



Challenges in supporting Life after stroke: experiences from Sweden

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ELASF webinar March 12th, 2021



Disclosures

Member of the data and safety monitoring boards for SOCRATES and THALES trials (Astra Zeneca) and the NAVIGATE-ESUS trial (Bayer).

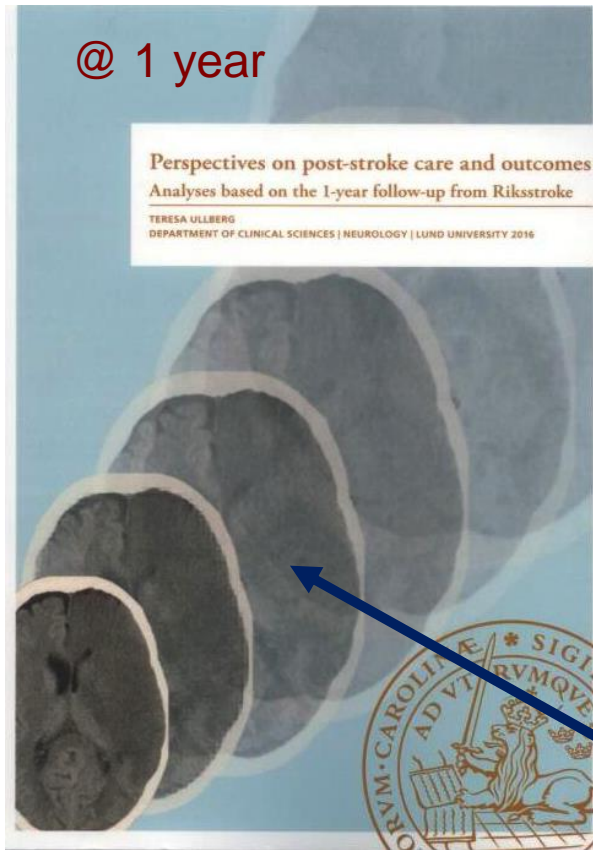
The Swedish Stroke Register (Riksstroke)

- The 1st national stroke register in the world (1994)
- Coverage approx 90 %
- Outcomes including patient-reported outcomes (PROMs) 3 and 12 months after stroke
- Several surveys on situation for patients and carers in the long term



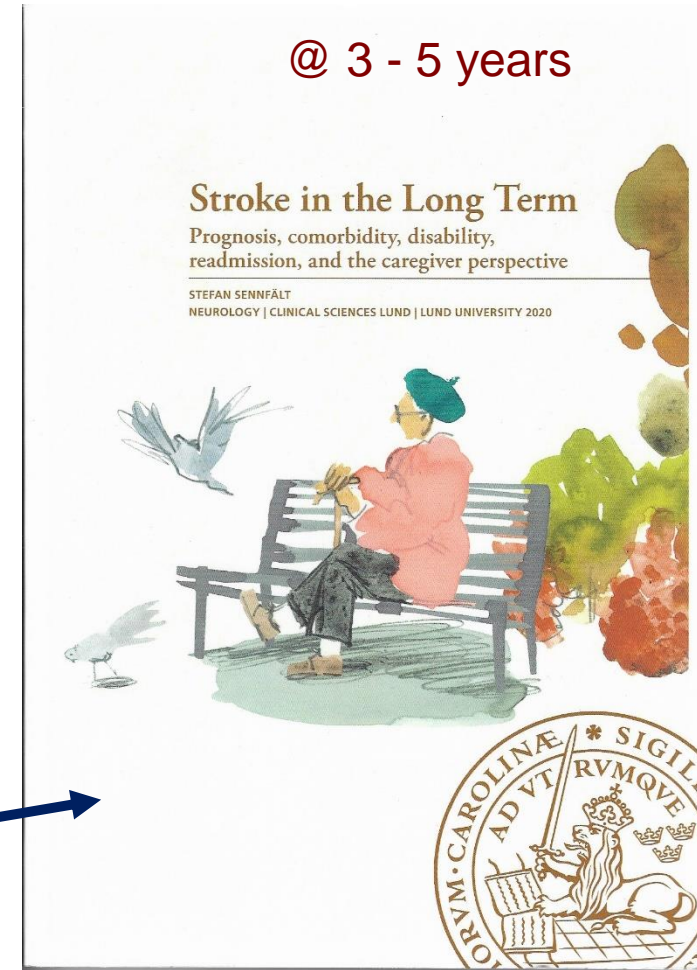
Stegmayr Asplund Terent Norrving
Hulter Åsberg Wester Back Danielsson





Insights on Life after Stroke from the Swedish Stroke Register

Two recent theses



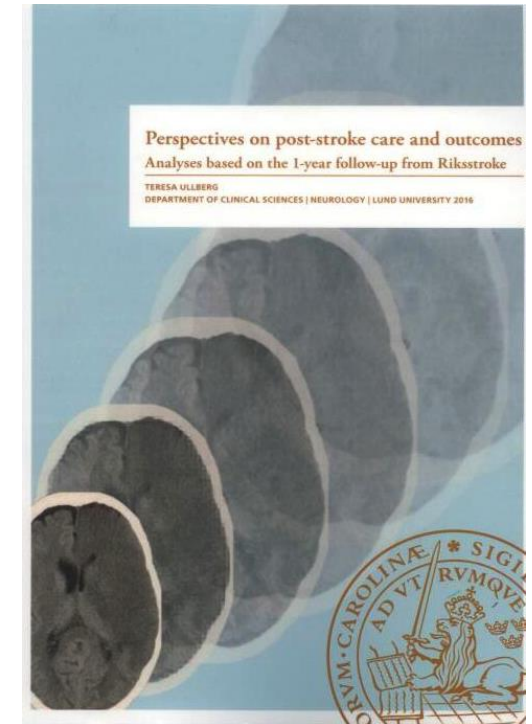
Perspectives on post-stroke care and outcomes
Teresa Ullberg
2016

Teresa Ullberg Stefan Sennfält. Jesper Petersson. Bo Norrving

Stroke in the long term
Stefan Sennfält
2021

@ 1 year after stroke

- Functional decline quite common
- One out of five reported unmet needs
 - High age, severe stroke, previous stroke
 - those most vulnerable
- A cluster: depression, pain, and dependency



Conclusion:

A need to follow up *all main* domains after stroke;
not only secondary prevention, and not only single items.

