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Follow up of patients after intensive care

Patient reported outcomes

Hans Flaatten, Haukeland University Hospital
University of Bergen
Norway

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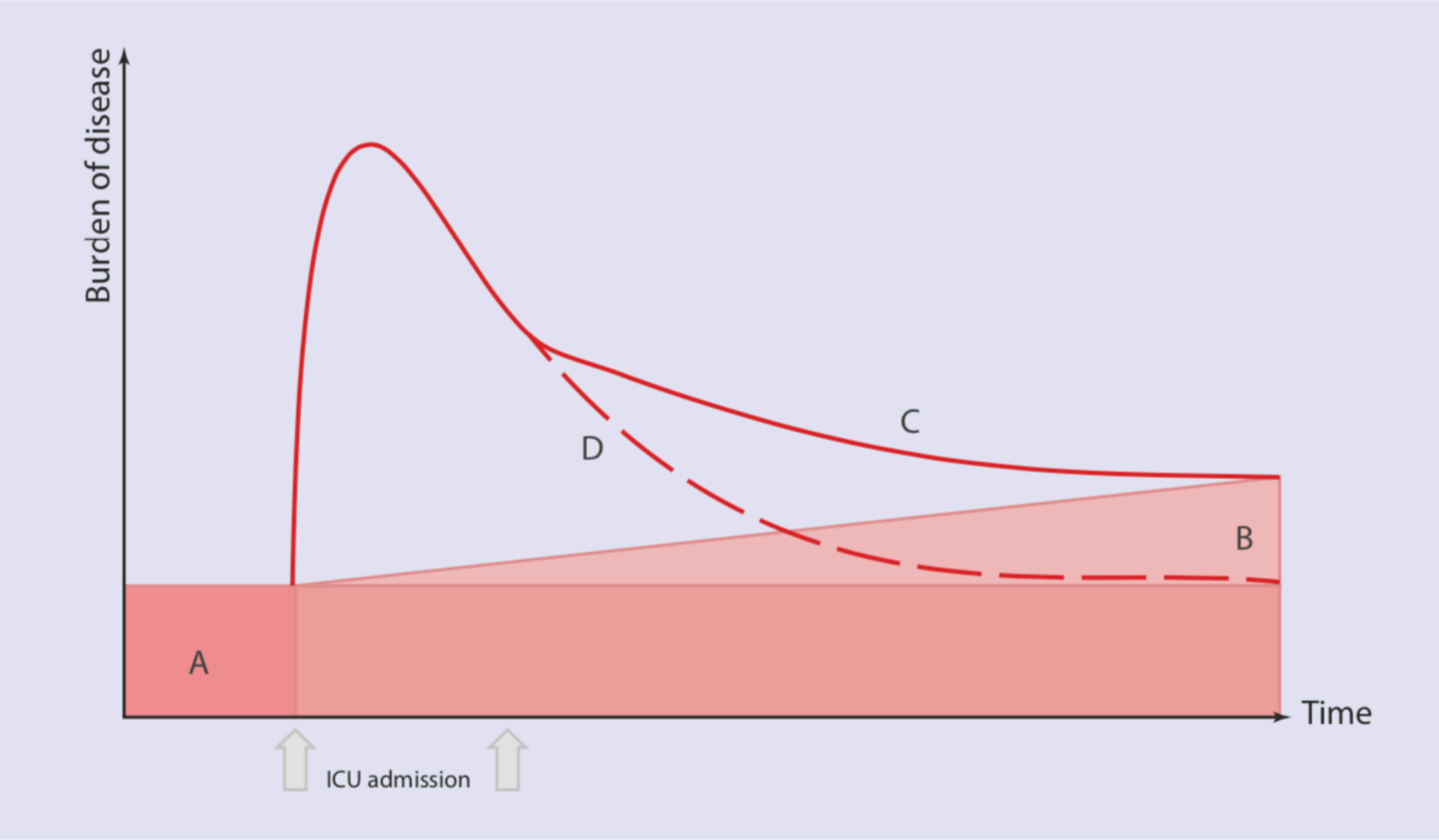
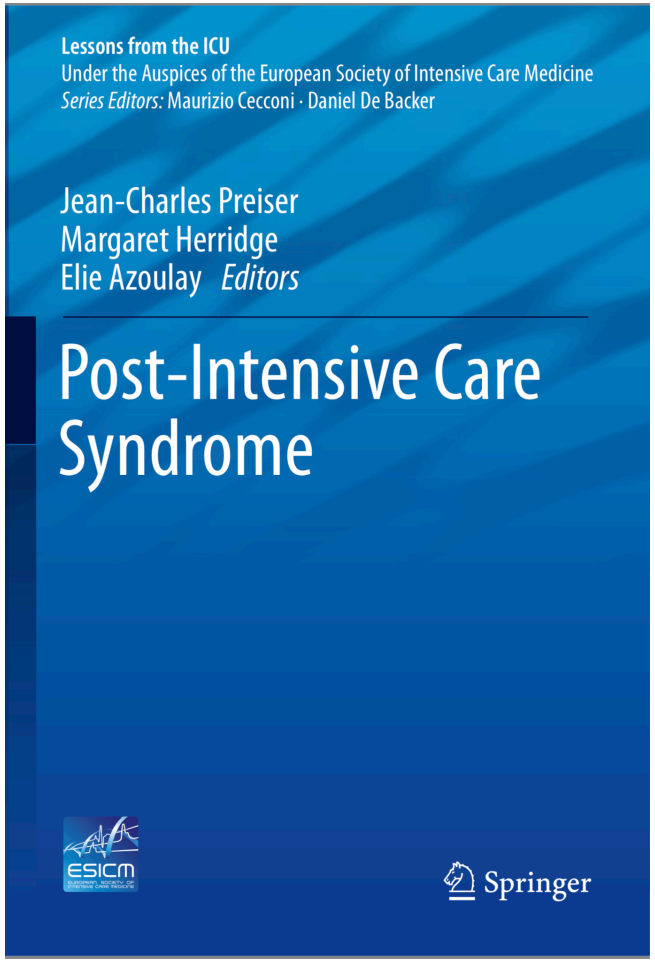
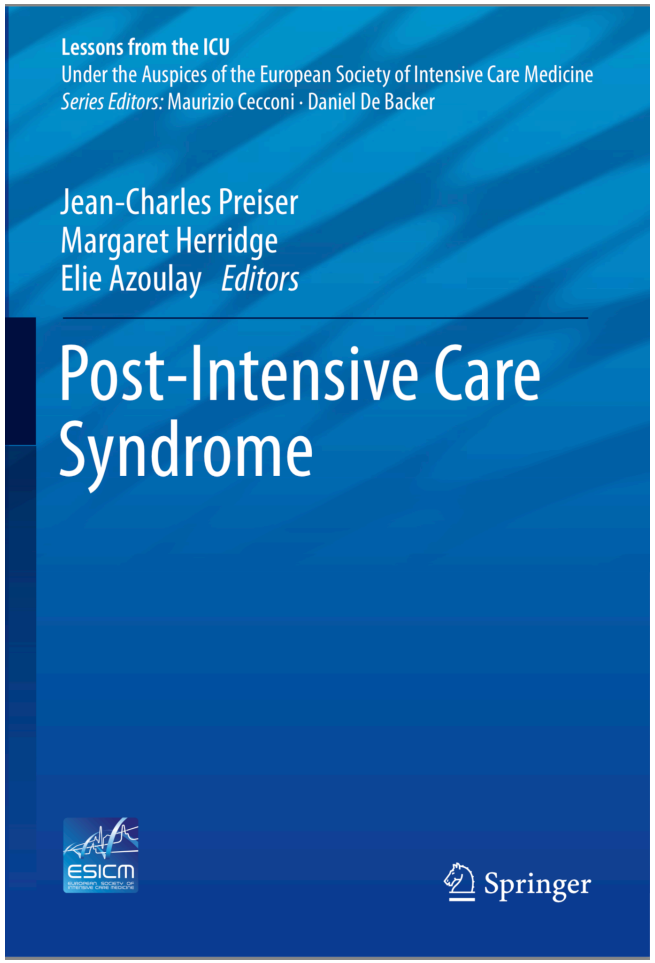
Post critical illness trajectories

