

Palliative Care: European Experience

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Disclosure of Interests

- Baxter Healthcare – speaker fees, educational grant, research grant
- Fresenius Medical Care – speaker fees, consultancy

Europe



- Approx 50 countries
- Population (2005) 731 million – 1/9 world
- 87 distinct "peoples of Europe", of which 33 form majority population in at least one sovereign state
- Home to the highest number of migrants of all global regions at 70.6 million people

Treatment withdrawal and palliative care related to country

Country	General comments
Netherlands	Euthanasia legal since 2002. Public knowledge of advance decisions found to be high. Symptom control less good among ethnic minorities (Turks, Moroccans)
Belgium	Euthanasia legal since 2002. Model of integral palliative care which is inclusive of euthanasia
Germany	German physicians more likely to exclude patients, patients' families and non-medical staff from decision making process. High level of opposition to euthanasia and physician assisted suicide, but high level of acceptance of palliative/terminal sedation

Gysels M et al, PLOS one 2012



Treatment withdrawal and palliative care related to country

Country	General comments
Norway	EOL care in Norwegian nursing home perceived as good by families, but general reluctance to talk about death. Norwegian physicians have more conservative attitudes than other western countries in regard to treatment limitation
Spain	Tradition of partial and non-disclosure. Majority of doctors state that they would inform patient only in certain circumstances or if requested by patient.
Italy	Expanding numbers of hospices and new palliative care policies since 1999. Still low and often incorrect awareness of palliative care among general public

Gysels M et al, PLOS one 2012



Treatment withdrawal and palliative care related to country

Country	General comments
Greece	Withholding CPR is common phenomenon in Greek ICUs; withholding other therapies is not routine and withdrawal of support is infrequent. Paternalistic model predominates in decision making.
France	Decisions not made by patients/families on their own. Multicentre ICU study showed 86% ICU staff members believed that families should be asked to participate in decision making round withholding/withdrawal life sustaining treatment but only 39% had actually done so.

Questions to European colleagues

- Is palliative care available just in hospitals or is there a community service as well?
- Do palliative care nurses visit patients at home?
- Are patients referred to palliative care just in the last few days of life or can they be referred earlier?
- Do hospices accept patients with ESRD or just cancer?

Questions to European colleagues

- Are costs of hospices covered by the healthcare system?
- Is palliative care included in the curriculum for renal trainees?

Palliative care: hospital or community?

- Hospital only – Romania
- Hospitals and nursing homes: Norway
- Hospital and community: UK, Ireland, Denmark, Germany, Austria, Spain (but varies between regions), Belgium
 - France, theoretically both, but mostly hospital

Community Palliative Care Nurses

- None – Romania
- Community nurses but not trained palliative care: Norway, Denmark, Spain
 - France but nurses directed from hospital
- Community palliative care nurses: UK, Ireland, Germany, Austria, Belgium

Timing of palliative care referral

- Early – UK, Romania, Ireland, Norway, Denmark, Germany, Austria, France, Belgium
- Spain – no barrier to early but usually referred late

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Access to hospices

- Cancer only: Romania, Norway, Germany,
- ESRD partial access: Ireland (parts)
- ESRD full access: UK, Ireland (parts), Denmark (if not on dialysis), Austria, Spain, France (if not on dialysis), Belgium (including on dialysis),

Hospice costs covered by healthcare system

- Yes: Romania, UK, Ireland, Norway, Denmark, Germany, Spain, France
- No:
 - Austria – palliative care in hospital wards and at home covered; patients have to pay for hospices
 - Belgium – medical costs covered; patients pay for food and board

Palliative care in renal curriculum

- Yes: UK, Ireland, Norway, Austria (but little emphasis),
- No: Romania, Denmark, Germany, France, Belgium
- Partial: Spain

Dialysis withdrawal and palliative care in Europe

Preliminary results of an international survey

KDIGO



Disclosure of Interests

Kitty Jager

- No relevant disclosures

KDIGO

Palliative care and dialysis withdrawal are high priority topics in Europe

In a consensus meeting of nephrologists and geriatricians on managing CKD in the old and frail (November 2013),
‘Organization of care’ and
‘Continuing dialysis or not (withdrawal)’
were ranked among the top 10 most important topics

Survey Respondents – Renal clinicians (n = 541)

Characteristics	%
Practicing as nephrologist (>20 years)	95 (47)
Aged 51 – 65 years	44
Working in university center	53
>75% of time spent in direct patient care	48
Number of patients under direct care	
>50 HD	58
>10 PD	62
Country of practice (top 3 of 45)	
Italy	15
Spain	9
UK	8

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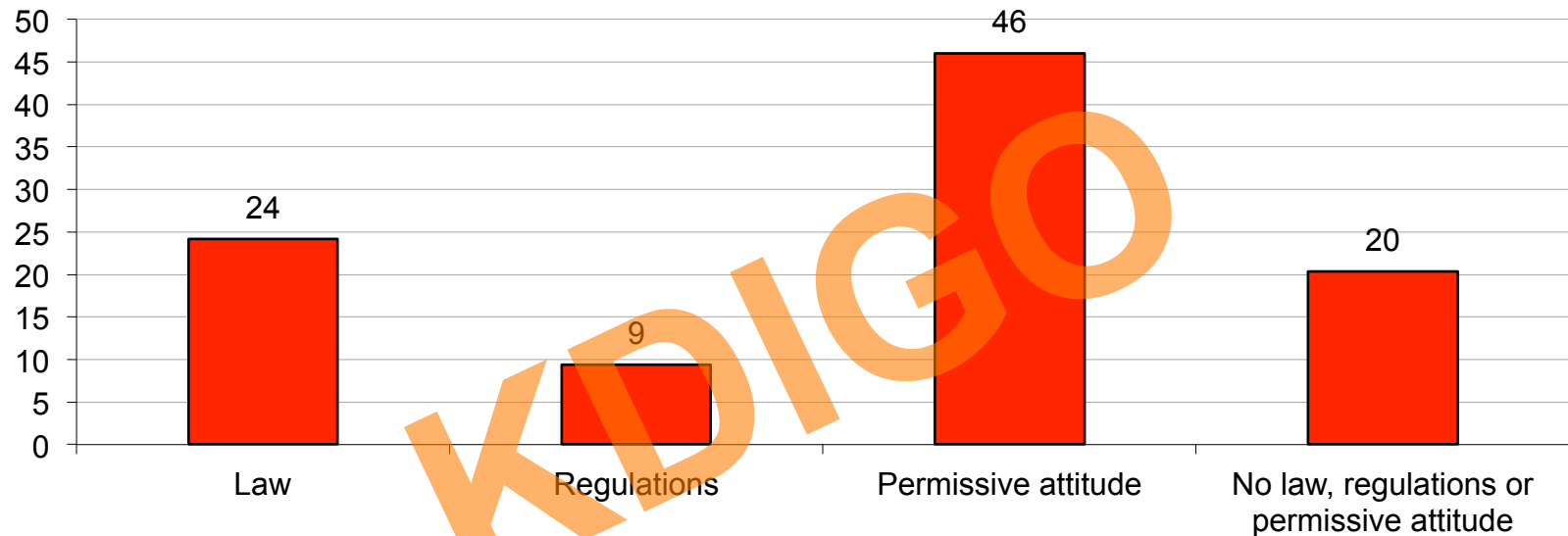
Survey Respondents – Geriatricians (n = 100)

