

Welche Kinder bekommen SAPV in Deutschland?

Silke Nolte-Buchholtz



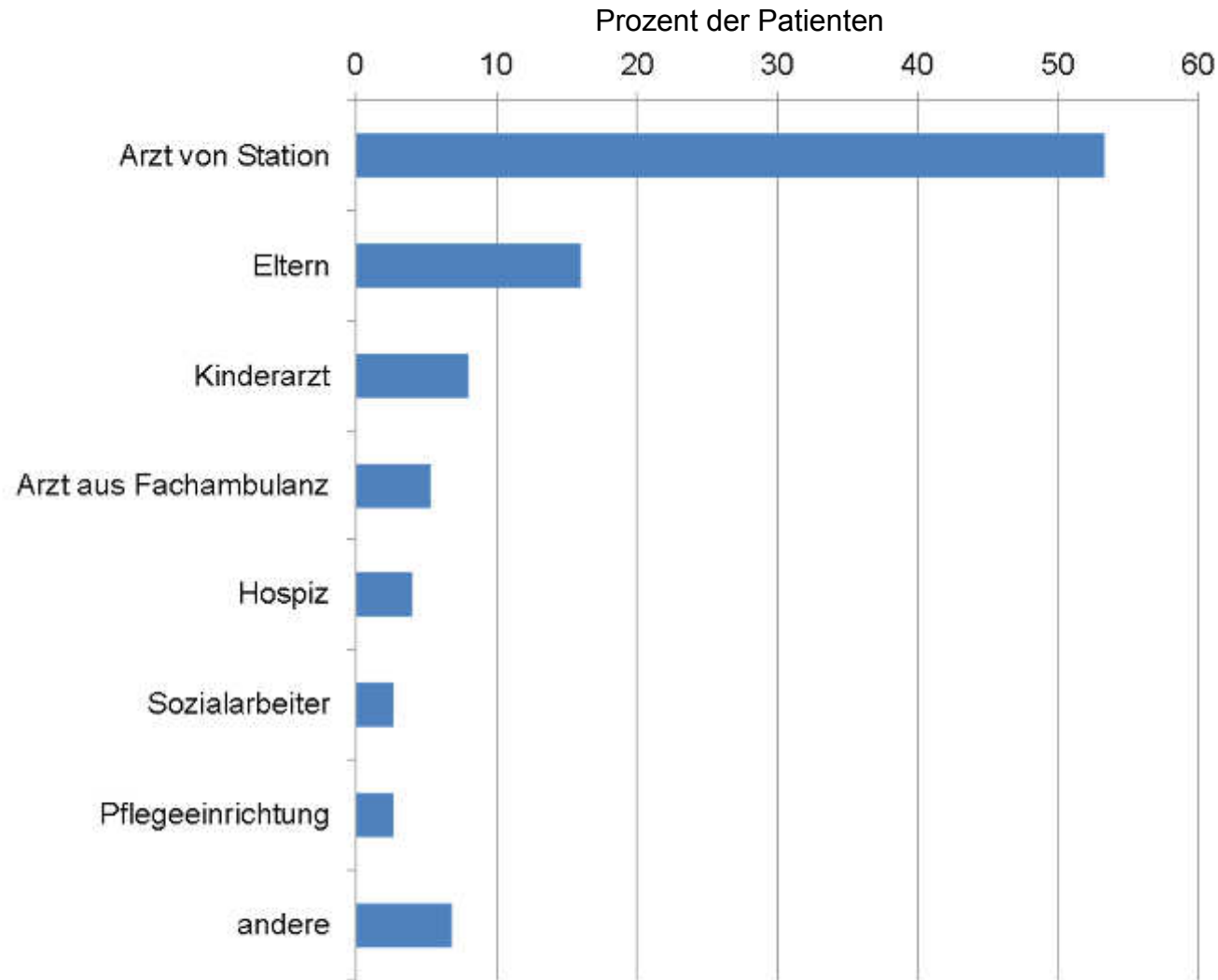


9/14 SAPV-Teams für Kinder,
Jugendliche und junge Erwachsene

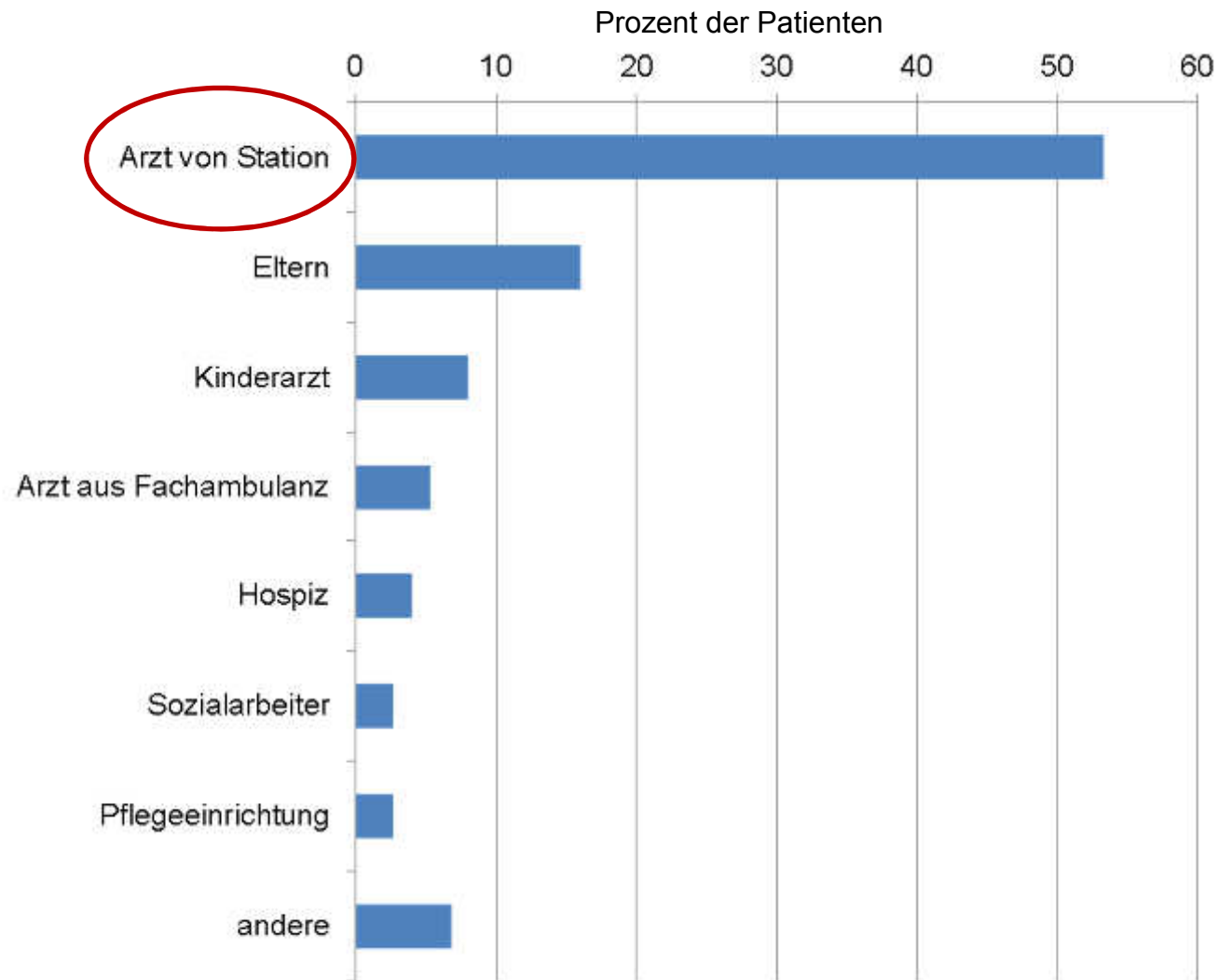


9/14 SAPV-Teams für Kinder,
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75 Patienten in einem Quartal



