6 maggio 2023
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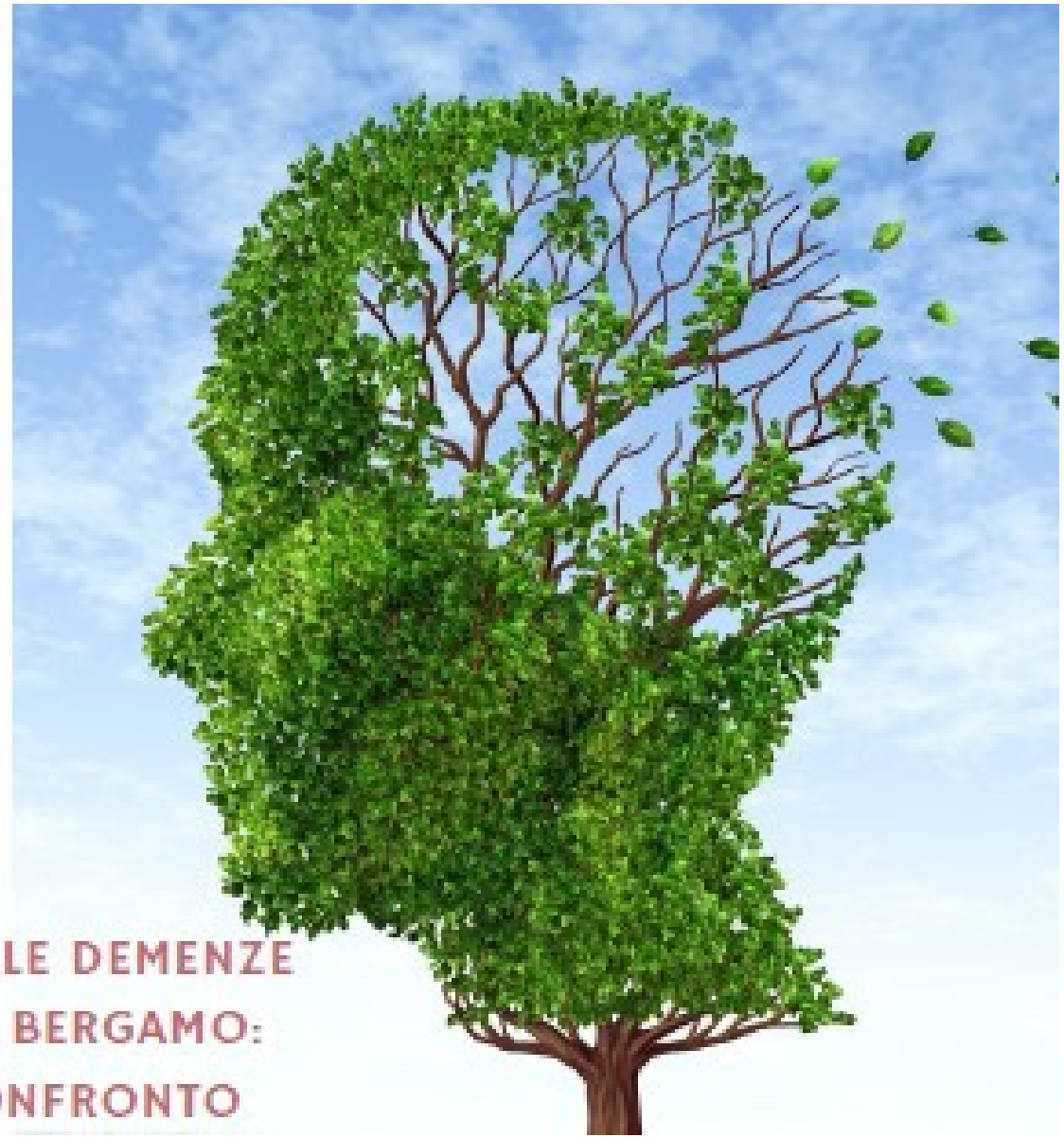


LA GESTIONE DELLE DEMENZE
IN PROVINCIA DI BERGAMO:
ESPERIENZE A CONFRONTO

La gestione delle crisi comportamentali alla luce dei risultati del progetto REcage

Dott.ssa Sara Fascendini
Centro di Eccellenza Alzheimer
Fondazione Europea di Ricerca Biomedica (FERB),
Ospedale "Briolini", Gazzaniga