Characteristics	%
Practizing \geq 10 years as a geriatrician	54
Aged 35-50 years	66
Working primarily in a hospital (university)	95 (66)
>75% of time spent in direct patient care	49
Country of practice (top 3 of 14)	
Spain	44
Belgium	15
United Kingdom	12

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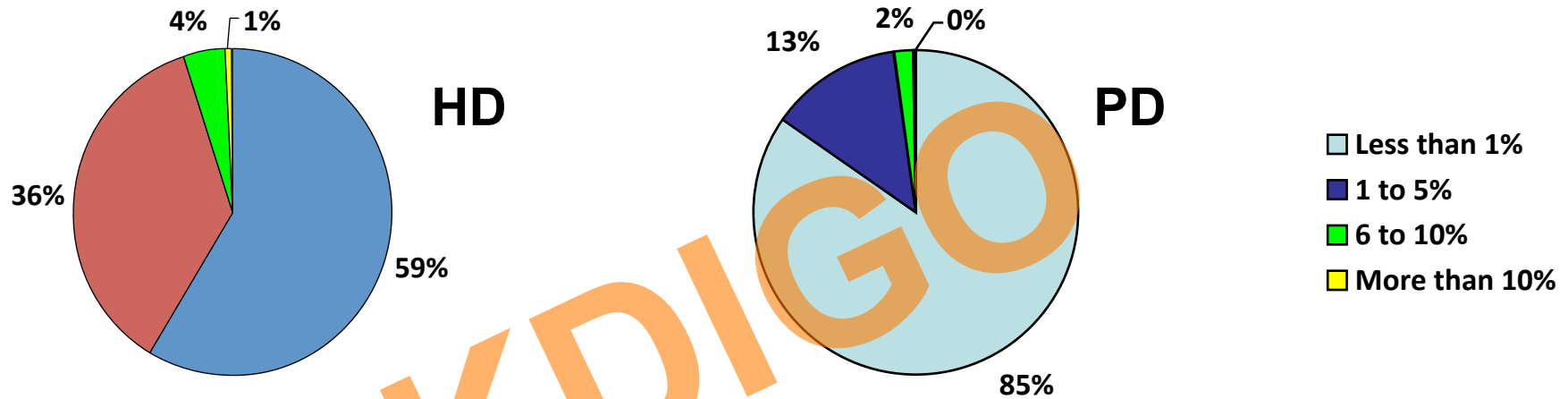
Palliative care: Laws, regulations and attitudes



In your country, is there an explicit law or official regulation on the right for palliative care in patients suffering from terminal stages of incurable disease who wish to abandon potentially life-extending treatment, like dialysis?

If not, do you feel that the general attitude in your country towards those who ask for or provide such care is 'permissive' or liberal?

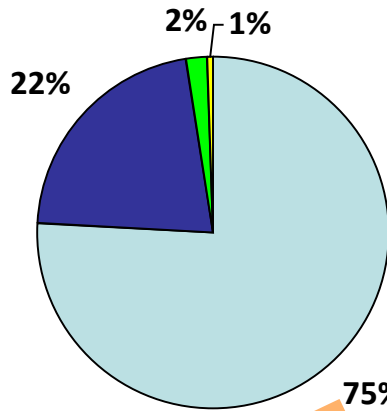
Occurrence of withdrawal *nephrologists (overall)*



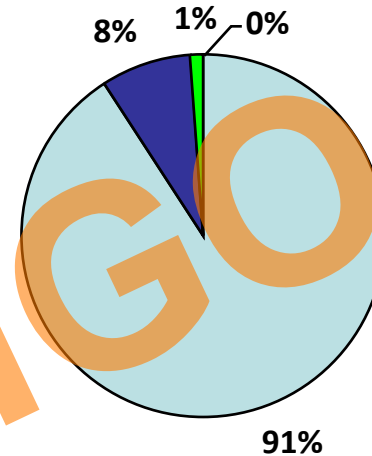
In the last 12 months, what was the (estimated) % of HD/PD patients under your direct care who actually withdrew or started the process of withdrawing from dialytic treatment?

