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Transition Procedures and Transfer Age in Adolescents and Young Adults with Chronic Renal Failure

- A Survey among the German Pediatric Renal Units -

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Adolescents and young adults with chronic renal failure:

- Critical phase of life, in many aspects
- Brain development and maturation not completed (re risk taking behavior, impulsiveness, etc.)
- Higher non-adherence rates, higher graft failure rates



Transfer/transition from the familiar and better resourced pediatric unit to the adult unit is a difficult task.



Definition

Transition = Process

Transfer = Single event during the process of transition when the patient actually changes the caregiving institution



Transition procedures need to be improved

- Broad discussion in the international literature.
- Implementing new concepts as well as changing inadequate administrative regulations needs to take into account the **local and national circumstances of the healthcare systems.**



Transition in German pediatric nephrology

- Heterogeneous administrative regulations and health care structures.
- Beginning discussion, some efforts to improve transition

Aim of this study:

To get an overview of the status quo, in order to find starting-points for improving the transition procedures and regulations.



Survey among the German pediatric renal units

Questionnaire with the topics:

- Age of transfer: experiences and suggestions
- Measures for supporting transition: which ones proved to be worthwhile?
- Modes of cooperation with adult units
- Do the teams see the need of improving the transition procedures?



Mailing of questionnaires

43 units with a pediatric nephrologist ,
according to the member list of the
German Society for Pediatric Nephrology (GPN)

Completing of questionnaires

- June-September 2012
- 26 (=60%) of the addressed units completed the questionnaire:
 - 11 small units with a limited treatment program
 - 15 units with the full renal replacement therapy program
= **83% of all the 18 German units with the full RRT program**