Long-Term Survival and Function After Stroke

A Longitudinal Observational Study From the Swedish Stroke Register

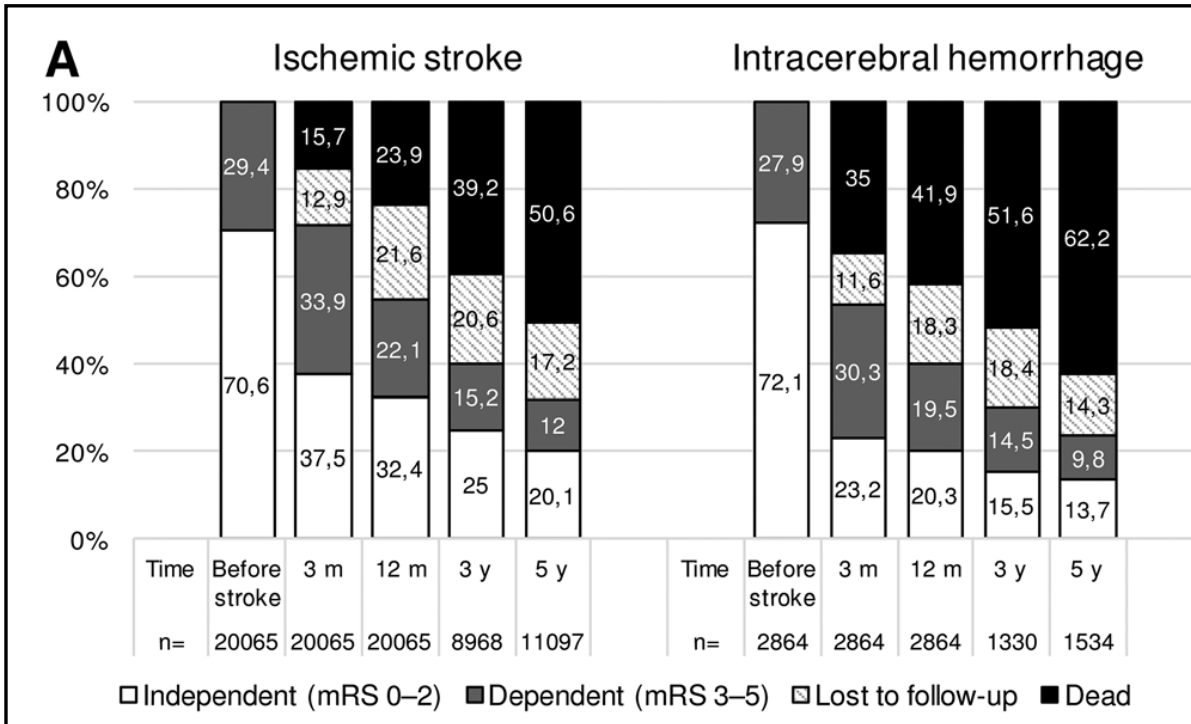
Stefan Sennfalt, MD; Bo Norrving, MD, PhD; Jesper Petersson, MD, PhD; Teresa Ullberg, MD, PhD

2011 half annual cohort followed up after 5 years
2013 half annual cohort followed up after 3 years

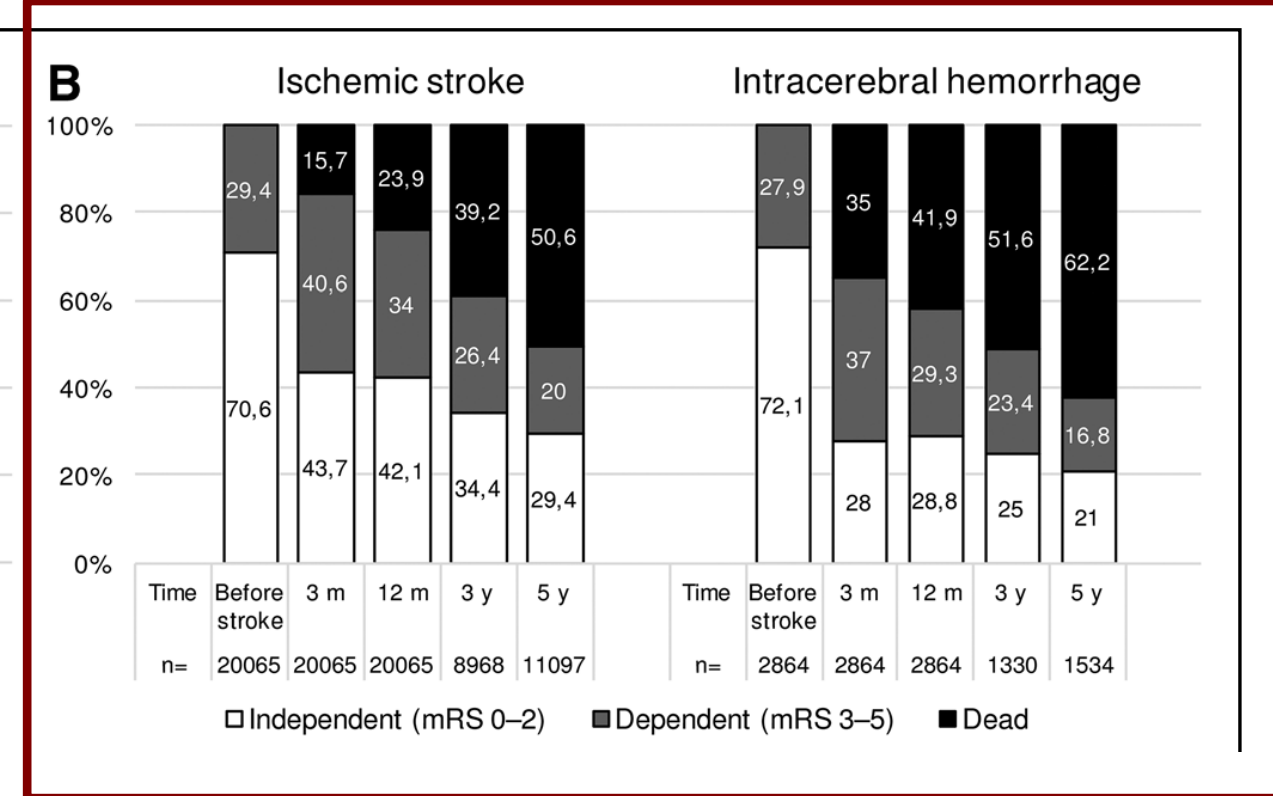
In total: data from about 23 000 patients