Occurrence of withdrawal nephrologists (by 'permitted category')

Not permitted



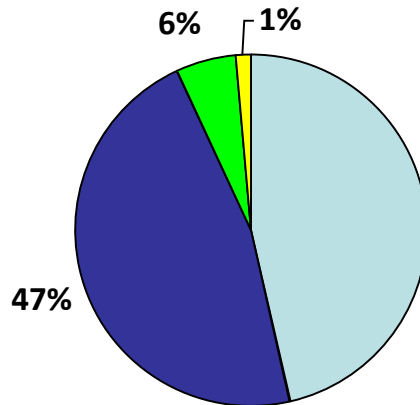
HD



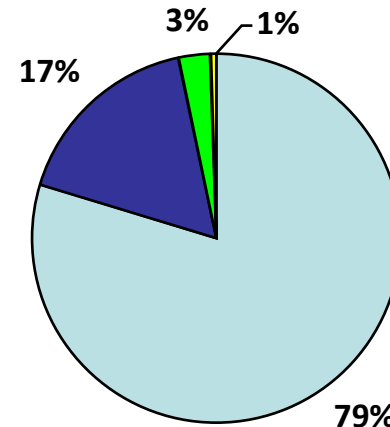
PD

- Less than 1%
- 1 to 5%
- 6 to 10%
- More than 10%

(In)formally permitted

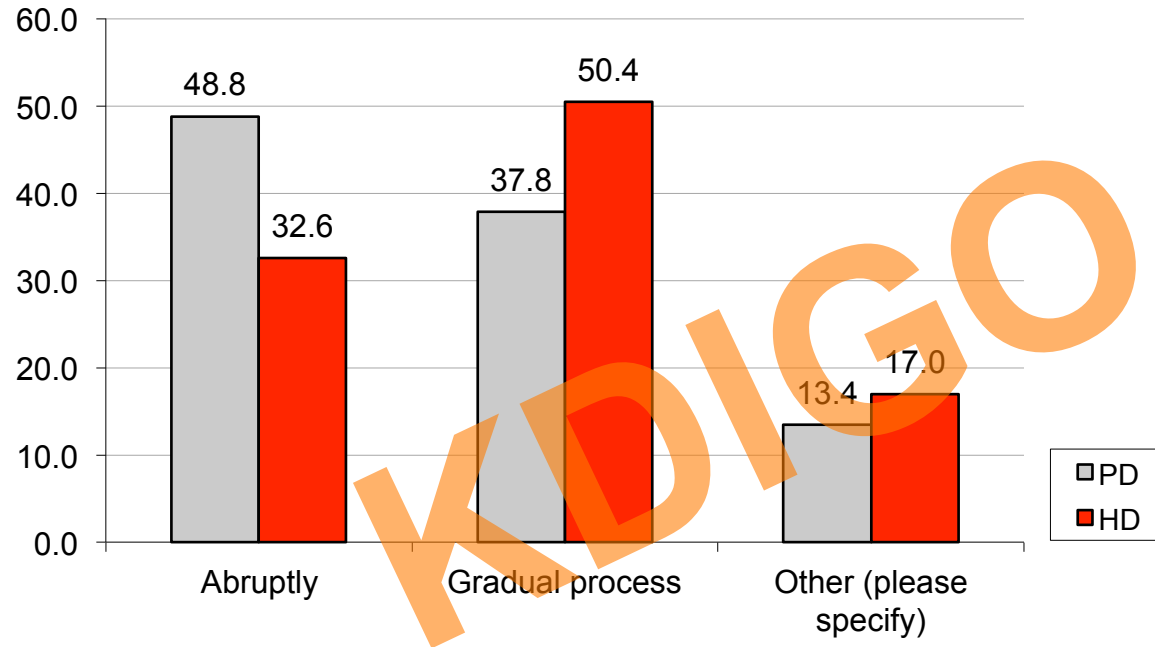


HD



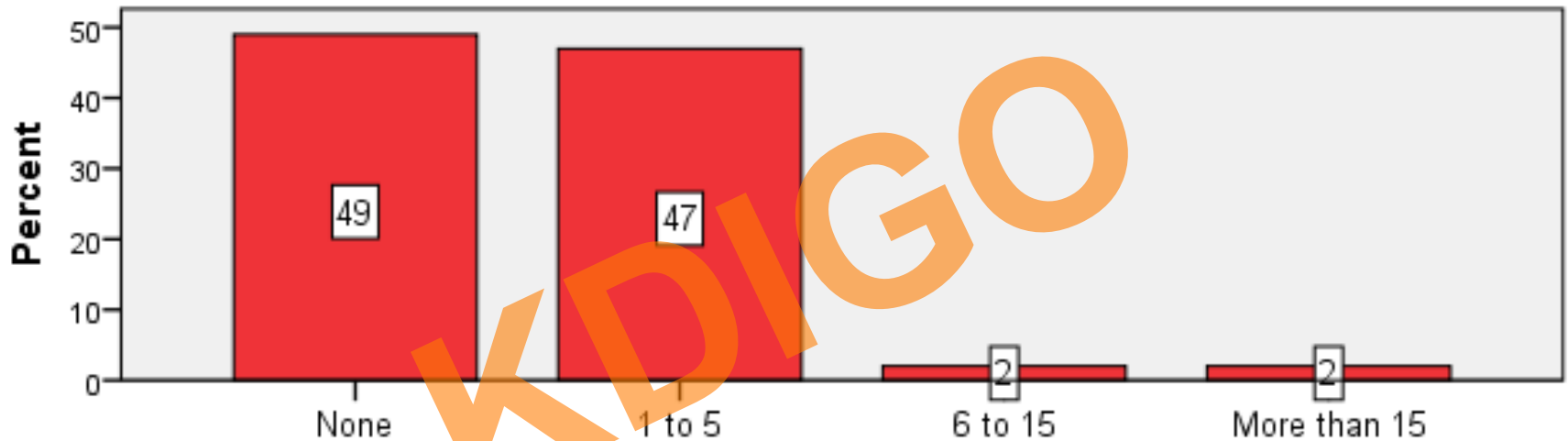
PD

Withdrawal: abrupt vs. gradual



In your unit, is PD/HD usually withdrawn abruptly or is it a gradual process, for example by gradually reducing the number of exchanges or sessions?