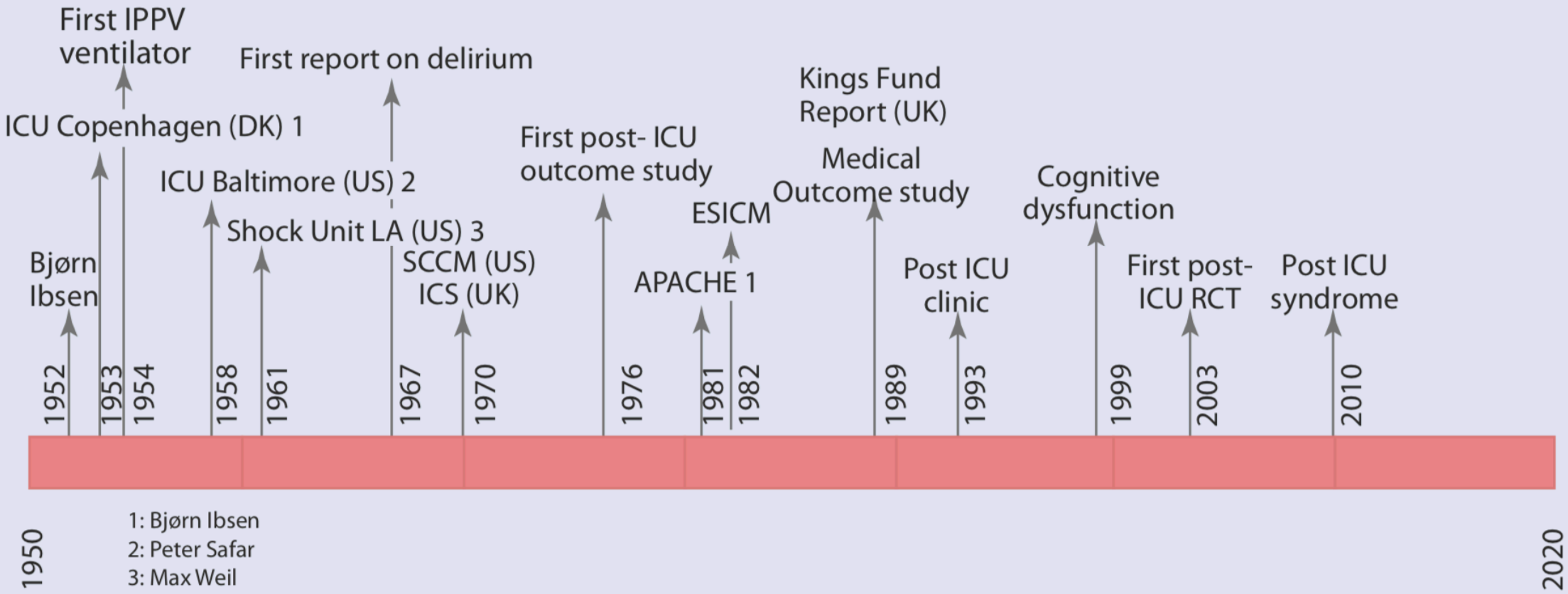




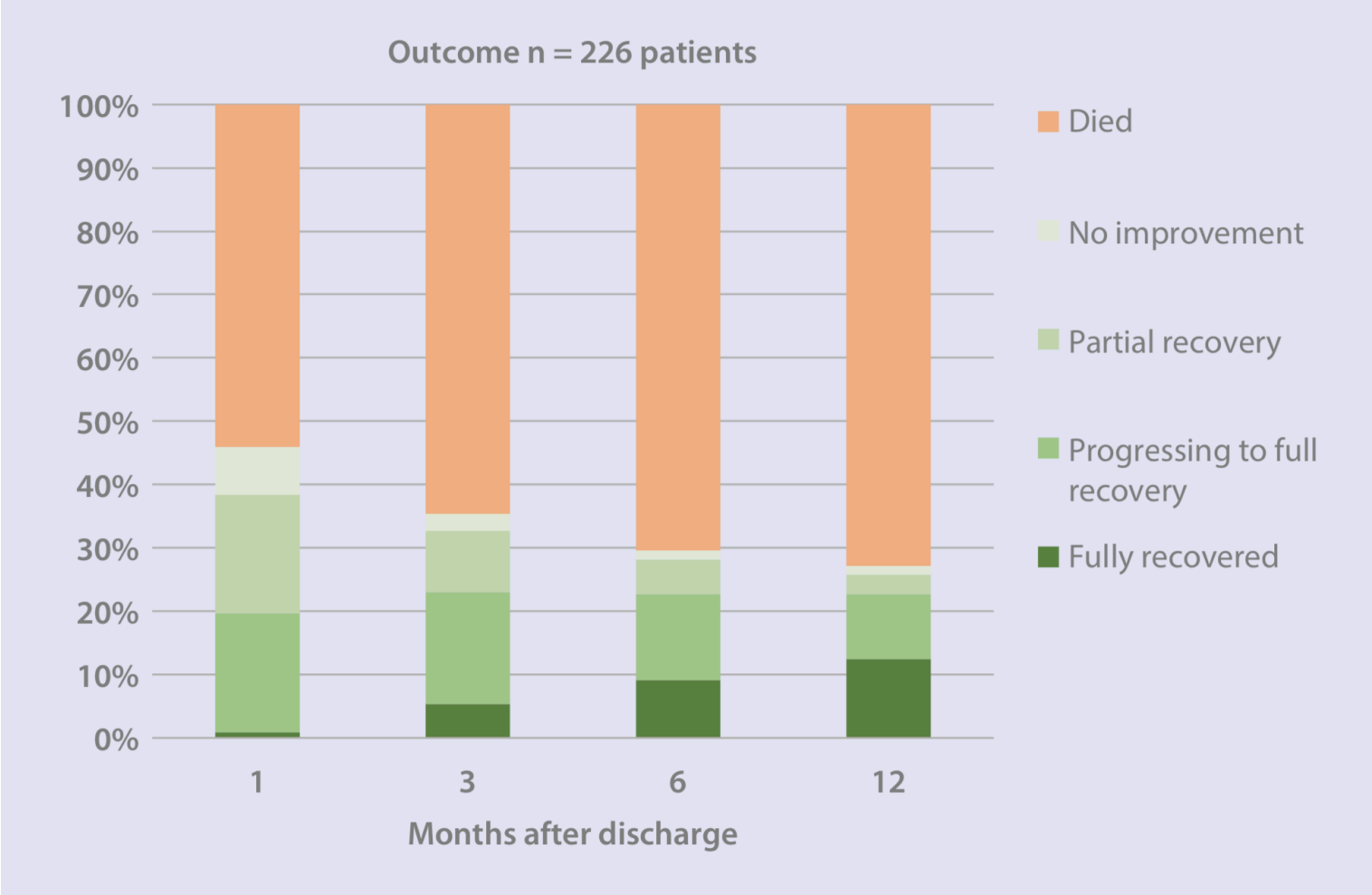
The name for all chronic disabilities that may appear because of critical illness is usually today called the post-ICU syndrome (PICS)



PICS	patients
PICS-F	family/care-givers



Important events in the history of the post-ICU syndrome



1976!

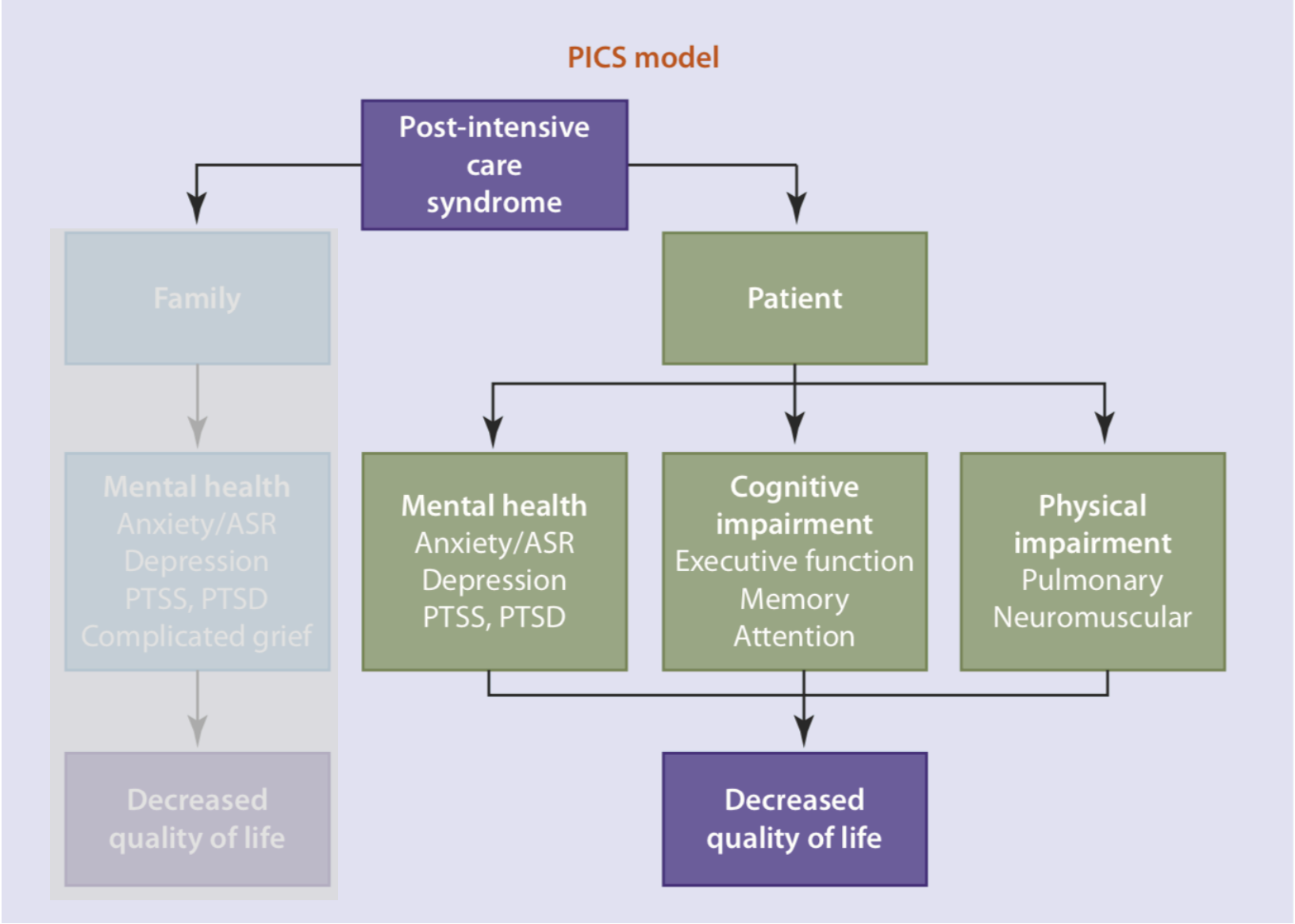
Cullen DJ, Ferrara L, Briggs B, et al. Survival, hospitalization charges and follow-up results in critically ill patients. NEJM. 1976;294:982–7.

Function

Mental

Productivity

Criterion	Age <41 Yr (46)*	Age 41-65 Yr (72)	Age >65 Yr (108)
Mean TISS points	40.4±1.8	43.4±1.4	45±1.1
Mean hospital days	43±6.5	39.5±4.5	28±2.4
Survivors	22 (48%)	19 (26%)	21 (19%)
Patient condition:			
Full recovery	9 (41%)	7 (37%)	11 (52%)
Progressing to full recovery	8 (36%)	9 (47%)	7 (33%)
Partial recovery at best	3 (14%)	2 (11%)	3 (14%)
No improvement	1 (5%)	0	0
Functional state:			
Freely ambulatory	11 (50%)	10 (53%)	13 (62%)
Limited activities	8 (36%)	8 (42%)	8 (38%)
Bed ridden — self care	1 (5%)	0	0
Bed ridden — no self-care	1 (5%)	1 (5%)	0
Mental status:			
Fully alert	17 (77%)	17 (89%)	21 (100%)
Communicates, but not as well as before illness	3 (14%)	1 (5%)	0
Communicates inadequately	0	1 (5%)	0
Comatose	1 (5%)	0	0
Degree of productivity:			
As productive as before illness	9 (41%)	8 (42%)	9 (43%)
Limited	4 (18%)	1 (5%)	6 (29%)
Active with assistance	4 (18%)	5 (26%)	3 (14%)
Independent self-care	0	0	1 (5%)
No self-care	0	1 (5%)	0
Hospitalized or nursing home	4 (18%)	4 (21%)	2 (10%)


PICS model
Post-intensive care syndrome
Family
Mental health
Anxiety/ASR
Depression
PTSS, PTSD
Complicated grief
Decreased quality of life
Patient
Mental health
Anxiety/ASR
Depression
PTSS, PTSD
Cognitive impairment
Executive function
Memory
Attention
Physical impairment
Pulmonary
Neuromuscular
Decreased quality of life

ICU implications

- What we do, or not do, in the ICU may have profound effects on patients post-ICU
  - Mobilisation
  - Nutrition
  - Medications (sedatives-NMB etc)
- Hence, to improve post-ICU morbidity-we also need to look at what is done in the ICU

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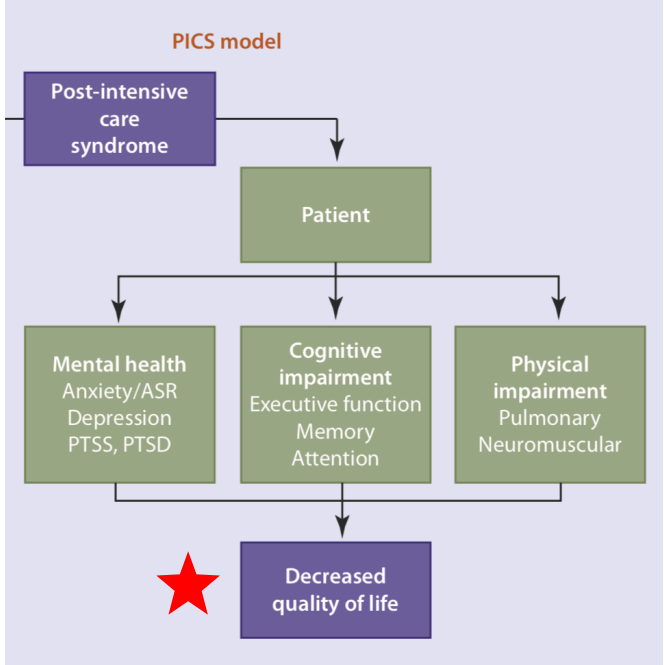

Orwelius *et al. Intensive Care Medicine Experimental* 2015, **3**(Suppl 1):A408
http://www.icm-experimental.com/content/3/S1/A408

Intensive Care Medicine Experimental
a SpringerOpen Journal

POSTER PRESENTATION Open Access

Health-related quality of life at 2, 6 and 12 months after critical illness - lessons learnt from a nationwide follow-up of 4,500 ICU admissions

L Orwelius[1,2,3*], E Åkerman[3,4], C-J Wickerts[3], SM Walther[3,5,6]

At 12 months 10-25% of patients had scores < 2SD of the adjusted Swedish norm.

Table 1. Longitudinal HRQoL (SF

	Physical functio						notional	Mental health
2 mths (N = 1438)	50 (25-75)	0 (0-25)	52 (32-84)	54 (37-72)	45 (25-60)	63 (38-88)	33 (0-100)	72 (52-88)
6 mths (N = 1438)	65 (40-85)	25 (0-100)	62 (41-100)	57 (40-77)	55 (35-70)	75 (50-100)	100 (0-100)	80 (60-92)
12 mths (N = 1438)	70 (40-85)	25 (0-100)	62 (41-100)	57 (35-77)	55 (35-75)	75 (50-100)	100 (0-100)	80 (60-92