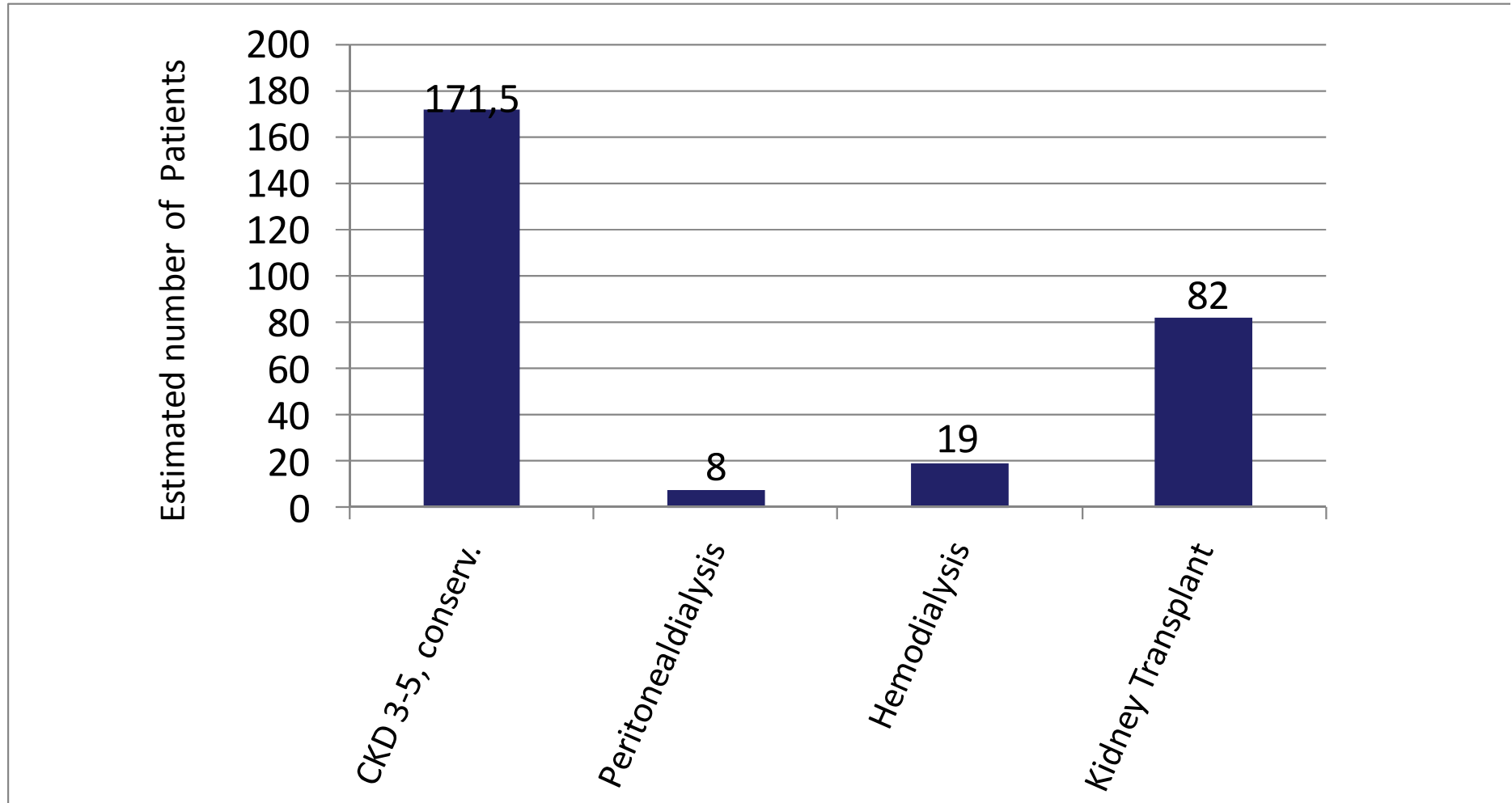


Germany: 18 pediatric renal units with full RRT program



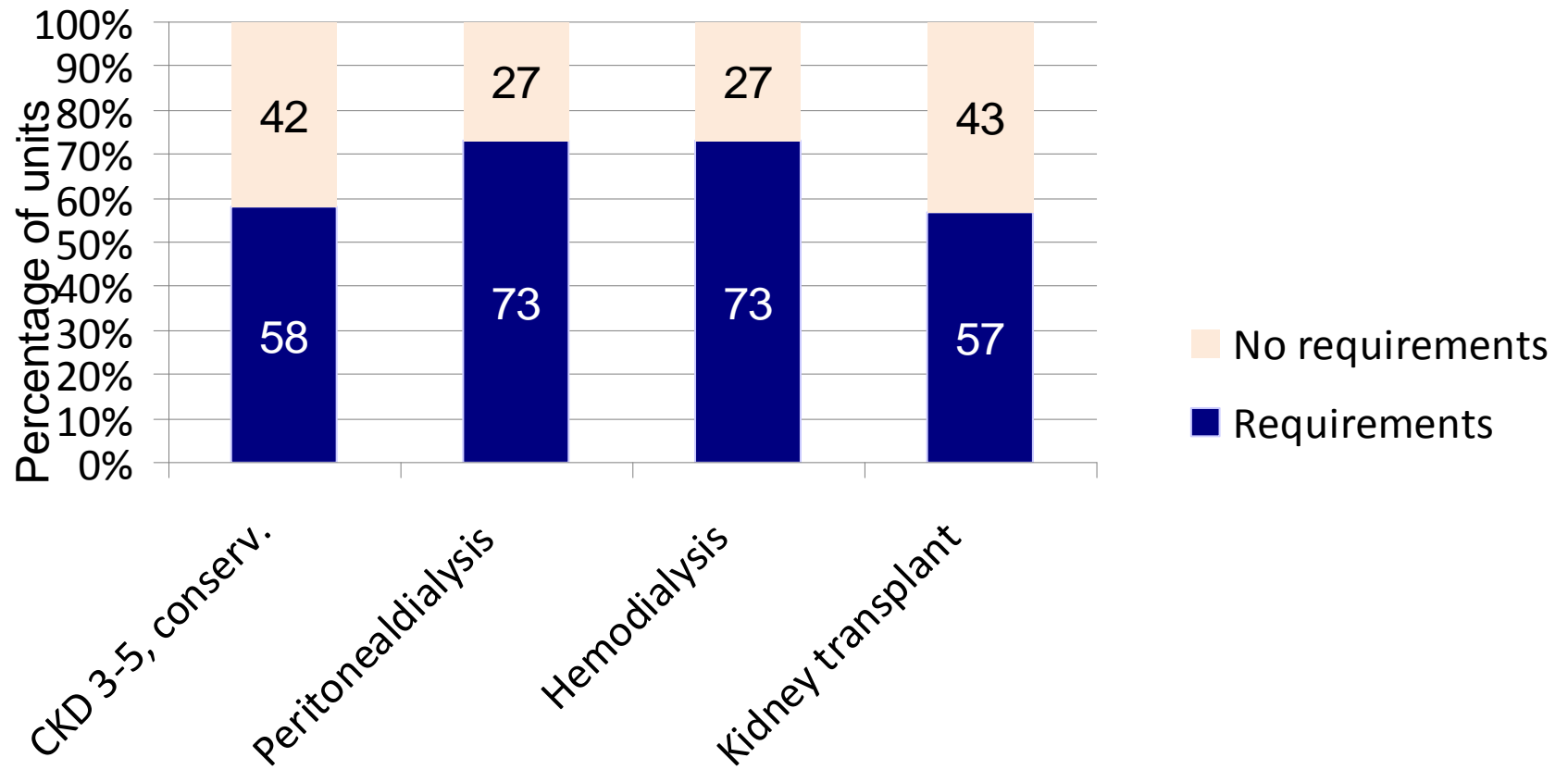


Estimated number of patients being transferred per year
(Sums of **estimations** of the participating 26 units)