Consulted/involved in withdrawal *geriatricians*



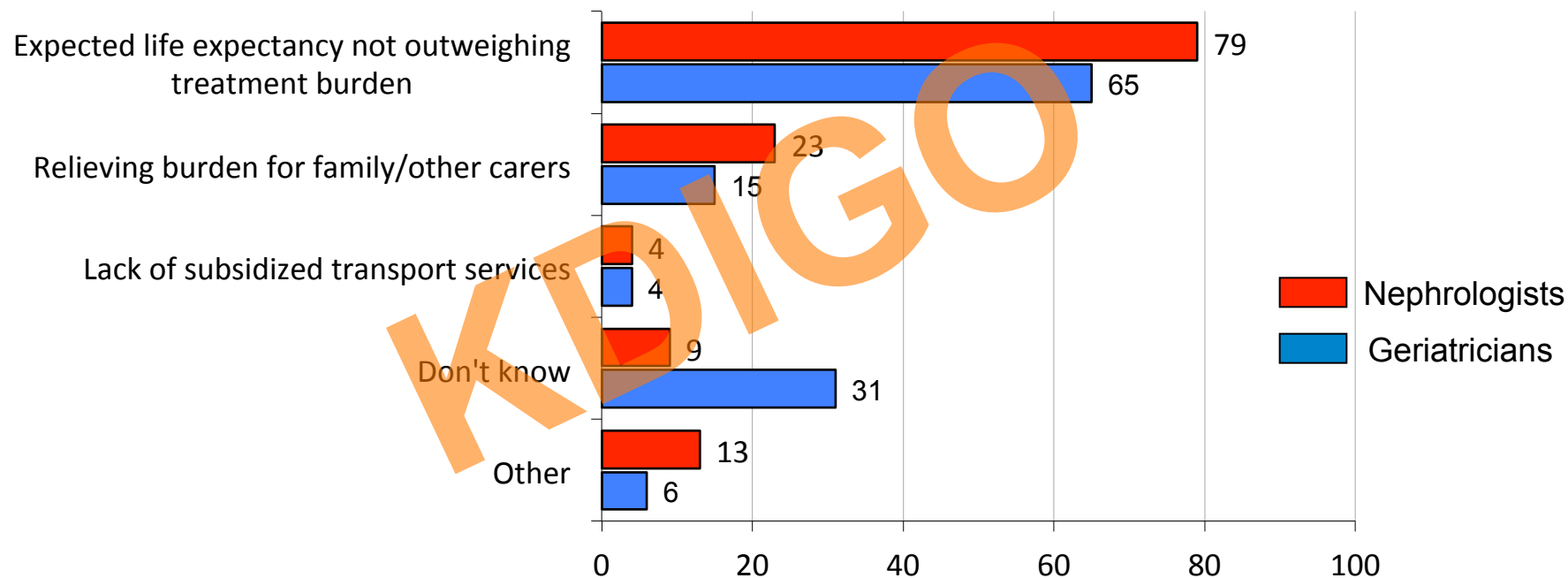
In the last 12 months, what was the absolute number of actual dialysis withdrawals in your institution in which you were consulted or involved as the attending physician?

Involvement of geriatricians in decision making and palliative care

- **Nephrologists:**
 - **90% reported that a geriatrician was consulted/ involved in <25% of the decisions on withdrawal**
- **Geriatricians:**
 - **65% considered care of frail and older dialysis patients a joint effort of nephrologists and geriatricians**
 - **84% said a policy for referral for geriatric assessment of such patients was lacking**
 - **86% said geriatricians' involvement in withdrawal decision making was not protocolized**
 - **89% said organizing/providing palliative care after withdrawal was not protocolized;**