Stroke 2019;50:53-61

A. Crude data



B. After imputation for missing data



Despite recent advances in therapies and care, the prognosis after stroke remains serious

Very much more needs to be developed and done

What about the carers?

Research

Informal caregivers in stroke: Life impact, support, and psychological well-being—A Swedish Stroke Register (Riksstroke) study

Stefan Sennfält  and Teresa Ullberg

Int J Stroke. 2019 Jun 25:1747493019858776

International
Journal of Stroke 

International Journal of Stroke

0(0) 1–9

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DOI: 10.1177/1747493019858776

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RIKSSTROKE
The Swedish Stroke Register

Questionnaire to **both** patients **and** carers at 3-5 years

5063 community-dwelling dyads (72 % response rate)
(dyad = both patient AND carer responded to survey)

Patients functional status:

56,5 % independent

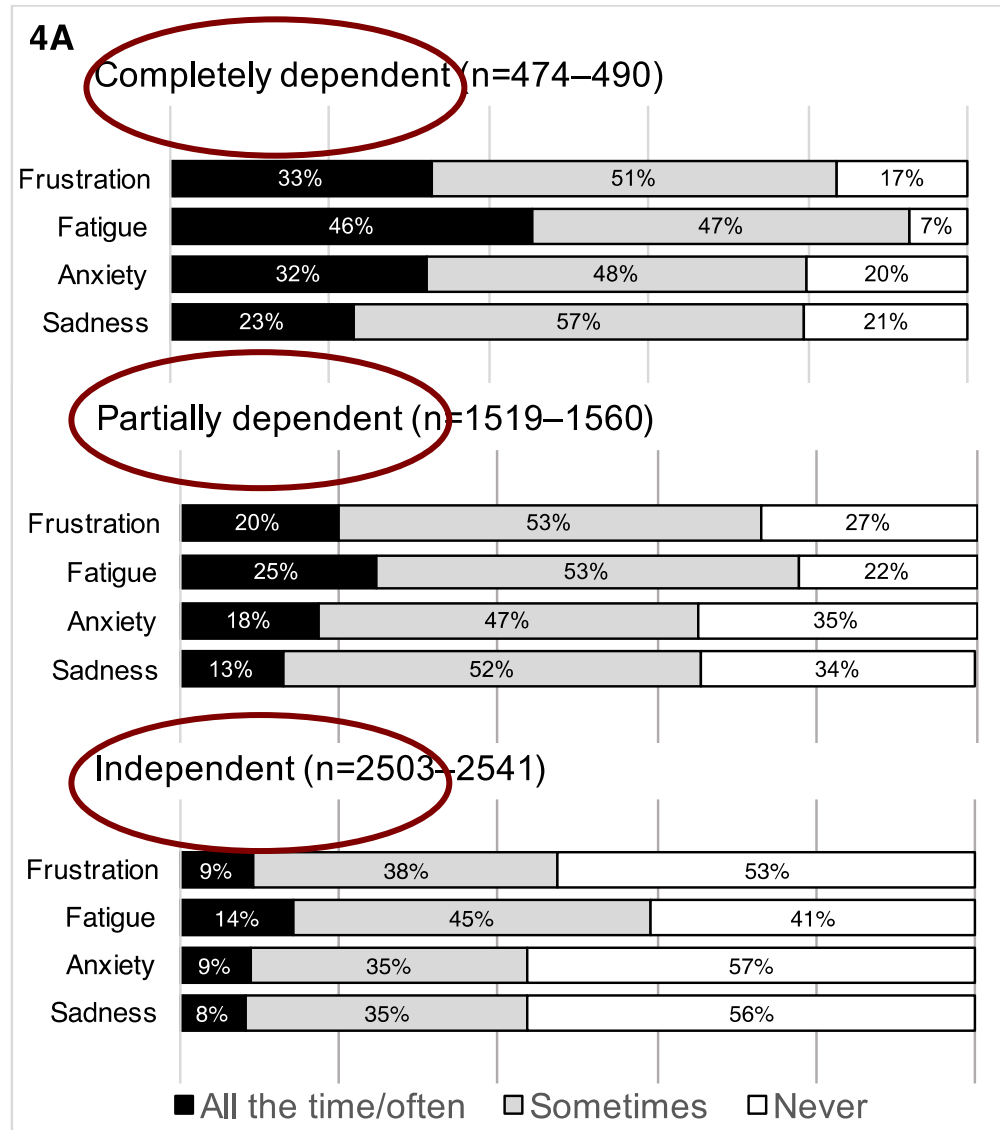
33,4 % partially dependent

10,1 % completely dependent



Photo Sune Jonsson 1960

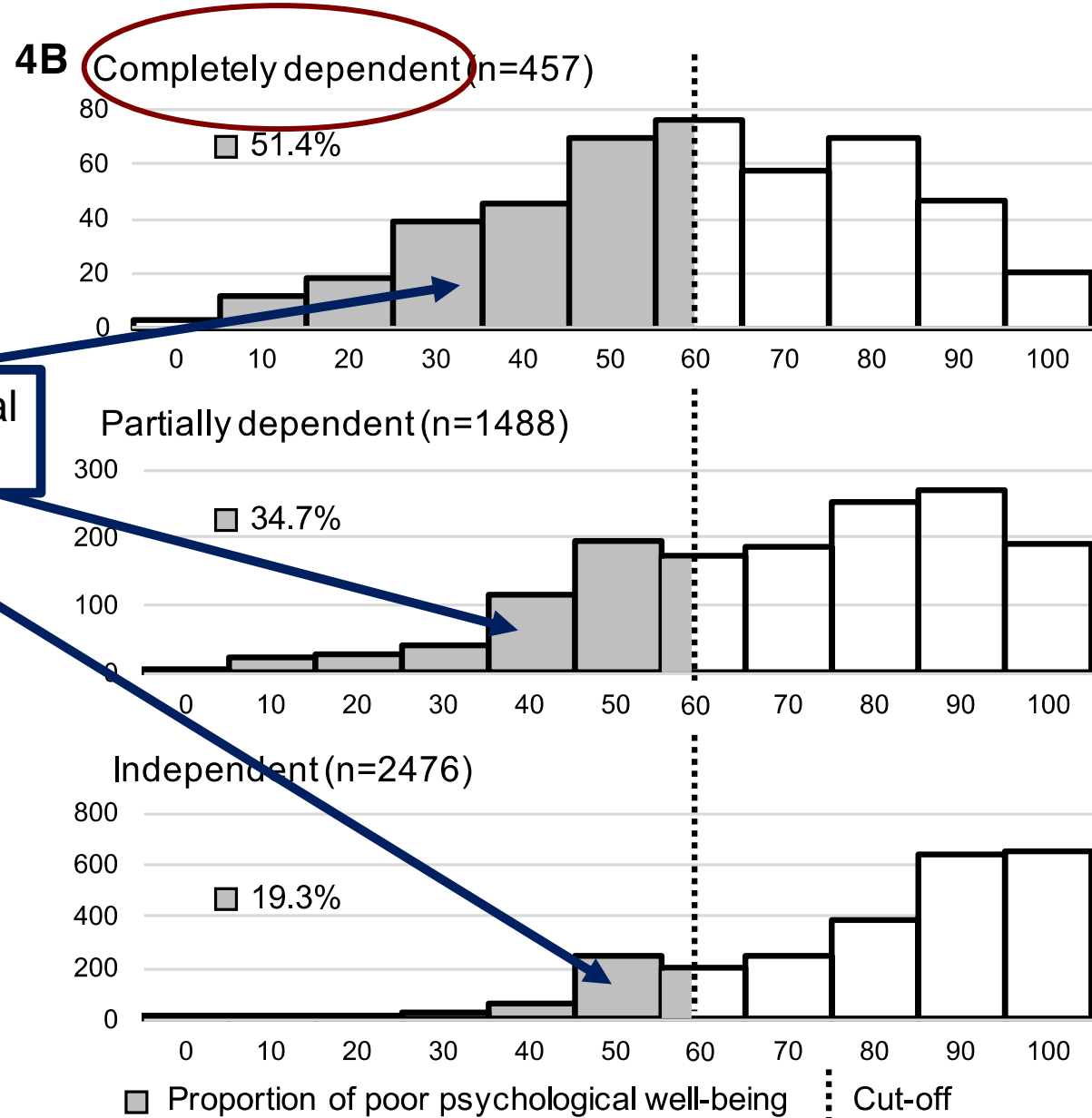
To carer: "How often during the past four weeks have you felt...?"



In carers:

- Frustration, fatigue, anxiety, sadness common
- Related to patient's function

Distribution of poor psychological well-being (in carers)



- Frustration
- Sadness
- Depression
- Anxiety

Poor psychological well.-being

Effects on life after stroke are highly variable in patients and carers

There is no standard "life after stroke"

A need to have a structured follow up after stroke was recognized

- Highly prioritized in the 2019 Swedish national guidelines for stroke care (prio 2 on a 1-10 scale)
 - For all patients with stroke
 - Post-stroke checklist
- How to organize and implement?

