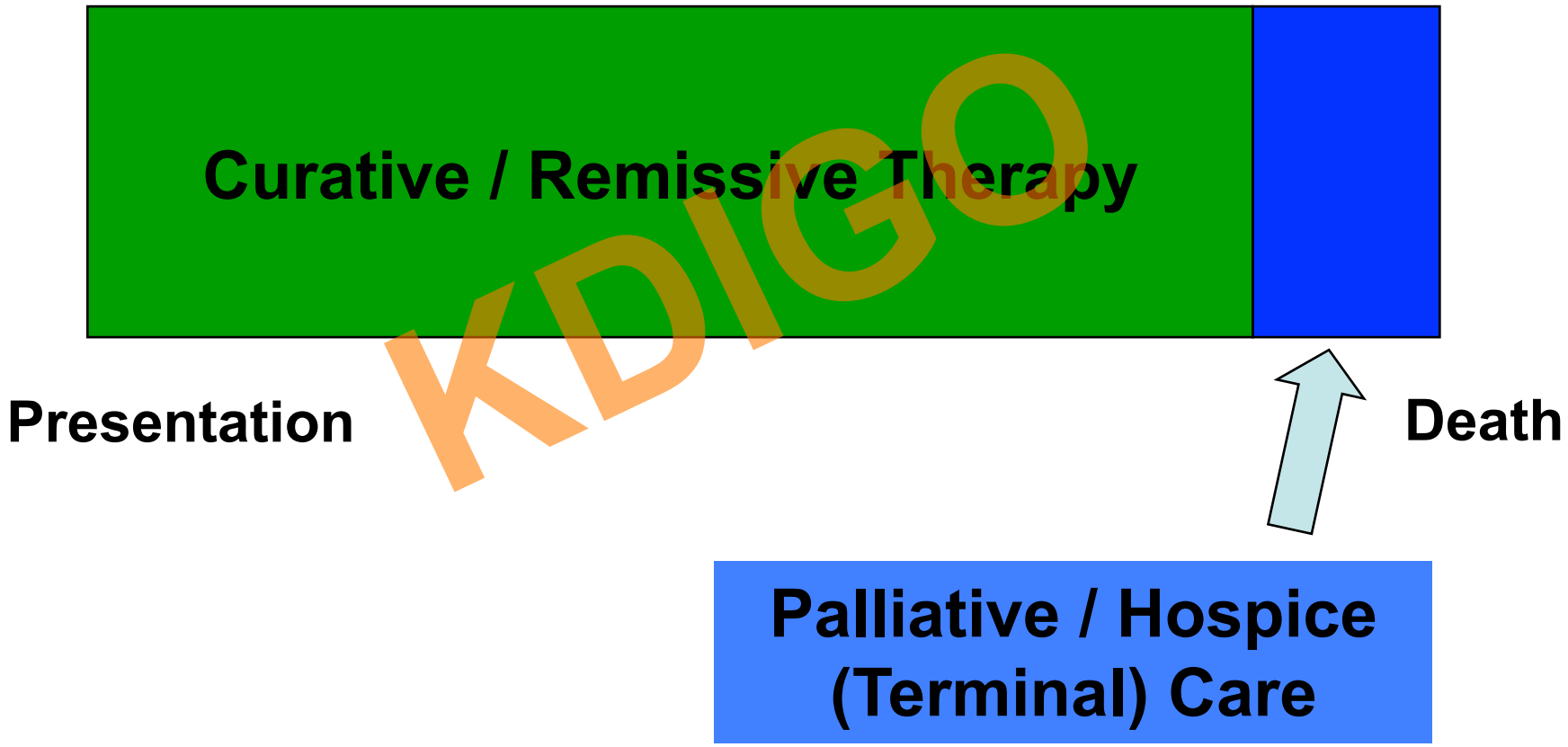
Aims of This Controversies Conference

A comprehensive analysis of palliative and end-of-life care for patients with advanced CKD is timely and represents an area of great clinical need.

1. Summarize the state of knowledge of renal palliative care
2. Discuss what recommendations can be derived from the available knowledge
3. Determine whether there is sufficient evidence to move forward with guideline development
4. Assess what needs to be undertaken in the future to improve the evidence-base for clinical management
5. Consolidate findings and submit a consensus statement for publication.

The global integration of appropriate and quality palliative care into standard renal care

What is Palliative and Supportive Care?