FERB FONDAZIONE EUROPEA RICERCA BIOMEDICA ONLUS

Gazzaniga (Bergamo), Val Seriana Region, Italy

FONDAZIONE EUROPEA RICERCA BIOMEDICA ONLUS

- CDCD *(> 3000 visite/anno)*
- Attività di ricerca

Sistema Socio Sanitario Regione Lombardia ASST Bergamo Est

FERB FONDAZIONE EUROPEA RICERCA BIOMEDICA ONLUS

- reparto di degenza (*46 posti letto*)

UNITÀ SPECIALE DI CURE

classificata come *struttura riabilitativa specialistica cod. 56*

nata da una collaborazione pubblico-privato

MISSION

OFFRIRE AI PAZIENTI E ALLE FAMIGLIE
LA POSSIBILITÀ DI UN RICOVERO
QUANDO I DISTURBI COMPORTAMENTALI NON SONO GESTIBILI A DOMICILIO,
MIRANDO AD OTTENERNE IL CONTROLLO
ED A REINSERIRE I PAZIENTI AL DOMICILIO.

Centro di Eccellenza Alzheimer

FERB FONDAZIONE EUROPEA RICERCA BIOMEDICA ONLUS

APPROCCIO TERAPEUTICO

- ✓ **TRATTAMENTO FARMACOLOGICO PRUDENTE**
- ✓ **TERAPIE NON FARMACOLOGICHE**
- ✓ **AMBIENTE APPROPRIATO**
- ✓ **ÉQUIPE CON SPECIFICA FORMAZIONE**

MODELLI

- GENTLECARE

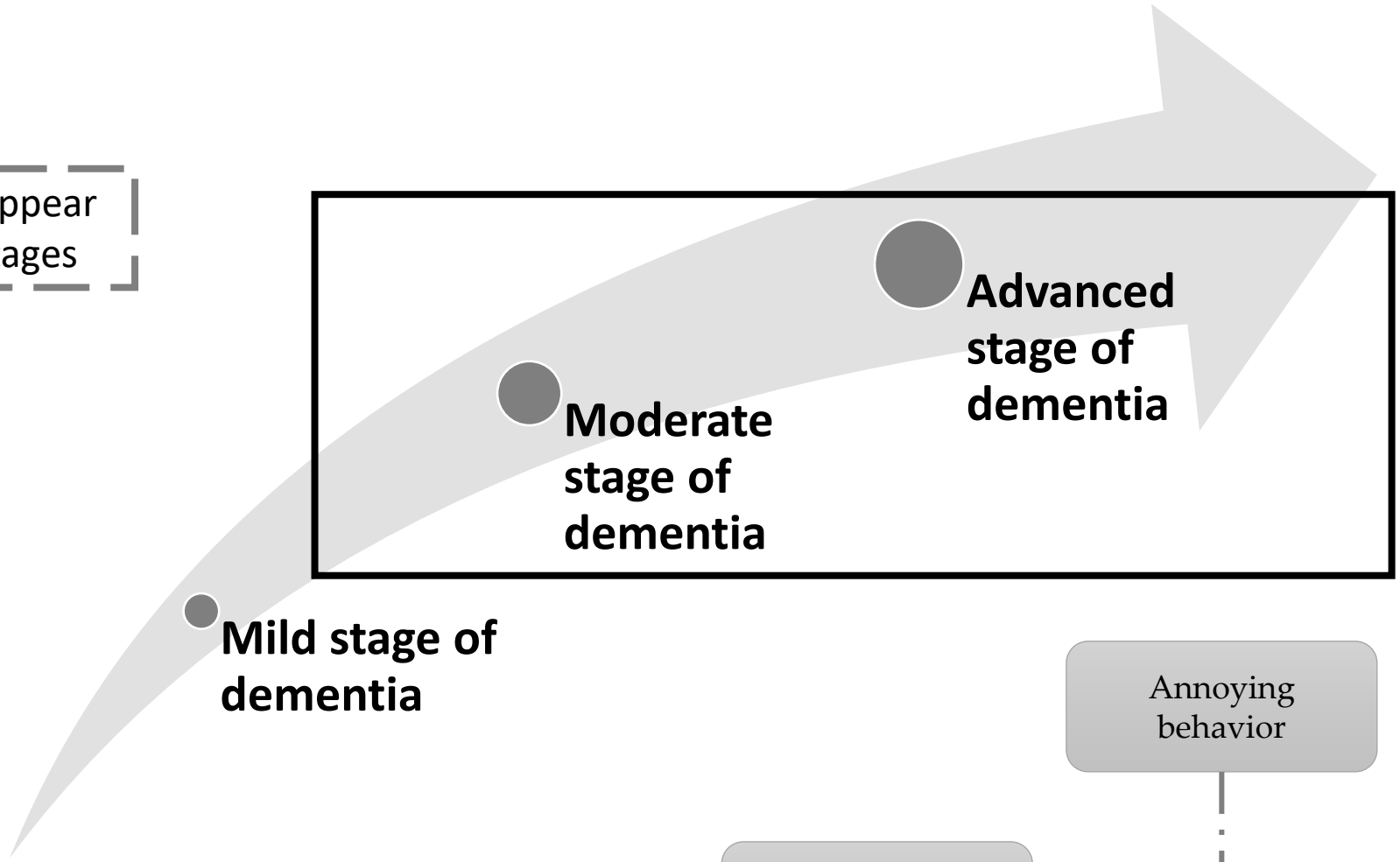
  (Jones M. Gentlecare. Changing the experience of Alzheimer's in a positive way. Hartley and Marks, Vancouver ,1998)