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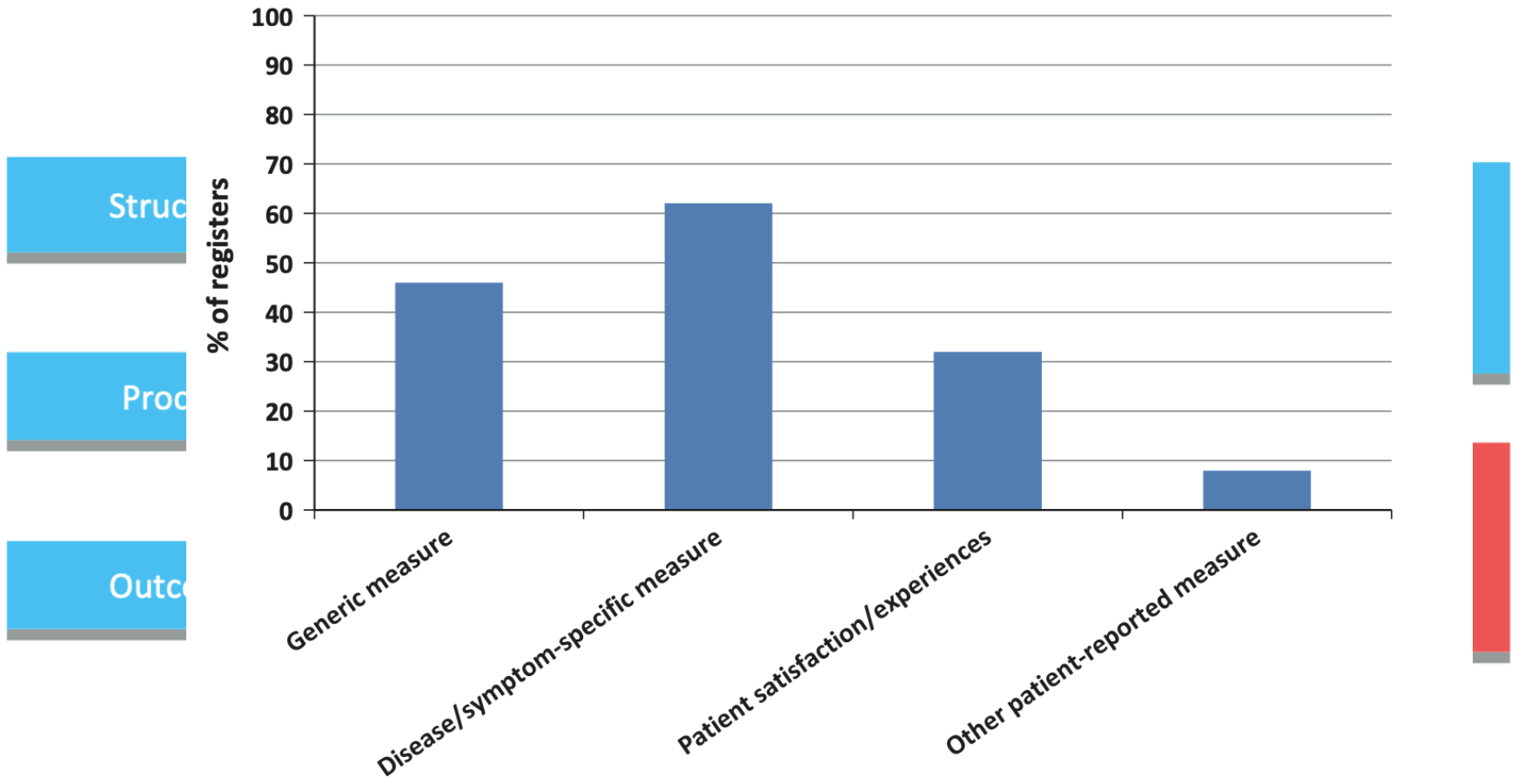
PROM and PREM

Review | Journal of INTERNAL MEDICINE

doi: 10.1111/joim.12409

Patient-reported outcomes in the Swedish National Quality Registers

E. Nilsson[1,2], L. Orwelius[3] & M. Kristenson[2]



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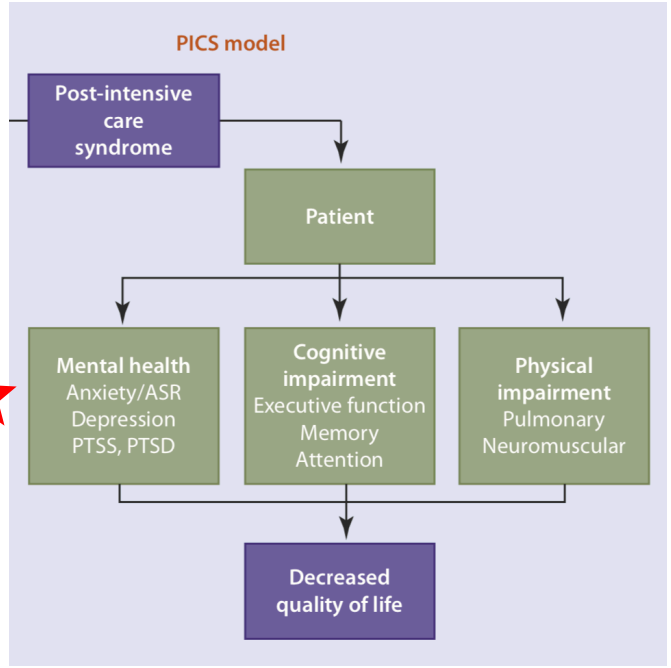


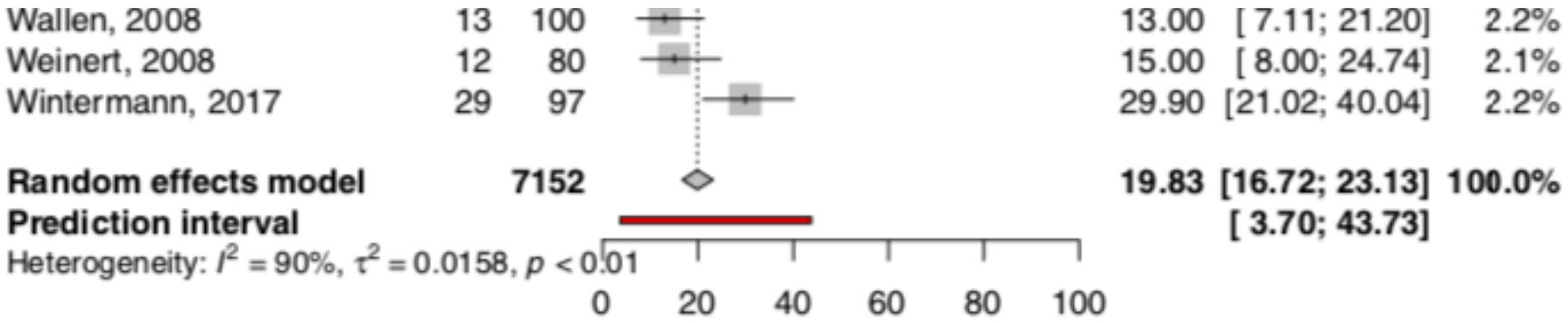
Righy *et al. Critical Care* (2019) 23:213
https://doi.org/10.1186/s13054-019-2489-3

Critical Care

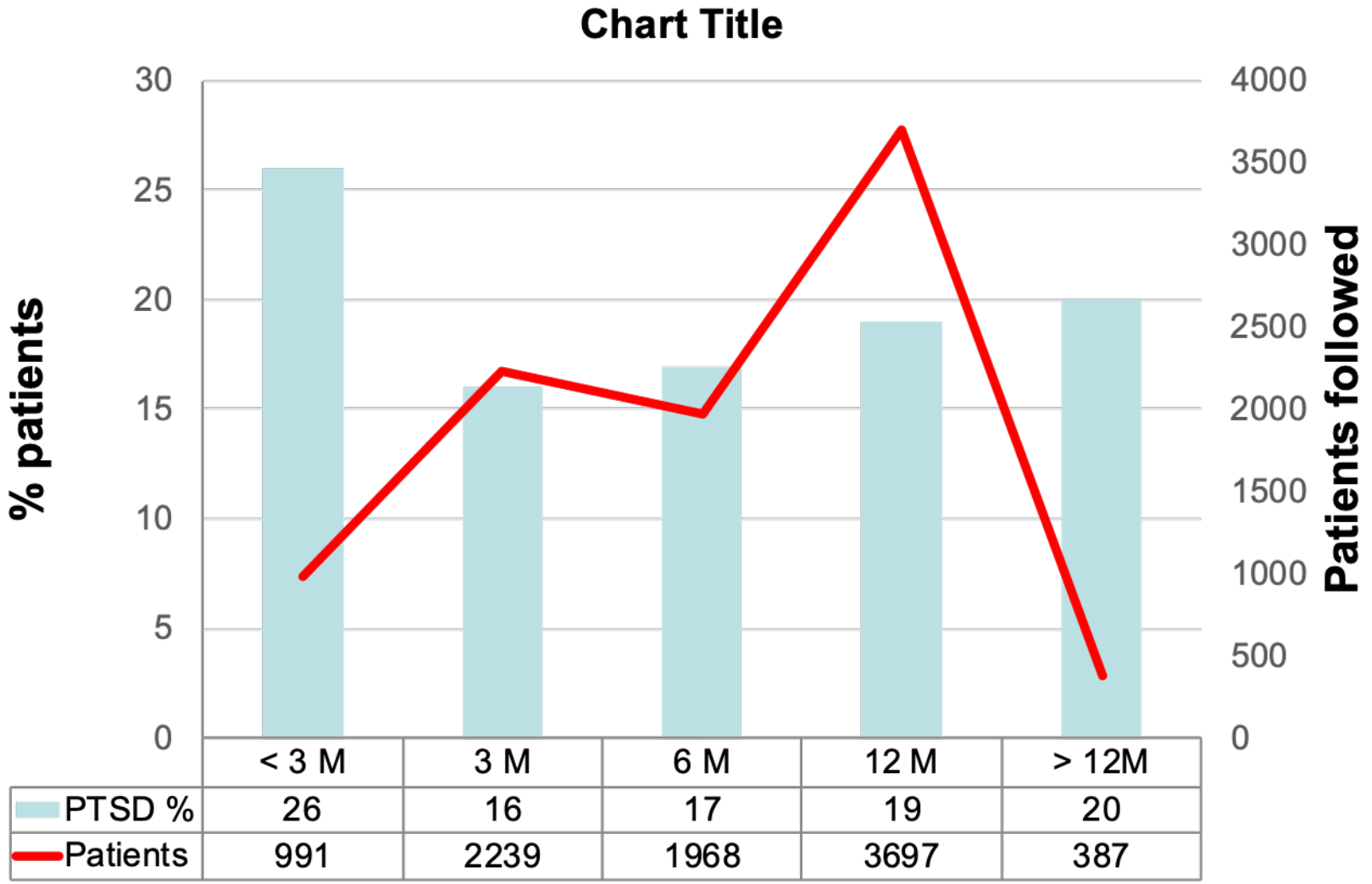
RESEARCH Open Access

Prevalence of post-traumatic stress disorder symptoms in adult critical care survivors: a systematic review and meta-analysis

Cássia Righy[1,2], Regis Goulart Rosa[3,4*], Rodrigo Teixeira Amancio da Silva[1,5], Renata Kochhann[4], Celina Borges Migliavaca[4,6], Caroline Cabral Robinson[4], Stefania Pigatto Teche[7,8], Cassiano Teixeira[3], Fernando Augusto Bozza[1,9] and Maicon Falavigna[4,6]



Time development: PTSD



	< 3 M	3 M	6 M	12 M	> 12M
PTSD %	26	16	17	19	20
Patients	991	2239	1968	3697	387

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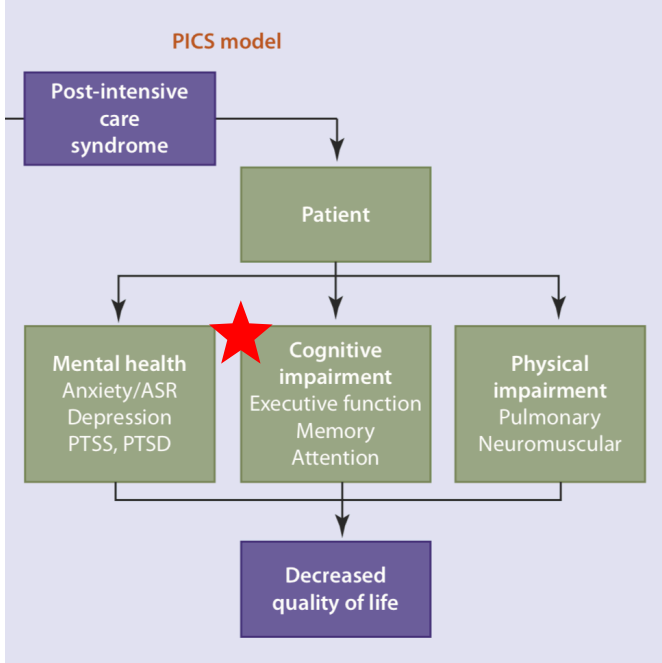

Intensive Care Med (2013) 39:376–386
DOI 10.1007/s00134-012-2784-9

REVIEW

Annemiek E. Wolters
Arjen J. C. Slooter
Arendina W. van der Kooi
Diederik van Dijk

Cognitive impairment after intensive care unit admission: a systematic review

Summary:

- 19 studies
- 30-275 pts (4 > 100)
- 11-56% reduced cognitive status
- No pre-ICU cognitive measurement

Methodological problems

- Pre-ICU cognitive status
- Small number of patients
- Different methods to screen and investigate cognitive function, no “gold standard”
- Very few use standard battery with cognitive tests
- Inclusion criteria varies a lot

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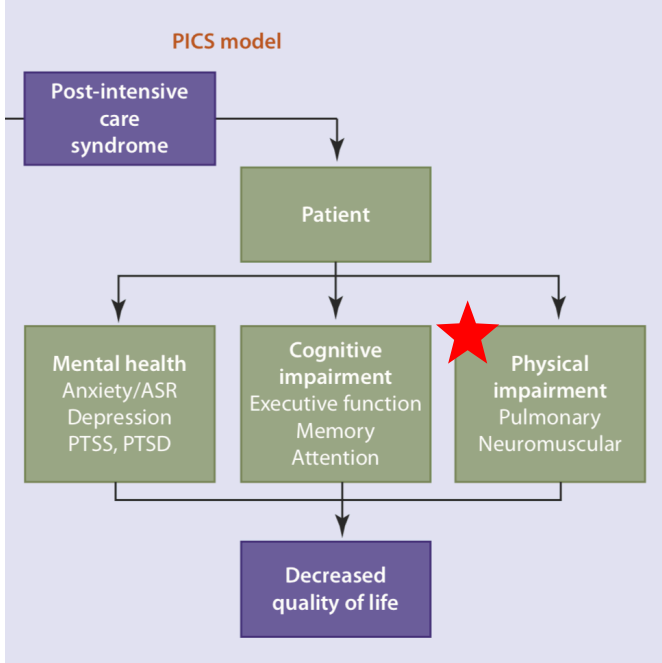

- ICU acquired weakness
  - Myopathy
  - Neuropathy
- Pulmonary dysfunction (ARDS)
- Endocrinopaty
- ICU acquired immunosupression
- Pain
- Insomnia
- Sexual dysfunction

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Table 2. Incidence of ICUAW.