Structured post-stroke follow-up in Malmö – The Struct-FU study

a feasibility and explorative study

Aims:

- I. To evaluate a **nurse-led multidisciplinary stroke follow-up model** managed by an in-hospital stroke team
- II. To map stroke-related health problems using the **Post-stroke checklist** (PSC) at 3 months, 1 year and 3 years post-stroke
- III. To **map** all stroke-team **interventions** made within the study
- IV. To **validate** patient-reported health problems (PSC items) to gold standard scales (cognition, depression, fatigue, post-stroke pain, quality of life)

Teresa Ullberg, Kristina Månsson, Ida Berihn, Helene Pessah-Rasmussen
Journ of Stroke and Cerebrovascular Disease, Nov 27, 2020

Modified Post-stroke Checklist (PSC)

Items:

1. Secondary prevention

8. Communication

2. Activities of daily living

9. Mood

3. Oral health and nutrition

10. Cognition

4. Mobility

11. Mental fatigue

5. Spasticity

12. Relationships

6. Post-stroke pain

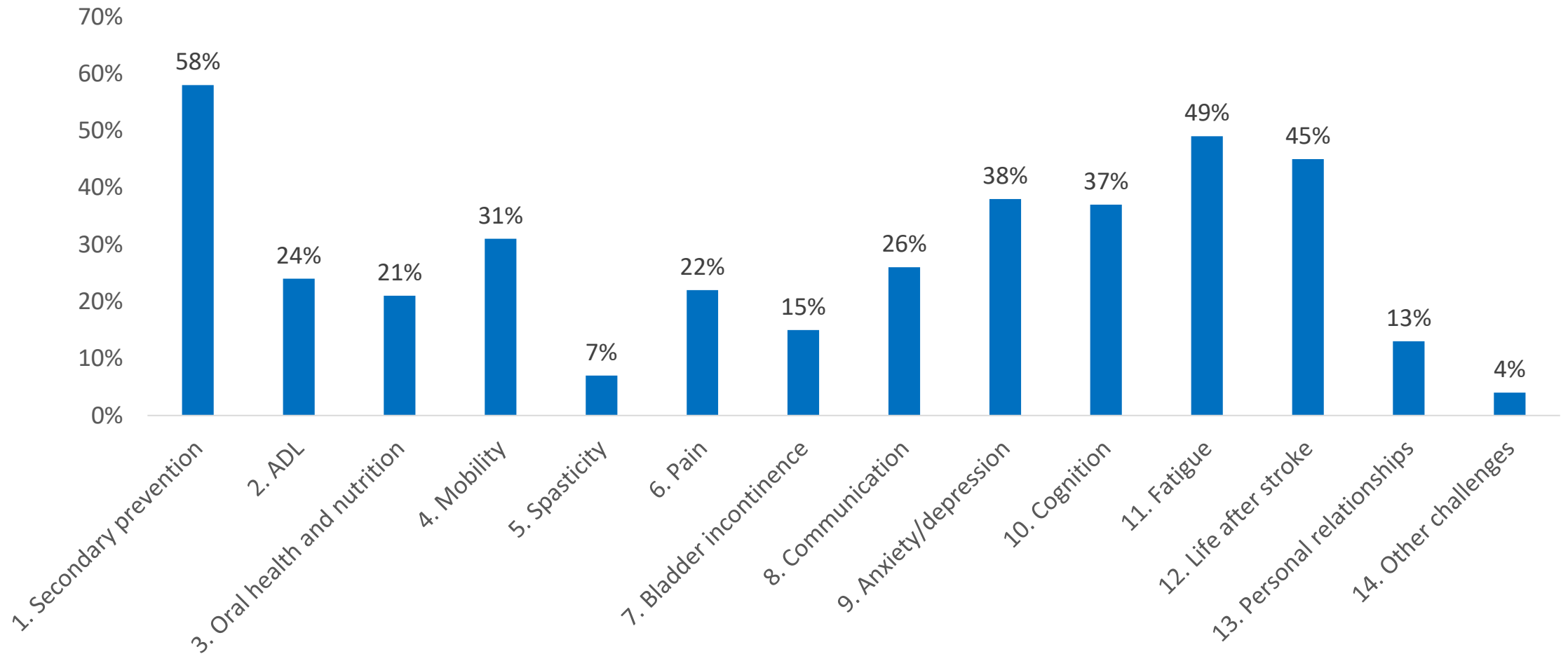
13. Life after stroke

7. Incontinence

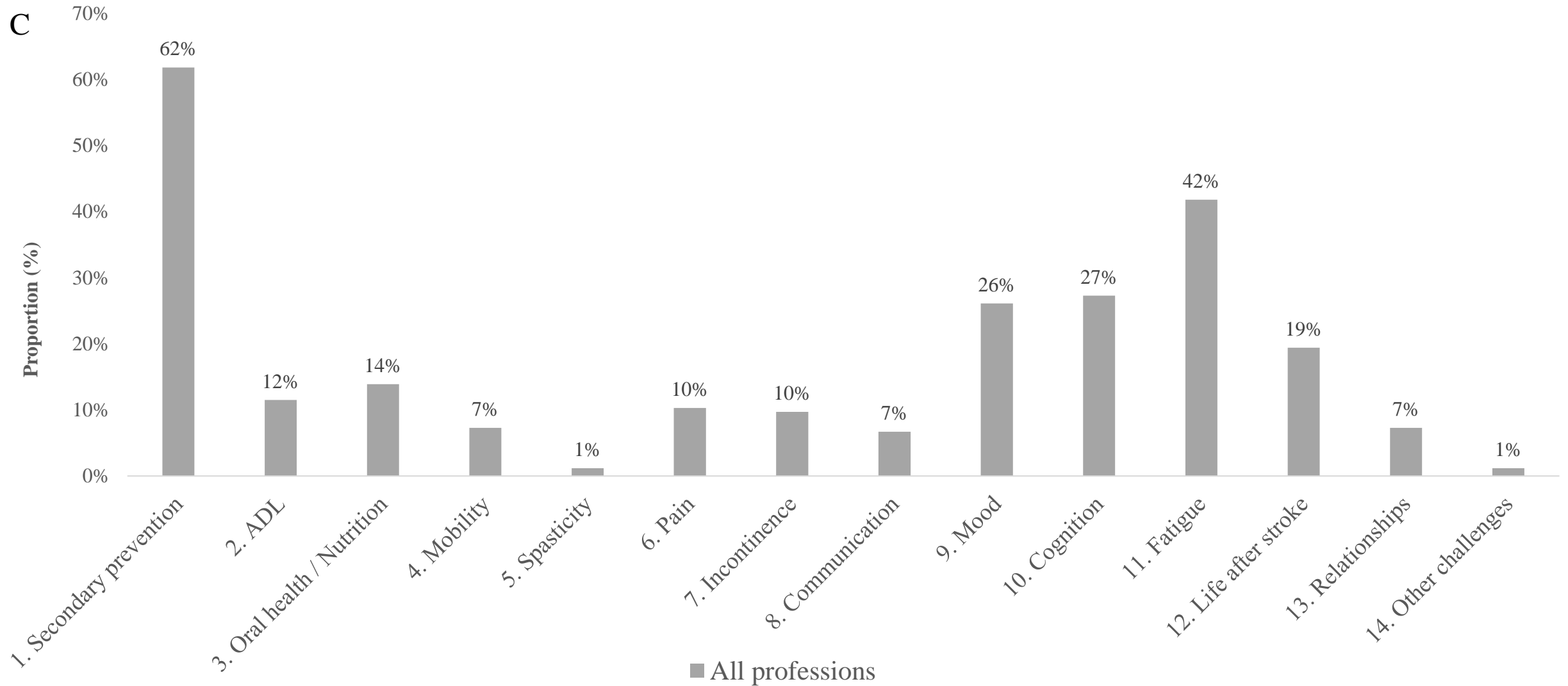
14. Other challenges

Stroke-related health problems at 3 months

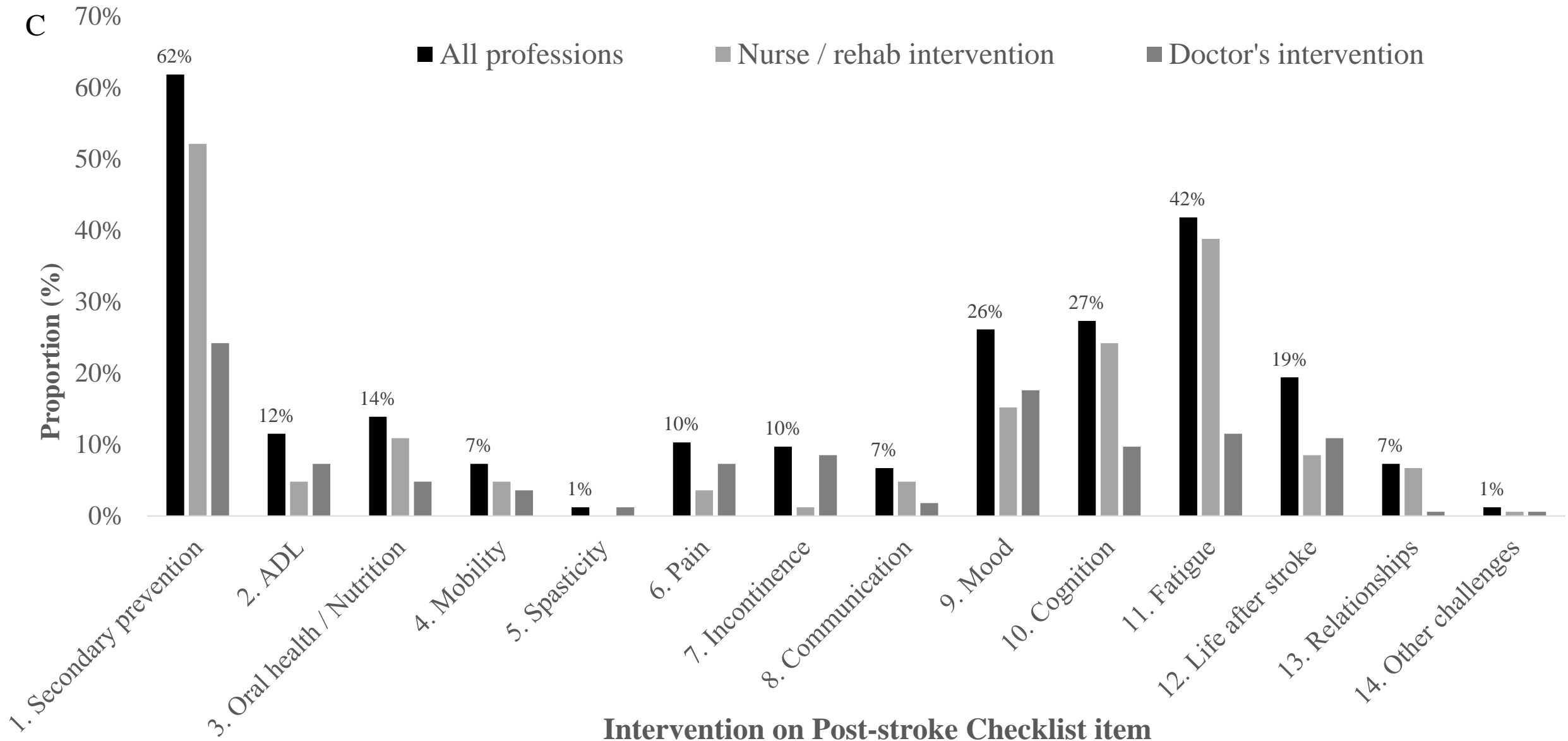
Proportion reporting individual stroke related health problems