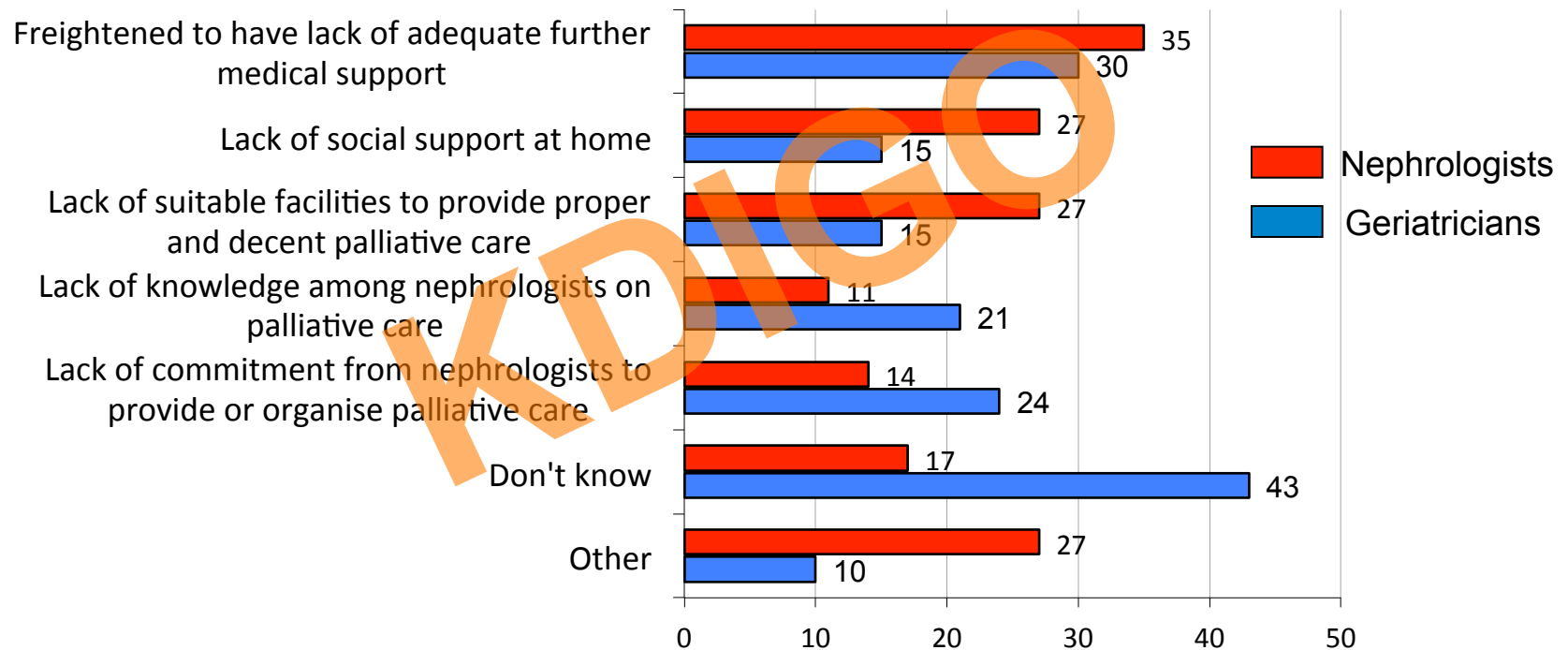
Patient reasons to withdraw

as perceived by nephrologists or geriatricians



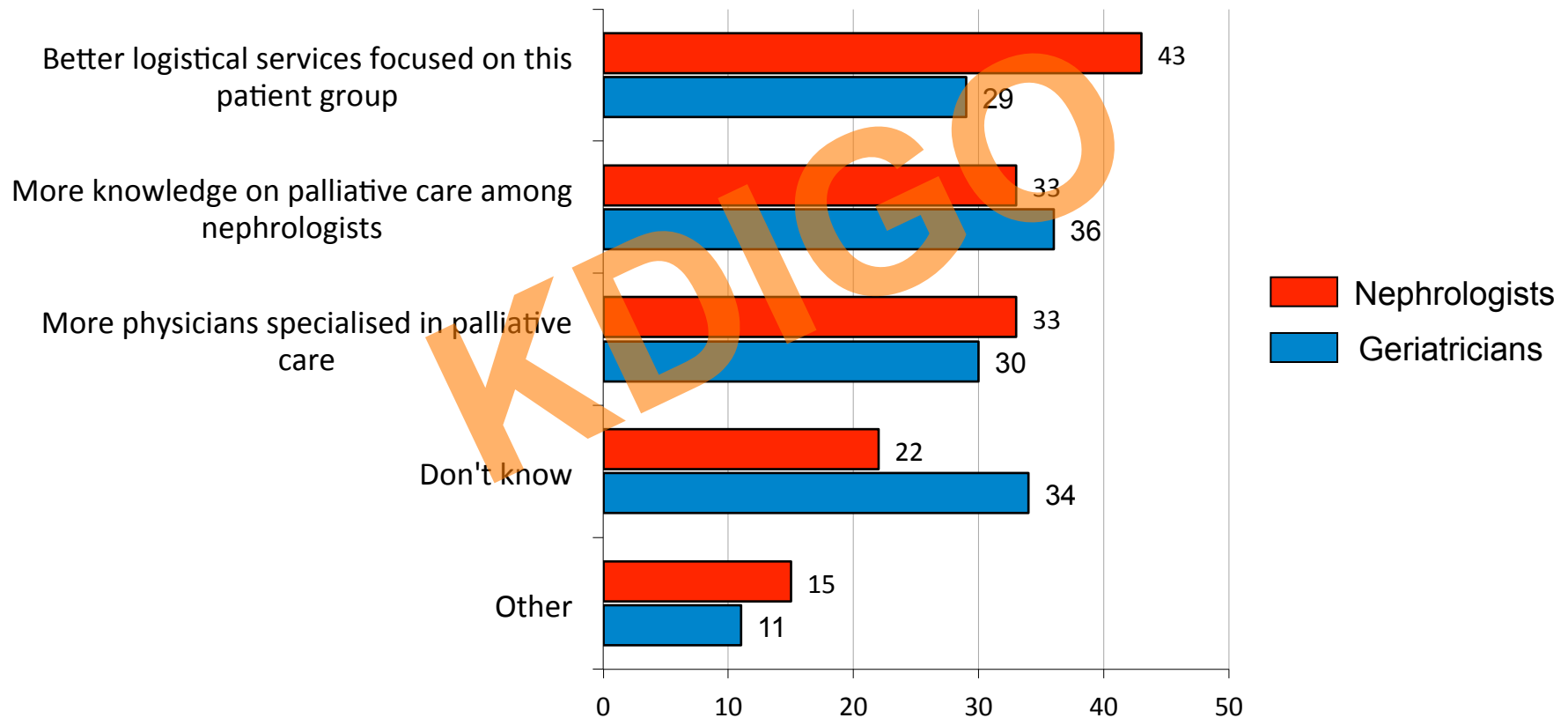
For patients in my institution who decided to actually withdraw from dialysis, I believe their main reason was ...(tick all that apply)

Patient reasons not to withdraw *as perceived by nephrologists/geriatricians*



**For patients in my institution who considered withdrawal but in the end decided to continue dialysis, I believe their main reason for continuation was...
(tick all that apply)**

More patients would withdraw if ... *as perceived by nephrologists/geriatricians*