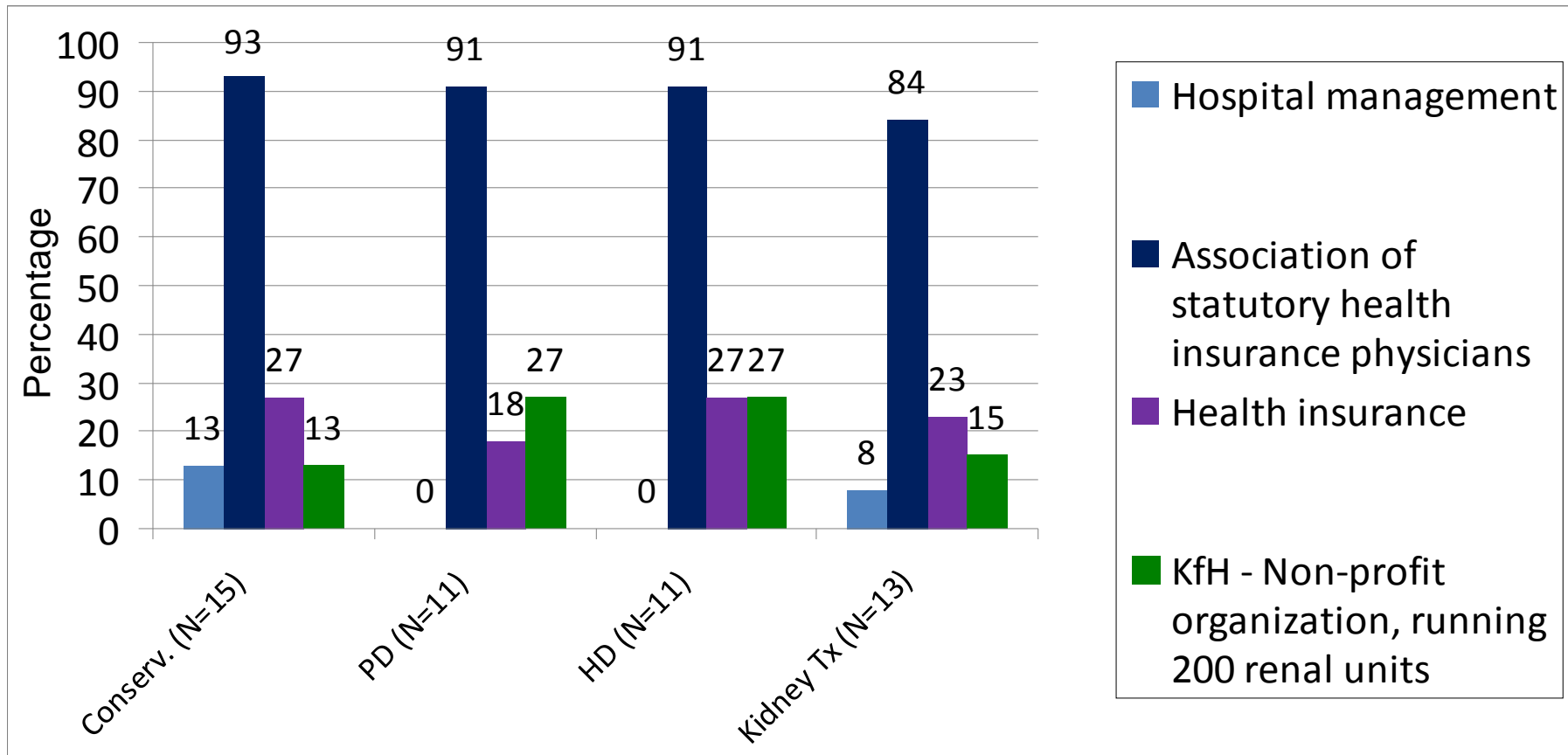


„In your unit, are there any administrative requirements when to transfer the patients?“



