

# **Hometherapies: What can we learn from ERA-EDTA**

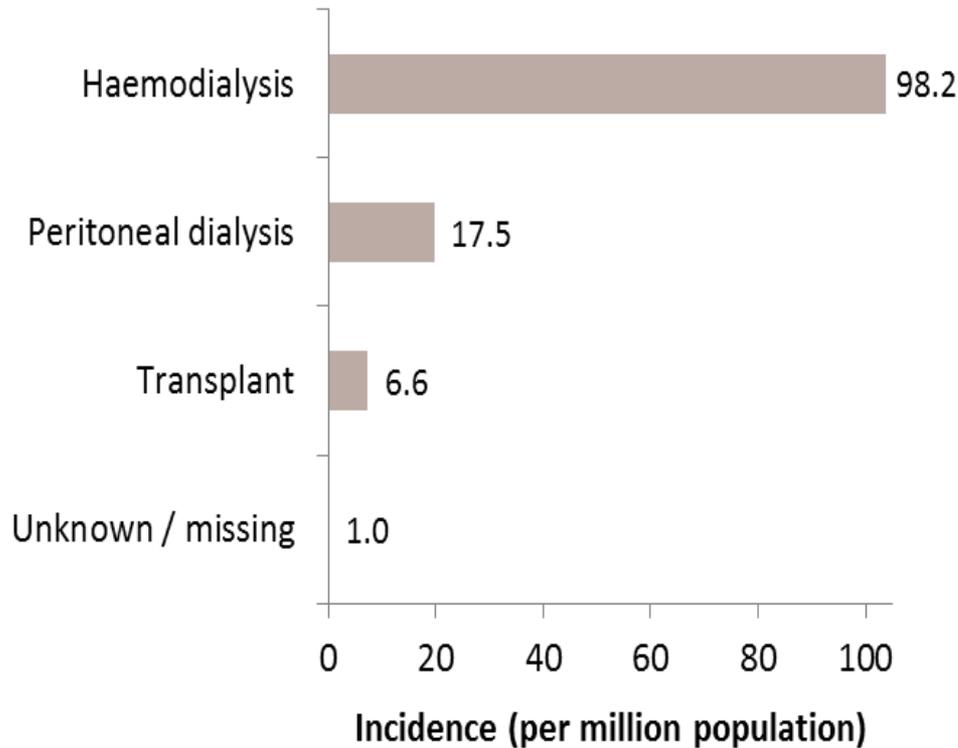
**W. Van Biesen,  
Ghent University Hospital**

**SOMETIMES  
THE  
INFORMATION  
MISSING  
PROVIDES  
THE MOST  
INFORMATION**

# Incident patients accepted for RRT in 2013, at day 91 *by established modality*

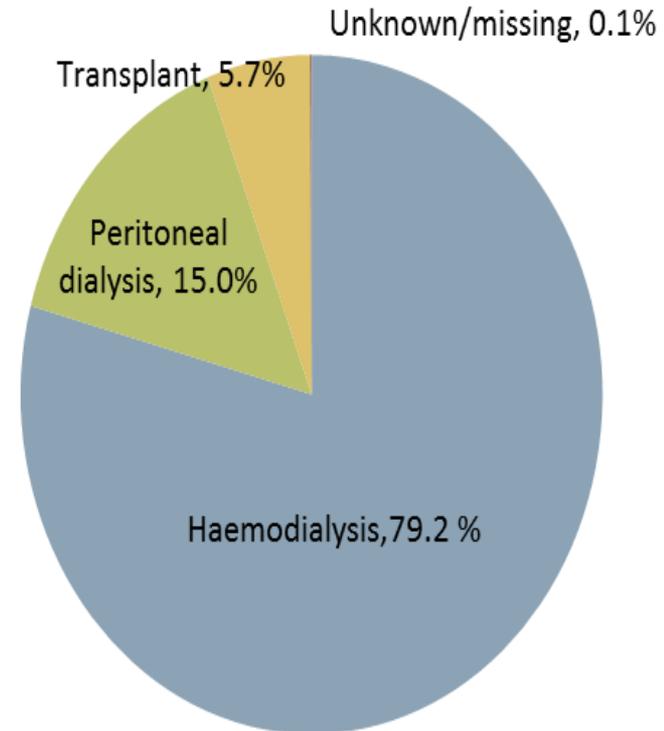
## Incidence at day 91, by established modality

*all patients starting RRT in 2013*



## Incidence at day 91, by established modality

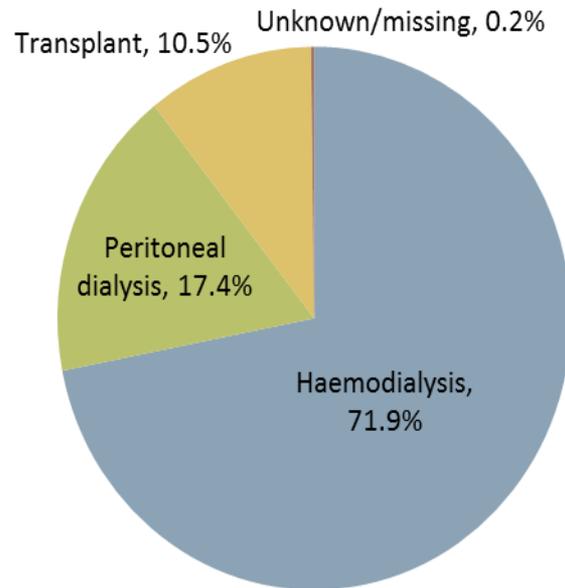
*all patients starting RRT in 2013*



# Incident patients accepted for RRT in 2013, at day 91 *by established modality and age category*

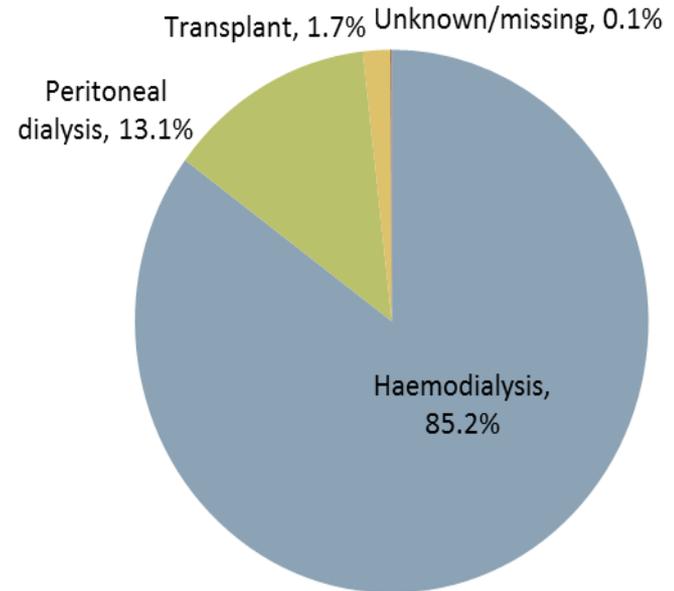
## Incidence at day 91, by established modality