- PERSON-CENTRED APPROACH

  (Kitwood T. Dementia reconsidered: the person comes first. Open University Press, London 1997)

Behavioral and Psychological Symptoms of dementia (BPSD)

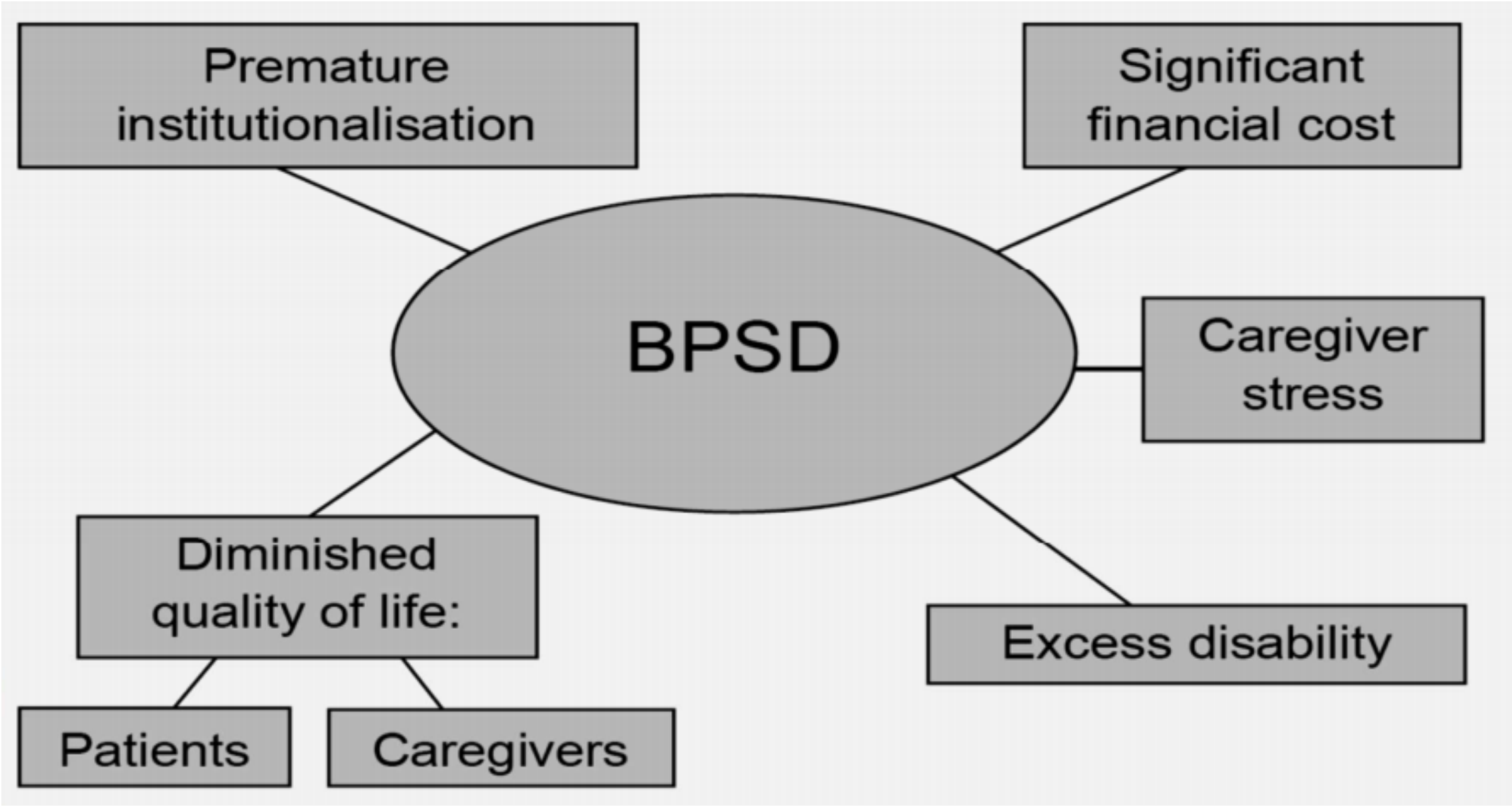
90% of PwD appear BPSD in all stages



Annoying behavior

Caregiver's burden

Large costs to the public health system



Introduction to BPSD. Sanford Finkel
Int. J. Geriat. Psychiatry 15, S2-S4 (2000)

frontiers in Pharmacology

REVIEW
published: 31 July 2020
doi: 10.3389/fphar.2020.01168

Pharmacotherapy of Behavioral and Psychological Symptoms of Dementia: State of the Art and Future Progress

*Radoslaw Magierski[1], Tomasz Sobow[2], Emilia Schwertner[3] and Dorota Religa[3,4]**

[1] Department of Old Age Psychiatry and Psychotic Disorders, Medical University of Lodz, Lodz, Poland, [2] Dialog Therapy Centre, Warsaw & Institute of Psychology, University of Lodz, Lodz, Poland, [3] Center for Alzheimer Research, Division of Clinical Geriatrics, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden, [4] Tema Aging, Karolinska University Hospital, Stockholm, Sweden

In practice, a range of drugs are used, although most are antipsychotics. Unfortunately, many of the pharmacological options lack strong evidence from clinical trials confirming their effectiveness, and many others are used as off-label treatments.

frontiers | Frontiers in Psychiatry

ORIGINAL RESEARCH
published: 01 April 2022
doi: 10.3389/fpsyt.2022.843088

Clinical Perception and Treatment Options for Behavioral and Psychological Symptoms of Dementia (BPSD) in Italy

Fabrizia D'Antonio[1]*, *Lucio Tremolizzo*[2], *Marta Zuffi*[3], *Simone Pomati*[4], *Elisabetta Farina*[5] *and the Sindem BPSD Study Group*

[1] *Department of Human Neuroscience, Sapienza University of Rome, Rome, Italy,* [2] *Neurology "San Gerardo" Hospital Monza and University of Milano-Bicocca, Milan, Italy,* [3] *Neurology Department, MultiMedica Castellanza, Milan, Italy,* [4] *Centro per il Trattamento e lo Studio dei Disturbi Cognitivi, Ospedale Luigi Sacco, Milan, Italy,* [5] *IRCCS Fondazione Don Carlo Gnocchi ONLUS, Milan, Italy*