References	No. of patients	No. with ICUAW	Proportion with ICUAW (%)	95% CI
Ahlbeck et al.[36]	10	5	50	24–76
Ali et al.[28]	136	35	26	19–34
Amaya-Villar et al.[43]	26	9	35	19–54
Bednarik et al.[51]	61	35	57	45–69
Bercker et al.[37]	45	27	60	46–73
Berek et al.[38]	22	18	82	62–93
Brunello et al.[16]	39	13	33	21–49
Campellone et al.[25]	77	7	9	5–18
Coakley et al.[44]	23	12	52	33–71
Coakley et al.[39]	44	37	84	71–92
De Jonghe et al.[20]	95	24	25	18–35
De Letter et al.[45]	98	32	33	24–42
Douglas et al.[40]	25	4	16	6–35
Druschky et al.[41]	28	16	57	39–74
Garnacho-Montero et al.[14]	73	50	69	57–78
Garnacho-Montero et al.[12]	64	34	53	41–65
Hermans et al.[23]	420	188	45	40–50
Hough et al.[32]	30	6	20	10–37
Hund et al.[46]	28	20	71	53–85
Kesler et al.[29]	170	30	18	13–24
Khan et al.[47]	20	10	50	30–70
Latronico et al.[27]	92	28	30	22–41
Leijten et al.[48]	38	18	47	33–63
Mohr et al.[49]	33	7	21	11–38
Nanas et al.[24]	185	44	24	18–30
Routsi et al.[31]	52	14	27	17–40
Schweikert et al.[8]				
Sharshar et al.[15]				
Tepper et al.[26]				
Thiele et al.[50]				
Van den Berghe et al.[22]				
Weber-Carstens et al.[30]				
Witt et al.[42]				
Total				

Note: ICUAW, intensive care unit-acquired weakness; CI, confidence interval.

Review article

jics

Journal of the Intensive Care Society
2015, Vol. 16(2) 126–136

DOI: 10.1177/1751143714563016
jics.sagepub.com
SAGE

The incidence of intensive care unit-acquired weakness syndromes: A systematic review

Richard TD Appleton[1], John Kinsella[2] and Tara Quasim[2]

33 prospective studies
2686 patients
40% ICUAW

Witt et al.[42]	43	30	70	55–81
Total	2686	1080	40	38–42

Note: ICUAW, intensive care unit-acquired weakness; CI, confidence interval.

Hashem et al. Critical Care (2016) 20:345
DOI 10.1186/s13054-016-1516-x

Critical Care

RESEARCH Open Access

Table 4 Qualitative themes of physical health

From: Patient outcomes after critical illness: a systematic review of qualitative stu

Patient outcomes after critical illness: a systematic review of qualitative studies following hospital discharge

Mohamed D. Hashem[1,2], Aparna Nallagangula[1,2], Swaroopa Nalamalapu[1,2], Krishidhar Nunna[1,2], Utkarsh Nausran[1], Karen A. Robinson[3], Victor D. Dinglas[1,2], Dale M. Needham[1,2,4] and Michelle N. Eakin[1,2*]

Theme	Example quote(s)	
Mobility	1. "I can move now, before, I thought I will stay han up with a walker and I just couldn't. I couldn't even	the ability to walk again …" 2. "Then I had to try to get
Activities of daily living	1. "My day-to-day life is anything but normal. I wan couple of weeks, we were sort of … doing things li little bits for him, organizing what tablets he had t	hops … recovery has been reasonable." 2. "For the first ort of thing. I practically was just running around doing
Fatigue	1. "I probably went too far. I mean, I was at home a it anyway." 2. "I need an afternoon nap, sometimes	and do things. But then I was tired and couldn't handle
Appetite	"Now it's going ok again, I'm eating well, and I'm sl really knowing where they should be …."	frustration at not having an appetite and my insides not
Sensory changes	"I also have double vision … I can't read … I can't	
Muscle weakness	"The most difficult bit was … I felt it took forever I am up to my usual strength yet … I feel that I nee	ngth at the hospital and I still feel it. I mean, I don't feel I uite strong before I got sick."
Sleep disturbances	1. "I slept so badly, I had these awful dreams, really just to check …" 2. "I'm sleeping really badly, I wak	find that, well, everything's OK, and you wake up anyway ot doing me good."

PREM

- Mobility
- ADL
- Fatigue
- Sensory changes
- Muscle weakness
- Sleep disturbance

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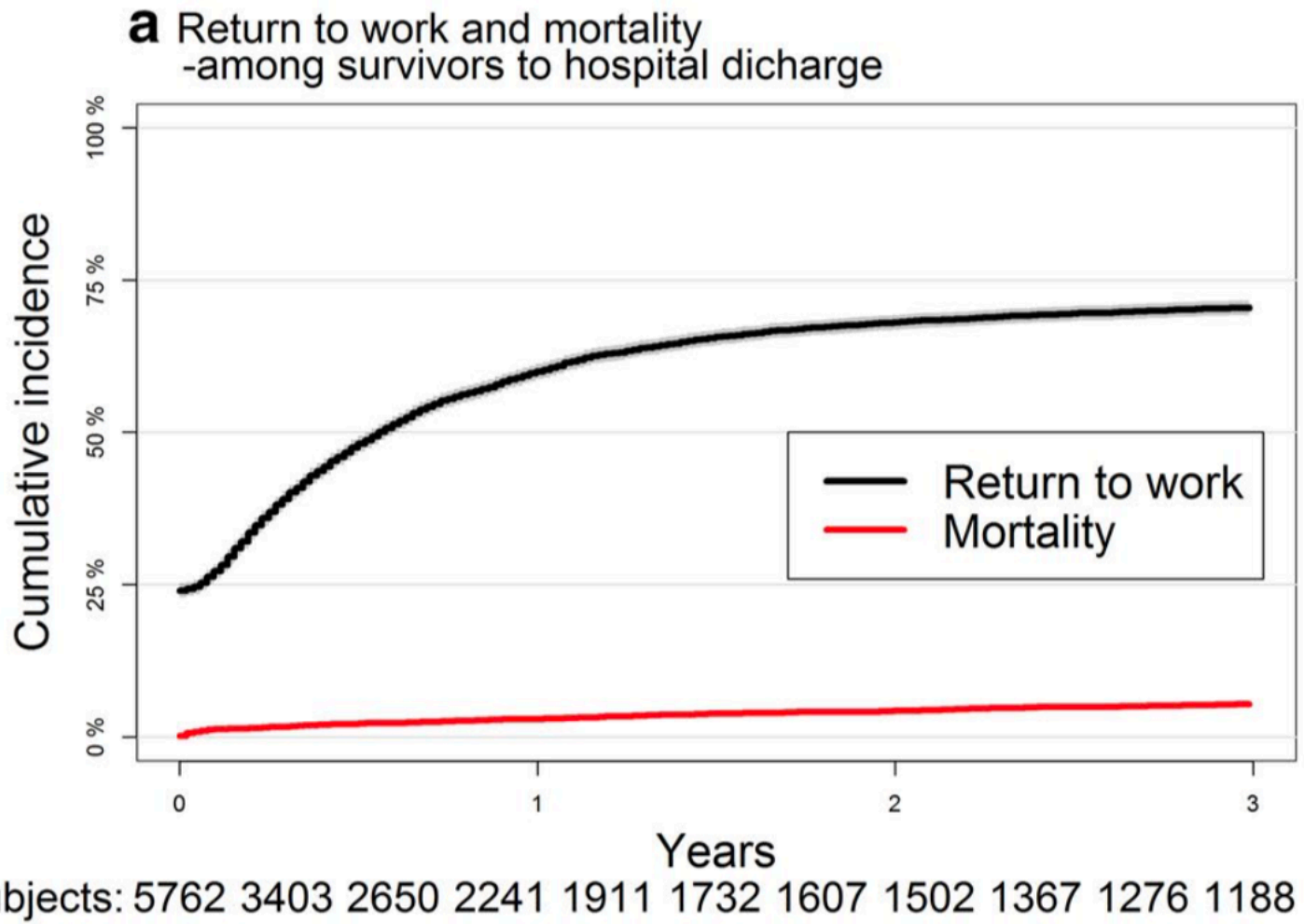
Return to work



Intensive Care Med
https://doi.org/10.1007/s00134-018-5157-1

ORIGINAL

Organ support therapy in the intensive care unit and return to work: a nationwide, register-based cohort study

ıe Riddersholm[1,2*], Steffen Christensen[3], Kristian Kragholm[4,5], Christian F. Christiansen[6]
ł Bodil Steen Rasmussen[1,2]

Conclusions so far

- Post intensive care syndrome is very common
- Most former ICU patients at some time after ICU discharge have symptoms of PICS

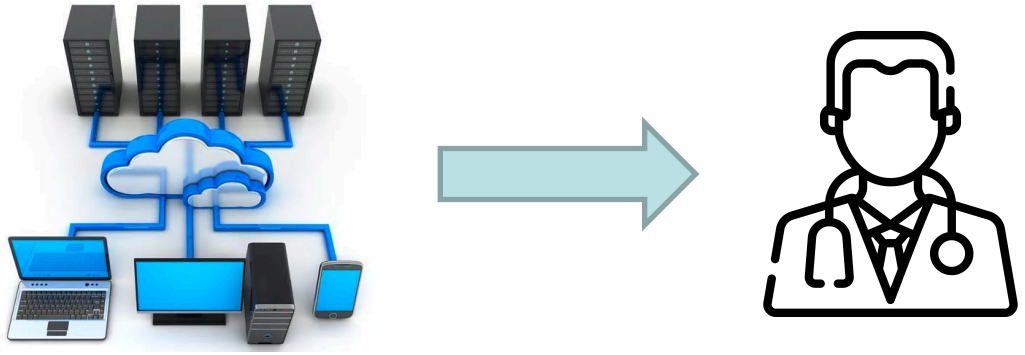
- Many would consider this of importance for ICUs as well as intensivists
- What can we do with this?

What is ICU follow up?

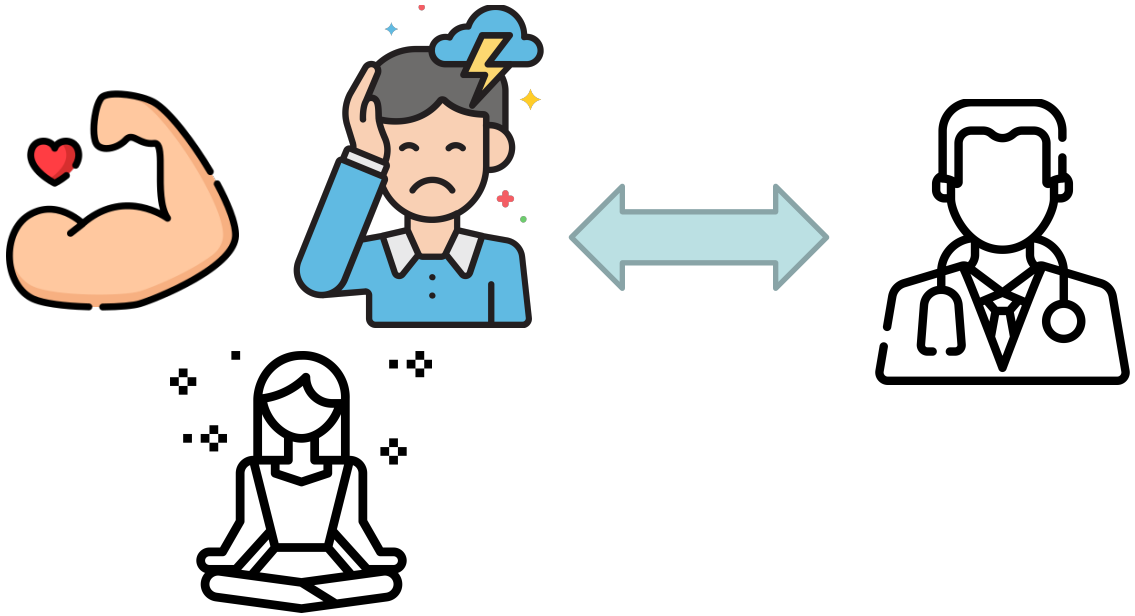
- Not easy to define
- In its essence it is just the act of tracking (following) ICU patients and/or caregivers after ICU/Hospital discharge
  - By various registries
    . Official registries, quality registries, hospital records
  - By “indirect” contact (mail, e-mail):
    - Questionnaires
  - By direct contact, by telephone (interview) by home visit or as out-patient

Another classification

- “Passive” follow up:
  - Retrieval of stored data



- “Active” follow up:
  - Direct contact with former ICU patients to have their feedback
  - Giving support/treatment/training to the patient/family



An important issue

- Most patients are in fact followed-up
- Focus on one or more underlying disease: examples
  - Post surgery
  - Coronary check-up
  - X-rays, tests etc
- Seldom focus on ICU related problems
- In fact: What do our colleagues know about problems with its root in the ICU?