The Evolution of ~~Palliative~~ Supportive Care

Palliative care is an approach that **improves the quality of life** of patients and their families facing (~~life-threatening/serious~~) illness, through the **prevention and relief of suffering** by early identification and impeccable assessment and treatment of **pain and other physical, psychosocial or spiritual concerns**.

It is appropriate at **any age** and **early in the course of illness**, and can be provided together with other therapies that are intended to **prolong life**, such as dialysis.

Palliative care offers a support system to help patients live as actively as possible until death and also offers a support system to help the family cope during the patient's illness and in their own **bereavement**.

Conceptual Framework for Palliative Care/Supportive Care

Elements of Palliative Care for Patients with Complex Chronic Illness

- Pain and Symptom Assessment/Management
- Team approach to honest communication about prognosis and treatment options
- Shared decision-making: inclusion of family/legal agent in discussions
- Timely completion of advance care planning and determination of medically appropriate goals of care
  - Transferrable throughout health care settings

Specialist v. Generalist Palliative Care

Much of the provision of palliative care will and needs to be delivered by clinicians other than PC specialists such as those caring for patients with chronic disease (renal, cardiology etc.), GPs, community nurses, home care staff, hospital staff etc.

Specialist palliative care

Health and allied health professionals with specialist or accredited training in palliative care delivery.

Generalist palliative care

Health and allied health professionals with no specialist or accredited training in palliative care..

Challenges / Barriers to Consider

Physician attitudes & behaviours: key drivers of care gaps

There are not enough specialists (PC/nephrology) – even in developed countries

- Role of nephrology v. role of specialist palliative care?
- High levels of integration of palliative care with nephrology
- Multidisciplinary teams

Lack of knowledge/training/education in EOL care

- Difficult to model and change behaviour
- will likely require mandated policy changes (KDIGO guidelines)
- Implications for implementation?

Challenges / Barriers to Consider

Developing Countries

Population is aging with a heavy burden of noncommunicable disease – there is a high demand for palliative care

WHO Bulletin on PC (2013) "The majority of people who need palliative care live in low and middle income countries where there is little or no access to even basic palliative care services and where the majority die in needless pain and suffering."

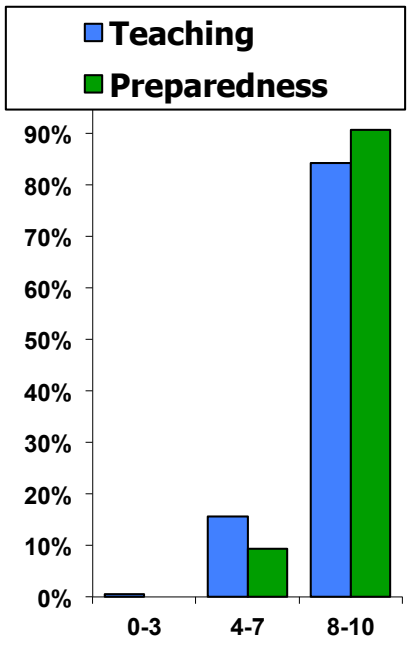
Estimated that a 40 million people worldwide need PC every year (Global atlas of palliative care),

- ~42% of countries have no PC
- ~30% very limited PC services that reach a small % of the population

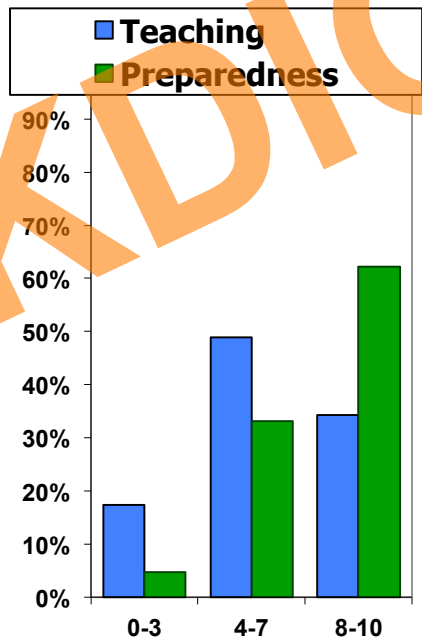
Lack of Training & Comfort with EOL Care

61% of US/Canadian nephrologists report feeling not well prepared to make EOL decisions Davison CJASN 2006