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ORIGINAL RESEARCH
published: 01 April 2022
doi: 10.3389/fpsyt.2022.843088

Clinical Perception and Treatment Options for Behavioral and Psychological Symptoms of

Conclusion: The survey results revealed many differences in BPSD perception, treatment options, and observed side effect according to the clinical setting. This variability can be explained by the absence of clear guidelines, by differences in patients' characteristics, and by clinical practice based on subjective experience. These results suggest that producing guidelines for the pharmacological treatment of BPSD is a major need.

trattamento e lo Studio del Distretto Cognitivo, Ospedale Luigi Sacco, Milan, Italy, [7] IRCCS Fondazione Don Carlo Gnocchi ONLUS, Milan, Italy

Study of mirtazapine for agitated behaviours in dementia (SYMBAD): a randomised, double-blind, placebo-controlled trial

Sube Banerjee, Juliet High, Susan Stirling, Lee Shepstone, Ann Marie Swart, Tanya Telling, Catherine Henderson, Clive Ballard, Peter Bentham, Alistair Burns, Nicolas Farina, Chris Fox, Paul Francis, Robert Howard, Martin Knapp, Iracema Leroi, Gill Livingston, Ramin Nilforooshan, Shirley Nurock, John O'Brien, Annabel Price, Alan J Thomas, Naji Tabet

Summary

Background Agitation is common in people with dementia and negatively affects the quality of life of both people with dementia and carers. Non-drug patient-centred care is the first-line treatment, but there is a need for other treatment when this care is not effective. Current evidence is sparse on safer and effective alternatives to antipsychotics. We assessed the efficacy and safety of mirtazapine, an antidepressant prescribed for agitation in dementia.

