



LUDWIG-
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What do we know about patients' and citizens' perspectives on assisted suicide in Germany?

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1. Studies with patients and relatives
2. Public opinion polls
3. Conclusions for the political debate



- End-of-life decisions affect various stakeholders and society in general, but **most existentially** the patients
- The patients' perspective has to be taken into account before making **legal regulations**
- Patients' individual perspectives are not necessarily represented by **“patient organizations”**
- Publicized **single cases** may bias the debate
- Clinician and family experiences should be complemented by **research** on patient perspectives



- Most studies on patient perspectives on assisted suicide stem from the **USA**, **BeNeLux** and **CH**
- In Germany, studies focused on the subsets of patients with **cancer** or **amyotrophic lateral sclerosis (ALS)**
- **Desire for hastened death (DHD)**: wish to die prior to natural dying by (assisted) suicide or termination of life on request
- DHD is a **state of mind** distinct from depression, anxiety, and physical suffering that can be assessed by the “Schedule of Attitudes towards Hastened Death” (SADH)

Galushko M et al. Palliat Support Care 2015



- Frequency of *current* DHD in terminally ill German patients found to be **20-29%** across different measures

*Galushko et al. Pall Supp Care 2015; Stutzki et al. ALSFTD 2014,
Lulé D et al. J Neurol 2013*

- 1/3 of ALS patients **sought information** on hastening death
Lulé D et al. J Neurol 2014

- DHD also expressed by patients in **palliative care** settings

*Pestinger M et al. Palliat Med 2015; Stutzki R et al. ALSFTD 2014
Van Oorschot B et al. Psychother Psych Med 2005*

- Representative **physician poll**: 34% have been asked for DHD at least once (50% of primary care physicians)

Allensbach 2009 (commissioned by Bundesärztekammer)



Table 2 All cases per year and country

	2008	2009	2010	2011	2012	Total
Germany	59	37	28	67	77	268
UK	23	27	24	23	29	126
France	19	7	8	13	19	66
Italy	2	4	4	12	22	44
USA	0	0	5	9	7	21
Austria	4	3	1	2	4	14
Canada	5	0	5	0	2	12
Spain	2	0	3	1	2	8
Israel	3	2	1	1	1	8
Australia	1	0	3	1	0	5
Total	123	86	90	140	172	611

48% 43% 31% 48% 45% 44%

- Retrospective analysis of cases of assisted suicide
- 2008-2012
- Legal Medicine Univ. Zurich

Gauthier S et al.
J Med Ethics 2014



- **Determinants** of DHD in 2 ALS studies:

- NOT: physical disability, symptom burden, age, social support, country of residence (Germany vs. CH)
- YES: feeling to be a burden to others, loneliness, low religiosity
- YES/NO: depression, anxiety, quality of life

Stutzki R et al. ALSFTD 2014; Lulé D et al. J Neurol 2014

- **Motives** according to qualitative interviews with 12 patients on palliative care units who expressed a DHD:

- Self-determination, wish for control, disburden relatives from decision
- Fear of future dependency, loss of communication, agony, lingering
- Perception that the right time has come to die
- Longing for certainty about a last resort

Pestinger M et al. Palliat Med 2015



- DHD slightly decreased between two questionnaire surveys of ALS patients

Lulé D et al. J Neurol 2014

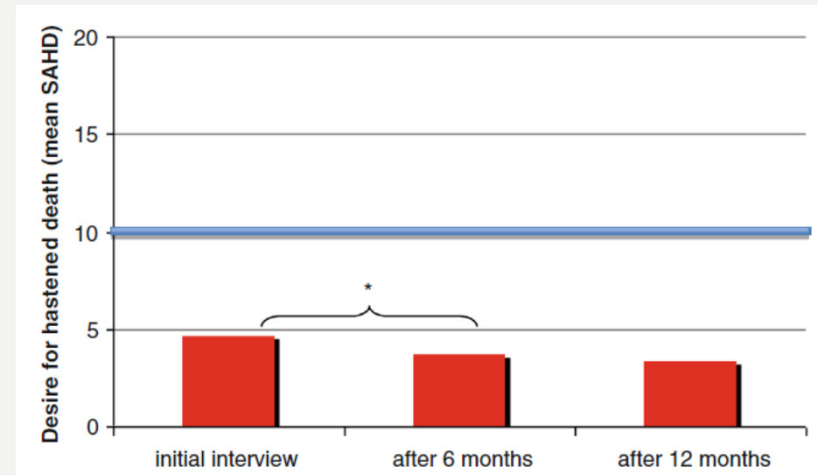


Table II. The wish to hasten death among ALS patients.