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PICS and ICU follow-up

- The general aims for ICU follow-up services have been to provide a forum where unmet health care needs can be identified and met

- The first ICU follow-up clinics were established in the UK in 1985

•(www.nice.org.uk, Lasiter et al 2016, Schofield-Robinson et al 2018)

Official recommendations for follow-up after ICU discharge

- Few international guidelines
  - Including Scandinavia
- The United Kingdom
  - The National Institute for Health and Care Excellence, NICE guidelines
  - Assessment of functional status, health and social care needs 2–3 months post discharge
  - Face to face in the community or in the hospital
  - Skilled healthcare professionals

•www.nice.org.uk, Lasiter et al (2016), Schofield-Robinson et al (2018)

UK experience

Quality statement

Adults who stayed in critical care for more than 4 days and were at risk of morbidity have a review 2 to 3 months after discharge from critical care.

> 4 days: Review at 2-3 months

Rationale

Follow-up is needed for adults who were in critical care for more than 4 days and at risk of morbidity, because further needs may become apparent after discharge. A review to reassess health and social care needs 2 to 3 months after discharge from critical care ensures that any new physical or non-physical problems are identified and further support is arranged as needed. Some adults who were in critical care for 4 days or less may also experience problems that need a review. Also, problems may emerge more than 3 months after discharge. The lifelong impact of a stay in critical care means that all adults who have experienced this should be able to self-refer and be reassessed at any time.

Intensive and Critical Care Nursing (2013) 29, 103–111

Available online at www.sciencedirect.com

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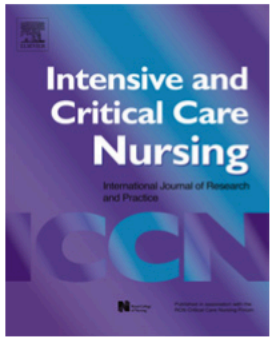
journal homepage: www.elsevier.com/iccn



ORIGINAL ARTICLE

ICU-recovery in Scandinavia: A comparative study of intensive care follow-up in Denmark, Norway and Sweden

Ingrid Egerod[a,*], Signe S. Risom[b], Thordis Thomsen[c], Sissel L. Storli[d], Ragne S. Eskerud[e], Anny N. Holme[f], Karin A.M. Samuelson[g]

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Model 1
Nurse-led follow-up with patient diary (Denmark, Norway, Sweden)
Variations
- Follow-up at ward during diary handover
- Follow-up at ICU after hospital discharge
- Follow-up at hospital 2-3 months post hospital discharge
- Follow-up at hospital > 3 months post hospital discharge + optional phone call after 6-12 months
- Follow-up targeted long-term patients only (> one week in ICU)

Model 2
Nurse-led follow-up without patient diary (Denmark)
- Follow-up at hospital 2-3 months post hospital discharge

Model 3
Multidisciplinary follow-up with patient diary (Sweden)
Variations
- Follow-up at hospital after discharge based on diary and hospital chart
- Follow-up at hospital after discharge based on validated instruments

Model 4
Multidisciplinary follow-up without patient diary (Denmark)
- Follow-up at hospital 2-3 months post hospital discharge

Intensive and Critical Care Nursing (2013) 29, 103–111

Available online at www.sciencedirect.com
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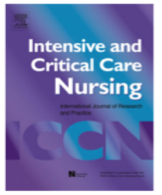

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Ingrid Egerod[a,*], Signe S. Risom[b], Thordis Thomsen[c], Sissel L. Storli[d], Ragne S. Eskerud[e], Anny N. Holme[f], Karin A.M. Samuelson[g]

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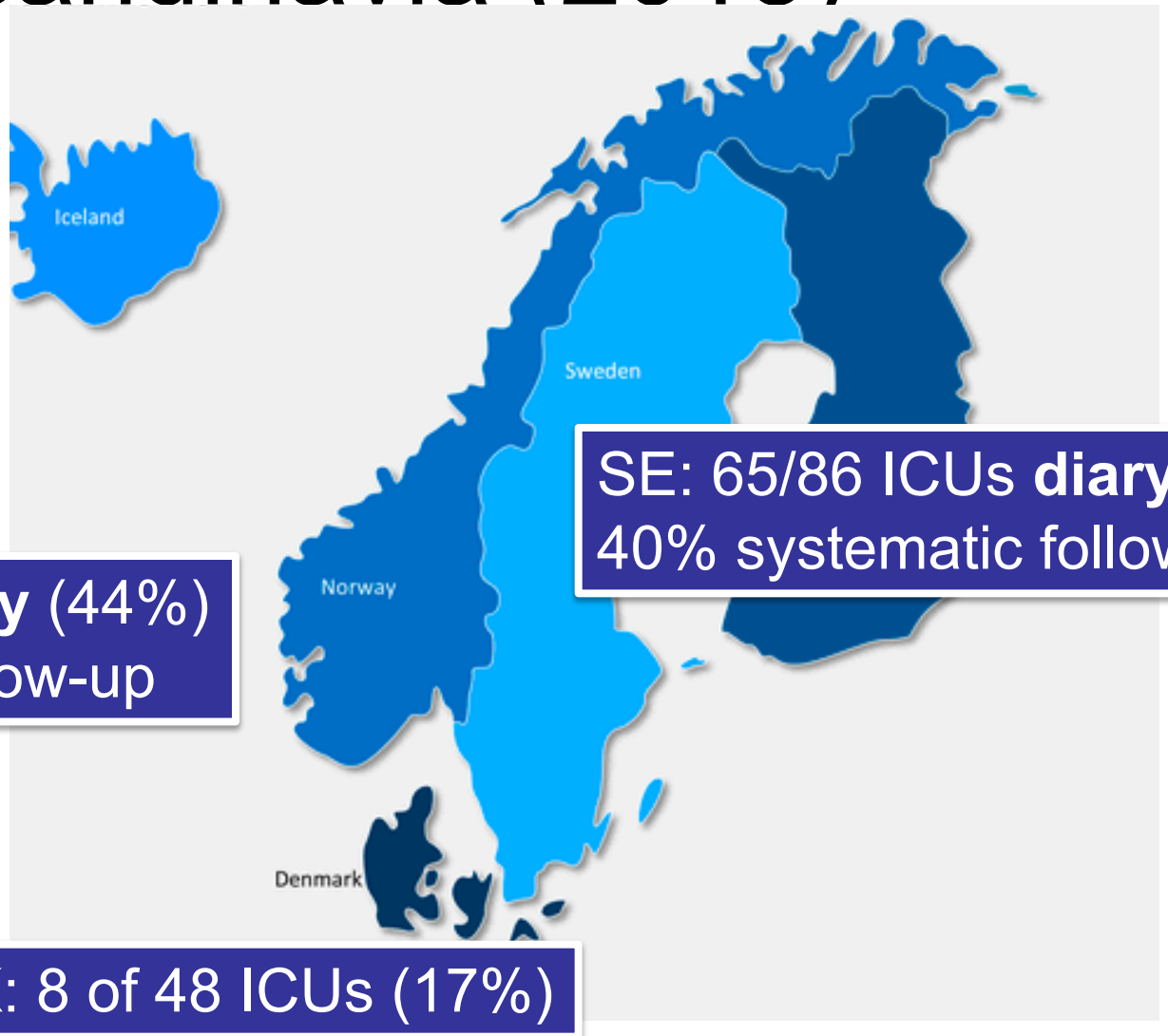
Status Scandinavia (2013)



NO: 31/70 ICUs **diary** (44%)
18/70 systematic follow-up

SE: 65/86 ICUs **diary** (76%)
40% systematic follow-up

DK: 8 of 48 ICUs (17%)

Description of content and follow-up in Scandinavia

Stage of trajectory	Time of intervention	Common elements in follow-up
During ICU stay	In ICU	Patient diary written by nurses and in some cases family
		Rehabilitative interventions: Minimal sedation, early mobilisation, delirium prevention, reorientation, patient and family collaboration
After ICU transfer	At transfer	Transfer from ICU to ward, step-down, or other ICU
	3-5 days post transfer	ICU-nurse visits patient on ward, follow-up initiated, consent for contact after discharge, assessment using ICU-Memory Tool
After hospital discharge	At discharge	Discharge from hospital to home or rehabilitation facility
	1 month post discharge	Information material sent to patient
	1-2 months post discharge	Invitation to follow-up visit
	2-3 months post discharge	Follow-up visit (nurse-led or interdisciplinary), diary review, revisit ICU, patient tells story, family collaboration, patient assessment for anxiety and depression (HADS), posttraumatic stress (PTSS-14), self-assessed health (SF-36)
	3, 6, 12 months post discharge	Additional follow-up, telephone contact, repeat SF-36

HADS (Hospital Anxiety and Depression Scale); SF-36 (Short-Form 36-Question Health Survey);
PTSS-14 (Post Traumatic Stress Syndrome 14-Questions Inventory)

(Egerod et al 2013)

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Follow-up research

Journal of Critical Care 52 (2019) 115–125

Contents lists available at ScienceDirect

Journal of Critical Care

journal homepage: www.journals.elsevier.com/journal-of-critical-care

Effects of post-ICU follow-up on subject outcomes: A systematic review and meta-analysis

Regis Goulart Rosa [a,d,*], Giovanni Esteves Ferreira [b], Thiago Wendt Viola [c], Caroline Cabral Robinson [d], Renata Kochhann [d], Paula Pinheiro Berto [e], Livia Biason [a], Paulo Ricardo Cardoso [e], Maicon Falavigna [d], Cassiano Teixeira [a]

Aim: The aim was to synthesize data on effects of post-ICU follow-up on subject outcomes

Included studies: Observational and intervention studies (n=26)

Sample: Variety of patient conditions and illnesses (n=35567)

Intervention: In hospital wards, clinic based appointments or home visits

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Journal of Critical Care 52 (2019) 115–125

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Follow-up research

Results:

Effects of post-ICU follow-up on subject outcomes: A systematic review and meta-analysis

Regis Goulart Rosa [a,d,*], Giovanni Esteves Ferreira [b], Thiago Wendt Viola [c], Caroline Cabral Robinson [d], Renata Kochhann [d], Paula Pinheiro Berto [e], Livia Biason [a], Paulo Ricardo Cardoso [e], Maicon Falavigna [d], Cassiano Teixeira [a]

Post-ICU follow-up is associated with improvements in depressive symptoms and mental quality of life in the short term

Post-ICU follow-up may be beneficial to post-traumatic stress in the medium term

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Follow-up after ICU discharge

Aim: Identify the effectiveness of follow-up services

Intervention: consultations performed by ICU or allied health care professional

Main outcome: anxiety, depression, mortality, quality of life

Studies included: Five studies included (four were nurse-led)

Follow-up services for improving long-term outcomes in intensive care unit (ICU) survivors (Review)

Schofield-Robinson OJ, Lewis SR, Smith AF, McPeake J, Alderson P

Follow-up after ICU discharge

Results:

- No effect on quality of life and number of deaths 12 months
- No reduction in level of anxiety, depression and post-traumatic stress
- No improvement in physical or cognitive functioning
- No increased ability to return to work/ education

Summary and critique of the research

- One review concluded with no effect of follow-up services
- The other review indicated that follow-up services may make a difference on specific outcome measures

- Who performed the follow-up service
- Timing of the follow-up service varied
- Content of the follow-up service varied
- Outcome measure varied