Lancet 2021; 398: 1487–97

Study of mirtazapine for agitated behaviours in dementia (SYMBAD): a randomised, double-blind, placebo-controlled trial

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Summary

Background Agitation is common in people with dementia and negatively affects the quality of life of both people with dementia and carers. Non-drug patient-centred care is the first-line treatment, but there is a need for other treatment when this care is not effective. Current evidence is sparse on safer and effective alternatives to antipsychotics. We assessed the efficacy and safety of mirtazapine, an antidepressant prescribed for agitation in dementia.

Interpretation This trial found no benefit of mirtazapine compared with placebo, and we observed a potentially higher mortality with use of mirtazapine. The data from this study do not support using mirtazapine as a treatment for agitation in dementia.

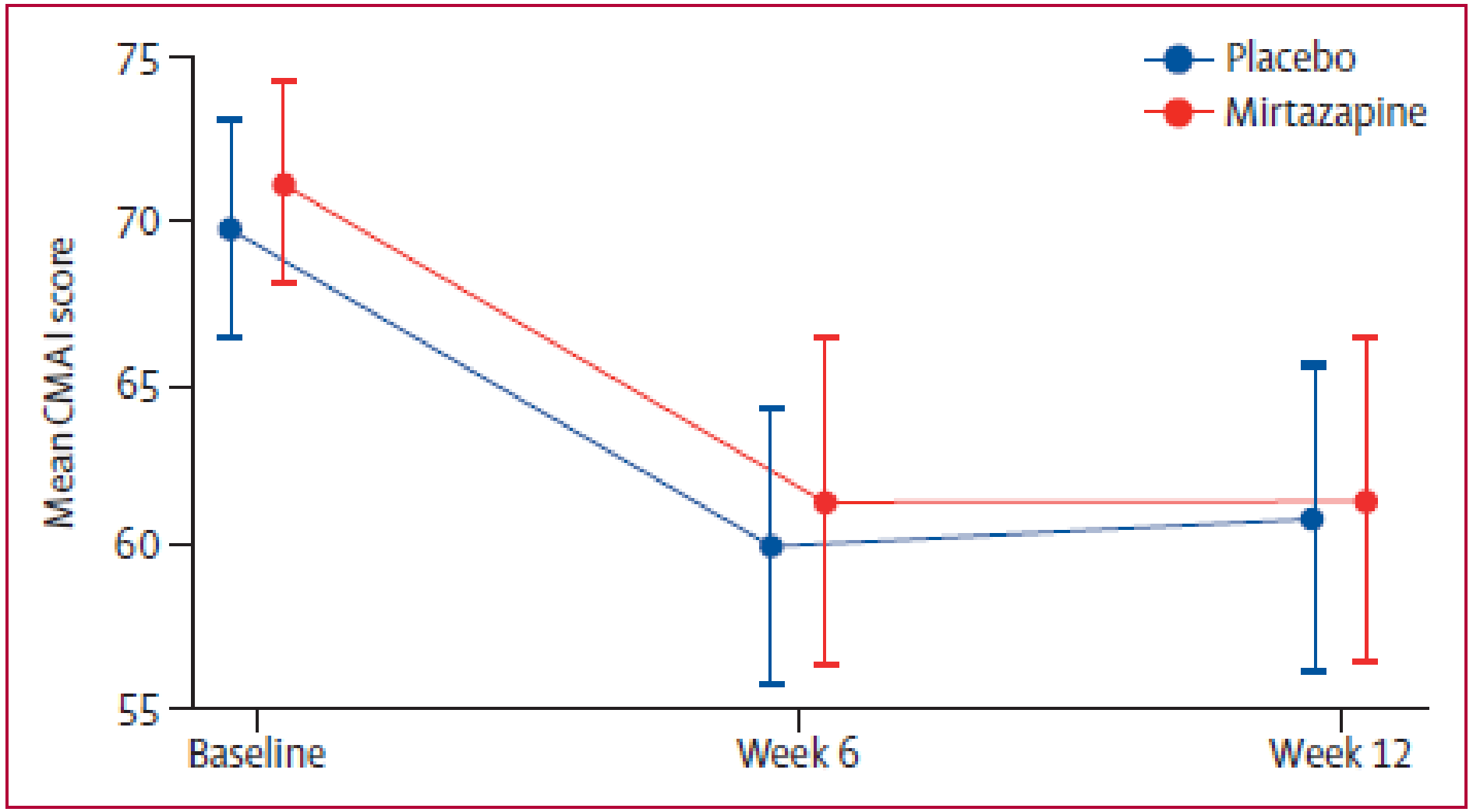


***Figure 2*: Unadjusted mean CMAI scores (95% CI) by treatment group**

Please note that the y-axis does not start at 0 in this figure. CMAI=Cohen Mansfield Agitation Inventory.