*patients younger than 65 years of age at start RRT in 2013*



## Incidence at day 91, by established modality

*patients older than 65 years of age at start RRT in 2013*

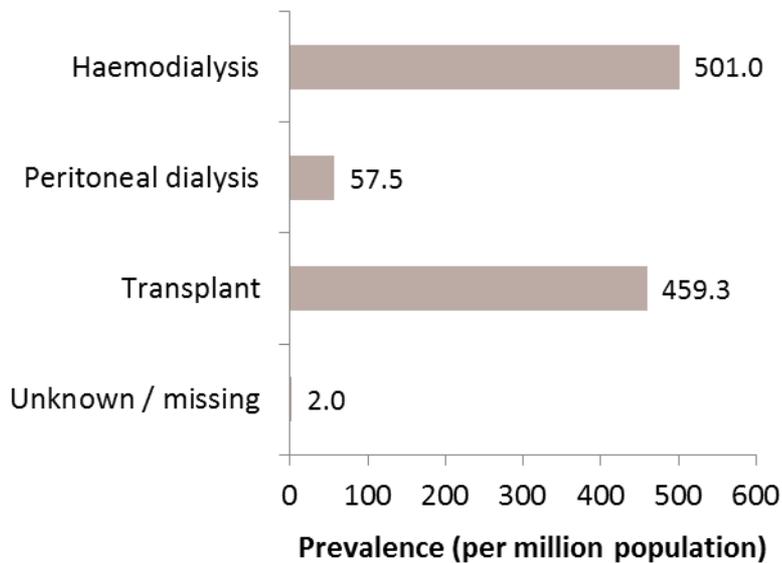


# Prevalent patients on RRT in 2013

*by established modality*

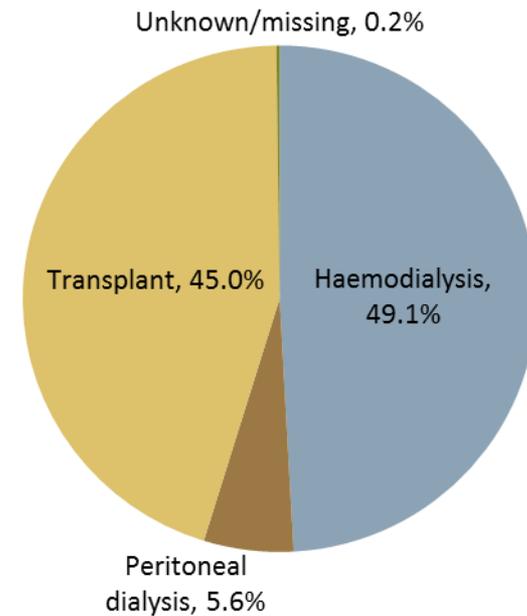
## Prevalence, by established modality

*all patients on RRT in 2013*



## Prevalence, by established modality

*all patients on RRT in 2013*



# Prevalent patients on RRT in 2013

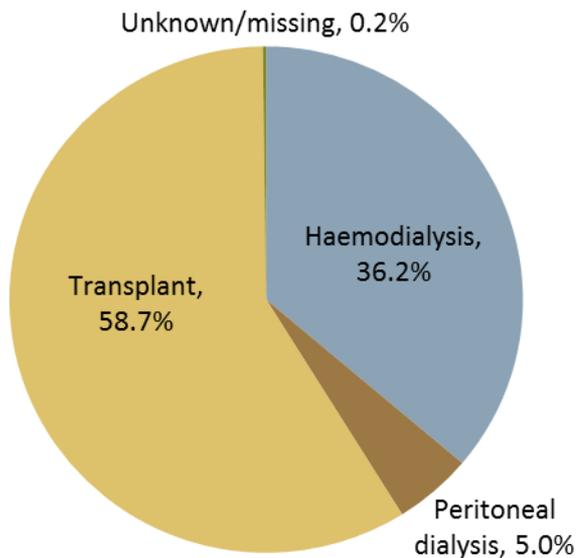
*by established modality and age category*