andere: SPZ, Wohngemeinschaft, Homecareversorger, Tagesklinik Brückenteam



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<i>Characteristics</i>	<i>Total patients</i>	
	<i>N</i>	<i>%</i>
Total	75	100.0
Gender	69	100.0
Female	34	49.3
Age	72	100.0
0-1 month	1	1.4
2-11 months	15	20.8
1-9 years	25	34.7
10-18 years	21	29.2
Older than 18 years	10	13.9
Siblings with LLC¹	72	100.0
	7	9.7

¹Life-limiting conditions



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DIAGNOSES OF PATIENTS IN THE COHORT

<i>Diagnoses</i>	<i>N</i>	<i>%</i>
Total	75	100.0
Cancer	21	28.1
Solid tumor	11	14.7
Brain tumor	8	10.7
Leukemia	2	2.7
Non-Cancer	54	71.9
Neuromuscular	28	37.3
Neurodegenerative	9	12.0
Chromosomal Aberration	6	8.0
Cardiovascular	6	8.0
Respiratory	1	1.3
Gastrointestinal	1	1.3
Other ¹	3	4.0

¹Vacterl Association, Agenesis of the Pons, Lennox Encephalopathy

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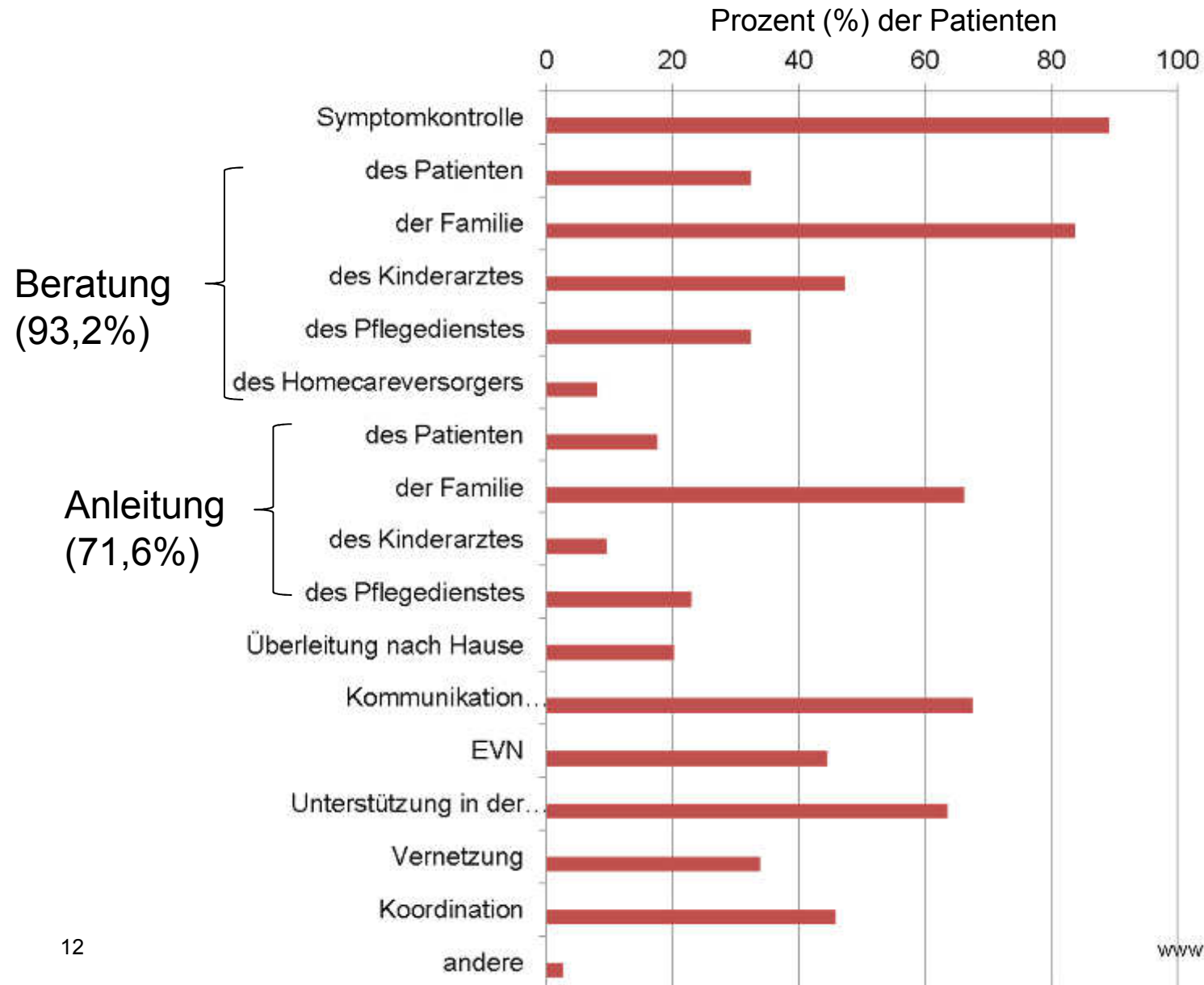