BMJ Open

Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series

Iosief Abraha,[1] Joseph M Rimland,[1] Fabiana Mirella Trotta,[1] Giuseppina Dell'Aquila,[1] Alfonso Cruz-Jentoft,[2] Mirko Petrovic,[3] Adalsteinn Gudmundsson,[4] Roy Soiza,[5] Denis O'Mahony,[6] Antonio Guaita,[7] Antonio Cherubini[1]

Abraha I, *et al. BMJ Open* 2017;7:e012759. doi:10.1136/bmjopen-2016-012759

BMJ Open Systematic review of systematic reviews of non-pharmacological interventions

Conclusions: A large number of non-pharmacological interventions for BPSD were identified. The majority of the studies had great variation in how the same type of intervention was defined and applied, the follow-up duration, the type of outcome measured, usually with modest sample size. Overall, music therapy and behavioural management techniques were effective for reducing BPSD.

ita,[7]

Abraha I, *et al. BMJ Open* 2017;7:e012759. doi:10.1136/bmjopen-2016-012759

DESCRIBE

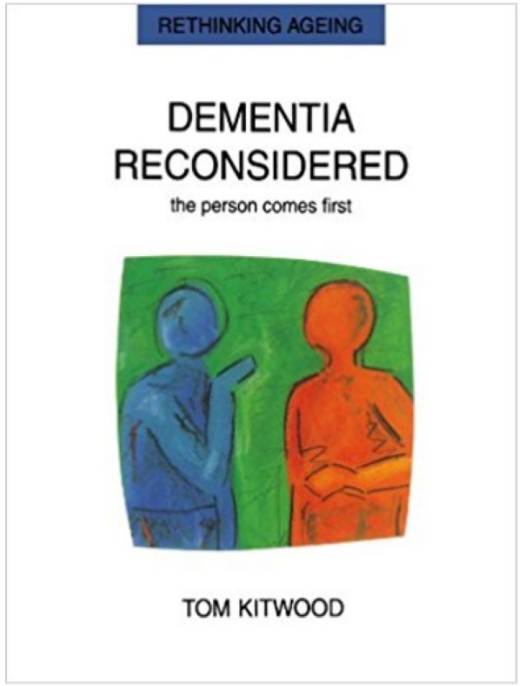
INVESTIGATE

CREATE

EVALUATE

Think the ***Person***, not the dementia

Person comes first!



Controversies in Long Term Care

The Broken Lens of BPSD: Why We Need to Rethink the Way We Label the Behavior of People Who Live With Alzheimer Disease