	Baseline survey <i>n</i> = 66	Follow-up survey <i>n</i> = 38
Can you imagine asking a physician for a prescription to commit suicide? <i>n</i> (%)		
Yes	33 (50)	17 (45)
No	30 (46)	21 (55)
Can you imagine asking a physician to administer a lethal medication? <i>n</i> (%)		
Yes	33 (50)	17 (45)
No	30 (46)	21 (55)

Stutzki R et al. ALSFTD 2014



- Family caregivers of ALS patients evaluated patients' DHD **similar** to the patients

Lulé D et al. J Neurol 2014

- 1/3 of family caregivers could imagine **helping** the patient in hastening death

Stutzki R et al. ALSFTD 2014

Have you ever talked about someone about the option to hasten death? <i>n (%)</i>	
Yes	44 (67)
No	19 (29)
With whom did you talk about the option to hasten death? <i>n (%)</i>	
With a family member	16 (84)
With a friend	–
With another ALS patient	1 (5)
With a chaplain	1 (5)
With a physician	1 (5)
Would you like to talk with a physician about the option to hasten death? <i>n (%)</i>	
Yes	20 (30)
No	37 (56)

Stutzki R et al. ALSFTD 2014

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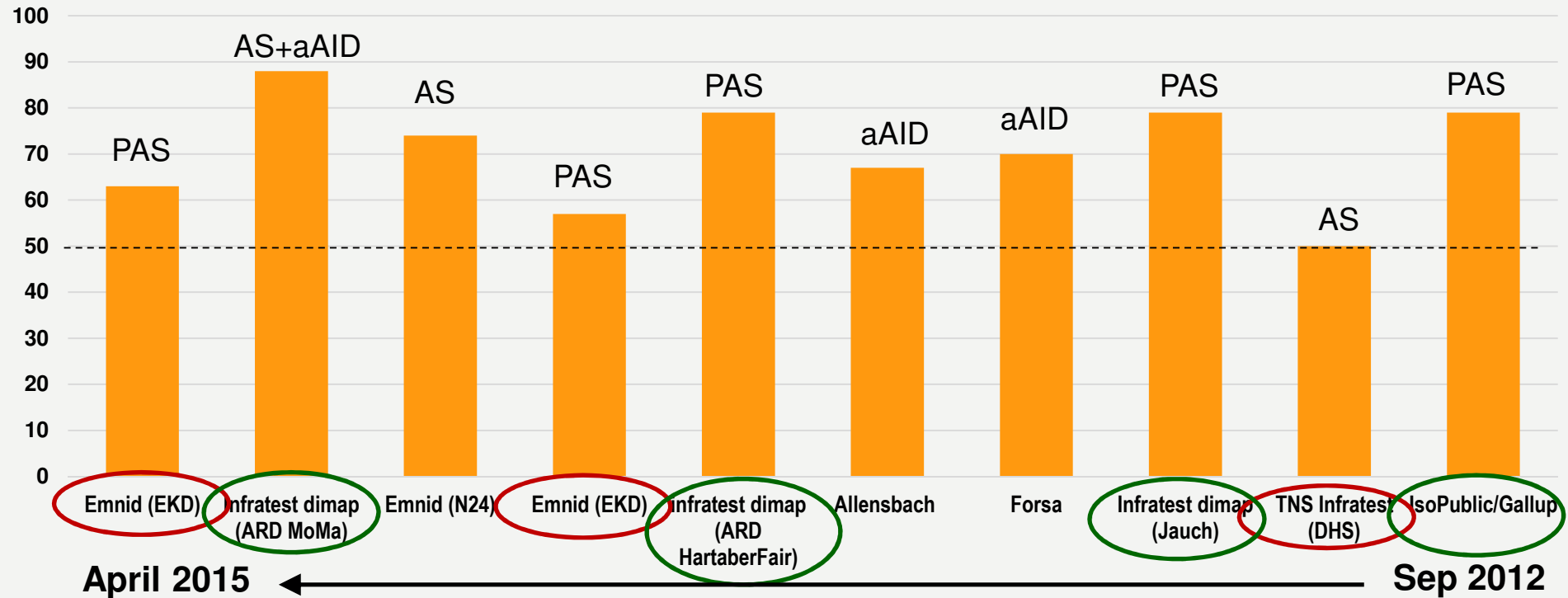
- End-of-life issues attract **high attention** in the public (meetings, talks, media publications...)
- End of life touches on **core value** in society (life, autonomy, dignity)
- **Democratic principles** demand a fair, inclusive public and parliamentary debate before any regulation
- **Public opinion polls:** a legitimate part of this debate
- Polls are subject to **biases** and variance according to methodology



% of the surveyed

PAS = physician-assisted suicide
AS = assisted suicide

aAID= „active aid in dying“
(termination of life on request)



Evangelical church, link to catholic church

State TV with a tendency to the political left

- **Questions** phrased somewhat differently according to:
 - *Assisted suicide / termination of life on request / aid in dying*
 - *Physician involvement (PAS or AS)*
 - *Legitimacy conditions (e.g. patients with terminal illnesses)*
 - *Hypothetical personal involvement or general attitude*

- Higher **support rates** among:

- *Eastern Germans*
- *Less religious ones*
- *Citizens with a higher education*
- *Younger/Middle-aged citizens*

Known factors from the
European Values Study

Cohen J et al. Eur J Public Health 2006
Cohen J et al. Soc Scie Med 2006

- 75% of **bereaved** relatives of cancer patients in favor of AS

Köhler N et al. Z Psychosom Med Psychother 2014

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1. DHD: situation- and personality-dependent feature of terminal illness, also occurring in Germany
2. DHD occurs also in palliative care as underlying problems/motives are not all amenable to change
3. Communication about DHD: a taboo in the physician-patient-encounter in Germany
4. Legal prohibition of organized assisted suicide would not change DHD, but increase the taboo, may lead to violent suicide, suicide tourism, and hidden suicide assistance, and is contrary to the stable, vast majority public opinion



**Thank you for
your attention!**

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