Leading  
European  
Nephrology

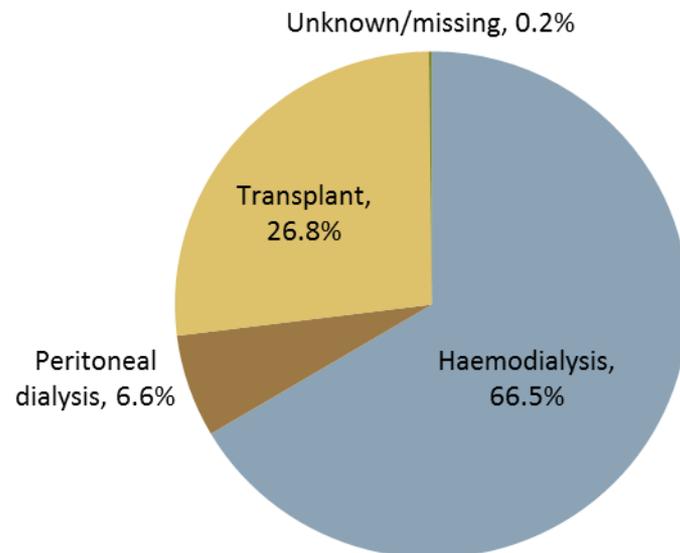
## Prevalence, by established modality

*patients younger than 65 years in 2013*



## Prevalence, by established modality

*patients older than 65 years of age in 2013*



# Missing pieces



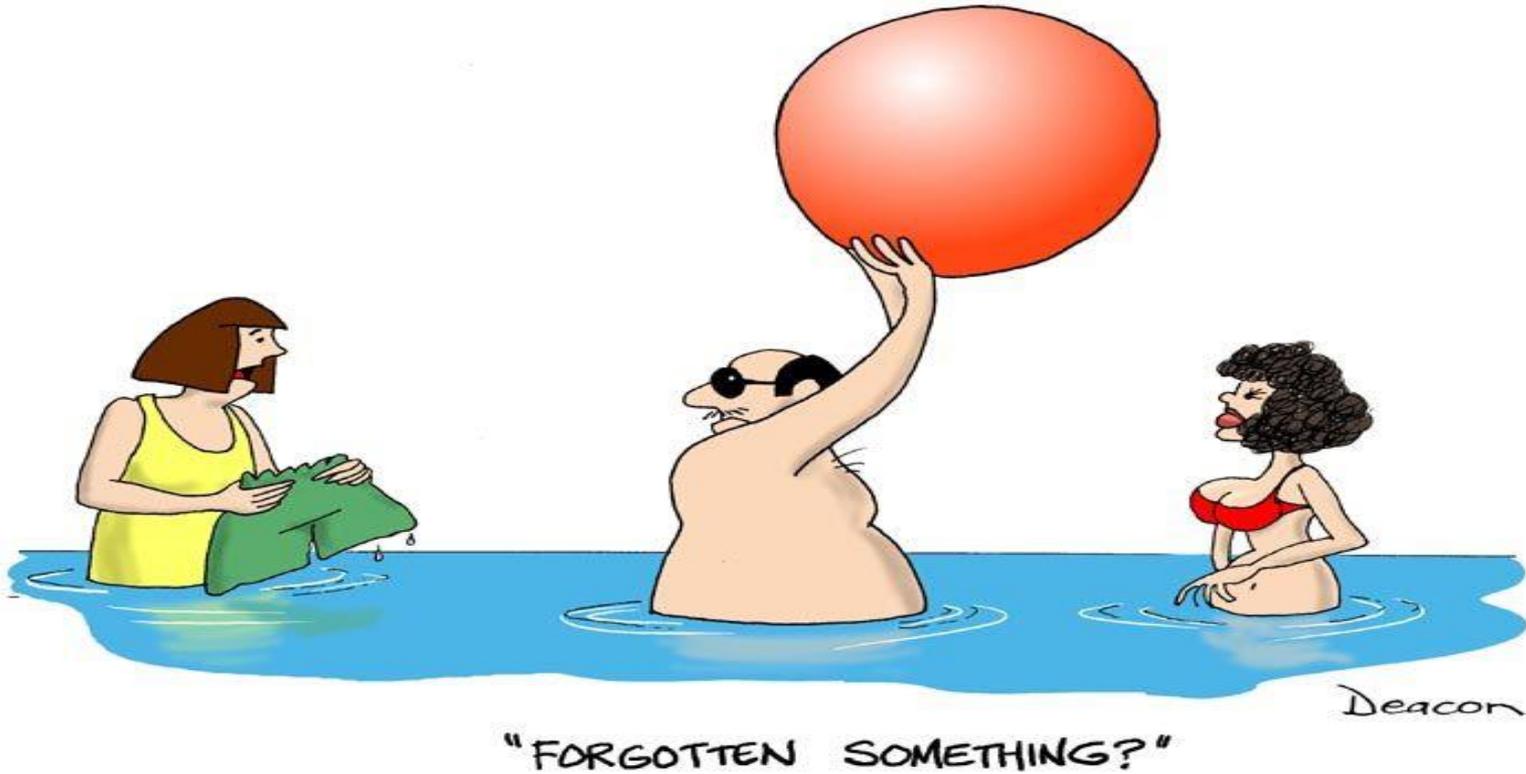
**It is not only about single modalities...  
there is a lot of transition too....**

# Renal Replacement Therapy Transitions: International Research Collaborative

**The present research consortium will leverage available national and international renal registries and will encourage incorporation of other potential datasets globally with the following research aims:**

- To identify the incidence, predictors, risk factors, rationale(s) and outcomes of transitions between RRT modalities that are relevant to patients and care-providers.**
- To compare crude and adjusted death rates, morbidities and risk factors during the continuum of a given RRT modality, in the early (<3, ≤6 months) and late (> 6 months) period following a transition from that modality to other forms of RRT.**
- To describe the experience and perspectives of patients transitioning between RRTs.**

# Missing pieces



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**Oeps... did we forget about home haemodialysis?**

# Incident homeHD patients within ERA-EDTA registry

Table A.3.6

## Incident counts

*at day 91, by established therapy*

	Total		
	N	HD hospital/ centre	HD home
Austria <i>f</i>	1117	866	1
Belgium, Dutch-speaking *	1077	595	64
Belgium, French-speaking *	780	495	6
Bosnia and Herzegovina	386	361	0
Denmark	622	375	0
Estonia	79	52	0
Finland	466	281	17
France	9586	6673	5
Greece	2128	1894	0
Iceland	24	10	0
Norway	488	302	0
Romania	2581	2410	0
Serbia	922	736	1
Slovenia	236	0	0
Spain, Andalusia	1025	803	0
Spain, Aragon	167	125	0
Spain, Asturias <i>f</i>	159	107	0
Spain, Basque country	249	155	1
Spain, Cantabria *	49	32	0
Spain, Castile and León *	267	213	0
Spain, Castile-La Mancha *	216	160	0
Spain, Catalonia <i>f</i>	1052	540	0
Spain, Extremadura <i>f</i>	132	111	1
Spain, Galicia	385	275	0
Spain, Community of Madrid	762	591	1
Spain, Region of Murcia	153	116	0
Spain, Valencian region	665	509	2
Sweden	1000	0	7
The Netherlands	1822	1241	0
United Kingdom, All countries * <i>f g</i>	6520	4111	22
United Kingdom, England * <i>f</i>	5564	3418	19
United Kingdom, Northern Ireland * <i>f</i>	158	110	0
United Kingdom, Scotland	486	368	1
United Kingdom, Wales * <i>f</i>	320	219	3