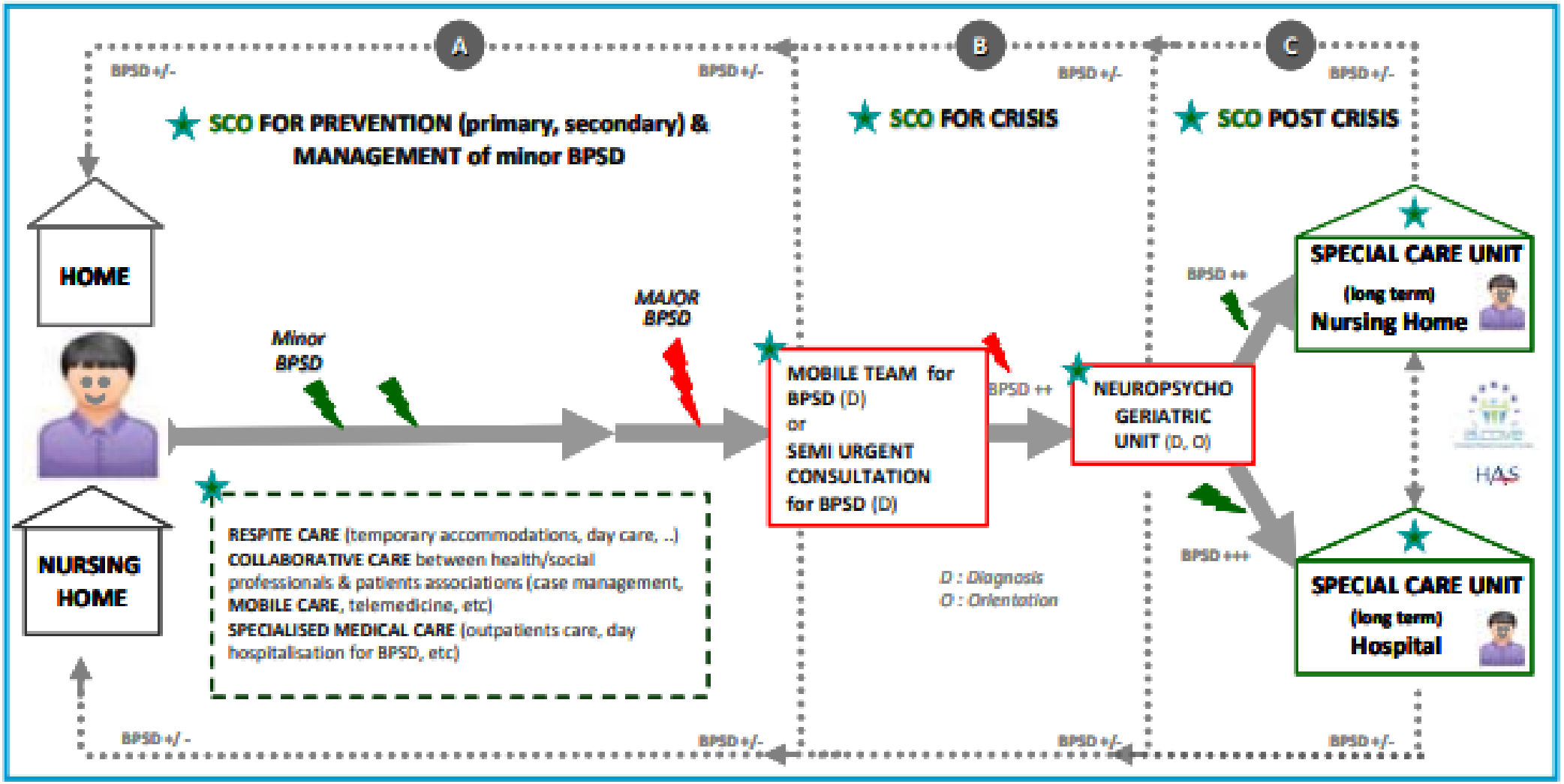
Susan Macaulay BA *

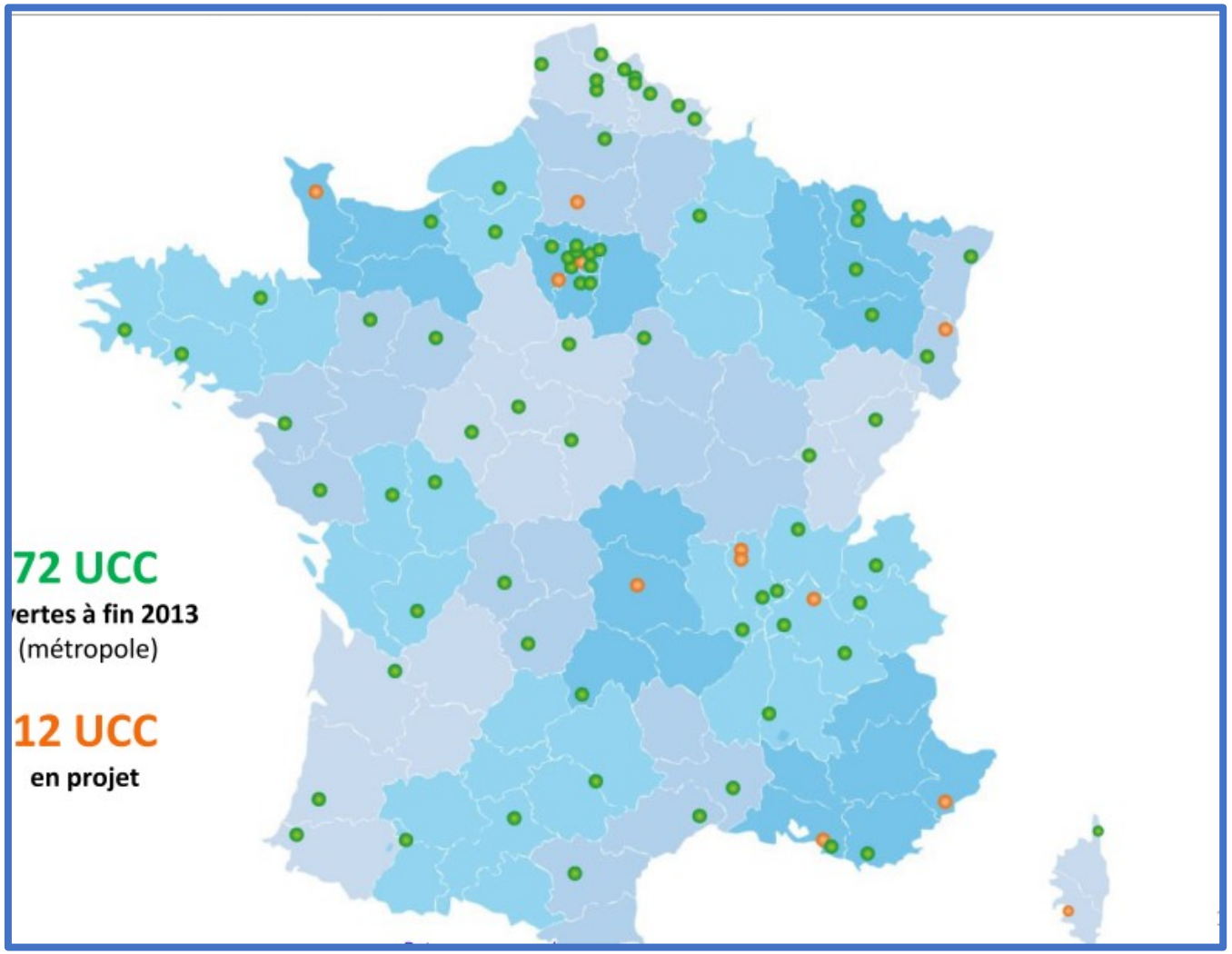
Quebec, Canada

CrossMark

Figure 1. Structures and Care Organisations for BPSD all along the Patient Pathway

Step A: minor BPSD prevention & management - Step B: major BPSD crisis management - Step C: BPSD management & prevention




72 UCC
vertes à fin 2013
(métropole)
12 UCC
en projet


VALLE D'AOSTA
PIEMONTE
LOMBARDIA
TRENTINO ALTO ADIGE
FRIULI VENEZIA GIULIA
VENETO
LIGURIA
EMILIA ROMAGNA
TOSCANA
MARCHE
UMBRIA
ABRUZZO
LAZIO
MOLISE
CAMPANIA
PUGLIA
BASILICATA
SARDEGNA
CALABRIA
SICILIA

Horizon 2020

Call: H2020-SC1-2016-2017

(Personalised Medicine)

Topic: SC1-HCO-07-2017

Type of action: RIA

(Research and Innovation action)

Proposal number: 779237

Proposal acronym: RECAGE

The major objective of **RE**spectful **C**aring for **AG**itated **E**lderly (RECAGE) will *be to adapt and upscale the implementation of a peculiar intervention aimed at controlling BPSD, **the special medical care unit for persons with dementia and BPSD (SCU-B)***[10], an intervention that, albeit already implemented in some European countries, is not widespread and has not been sufficiently studied so far, although it seems to be promising, both for its short term efficacy (alleviating BPSD and improving quality of life of PwD) and possibly for its long term efficacy, measured as delay of NHP.

The SCU-B concept