Interventions for post-stroke problems for individual items

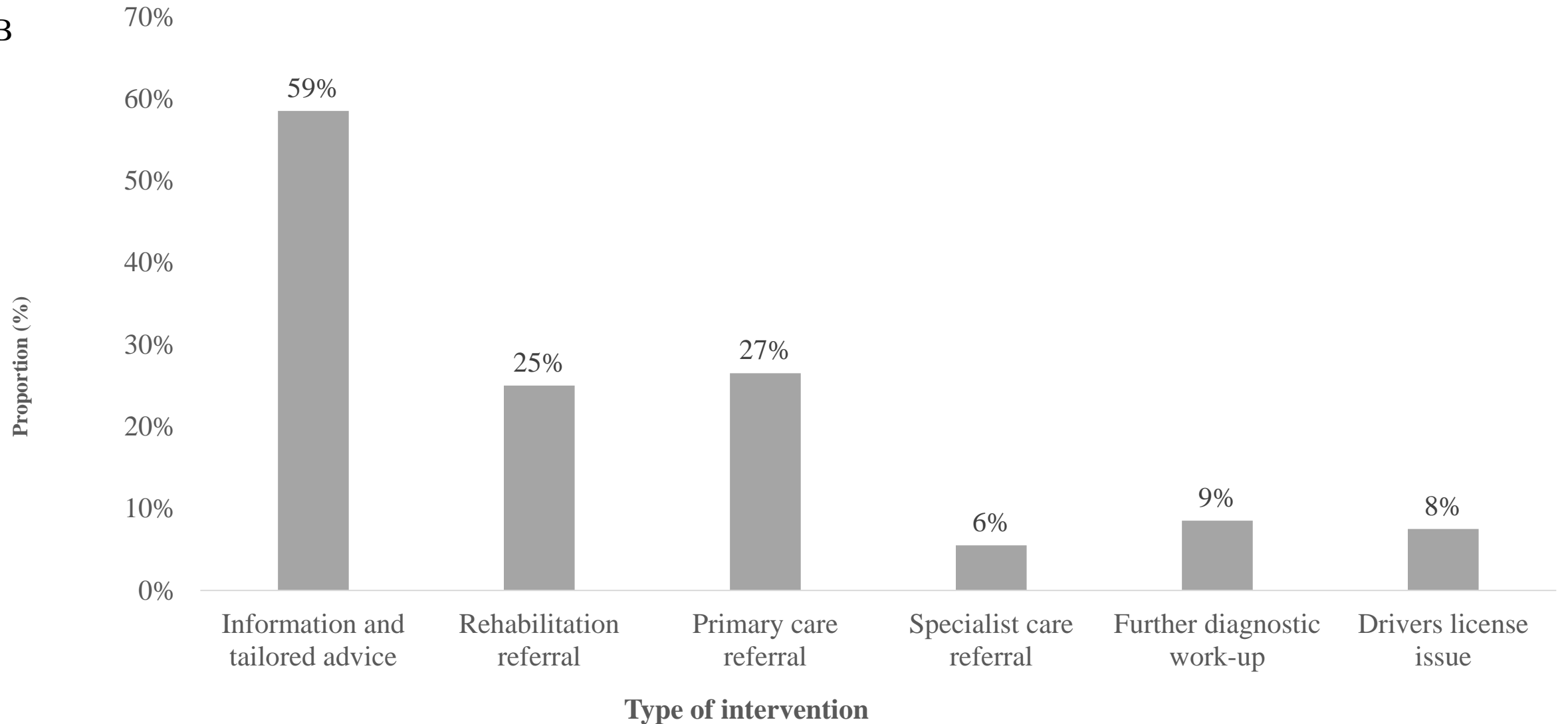


Intervention by profession



Interventions by type

B



Results from 3-month follow-up in the Struct-FU study

- 93% had any stroke-related health problem identified with the post-stroke checklist Almost all
- 50% had four or more stroke-related health problems identified with the post-stroke checklist Often many problems
- 86% needed stroke team interventions for their post-stroke problems Most required interventions
- Only 3% had “other” stroke-related problems than the 13 specified in the checklist The check list works extremely well

Structured stroke FU in Sweden

- where are we now?

- Highly prioritized in the Swedish national guidelines for stroke care since 2019
- In implementation phase
- Post-stroke checklist items introduced in the Swedish Stroke Register (Riksstroke) from 2021

Evidence for a structured follow-up model - STROKE-CARD



STROKE-CARD care to prevent cardiovascular events and improve quality of life after acute ischaemic stroke or TIA: A randomised clinical trial

Peter Willeit^{a,b,*,1}, Thomas Toell^{a,1}, Christian Boehme^{a,1}, Stefan Krebs^c, Lukas Mayer^a, Clemens Lang^c, Lisa Seekircher^a, Lena Tschiderer^a, Karin Willeit^{a,d}, Gerhard Rumpold^e, Gudrun Schoenherr^a, Andrea Griesmacher^f, Julia Ferrari^c, Michael Knoflach^a, Wilfried Lang^{c,g,2}, Stefan Kiechl^{a,*,2}, Johann Willeit^{a,2}, on behalf of the STROKE-CARD study group

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^c Department of Neurology, St. John's of God Hospital, Vienna, Austria

^d Department of Neurology, Inselspital, Bern University Hospital, University of Bern, Bern, Switzerland

^e Department of Medical Psychology, Medical University of Innsbruck, Innsbruck, Austria

^f Central Institute of Medical and Chemical Laboratory Diagnostics, University Hospital of Innsbruck, Innsbruck, Austria