**Total = 151**

# Incident homeHD patients within ERA-EDTA registry

Table A.3.8

**Incident rates per million population, adjusted at day 91, by established therapy, adjusted for age and gender**

	Total		
		HD hospital/ centre	HD home
	Pmp	Pmp	Pmp
Austria <i>f</i>	128.3	99.6	0.2
Belgium, Dutch-speaking *	155.4	85.6	9.2
Belgium, French-speaking *	173.6	110.1	1.3
Bosnia and Herzegovina	129.9	121.9	0
Denmark	108.7	65.5	0
Estonia	61.7	40.5	0
Finland	81.0	48.1	3.3
France	143.7	100.0	0.1
Greece	171.9	152.0	0
Iceland	85.0	36.9	0
Norway	103.1	64.6	0
Romania	130.5	121.9	0
Serbia	126.4	100.4	0.2
Slovenia	111.0	0	0
Spain, Andalusia	129.4	101.9	0
Spain, Aragon	113.2	84.1	0
Spain, Asturias <i>f</i>	122.0	81.0	0
Spain, Basque country	103.3	63.8	0.4
Spain, Cantabria *	76.6	48.8	0
Spain, Castile and León *	86.5	67.7	0
Spain, Castile-La Mancha *	102.6	75.5	0
Spain, Catalonia <i>f</i>	139.9	71.4	0
Spain, Extremadura <i>f</i>	111.2	92.9	1.3
Spain, Galicia	119.0	83.0	0
Spain, Community of Madrid	126.0	98.6	0.2
Spain, Region of Murcia	118.2	90.5	0
Spain, Valencian region	126.8	97.0	0.4
Sweden	100.5	0	0.8
The Netherlands	109.1	74.9	0
United Kingdom, All countries * <i>f g</i>	104.0	65.5	0.4
United Kingdom, England * <i>f</i>	106.1	65.1	0.4
United Kingdom, Northern Ireland * <i>f</i>	95.0	66.3	0
United Kingdom, Scotland	90.7	68.4	0.2
United Kingdom, Wales * <i>f</i>	98.8	66.3	1.3

# Prevalent homeHD patients within ERA-EDTA registry

Table A.3.9  
Percentages of established therapy, unadjusted at day 91

	Total		
	%	HD hospital/centre %	HD home %
Austria <i>f</i>	100	77.6	0.1
Belgium, Dutch-speaking *	100	55.2	5.9
Belgium, French-speaking *	100	63.5	0.8
Bosnia and Herzegovina	100	93.5	0
Denmark	100	60.3	0
Estonia	100	65.8	0
Finland	100	60.3	3.6
France	100	69.6	0.1
Greece	100	89.0	0
Iceland	100	41.7	0
Norway	100	61.9	0
Romania	100	93.4	0
Serbia	100	79.8	0.1
Slovenia	100	0	0
Spain, Andalusia	100	78.3	0
Spain, Aragon	100	74.9	0
Spain, Asturias <i>f</i>	100	67.4	0
Spain, Basque country	100	62.2	0.4
Spain, Cantabria *	100	65.3	0
Spain, Castile and León *	100	79.8	0
Spain, Castile-La Mancha *	100	74.1	0
Spain, Catalonia <i>f</i>	100	51.3	0
Spain, Extremadura <i>f</i>	100	84.3	1.0
Spain, Galicia	100	71.4	0
Spain, Community of Madrid	100	77.6	0.1
Spain, Region of Murcia	100	75.8	0
Spain, Valencian region	100	76.5	0.3
Sweden	100	0	0.7
The Netherlands	100	68.1	0
United Kingdom, All countries * <i>f</i> <i>§</i>	100	63.0	0.3
United Kingdom, England * <i>f</i>	100	61.4	0.3
United Kingdom, Northern Ireland * <i>f</i>	100	69.6	0
United Kingdom, Scotland	100	75.7	0.2
United Kingdom, Wales * <i>f</i>	100	68.5	0.9

Table A.4.6  
Prevalent counts  
*prevalent patients on December 31, by established therapy*

	Total		
	N	HD hospital/centre N	HD home N
Austria	8906	3034	4
Belgium, Dutch-speaking *	7823	2470	101
Belgium, French-speaking *	6005	2348	53
Bosnia and Herzegovina	2620	2098	0
Denmark	4973	1859	149
Estonia	754	243	0
Finland	4492	955	104
France	77199	30383	245
Greece	12832	7429	1
Iceland	222	48	0
Norway	4574	1062	17
Romania <i>  </i>	16162	13309	7
Serbia	5651	3631	28
Slovenia	2077	560	0
Spain, Andalusia	9295	4133	8
Spain, Aragon	1510	542	2
Spain, Asturias	1208	425	0
Spain, Basque country	2553	809	3
Spain, Cantabria *	588	198	0
Spain, Castile and León *	2817	1212	2
Spain, Castile-La Mancha *	2138	810	3
Spain, Catalonia	9534	1993	3
Spain, Extremadura	1194	579	8
Spain, Galicia	3363	1472	9
Spain, Community of Madrid	6491	2201	14
Spain, Region of Murcia	1767	897	0
Spain, Valencian region	6303	3321	10
Sweden	9020	0	143
The Netherlands	15887	5362	217
United Kingdom, All countries * <i>§</i>	56781	20710	1168
United Kingdom, England *	47961	17366	992
United Kingdom, Northern Ireland *	1548	577	31
United Kingdom, Scotland	4614	1812	55
United Kingdom, Wales *	2731	964	90

# Impact of Hemodialysis on HD quality

**Table 2.** Number of HD sessions per week

	<i>N</i>	Fewer than 3 sessions/week	3 sessions/week	4 sessions/week	Daily haemodialysis $\geq 5$ /week	<i>P</i> *
Modality		%	%	%	%	<0.0001
Full-care centre	15 709	6.1	92.4	1.1	0.4	
Limited care centre	4453	2.9	95.8	0.4	0.9	
Home care	339	0.6	83.8	8.0	7.7	

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**Table 3.** Mean dialysis length per session

	<i>N</i>	$\leq 3$ h	3–4 h	4–6 h	$\geq 6$ h	<i>P</i> *
Modality		%	%	%	%	<0.0001
Full-care centre	15 608	6.0	71.8	20.5	1.8	
Limited-care centre	4422	4.6	71.4	22.0	1.9	
Home care	338	9.8	41.7	34.0	14.5	

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**Table 4.** Total weekly HD duration

	<i>N</i>	<12 h/week	12 h/week	>12 h/week	<i>P</i> *
Modality		%	%	%	<0.0001
Full-care centre	18 169	18.5	58.8	22.7	
Limited-care centre	4416	11.9	63.7	24.4	
Home care	342	8.5	35.4	56.1	

# **Educating end-stage renal disease patients on dialysis modality selection: clinical advice from the European Renal Best Practice (ERBP) Advisory Board**

Adrian Covic<sup>1</sup>, Bert Bammens<sup>2</sup>, Thierry Lobbedez<sup>3</sup>, Liviu Segall<sup>1</sup>, Olof Heimbürger<sup>4</sup>, Wim van Biesen<sup>5</sup>, Denis Fouque<sup>6</sup> and Raymond Vanholder<sup>5</sup>