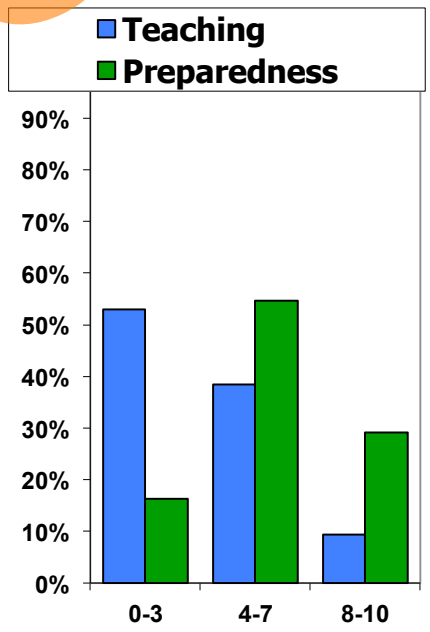
HD



Distal RTA



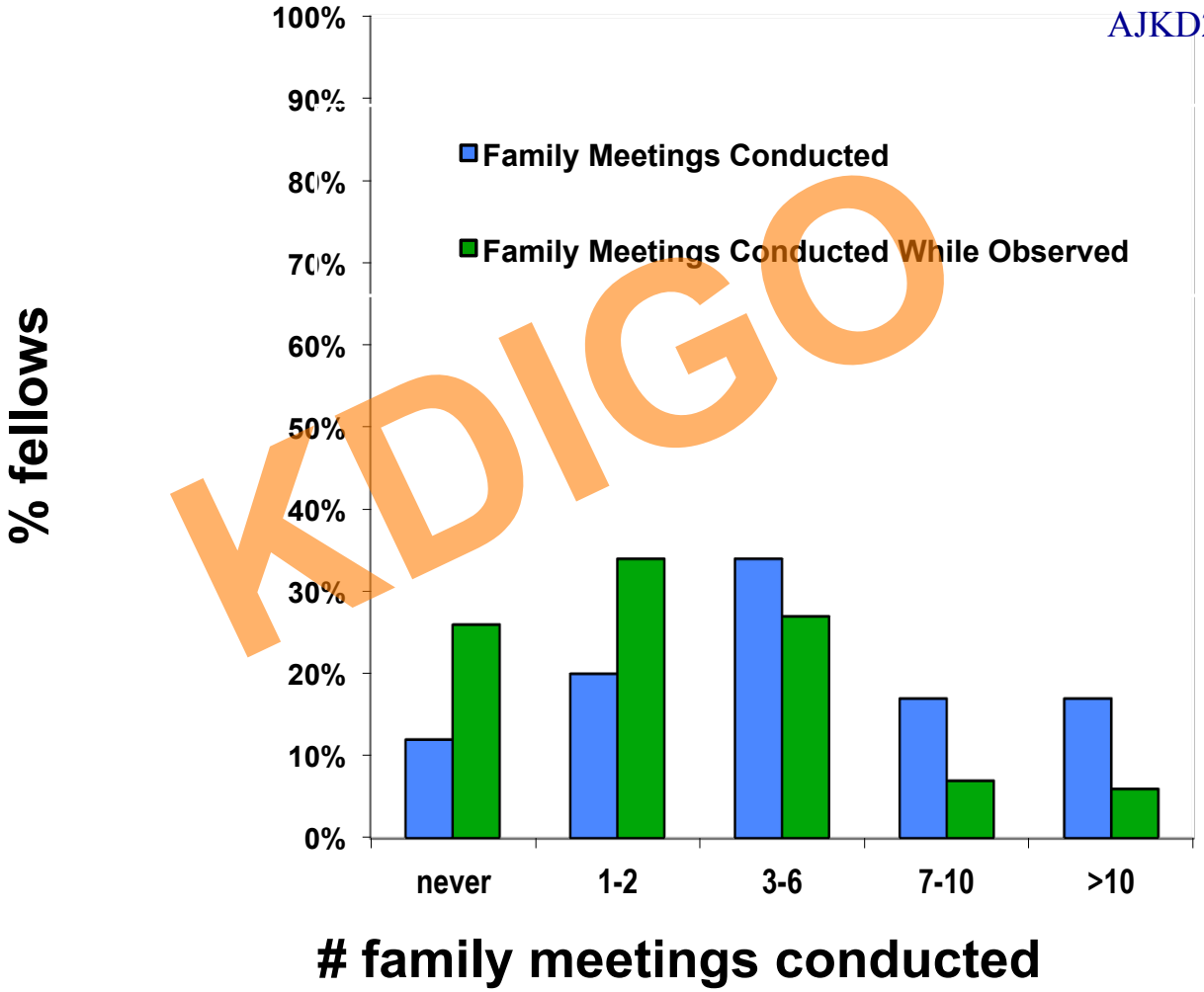