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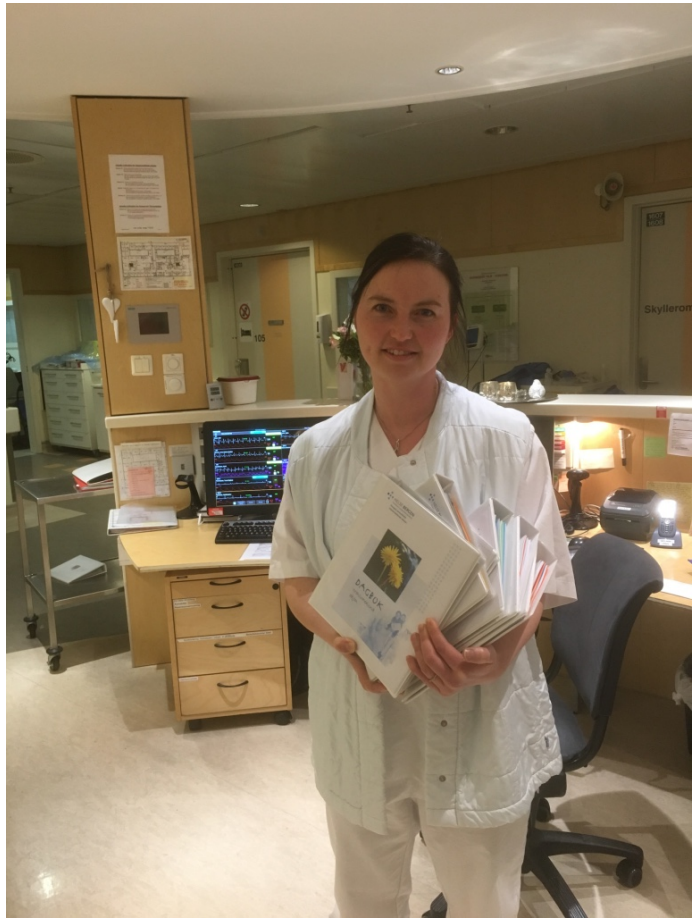
ICU diary: Experiences from our own unit



Jones *et al. Critical Care* 2010, **14**:R168
http://ccforum.com/content/14/5/R168

CRITICAL CARE

RESEARCH Open Access

Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial

Christina Jones[1,2], Carl Bäckman[3], Maurizia Capuzzo[4], Ingrid Egerod[5], Hans Flaatten[6], Cristina Granja[7], Christian Rylander[8], Richard D Griffiths[1,2*], the RACHEL group

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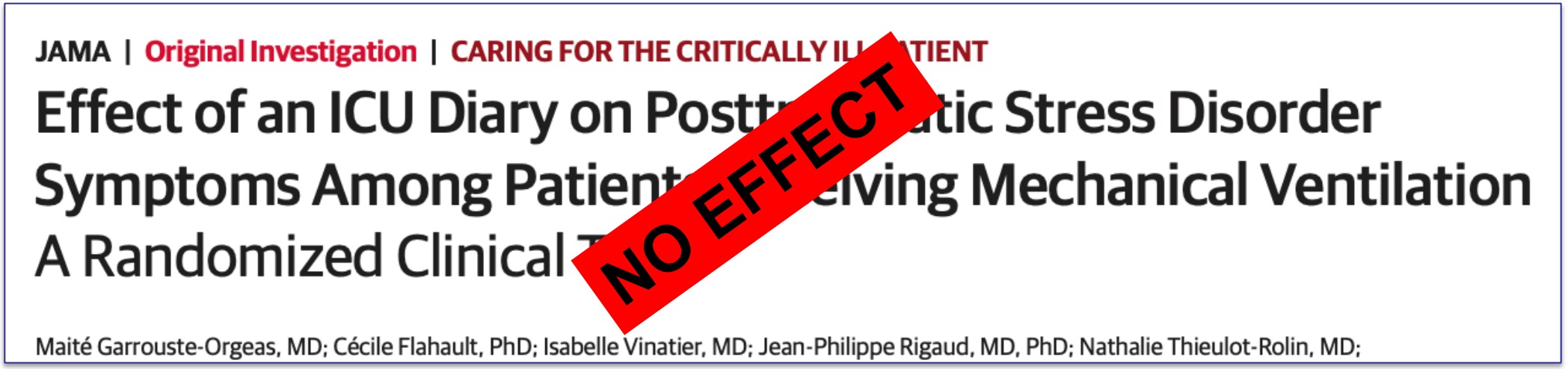
JAMA. 2019;322(3):229-239.



Looking at the right patients

Table 1 Comparison of p

Variables (median, range)			P values
		(n = 162)	
Age		15.5)	NS
ICU stay (days)		12.7)	NS
Hours ventilated		233)	NS
APACHE II severity score		7.3)	NS
Total PTSS 14 score at 1 mont		12.2)	NS

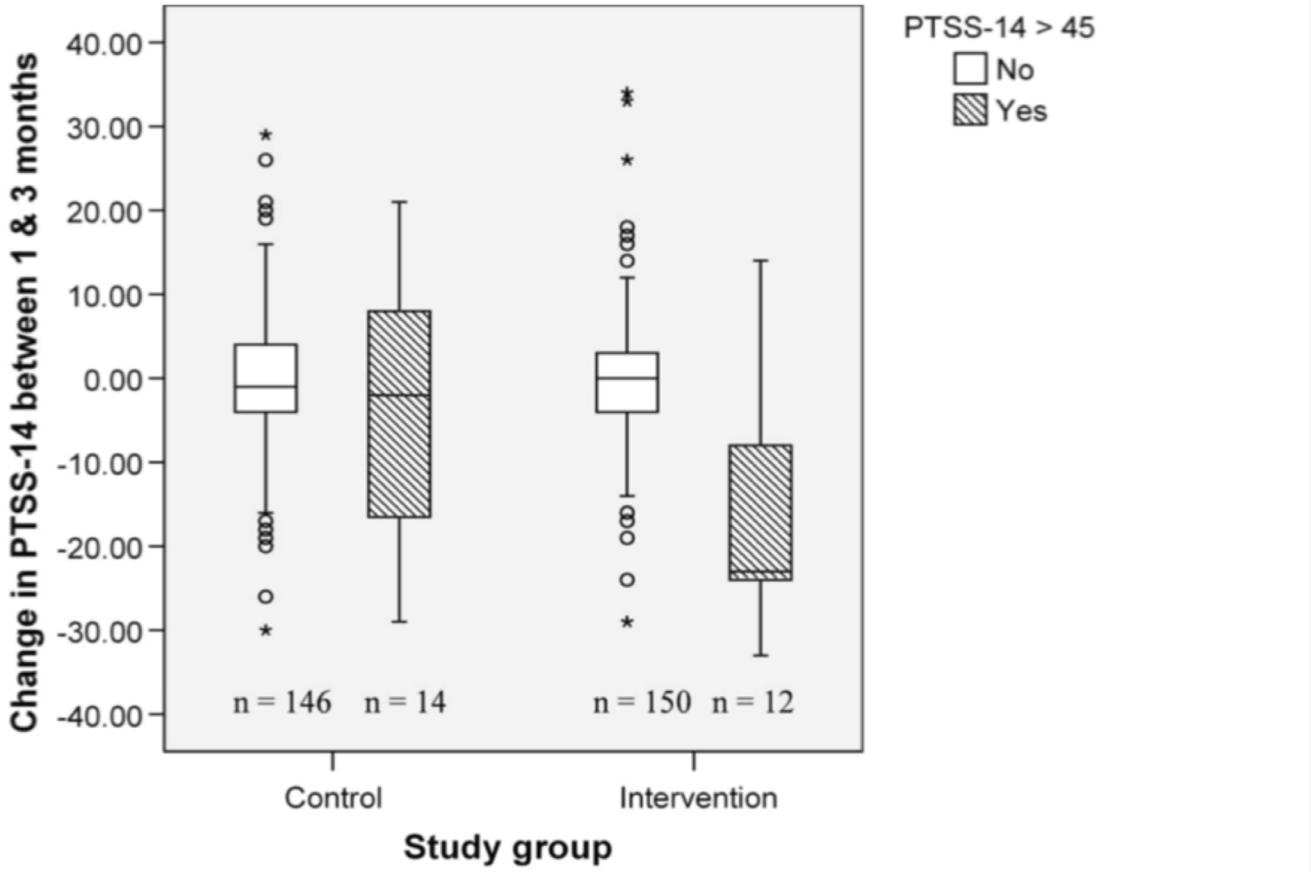


Figure 2 Change in PTSS-14 scores between one and three months by study group and PTSS-14 of 45 or more at one month. Patient n the intervention group with a post-traumatic stress syndrome (PTSS)-14 score above the cut-off of 45 at one month had a significant eduction in the PTSS-14 symptom score at three months (Fisher's exact test $P = 0.04$).

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PICS-F

WHAT ABOUT THE CARE-GIVERS?

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Symptoms, PTS and QOL in family Caregivers of ICU patients, a longitudinal study

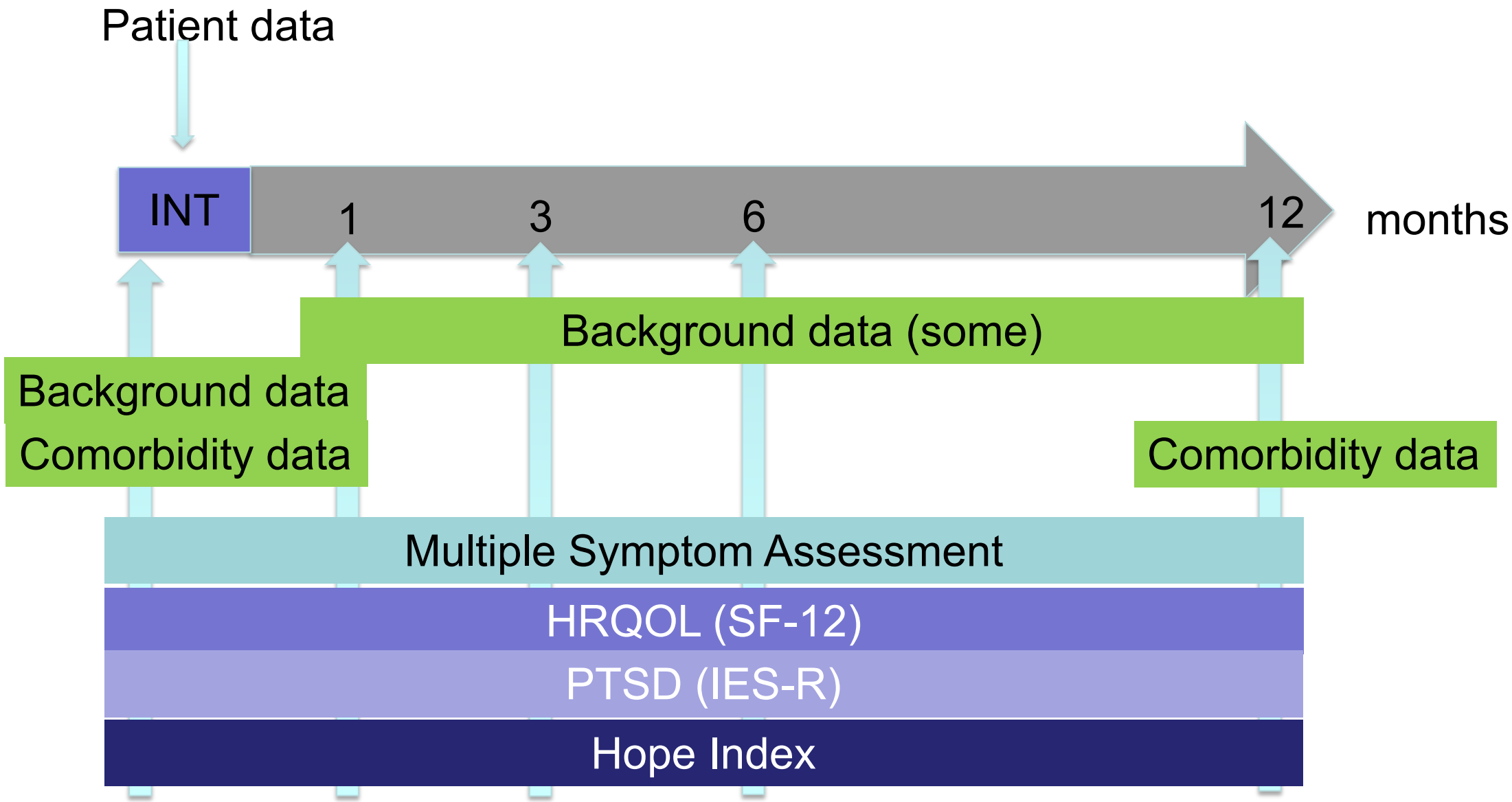
Symptoms, post-traumatic stress and quality of life in family caregivers of intensive care unit patients – a longitudinal study