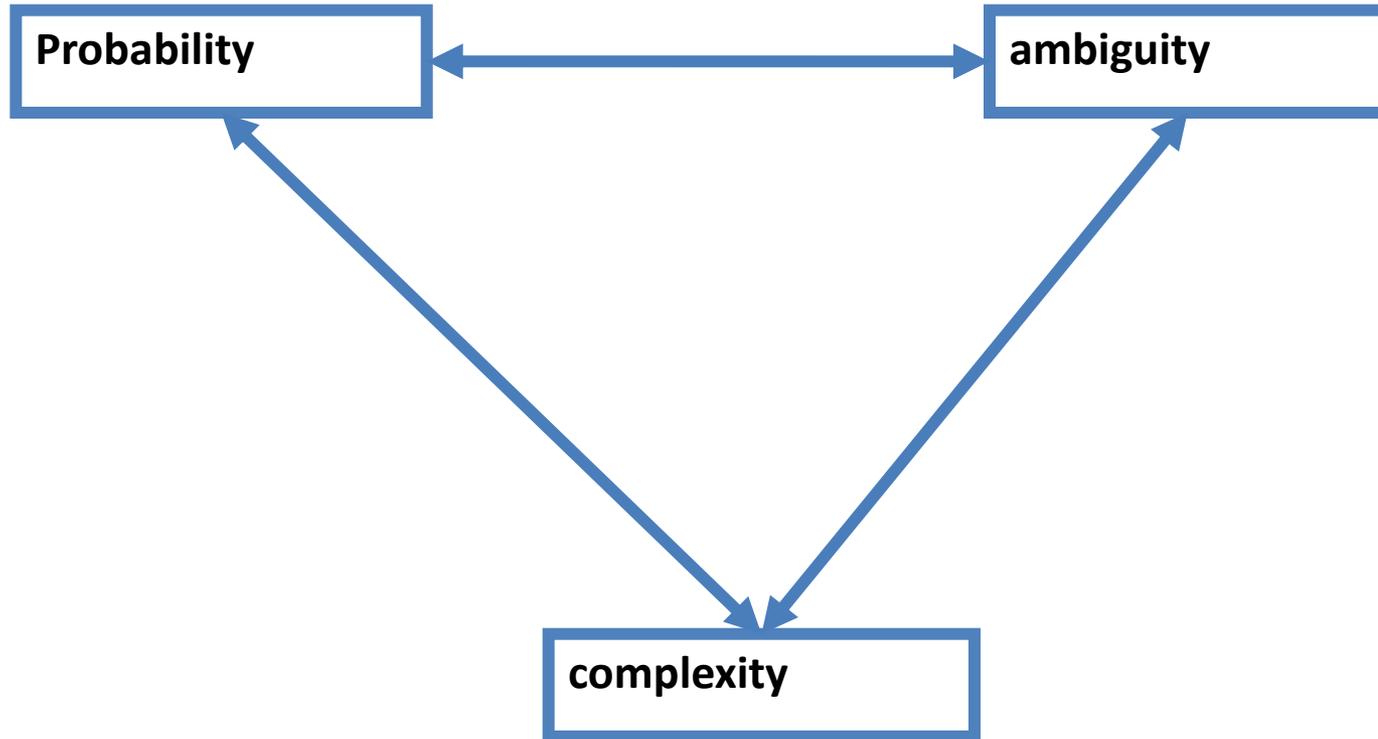
Nephrol Dial Transplant (2010) 25: 1757–1759

doi: 10.1093/ndt/gfq206

Advance Access publication 14 April 2010

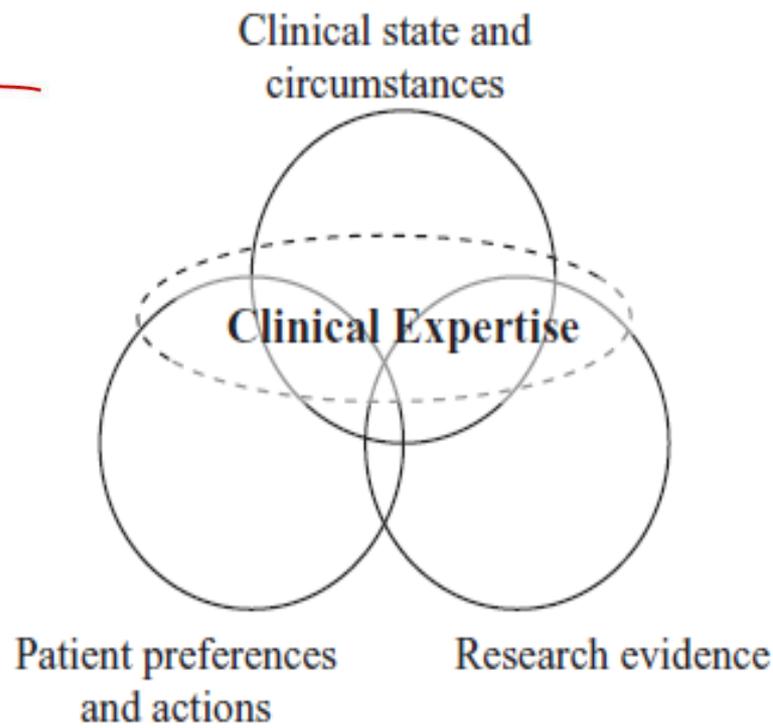
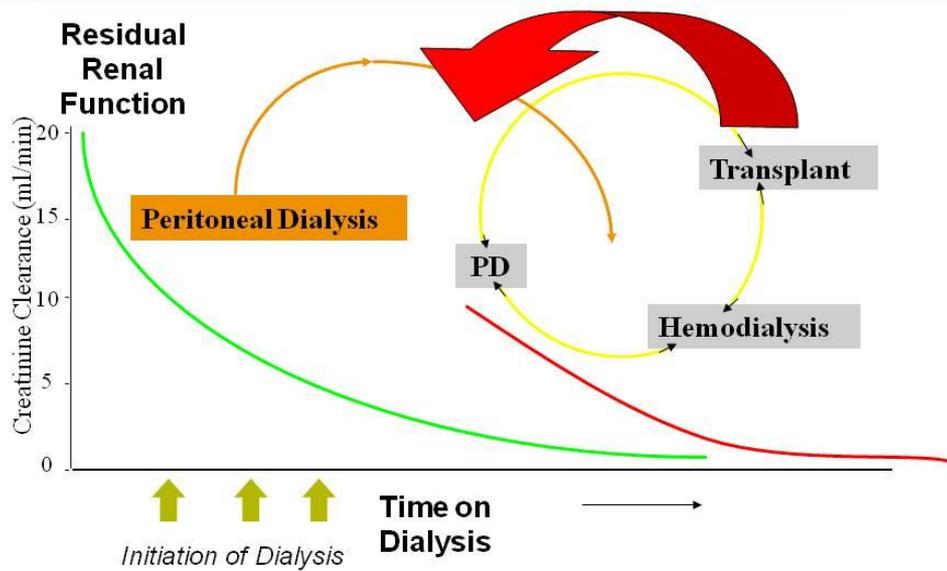
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**CONTEXT: the patient**