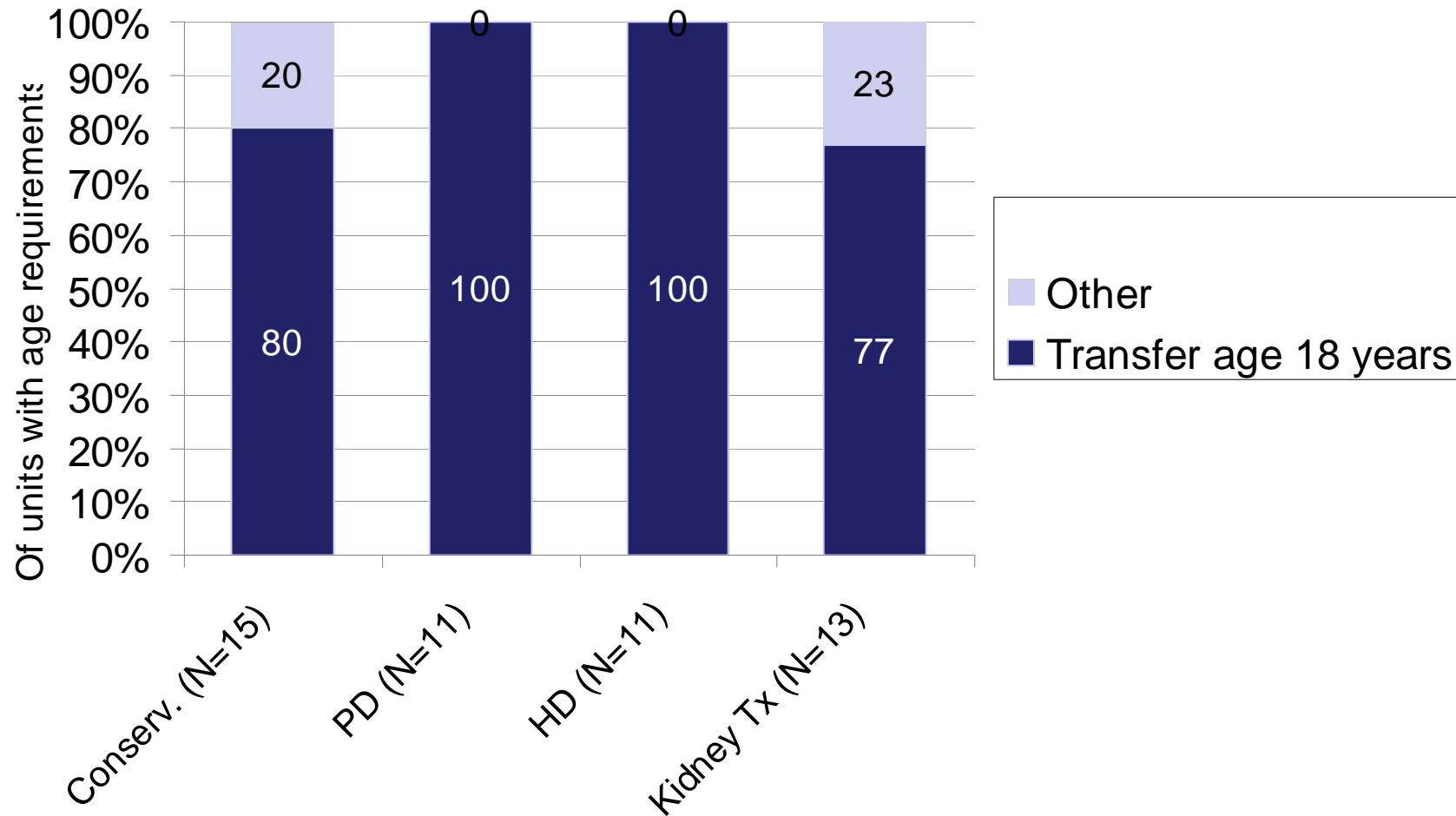


„In case of administrative requirements:
who is defining these requirements?“
(Multiple answers possible)