Hanne Birgit Alfheim, RN, MN

Institute of Clinical Medicine, Faculty of Medicine, University of Oslo
Division of Emergencies and Critical Care, Oslo University Hospital

UiO : Faculty of Medicine
University of Oslo

Oslo University Hospital


Patient data
INT
1
3
6
12
months
Background data (some)
Background data
Comorbidity data
Comorbidity data
Multiple Symptom Assessment
HRQOL (SF-12)
PTSD (IES-R)
Hope Index

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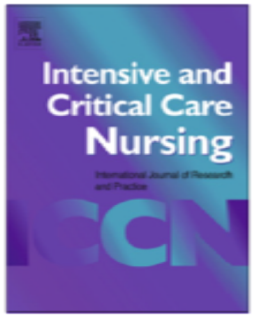
Post-traumatic stress

Intensive & Critical Care Nursing 50 (2019) 5–10

Contents lists available at ScienceDirect

Intensive & Critical Care Nursing

journal homepage: www.elsevier.com/iccn



Research Article

Post-traumatic stress symptoms in family caregivers of intensive care unit patients: A longitudinal study

Hanne Birgit Alfheim [a,b,c,*], Kristin Hofsø [b,d], Milada Cvancarova Småstuen [b,e], Kirsti Tøien [a,b], Leiv Arne Rosseland [b,c], Tone Rustøen [b,f]

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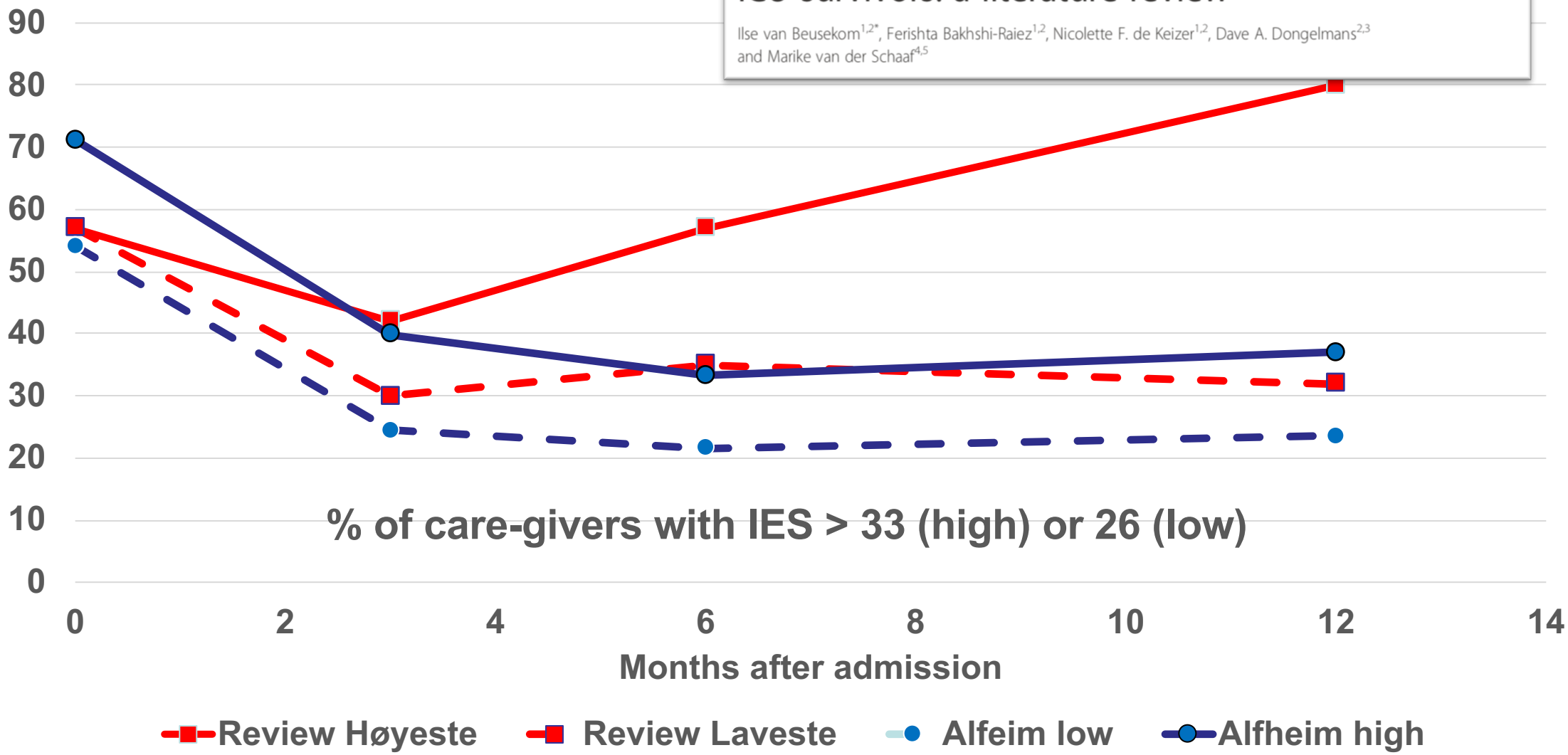
DOI 10.1186/s13054-016-1185-9
Critical Care
RESEARCH Open Access

Reported burden on informal caregivers of ICU survivors: a literature review

Ilse van Beusekom[1,2*], Ferishta Bakhshi-Raiez[1,2], Nicolette F. de Keizer[1,2], Dave A. Dongelmans[2,3] and Marike van der Schaaf[4,5]



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Hope

Table 3
Linear mixed model of fixed effects for post-traumatic stress symptoms.

Variable	Fixed effects		
	Estimate	P-value	95% confidence interval
Age	−0.17	0.019	−0. 31 to −0.03
Gender			
Female	2.27	0.155	−0.87 to 5.41
Male	Reference value		
Education			
Primary/secondary	1.40	0.334	−1.45 to 4.25
College/university	Reference value		
Employment status			
Sick leave	4.25	0.010	1.03 to 7.47
Not on sick leave	Reference value		
Relationship to the patient			
Spouse, child, other	4.51	0.024	0.59 to 8.44
Parent	Reference value		
Hope (HHI)			
Low level of hope (score 0–37)	5.68	<0.001	2.77 to 8.59
High level of hope (score 38–48)	Reference value		
Comorbidities (SCQ)	2.27	<0.001	1.61 to 3.71
Time			
1 month	−6.18	<0.001	−8.02 to −4.33
3 months	−10.65	<0.001	−12.62 to −8.67
6 months	−13.50	<0.001	−15.44 to −11.54
12 months	−13.72	<0.001	−16.09 to −11.35
At enrolment	Reference value		

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Quality of life

Contents lists available at ScienceDirect

Australian Critical Care

journal homepage: www.elsevier.com/locate/aucc

Research paper

Quality of life in family caregivers of patients in the intensive care unit: A longitudinal study

Hanne Birgit Alfheim, RN, MN [a, b, c, *]
Milada Cvancarova Småstuen, PhD [b, d]
Kristin Hofsø, RN, PhD [b, e]
Kirsti Tøien, RN, PhD [a, b]
Leiv Arne Rosseland, MD PhD [b, c]
Tone Rustøen, RN, PhD [b, f]

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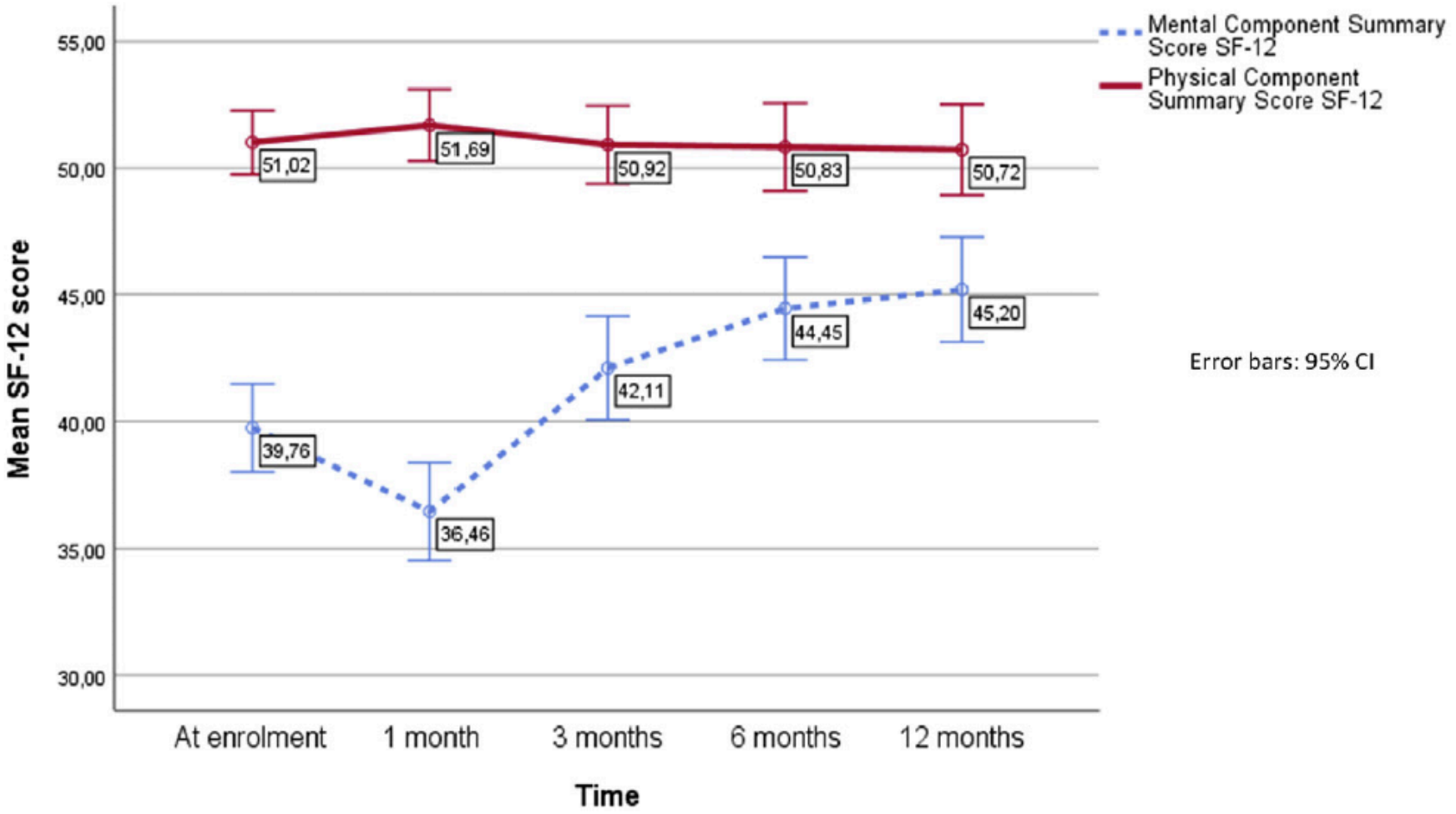
SF-12 in care-givers

H.B. Alfheim et al. / Australian Critical Care xxx (2018) 1–7



Research article | Open Access | Open Peer Review | Published: 09 January 2012

Posttraumatic stress symptoms and health-related quality of life: a two year follow up study of injury treated at the emergency department

Juanita A Haagsma, Suzanne Polinder, Miranda Olff, Hidde Toet, Gouke J Bonsel & Ed F van Beeck

BMC Psychiatry **12**, Article number: 1 (2012) | Cite this article

Results

Symptoms indicative of PTSD were associated with more problems on all EQ-5D and HUI3 domains of functional outcome and a considerable utility loss in both hospitalized (0.23-0.24) and non-hospitalized (0.32-0.33) patients. Differences in reported problems between patients with IES scores higher or lower than 35 were

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Annual report NIR-2018

Norsk intensivregister

Årsrapport for *2018*

med plan for forbetringstiltak

Versjon 1.1

Eirik Alnes Buanes[1], Reidar Kvåle[2] og Andreas Barratt-Due[3]

[1] *Leiar, Norsk intensivregister*
[2] *Norsk intensivregister*
[3] *Leiar av Fagrådet, Norsk intensivregister*