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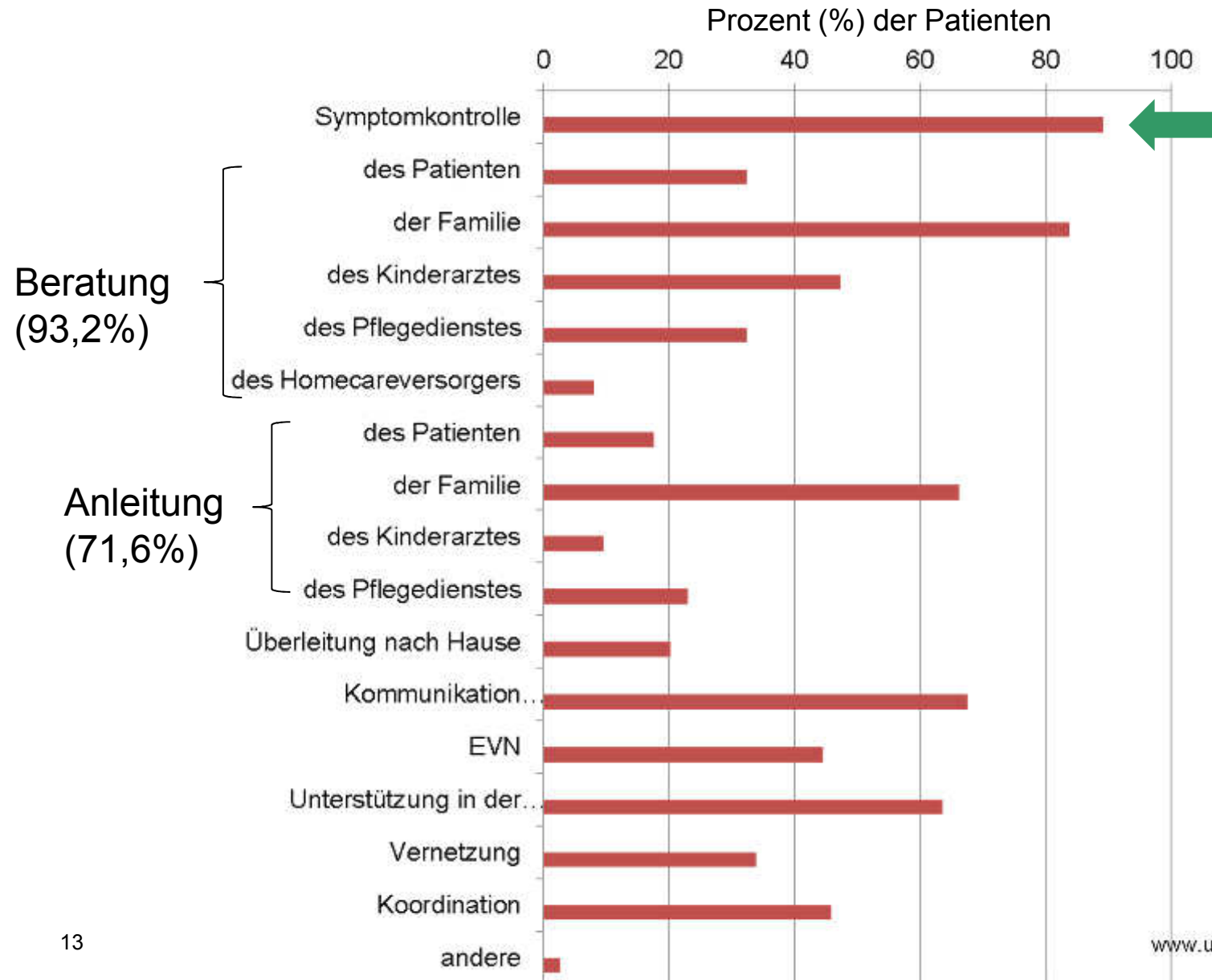
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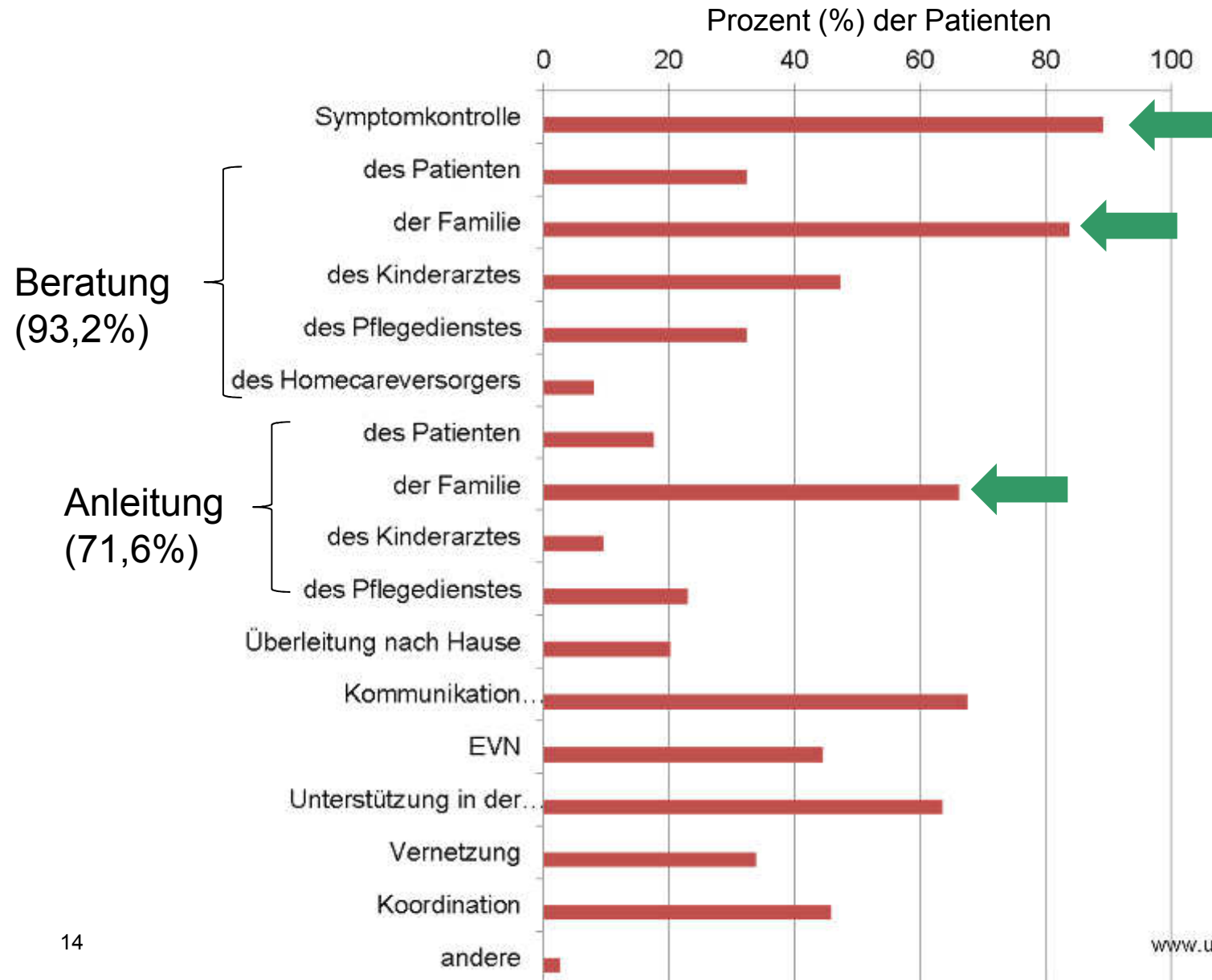
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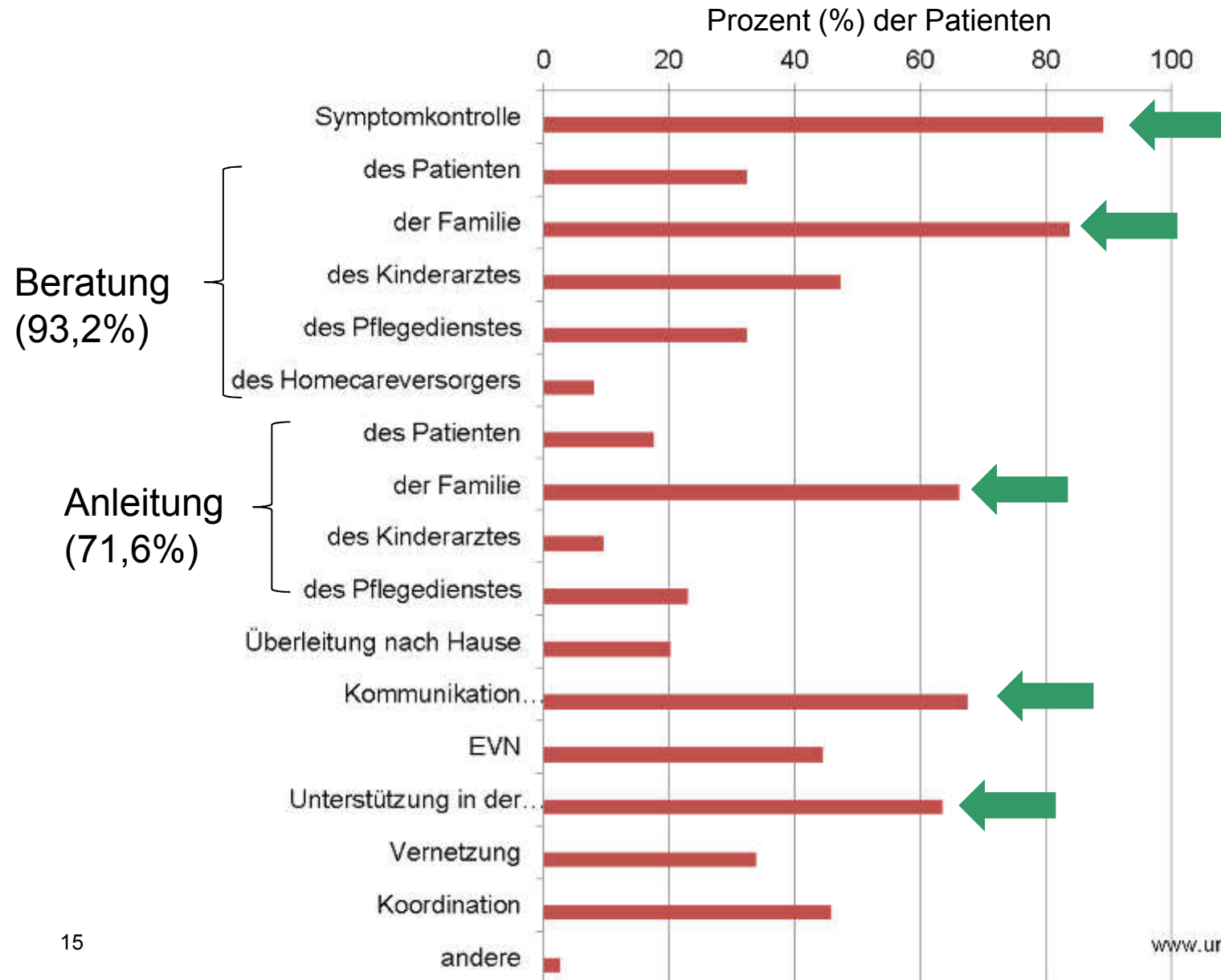
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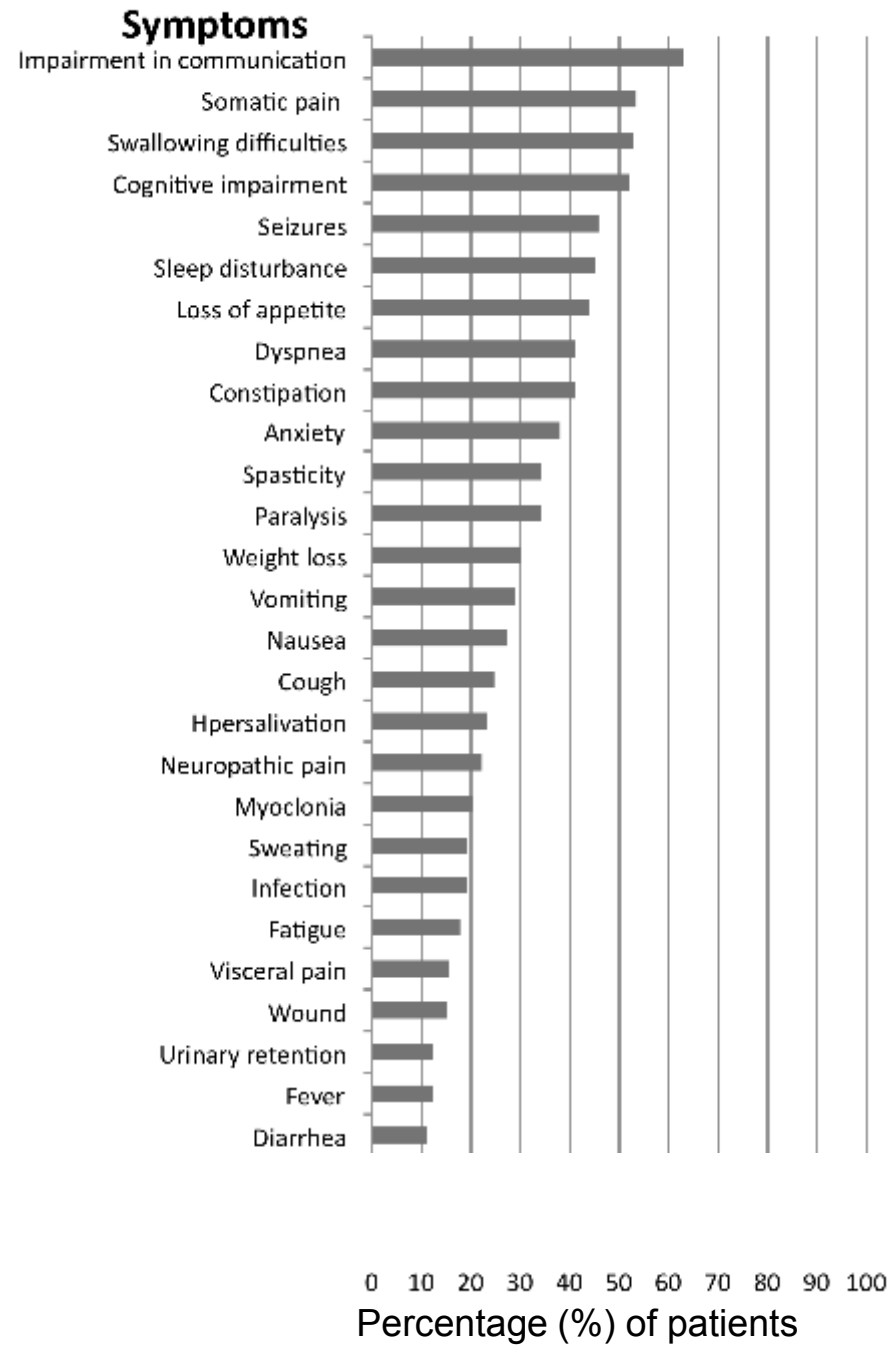
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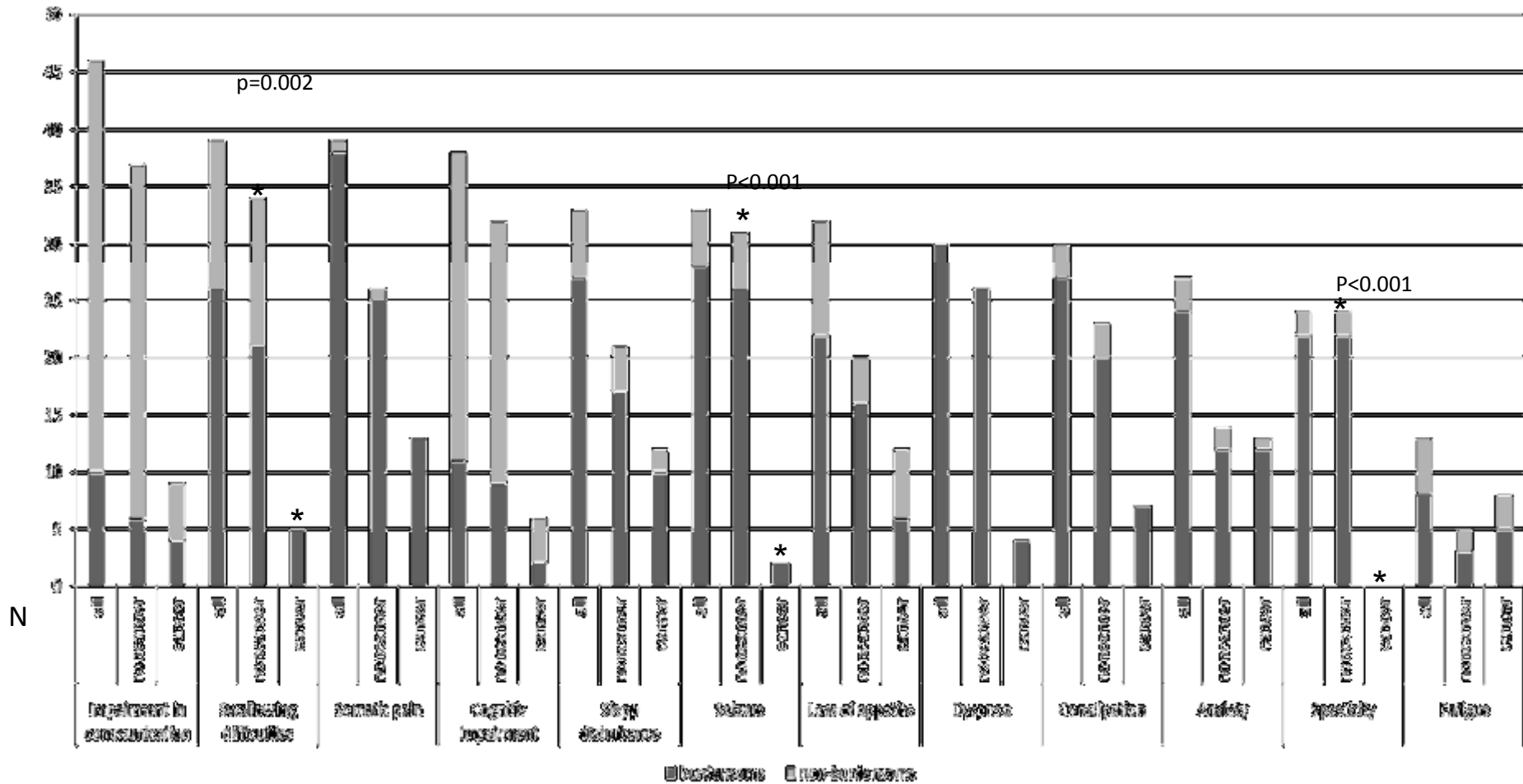