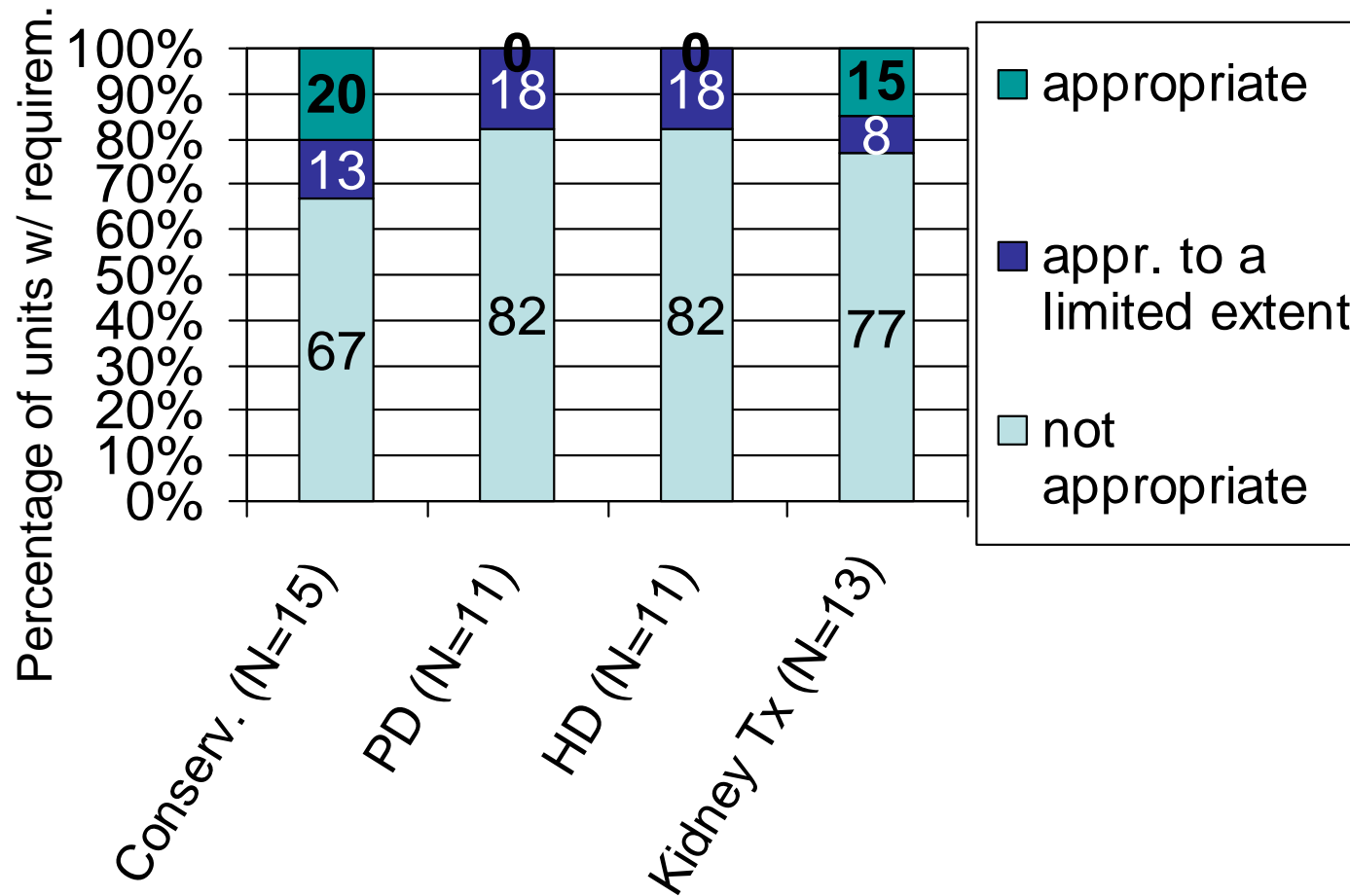


„In case of administrative requirements:
which transfer age is required?“



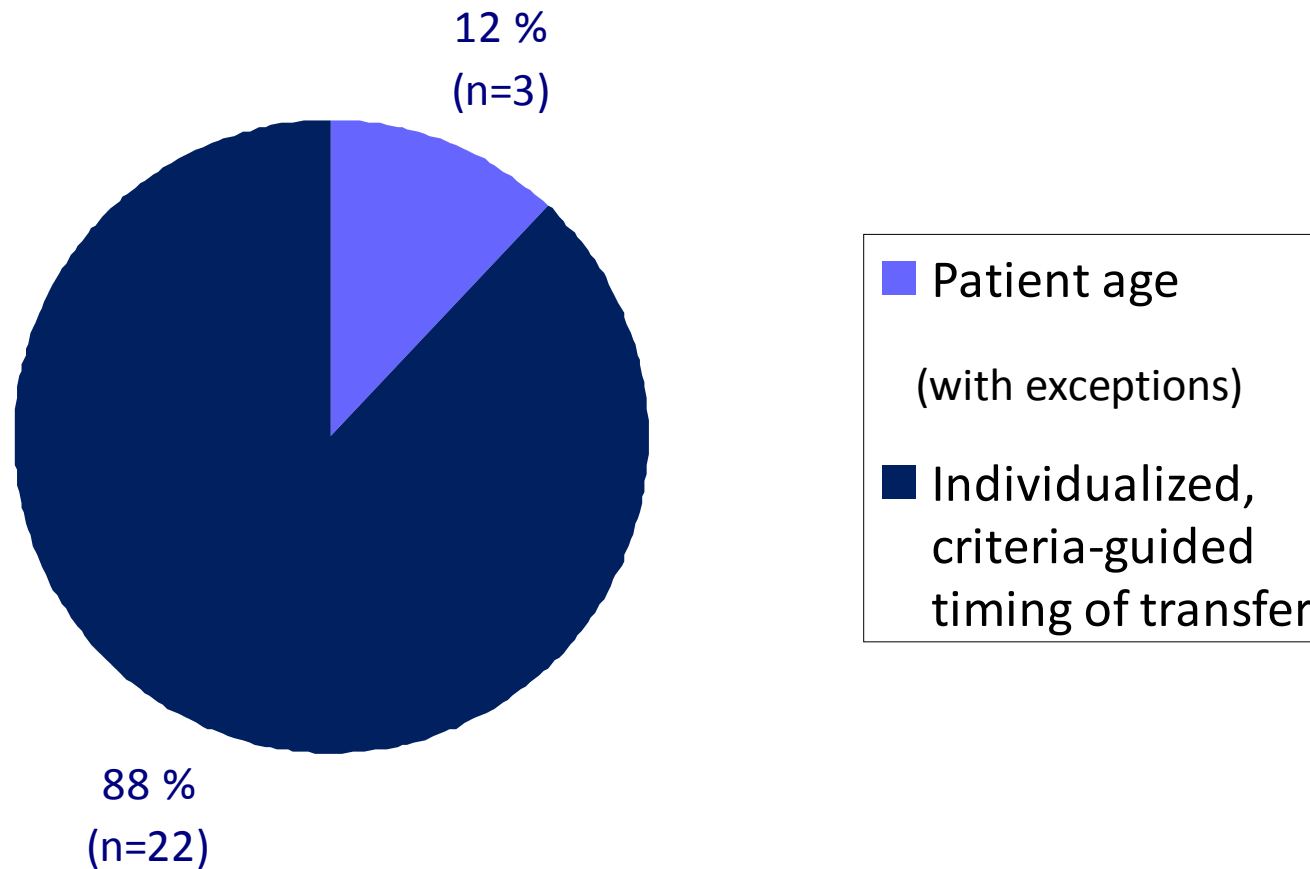


„In case of administrative requirements, **how does the caregiving team judge the transfer age requirement?**“





„Independently of administrative requirements and actual realizability, **which mode of determining the time of transfer does the caregiving team favor?**“





Individualized, criteria-guided timing of transfer

Criteria suggested by the units:

- Medical situation
 - Underlying disease, comorbidities
 - Growth, puberty
 - Current course

- Psychosocial situation
 - General development of self-sufficiency, taking over of patient role
 - School education completed and vocational education completed or on a stable course
 - Regarding special living circumstances (foster home, mental retardation)
 - Current psychological and emotional situation
 - Sufficient social support?

- Completion of transition program

- Patient family agrees with transfer (consensual decision)



„Which measures for supporting the transition of your patients proved to be worthwhile?“

The units reported:

- 1) Individual preparation in pediatric unit
- 2) Offers for patient *groups*
- 3) Pre-, peri-, post-transfer support



„Which measures for supporting the transition of your patients proved to be worthwhile?“

1) Individual preparation in pediatric unit

- Regular outpatients rounds, multidisciplinary evaluation of readiness for transition.
- Individual counseling and training by the MDT.
- Outpatient clinic without parents, but with contact to parents. Patient calls later to get blood values



„Which measures for supporting the transition of your patients proved to be worthwhile?“

2) Offers for patient groups

- Group training in unit
- Annual summer camp



„Which measures for supporting the transition of your patients proved to be worthwhile?“

2) Offers for patient groups

- Group training in unit
- Annual summer camp
- Helping with enrolling for nationwide program „Finally Grown Up“
- Helping with applying for a 3 weeks insurance-funded rehabilitation stay at a specialized rehabilitation center in Austria