EOL Care



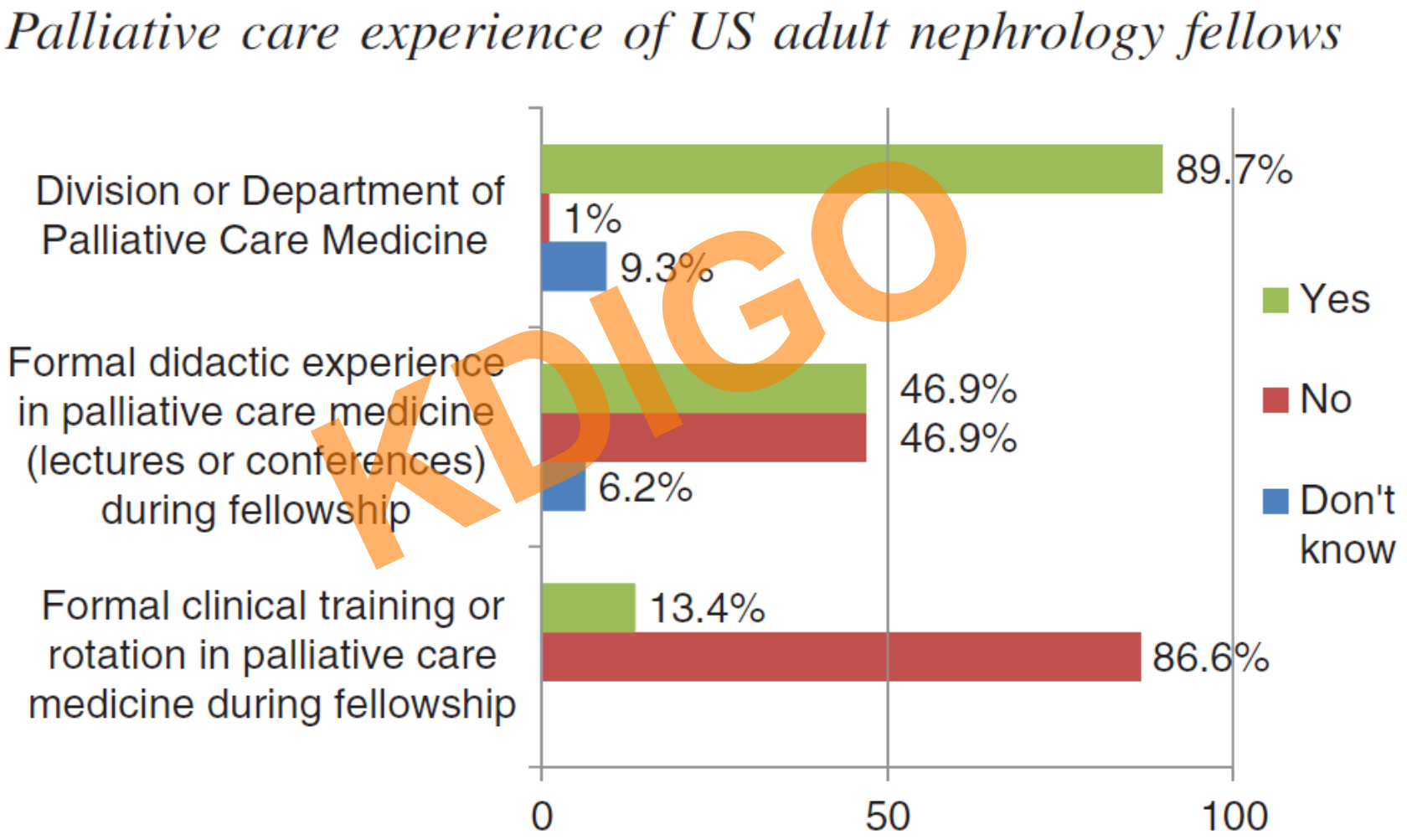
AJKD2003;42:813-820

End-of-life Care Training in Nephrology