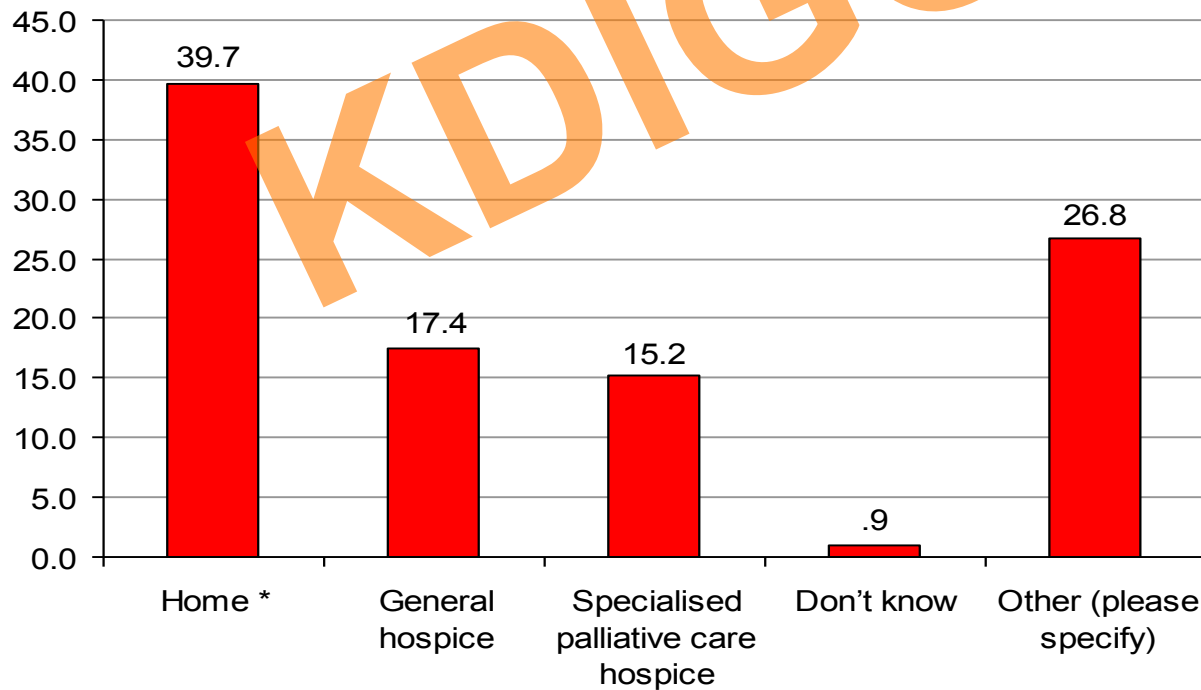


I believe more patients in my institution suitable for dialysis withdrawal would choose this option if... (tick all that apply)

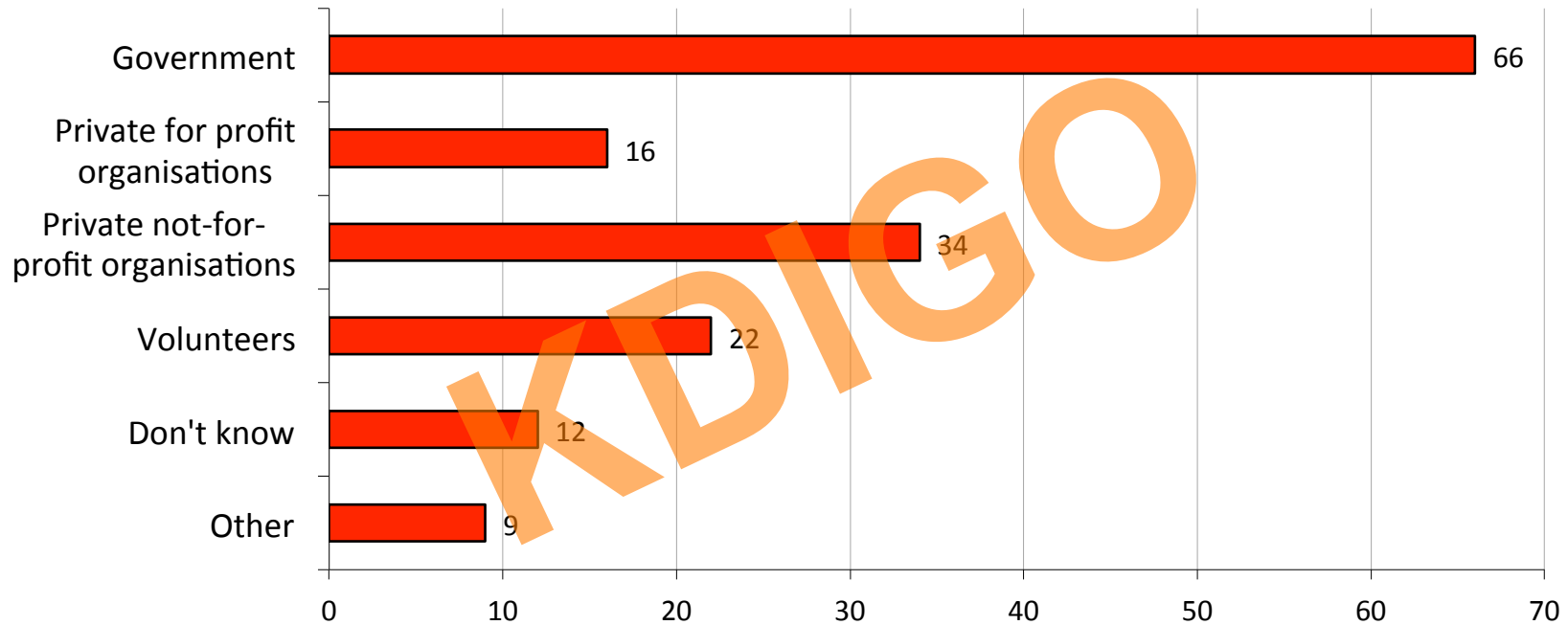
Organization of palliative care after withdrawal (institutional level)

- **Nephrologists**

- **84% said that organization of palliative care after withdrawal was not protocolized**
- **40% reported that patients were mostly referred home and two thirds of those without admission to the hospital to prepare them for the new situation**