^g Medical Faculty, Sigmund Freud Private University, Vienna, Austria

**Organized acute
stroke care
(Stroke units)**



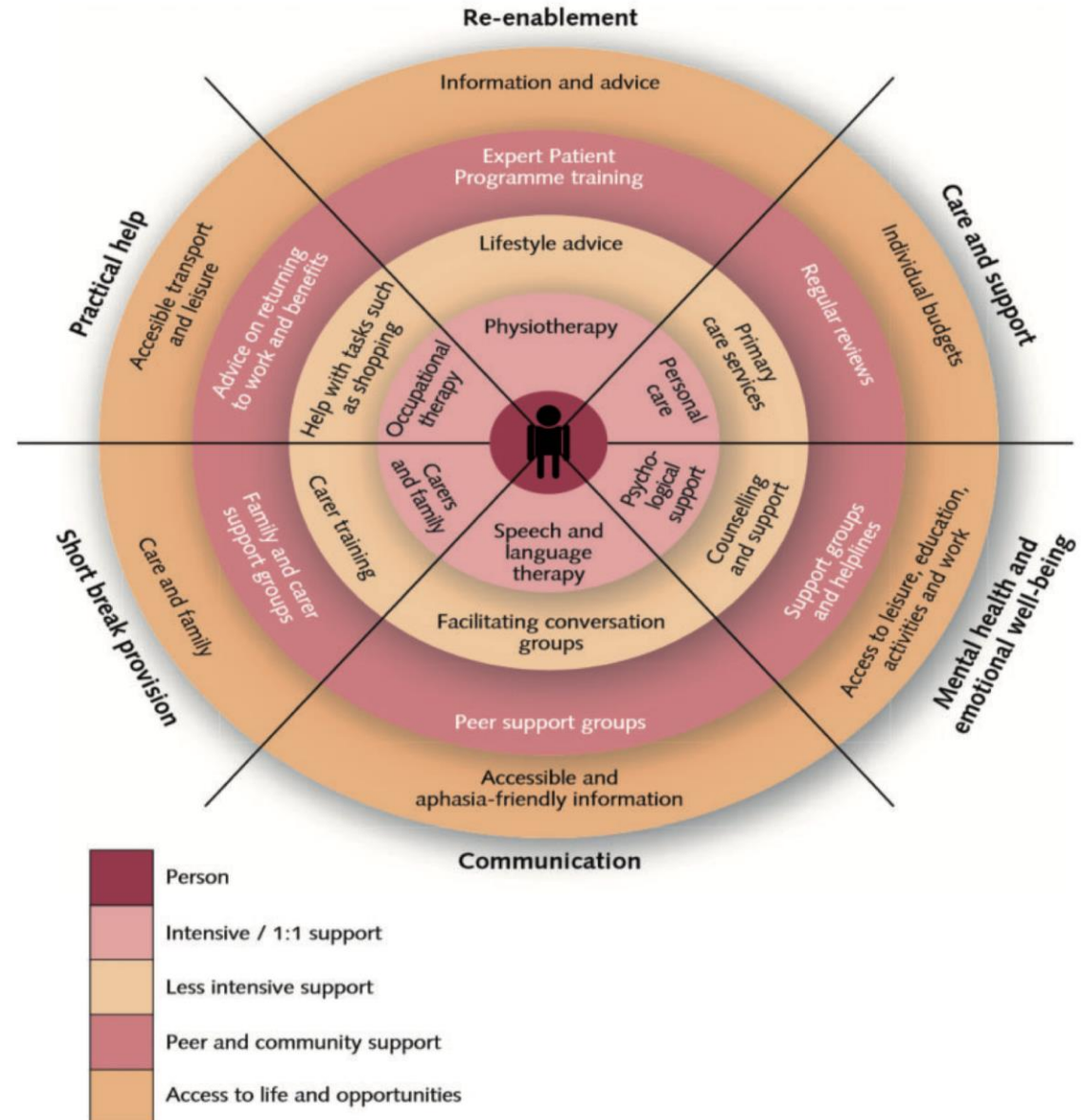
**Organized follow
up after stroke**

The final answer that solves everything?

**Action Plan for Stroke in Europe
2018–2030**

Bo Norrving¹, Jon Barrick², Antoni Davalos³, Martin Dichgans⁴,
Charlotte Cordonnier⁵, Alla Guekht⁶, Kursad Kutluk⁷,
Robert Mikulik⁸, Joanna Wardlaw⁹, Edo Richard¹⁰,
Darius Nabavi¹¹, Carlos Molina¹², Philip M Bath¹³,
Katharina Stibrant Sunnerhagen¹⁴, Anthony Rudd¹⁵,
Avril Drummond¹⁶, Anna Planas¹⁷ and Valeria Caso¹⁸;
on behalf of the Action Plan for Stroke in Europe
Working Group*

**The range of support someone
may need after a stroke**



Under the surface, there is the "second disease"

"First disease" = the medical aspects of the disease

The "second disease" = the existential aspects

What will my life look like?

How will it affect my family situation, my family role?

Will I make it financially?

Will I become disabled or demented?

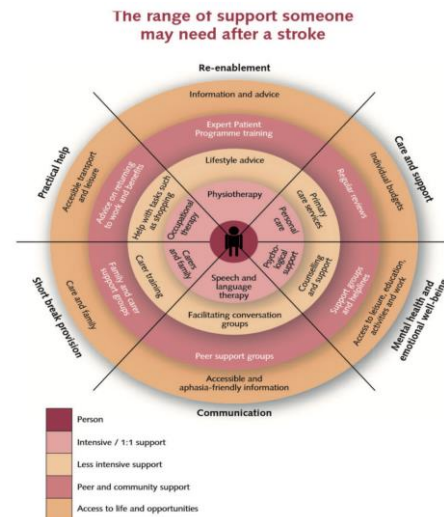
The "second disease" aspect has been largely overlooked by the health services



The voice of the healthcare professionals

AND

the voice of the patients



LIFE AFTER STROKE



One of medicine's and society's most neglected areas.

The time for a change is now.

United efforts are needed.

Thank you for your attention



My special thanks to

- Teresa Ullberg
- Stefan Sennfält
- Jesper Petersson
- Katharina Stibrant Sunnerhagen

for important contributions to this talk