# The Context - within the Integrated Care Model



**Figure 1** Evidence-based decision-making for clinical contexts.

# Shared decision making

**Inform**

# Shared decision making

**Inform**

**Deliberate**

# Shared decision making

**Inform**

**Deliberate**

**Decide**

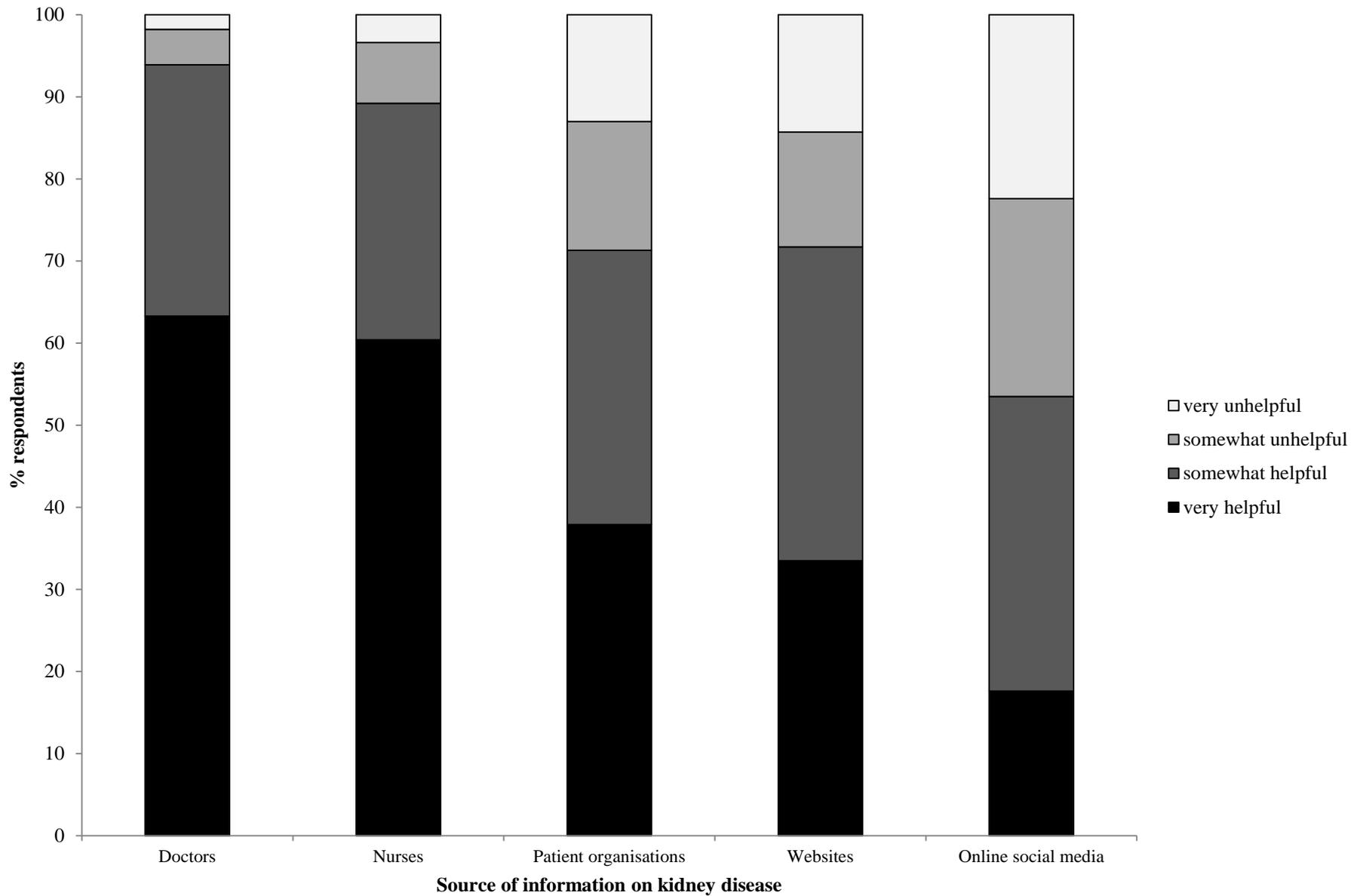
# Patient perspectives on informed decision-making surrounding dialysis initiation

**Methods.** Ninety-nine maintenance dialysis patients recruited from 15 outpatient dialysis centers in North Carolina completed semistructured interviews on information provision and communication about the initiation of dialysis. These data were examined with content analysis. In addition, informed decision-making (IDM) scores were created by summing