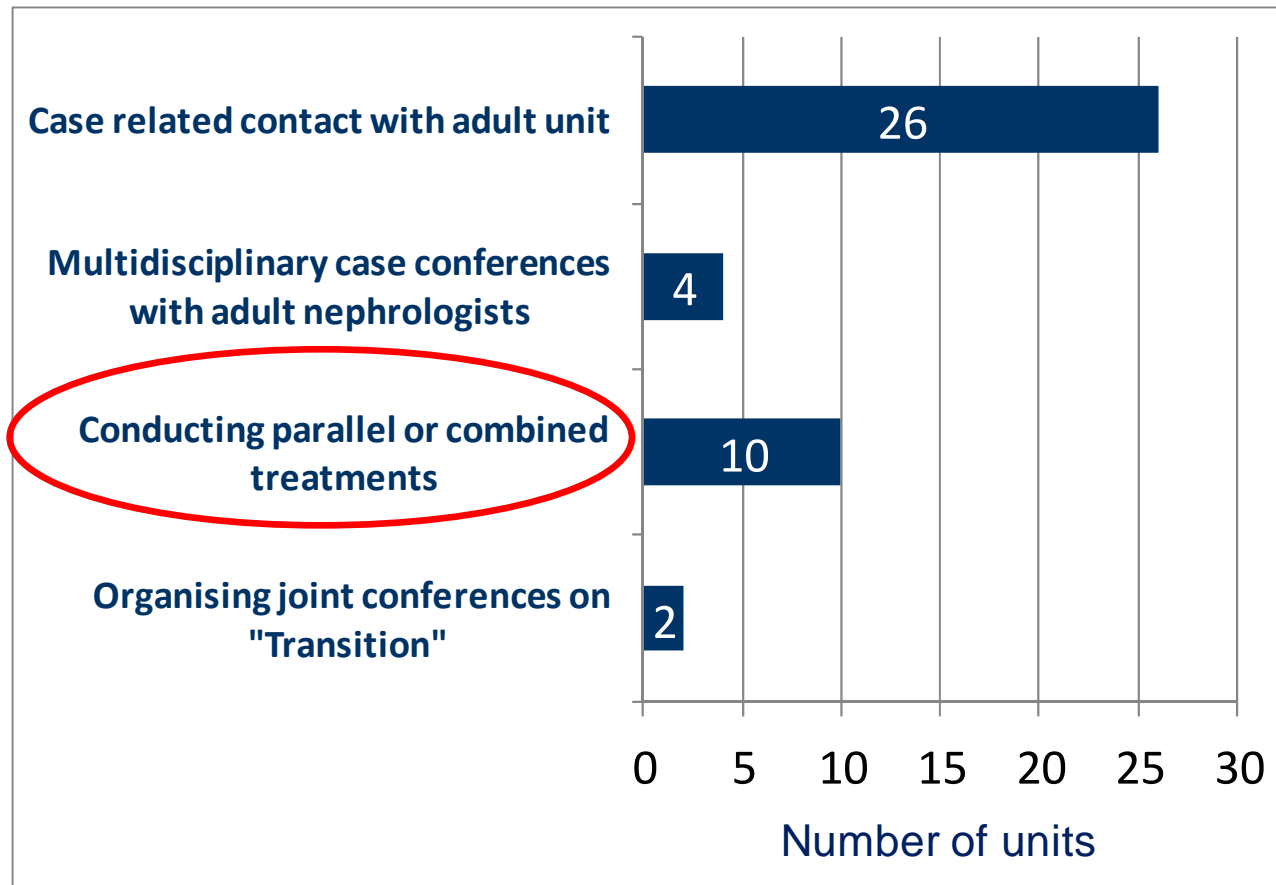
„Which measures for supporting the transition of your patients proved to be worthwhile?“

3.) Pre-, peri-, post-transfer support

- Personal conversation pediatric nephrologist/adult nephrologist
- Goodbye ritual in pediatric unit
- Accompanying patient to first visit in adult unit
- Special offers in adult unit
- Different methods of combined treatment (pediatric/adult)



„In which way do you cooperate with the adult units?“ (Multiple answers possible)





„In which way do you cooperate with the adult units?“

Cooperation models reported by some units:

- **„Double outpatient clinic“**

some time before final transfer, 2 doctors with a patient (pediatric+adult nephr.)