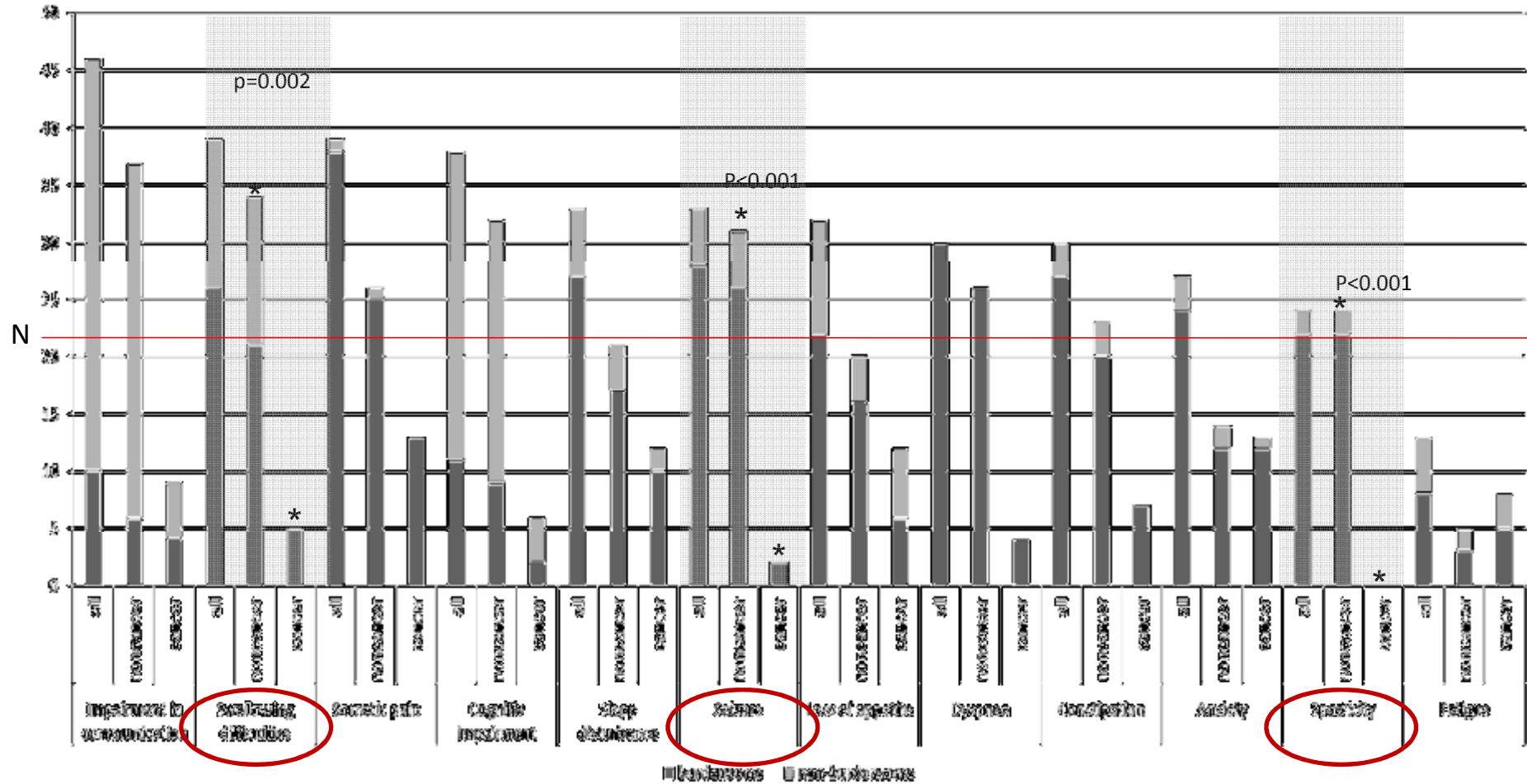




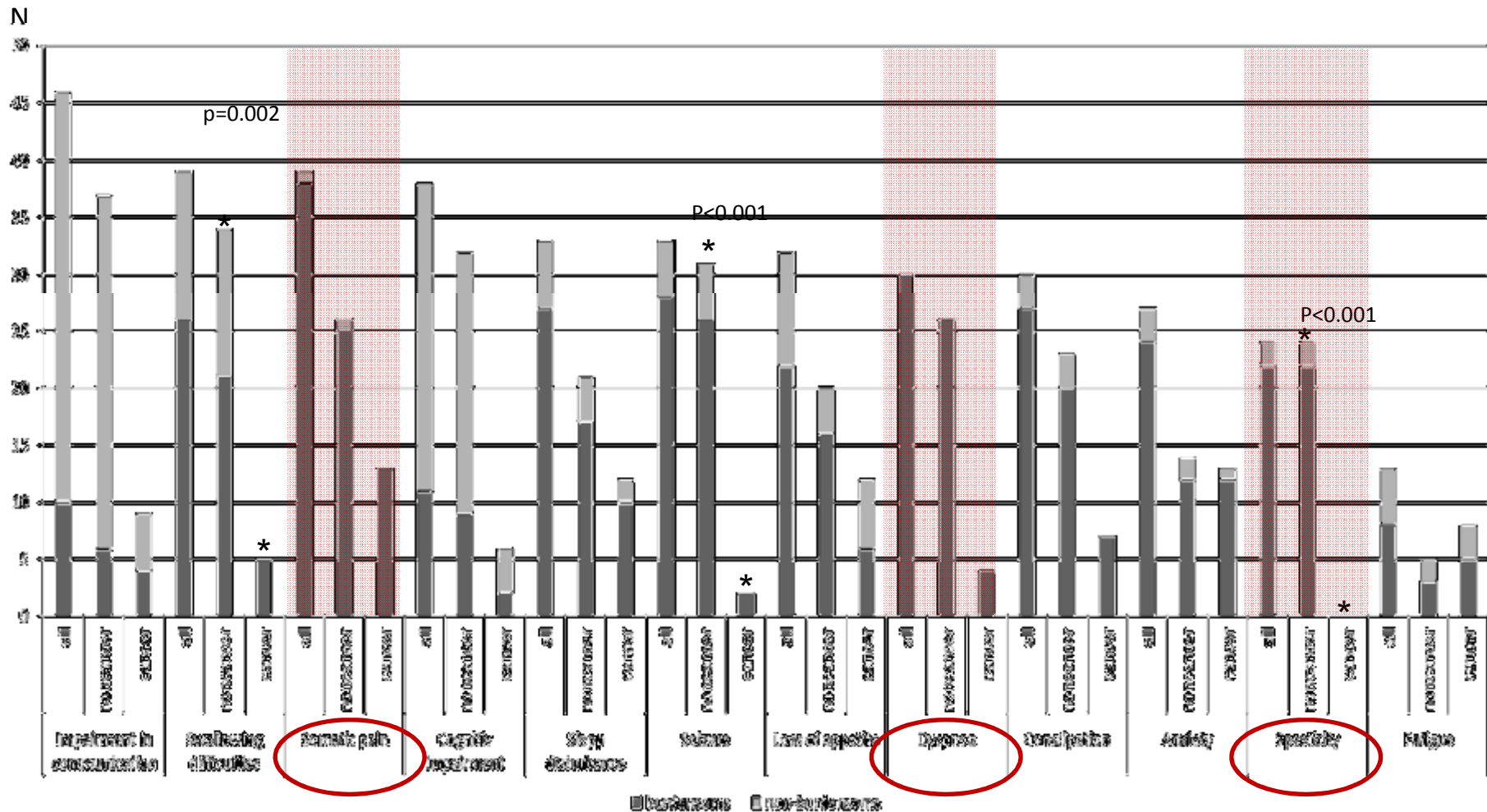




Burdensome vs. non-burdensome symptoms in cancer and non-cancer patients .
N= total number of patients.