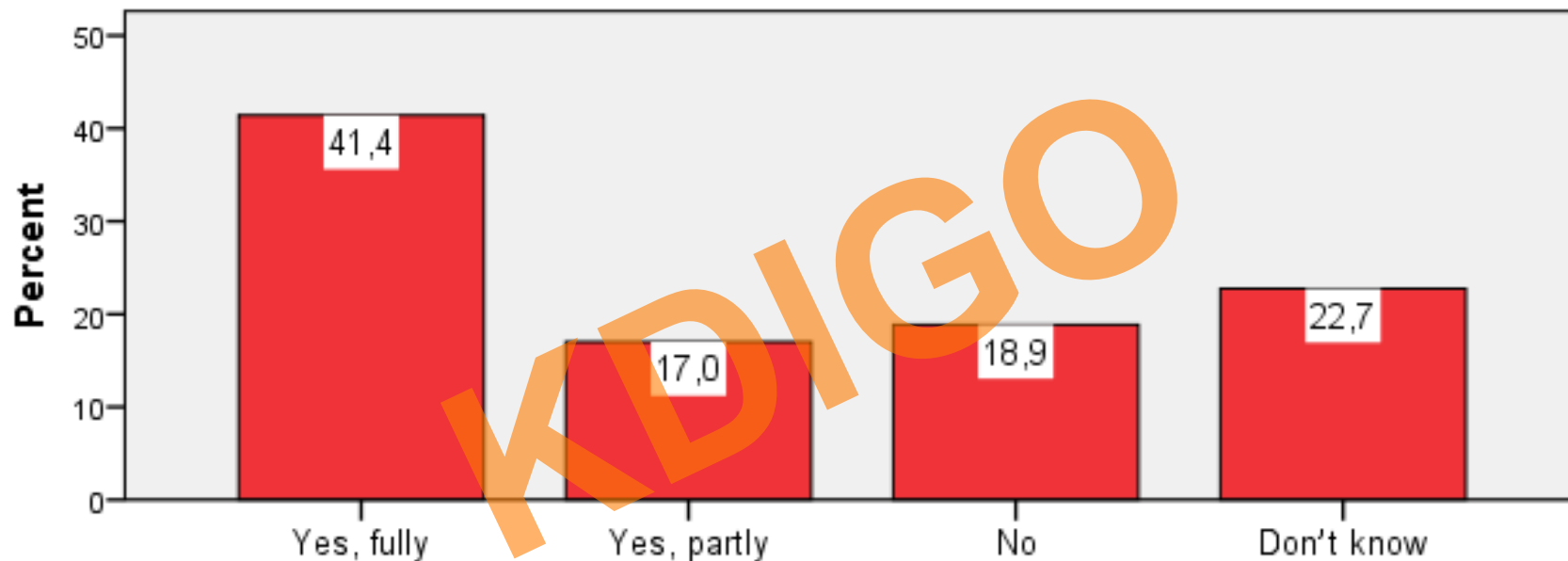


Organization of palliative care after withdrawal (national level)



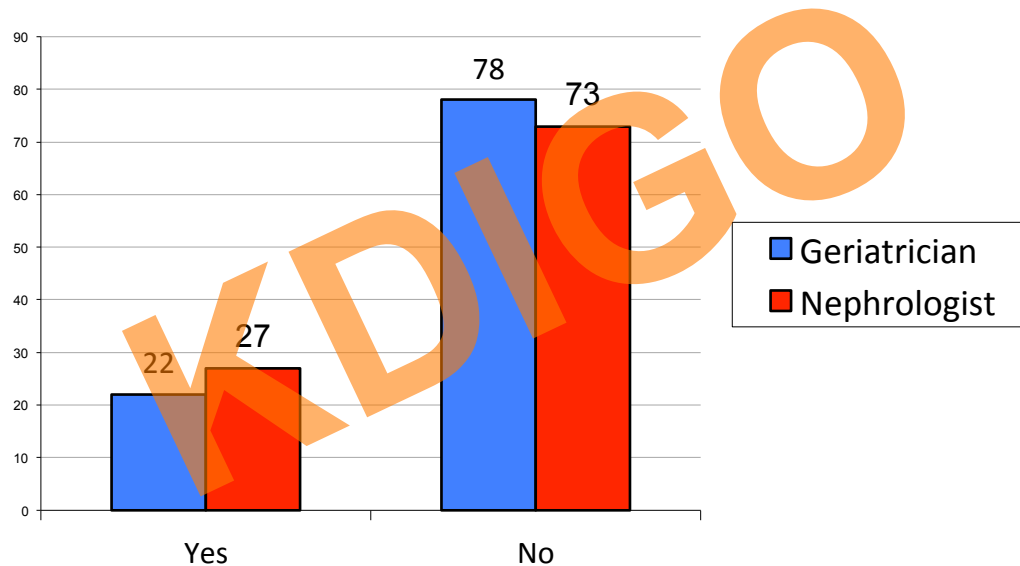
Who organises and/or supports palliative care in your country? (tick all that apply)

Reimbursement of palliative care after withdrawal



In your country, is palliative care reimbursed for patients who have withdrawn from dialysis?

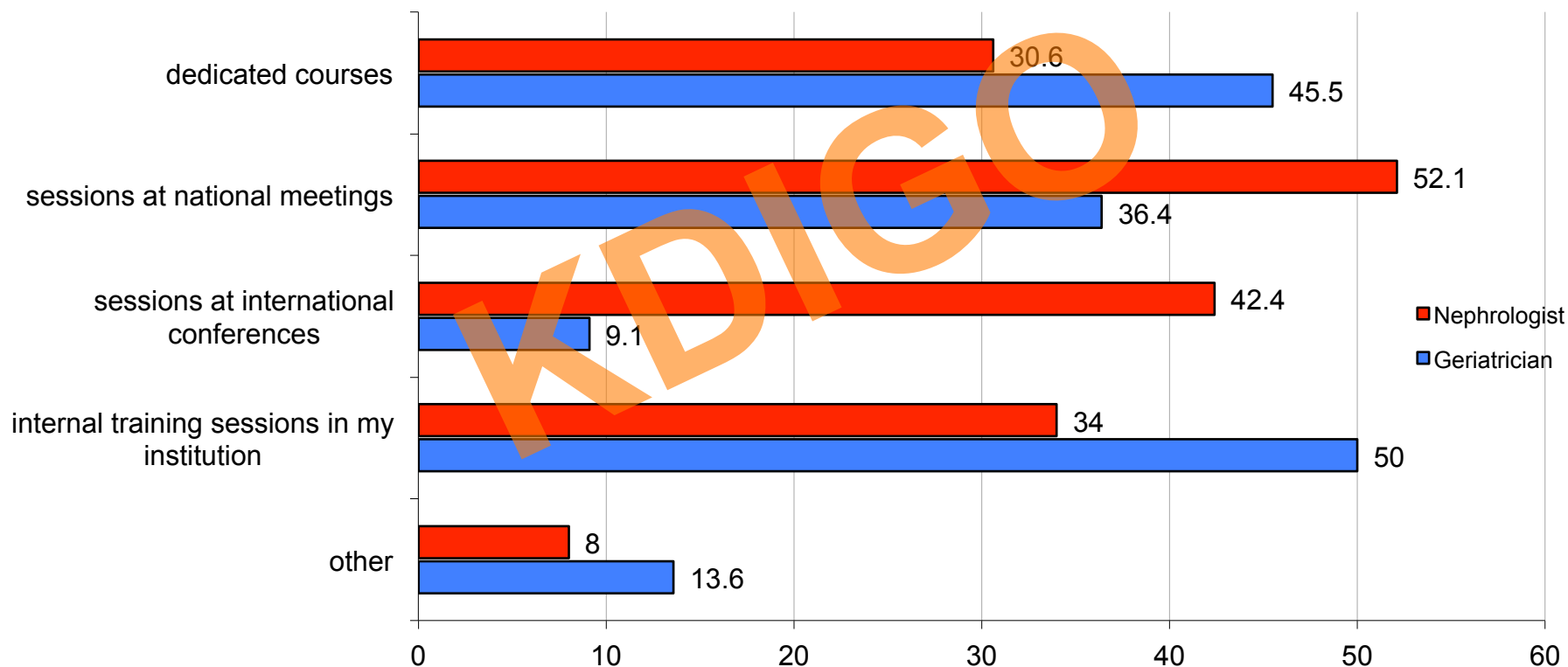
Palliative care: Knowledge and education