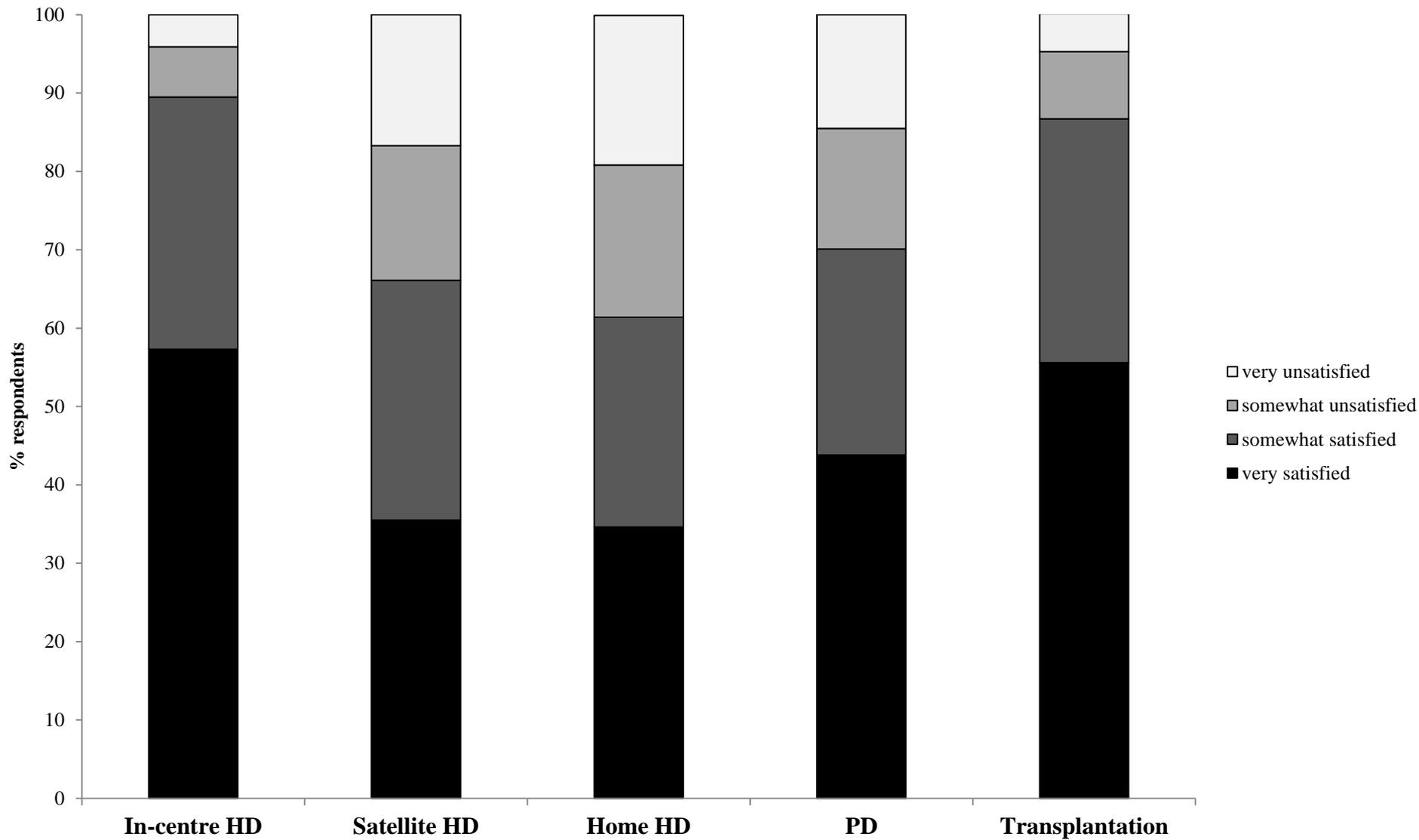
**Table 3. Number (%) of patients responding 'Yes' to each informed decision-making item**

Content of the item	<i>n</i> (%)
1. Condition that led to kidney failure	53 (53.5)
2. How long you would live with or without dialysis	45 (45.5)
3. Dialysis options, such as peritoneal dialysis and hemodialysis	59 (59.6)
4. Benefits and burdens associated with each type of dialysis	32 (32.3)
5. Doctor asked your values and preferences for those dialysis options	20 (20.2)
6. How your daily life might change after starting dialysis	44 (44.4)
7. Need for dialysis for the rest of your life unless you receive kidney transplantation	82 (82.8)
8. Not starting dialysis could be an option	1 (1.0)
9. Doctor tried to make sure you understood what he/she told you	74 (74.7)
10. Doctor tried to understand what was important to you	58 (58.6)