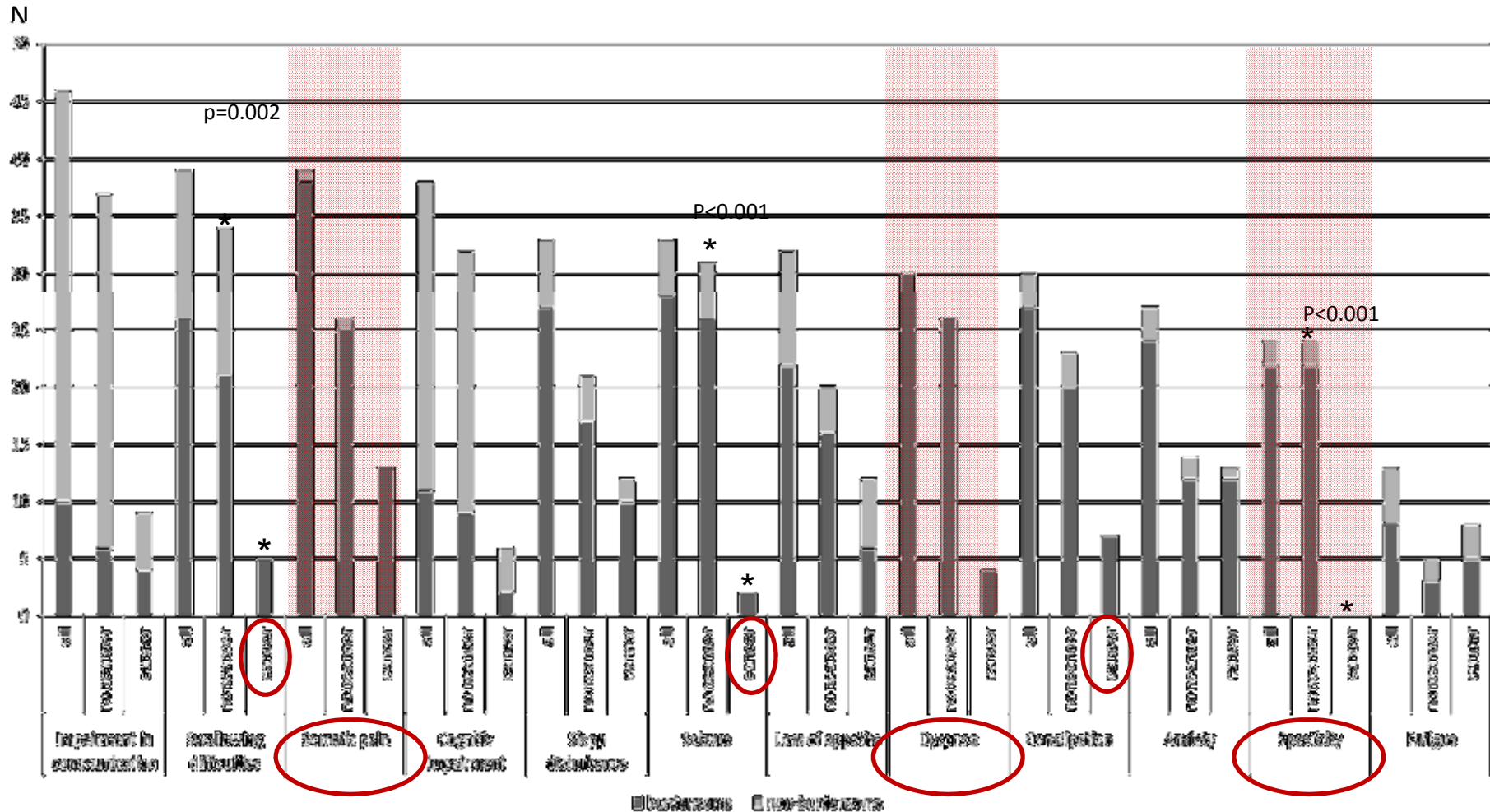


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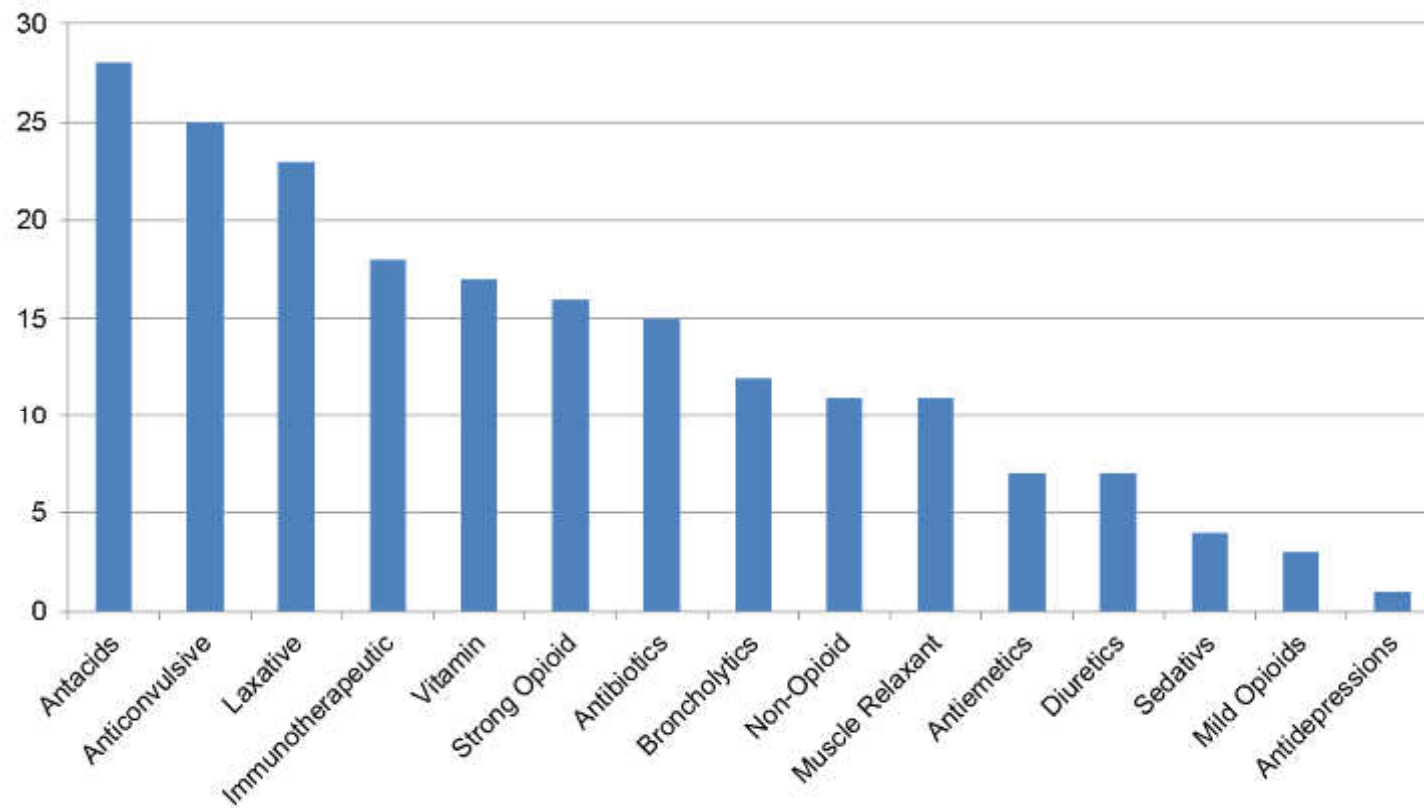