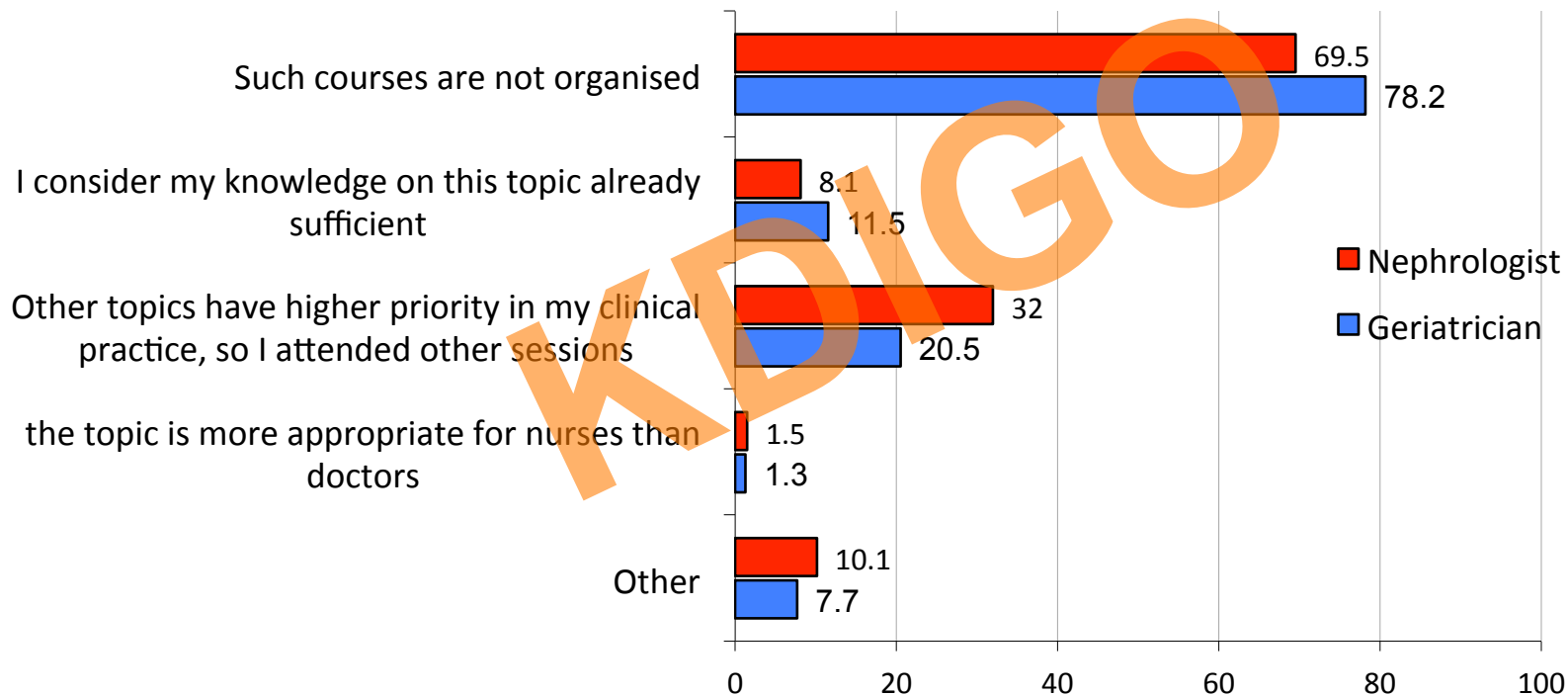
Have you attended any CME sessions on palliative care after dialysis withdrawal in the last 3 years?

Palliative care: Types of CME sessions

The CME sessions I attended were...



Palliative care: Reasons not to attend CME sessions



I did not attend any CME sessions on palliative care after dialysis withdrawal because... (tick all that apply)

Preliminary conclusions

- One third of nephrologists says there is an “official” regulation on the right of patients of withdrawal of dialysis
- Another half feels there is a “permissive” attitude
- In countries where it is not (in)formally permitted fewer physicians deal with withdrawal vs in countries where it is permitted
- Almost half of nephrologists believe more patients would withdraw if more and better logistical services were available
- Most dialysis centres lack clear protocols or guidance on how to address and handle withdrawal of dialysis

Preliminary conclusions

- Geriatricians are hardly involved in withdrawal, neither in the decision nor in the actual care
- Palliative care after withdrawal is mostly performed by non-specialists, either at home or in the nephrology ward
- The far majority of respondents feel that patients withdraw dialysis because of a disbalance between treatment burden and expected survival benefit
- There is an important need for more education on palliative care after withdrawal, as only a quarter of nephrologists and geriatricians have followed courses on this topic