AJKD2003;42:813-820

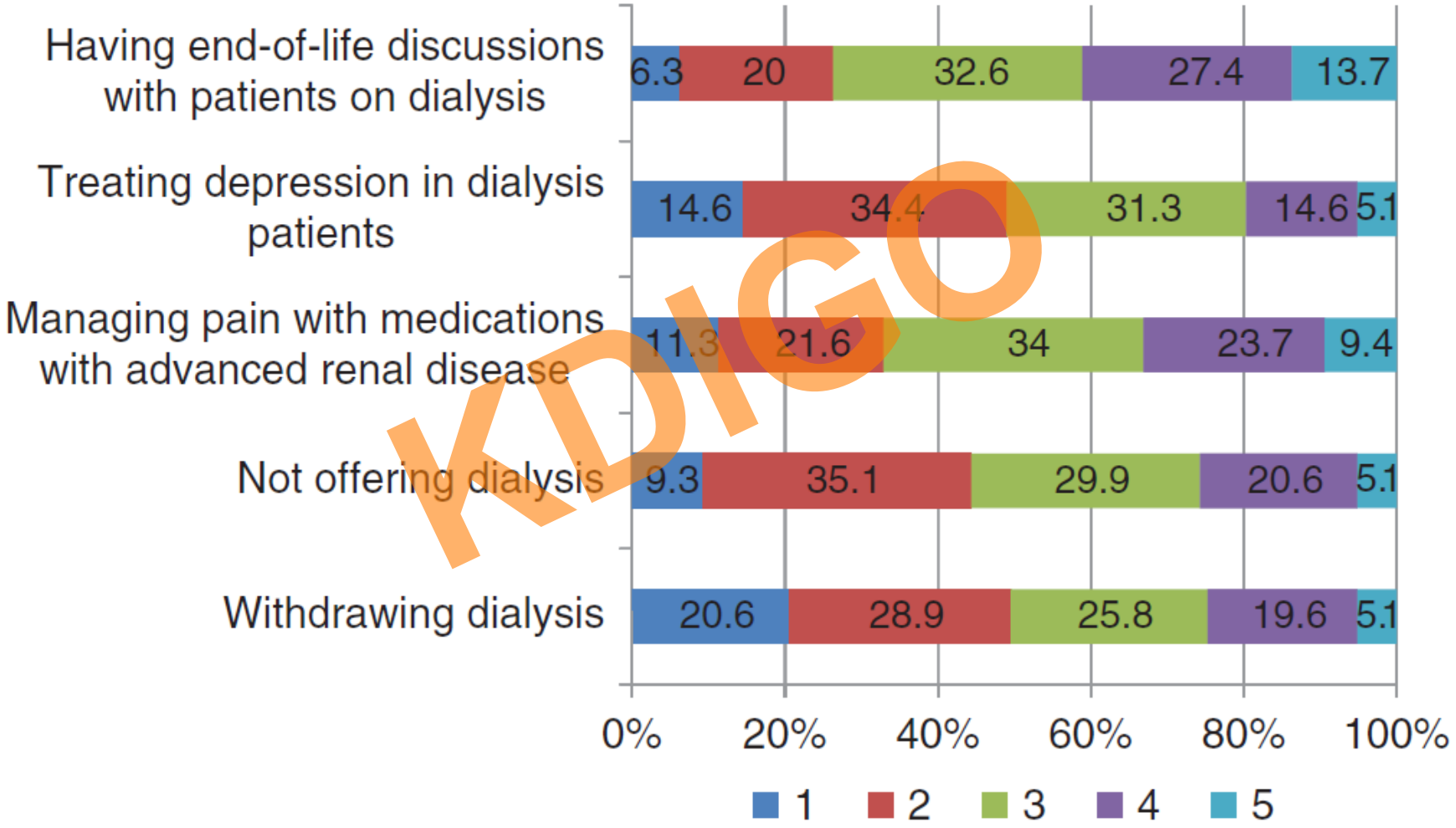


Palliative Care Experience of 105 US Adult