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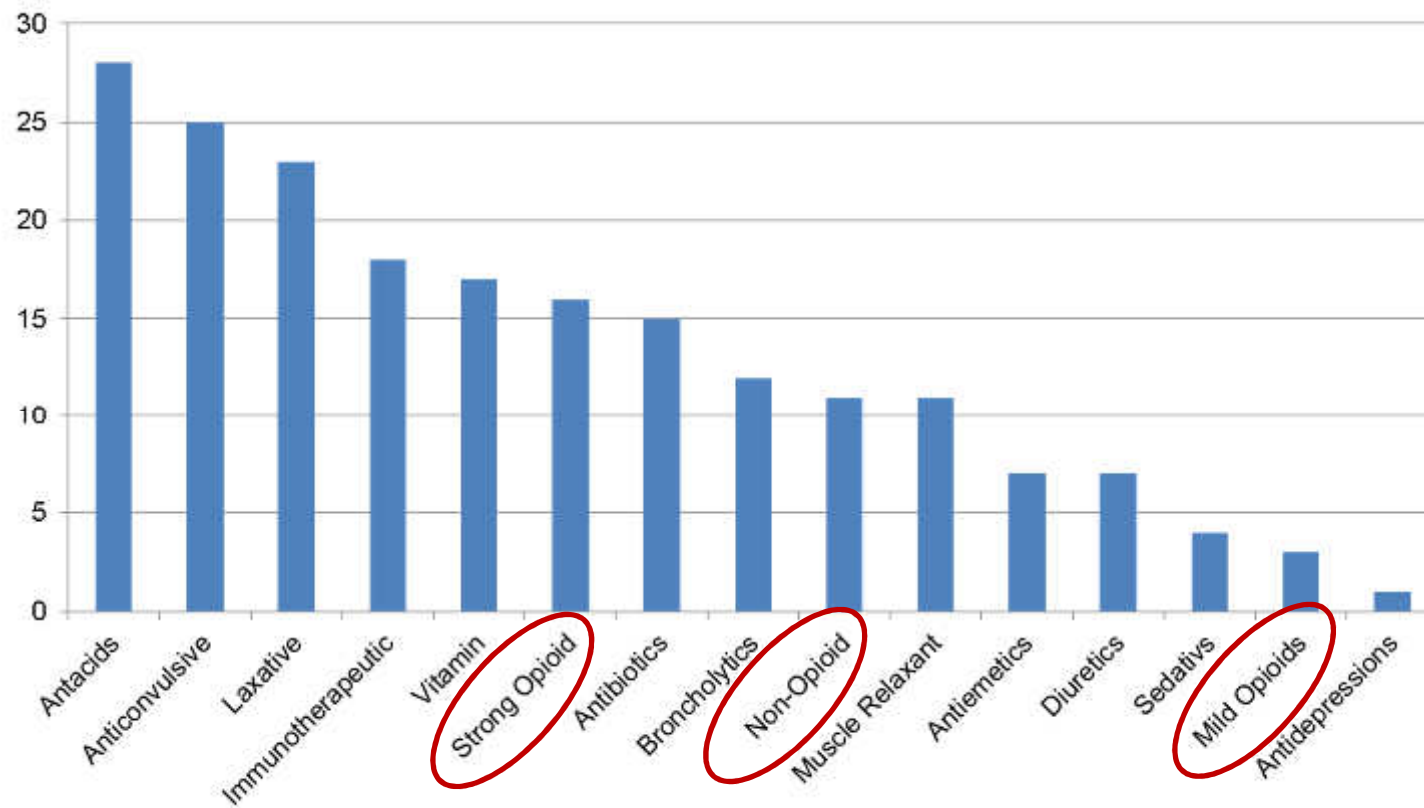
Anzahl der Patienten