16. oktober 2019

www.intensivregister.no

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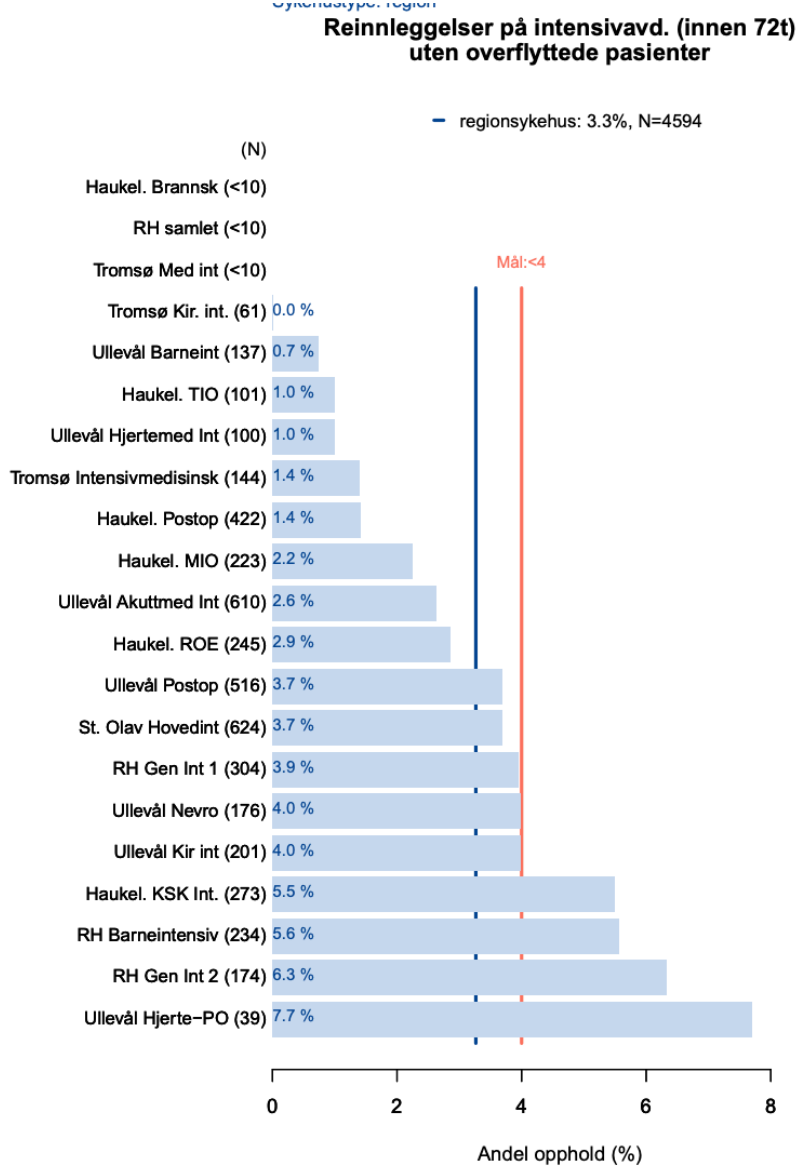

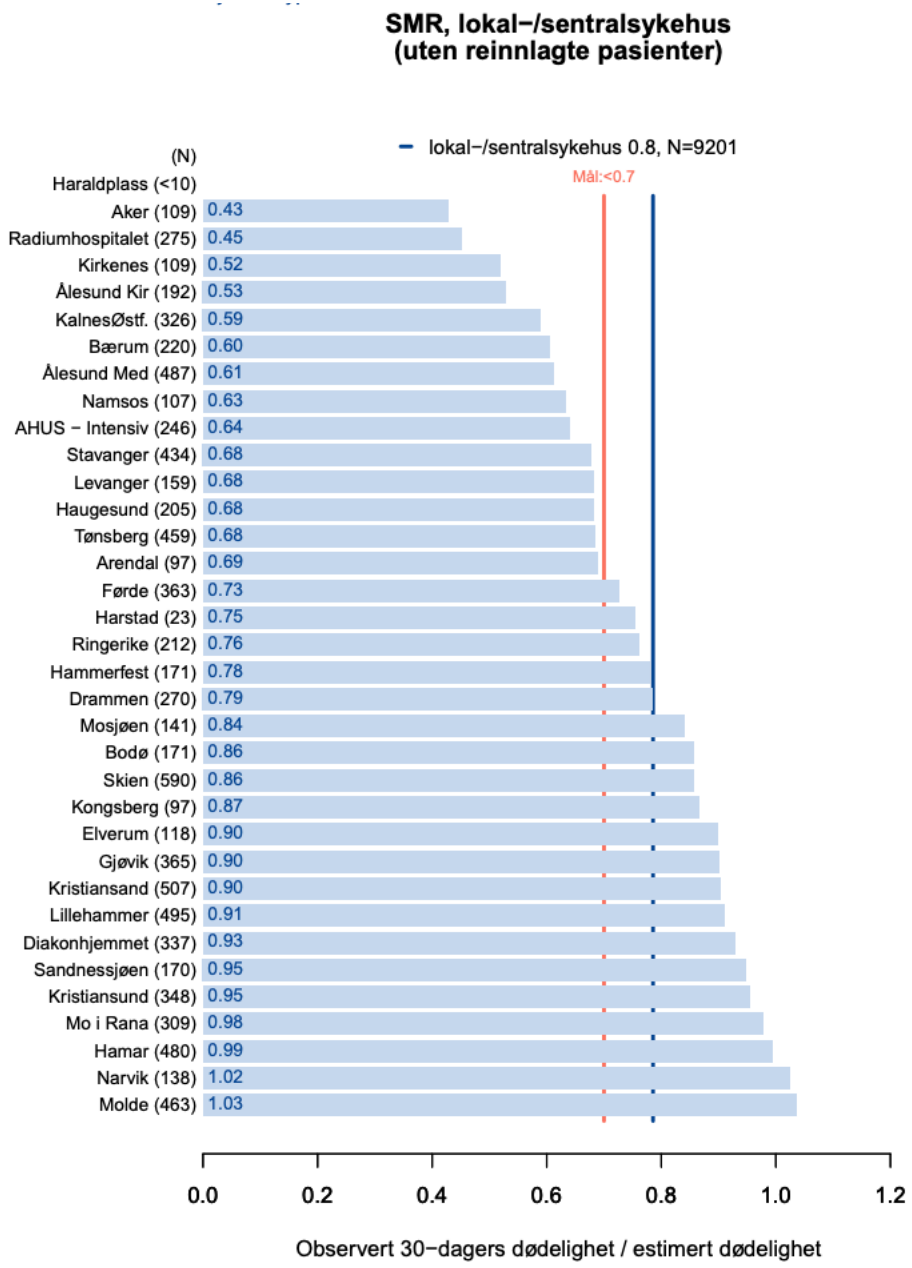

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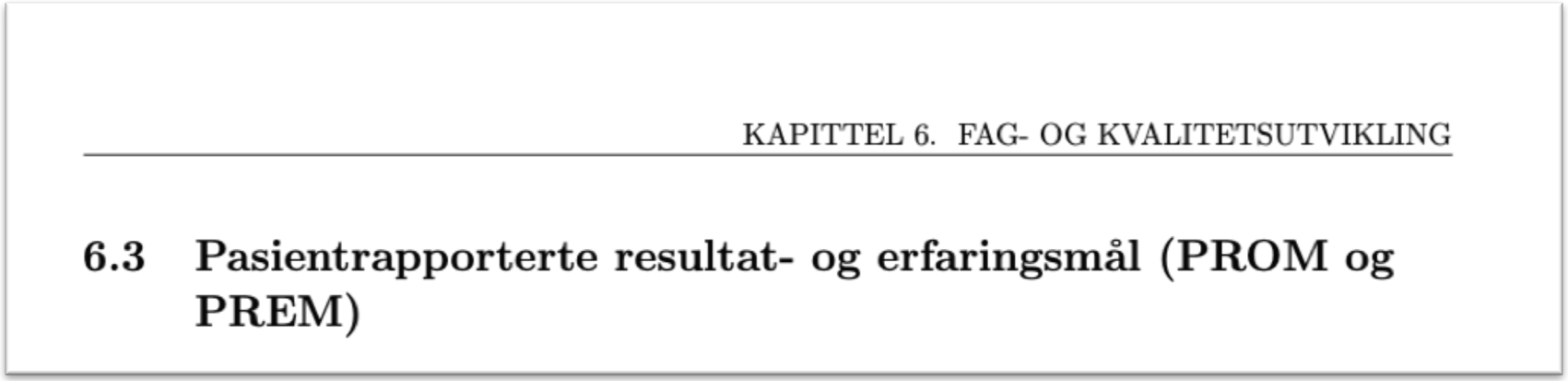

KAPITTEL 6. FAG- OG KVALITETSUTVIKLING

6.3 Pasientrapporterte resultat- og erfaringsmål (PROM og PREM)

- PROM
  - From 2019 we will use **EQ-5D**
  - Will be sent electronically to all survivors at 3 and 12 months post hospital discharge
- PREM
  - We have decided to use caregivers experience as a proxy to patient experience
  - FS-ICU
    - Family satisfaction in the Intensive Care Unit
    - A 24-item questionnaire
    - Well validates
    - Closely mirror patient experiences

https://www.ncbi.nlm.nih.gov/books/NBK333186/

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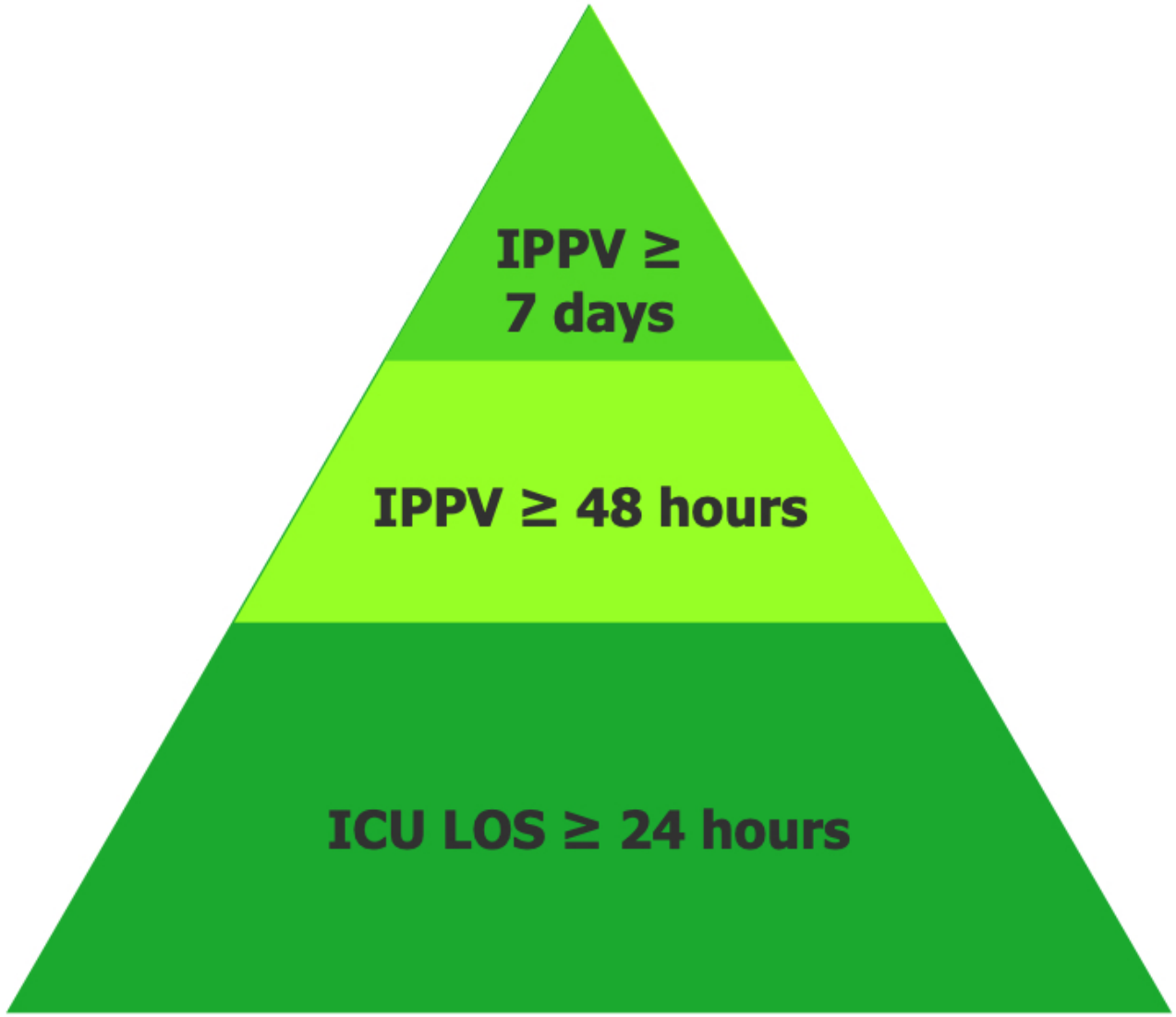
Where to start?



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The long and winding road….to recovery