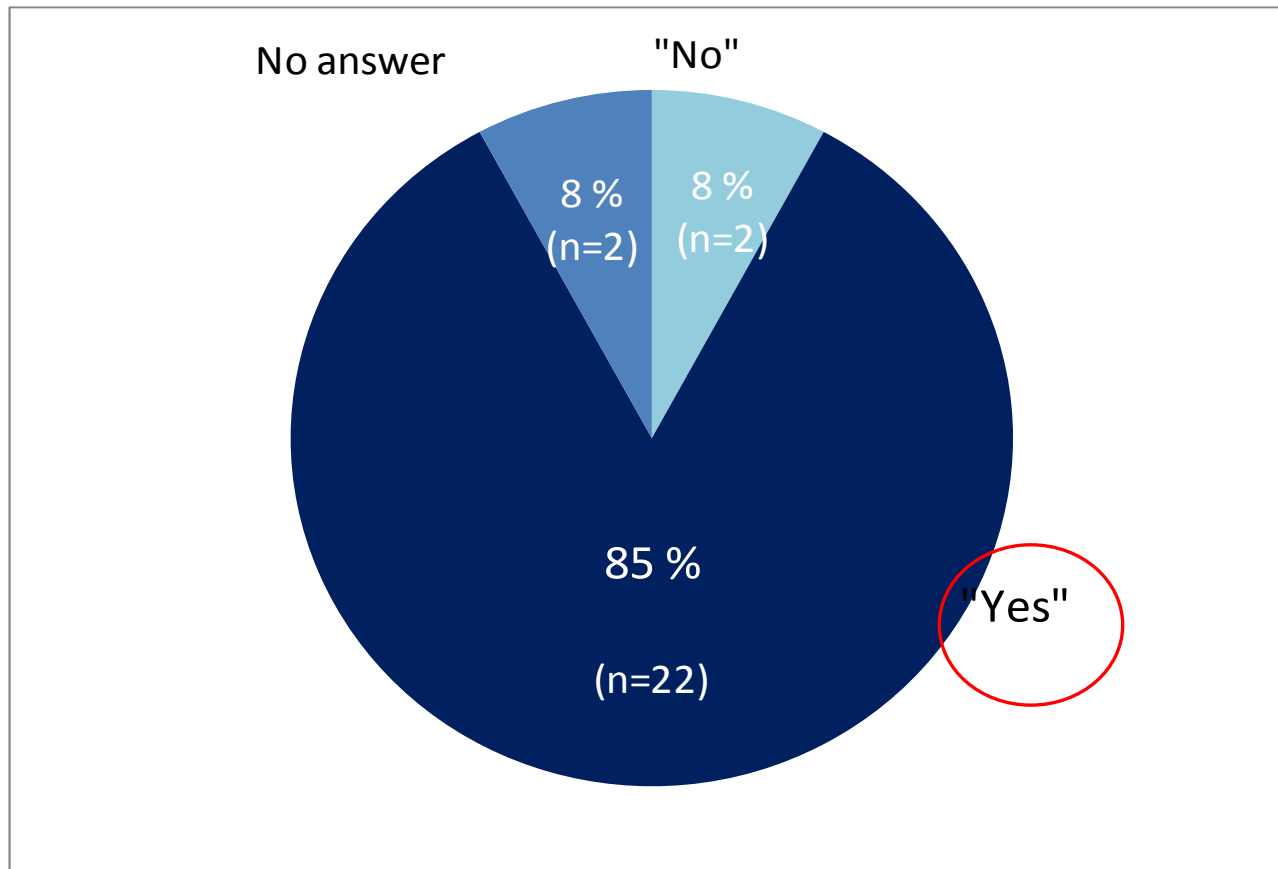
- **„Overlapping care“**

some time before final transfer, alternating single outpatient clinics in pediatric and adult unit.

Other units pointed out that they cannot realize these models due to administrative and financial hurdles.



„Does your team see the need of improving the transitional procedures?“





If **yes**, what should be improved?

Units suggest (among others):

- Timing of transfer should be individualized rather than age-dependent.
- Patient-related funding of care should base on pediatric rates even after 18.
- Starting earlier with transition preparations.
- Developing structured transition programs which are integrated into daily care
- Training for nurses and doctors.
- More multidisciplinary staff to carry out the new tasks.
- Funding of combined treatment pediatric/adult, e.g. „double outpatient clinic“, „treatment overlap“, etc.
- More sensitivity of adult nephrologists for the young patients.
- Some pattern of pediatric contact to the patients *after* transfer.



Conclusion 1

- The majority of the German units and patients is affected by the administrative regulation „Transfer with 18 years“. Sometimes units are successful in trying to get individual exceptions.
- 88% of all units prefer an individualized, criteria-guided timing of transfer.
- The units have started to develop structured and planned transition support measures. Due to the varying financial, administrative and staffing circumstances these measures are very heterogeneous. The units agree on the need for improving transition procedures and regulations and make concrete suggestions.



Conclusion 2

- The reported lack of sufficient transition support explains, at least partially, the comparably worse health outcomes (e.g., graft survival) in this age group. The health care needs of young people with CRF are not sufficiently met by the caregiving institutions.



Thank you!

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Thank you for your attention!