Nephrology Fellows



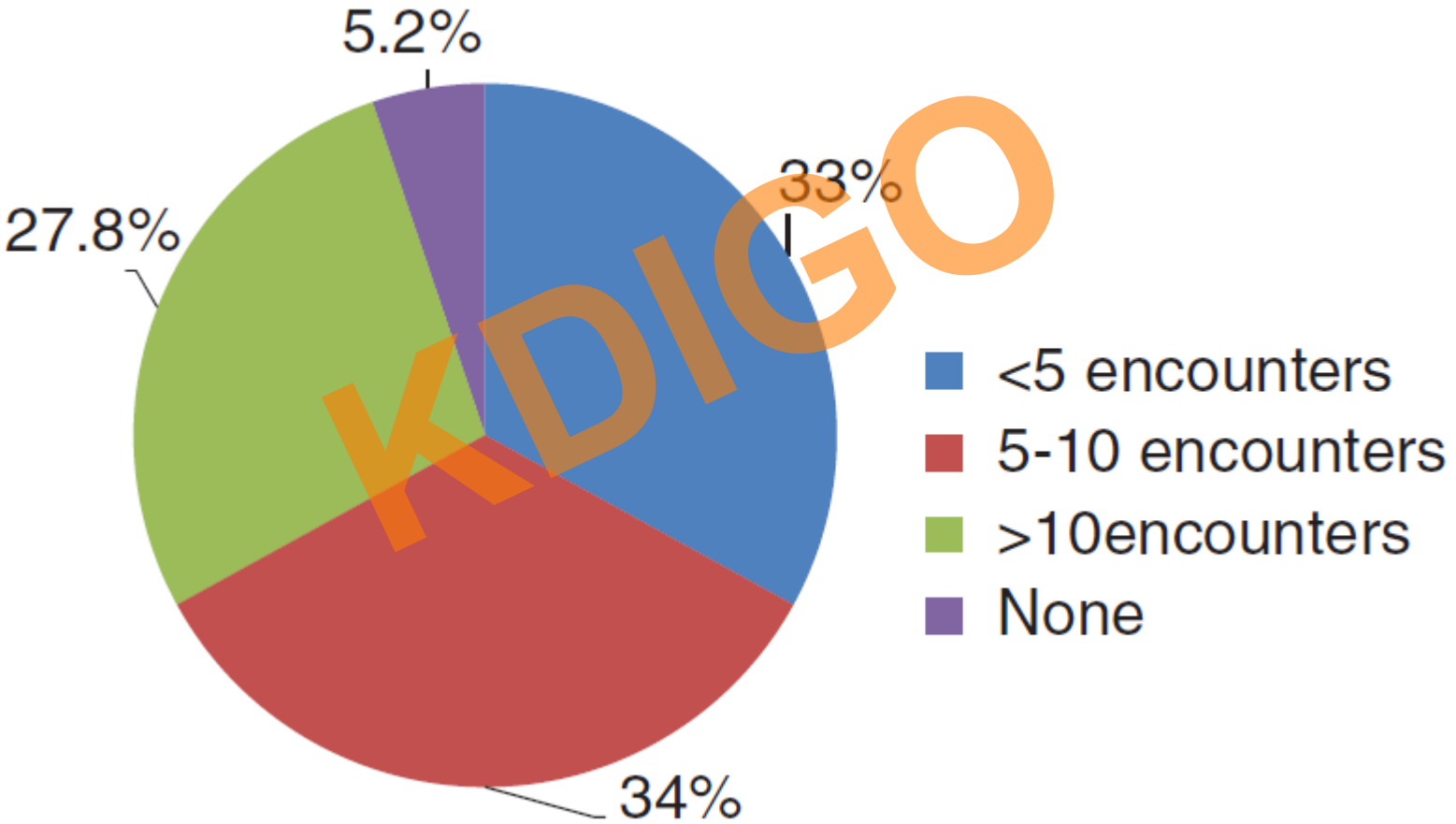
Shah H et al Renal Failure 2013 (in press)