Medikamente in der Dauertherapie (N=70)



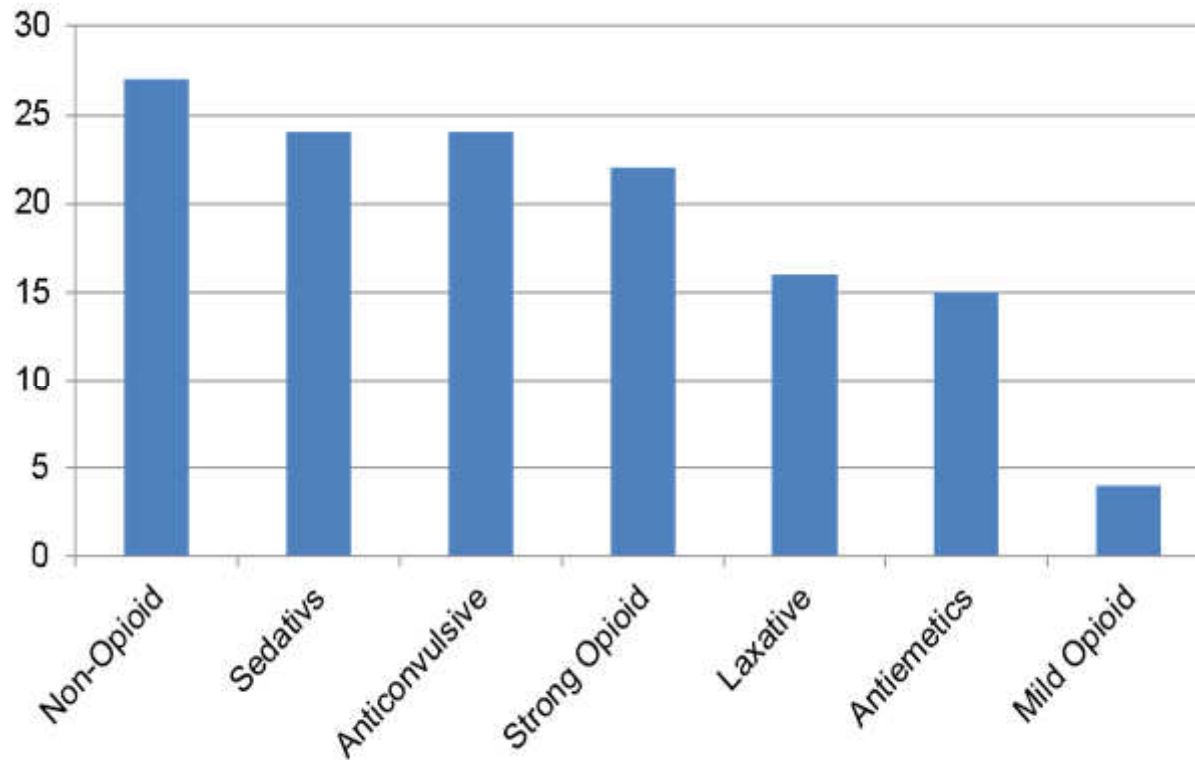
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Medikamente in der Dauertherapie (N=70)



Anzahl der Patienten



Bedarfsmedikamente (N=70)

Characteristics	All patients (N=70)		Cancer patients (N=21)		Non-cancer patients (N=49)		p ¹
	Mean (SD)	range	Mean (SD)	range	Mean (SD)	range	
Number of medication (permanent therapy)	3.80 (2.48)	0-12	3.33 (2.13)	0-7	4.00 (2.61)	0-12	ns
Number of medication (on demand medication)	2.44 (2.02)	0-12	2.24 (1.58)	0-7	2.52 (2.19)	0-12	ns
Medical technology	N	%	N	%	N	%	p ²
Any feeding tube	75	100	21	100	54	100	<0.001*
Nasogastric tube	43	57.3	1	4.8	42	77.8	
Gastro- or jejunost. tube	15	20.0	1	4.8	14	25.9	
Gastro- or jejunost. tube	29	38.7	0	0.0	29	53.7	
Central venous catheter	15	20.0	11	52.4	4	7.4	<0.001*
Tracheostomy	7	9.3	0	0.0	7	13.0	0.180
Any ventilation	11	14.7	0	0.0	11	20.4	0.028
Invasive ventilation	6	8.0	0	0.0	6	11.1	
Noninvasive ventilation	5	6.7	0	0.0	5	9.3	
Oxygen	25	33.3	1	4.8	24	44.4	0.003*
VP/VA shunt	3	4.0	2	9.5	1	1.9	0.188
Other therapy than medication	51	68.0	9	42.9	42	77.8	0.008*
Physiotherapy	49	65.3	8	38.1	41	75.9	
Ergotherapy	18	24.0	2	9.5	16	29.6	
Speech therapy	10	13.3	0	0.0	10	18.5	
Music therapy	5	6.7	0	0.0	5	9.3	
Homoeopathy	5	6.7	1	4.8	4	7.4	
Art therapy	1	1.3	0	0.0	1	1.9	
Acupuncture	0	0.0					

¹ T-test

² Fisher's exact test

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Der „typische“ SAPV-Patient in der Pädiatrie

Der nichtonkologische Patient wird vom Klinikarzt angemeldet. Er ist in seinen kommunikativen Fähigkeiten und kognitiv eingeschränkt, hat somatische Schmerzen und Schluckstörungen. Leid wird hauptsächlich durch Schmerzen ausgelöst. Seine Versorgungssituation ist komplex. Er hat eine Ernährungssonde, ist häufig beatmet und bekommt Sauerstoff. Er wird mit Antazida und Antikonvulsiva behandelt, für den Bedarfsfall stehen Nichtopioid-Analgetika zur Verfügung. Aufgaben sind die Beratung und Anleitung vorrangig der Familie sowie Symptomkontrolle. Des Weiteren soll über Symptome und Krankheitsverlauf informiert werden und es wird sich Unterstützung in der Entscheidungsfindung gewünscht.

Vielen Dank für Ihre Aufmerksamkeit!

Vielen Dank den Teams für ihre Unterstützung!

SAPPV-Team Schleswig-Holstein, Brückenteam der DRK-Heinrich-Schwesternschaft

SAPV-Team für Kinder und Jugendliche Datteln, Vestische Kinder- und Jugendklinik Datteln

Betreuungsnetz schwerkranker Kinder UG(h)

Brücken-Team der Kinderklinik des Univeristätsklinikums Münster

KinderPaCT Berlin – Björn Schulz Stiftung

KinderPaCT Hamburg e.V.

KinderPalliativteam Südhessen

Kinderpalliativteam Saar

Brückenprojekt Dresden