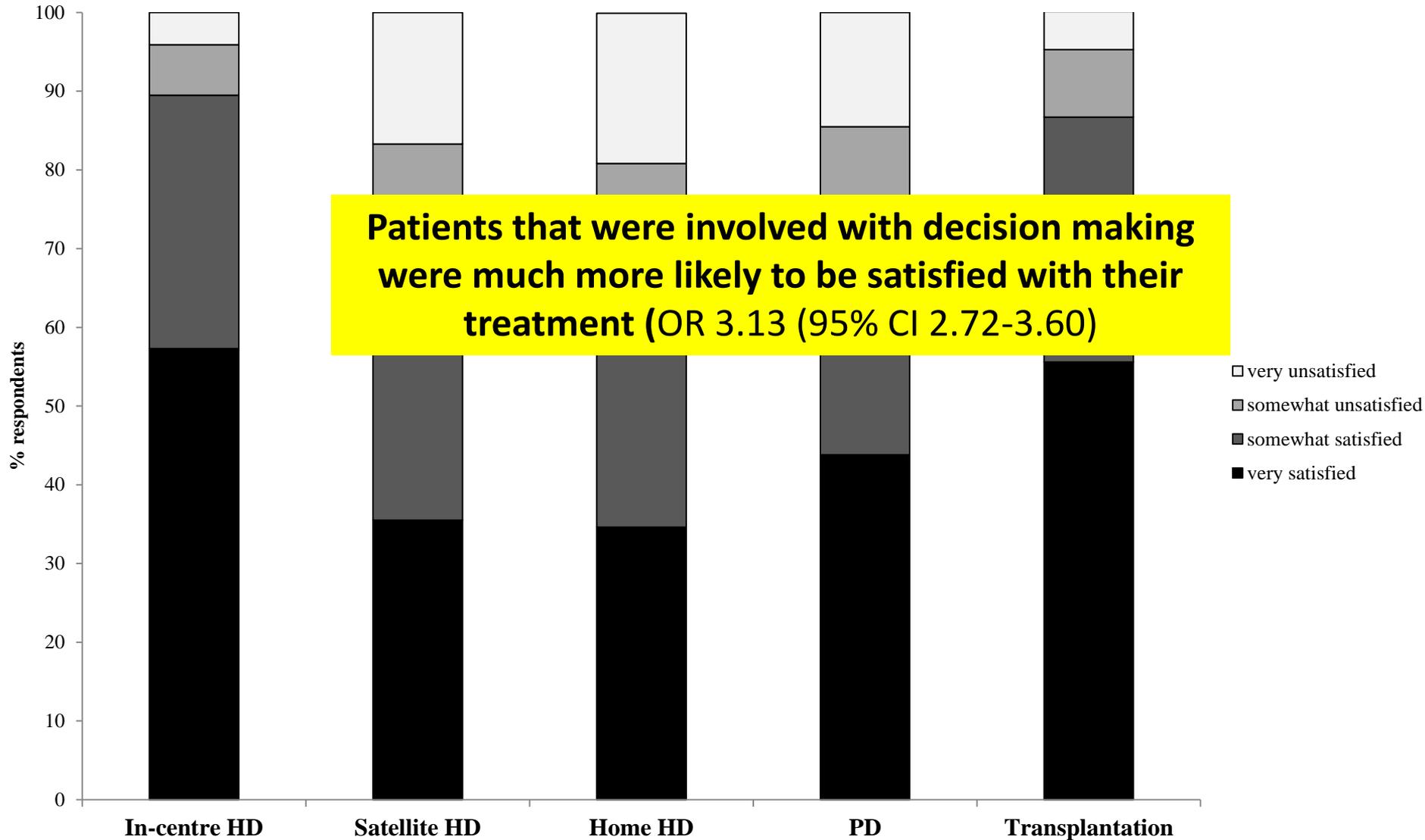
# Sources of patient information



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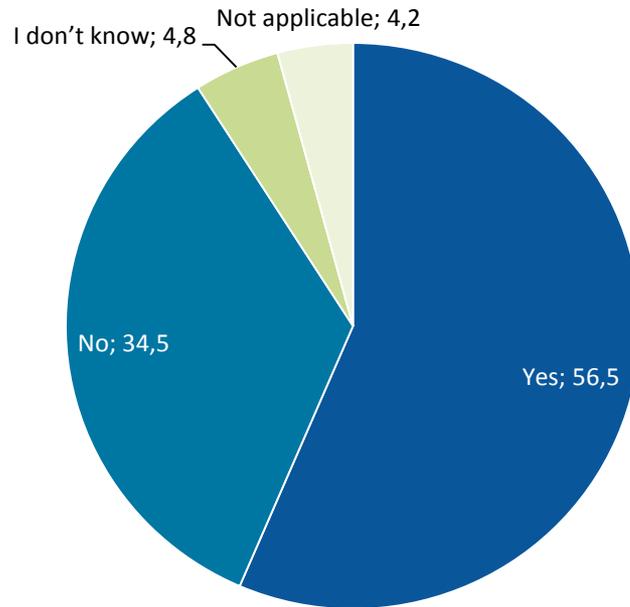


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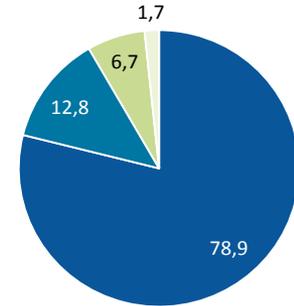


# Information about choice

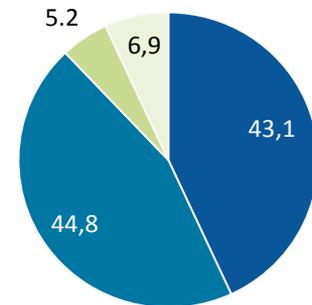
During this treatment time, has anyone ever spoken to you about alternative dialysis options and the possibility of changing treatments?



Hungary

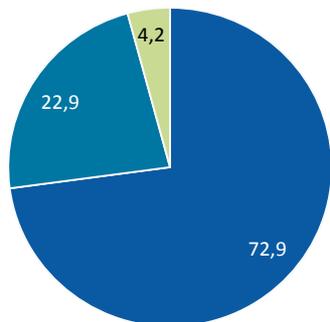


Italy

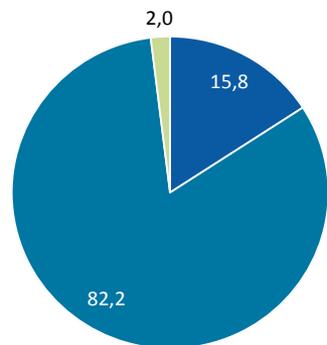


Almost a half of respondents in Europe do not recall having discussed alternative treatment options.

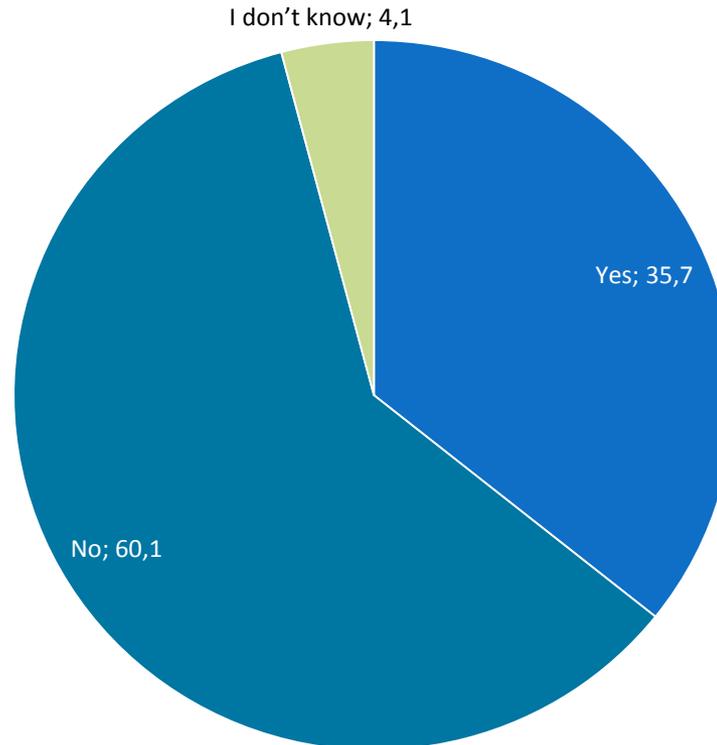
### Finland



### Germany



### Have you received education and / or rehabilitation to help you to manage in your day-to-day life?



Nearly two-thirds of patients did not receive the education or rehabilitation they need to help reconcile their kidney condition with their day-to-day life.

## The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies

*Lack of information*—Eleven of 18 studies reported that patients or their carers did not have the information they wanted on treatment options, regardless of whether transplantation, dialysis, or palliative care was preferred. Family members of patients were especially concerned about their lack of knowledge of the different treatments available and the practicalities in managing each treatment.

# The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies

*Timing of information*—Ten studies reported the importance of the timing of information on treatment options. Patients recounted being too unwell to take in the information presented or too rushed into making a decision without having time to discuss the options with their families. Information about kidney transplantation was commonly introduced to patients after dialysis had been established. For some patients information about treatment options came after undergoing surgery for vascular access.

*Maintaining lifestyle*—The medical outcomes of treatment were considered less important than the effect of the treatment on the patient's lifestyle—that is, patients were less concerned about their longevity than they were about their quality of life. Treatment choices were based on minimising disruption to usual activities, upholding responsibilities, and maintaining personal interests. Examples of this included the ability to continue working, maintain a social life, or care for grandchildren (see table 4).

## Patient Information: Predialysis

1. Patients do not recall having been informed at all
2. Patients are informed “too late” i.e. in a state when they are uraemic, desperate, depressed by their diagnosis....
  - Language too difficult
  - Irrelevant information
  - Too much information
3. There is a “communication problem” between medical staff and patients on which topics/factors to value
  - Empathic listening
  - Motivational interviewing
4. Patients tend to make heuristic, not objective decisions
  - Danger of exposing them to other patients



# ERBP

## “Shared Decision Making”