Comfort Level on Palliative Care Related Issues

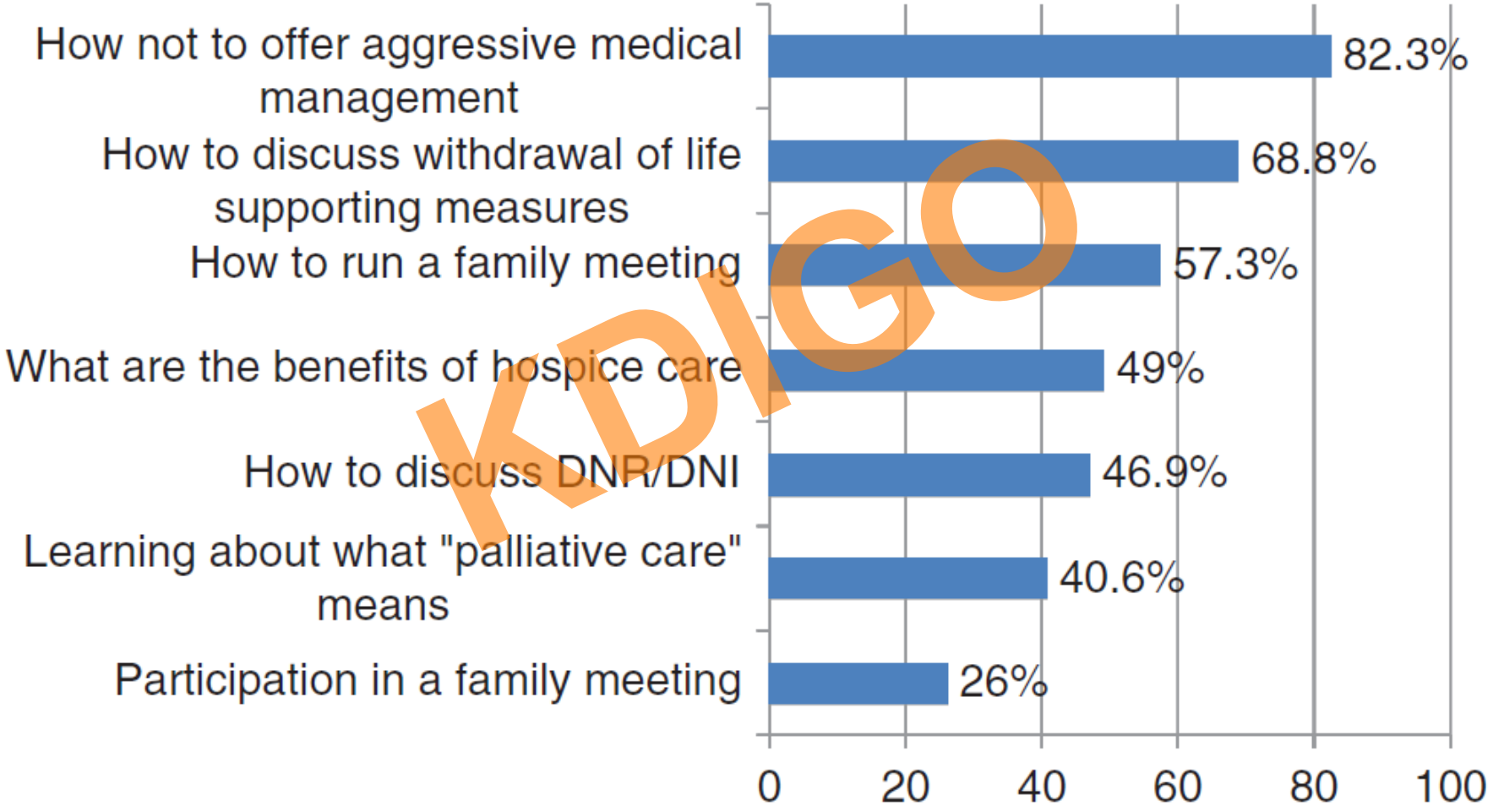


1 being least comfortable, 5 being most comfortable

EOL Discussions with Advanced CKD Patients



Perceived Benefits of Palliative Care Rotation During Nephrology Fellowship



Levels of Evidence Required to Promote Guideline Development

Lack of data should not be used to justify inaction if it is clear that the burden is substantial and that the status quo is not acceptable

- What levels of evidence are required?
- Shape clinical care and a research agenda concurrently?

American Society of Clinical Oncology:2012

"While evidence clarifying optimal delivery of palliative care to improve patient outcomes is evolving, no trials to date have demonstrated harm to patients and caregivers, or excessive costs, from early involvement of palliative care. **Therefore it is the Panel's expert consensus that combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.**"

"Strategies to optimize concurrent palliative care and standard oncology care, with evaluation of its impact on important patient and caregiver outcomes (e.g.. QOL, survival, health care services utilization, and costs) and on society, should be an area of intense research."