"a residential medical structure lying outside of a nursing home, in a general hospital or elsewhere, e.g., in a private hospital or a geriatric or psychiatric hospital, where patients with BPSD are temporarily admitted when their behavioral disturbances are not amenable to control at home"

SCU-B: Special Medical **C**are **U**nit for **B**PSD

- Differ from general day care centers for dementia or other special care units such as nursing homes
- Medical institutions
- Focused on the needs of PwD and severe BPSD
- Aim to mitigate the challenging symptoms and allow patients to get back home
- **With respect of dignity of PwD**

The idea and the philosophy of SCU-B

- A place where the staff can explore alternative solutions for the safety of people with dementia
- Identifies the demented patient's unmet needs

- **C**ommunication
- **A**ctivity
- **U**nwell/unmet need
- **S**tory
- **E**nvironment
- **d**ementia

The RECage clinical trial

- Three-year prospective observational study
- Comparison of two groups of community-dwelling patients with mild to severe dementia of any aetiology and significant BPSD
- The one followed up by centres with SCU-B, the other by centres lacking SCU-B
- Following up of patients every 6 months for three years
- Participanting 11 clinical centres from six European countries (Italy, Germany, France, Greece, Switzerland, Norway)
- 5 centres endowed with a SCU-B, 6 centres were lacking SCU-B

The RECage study

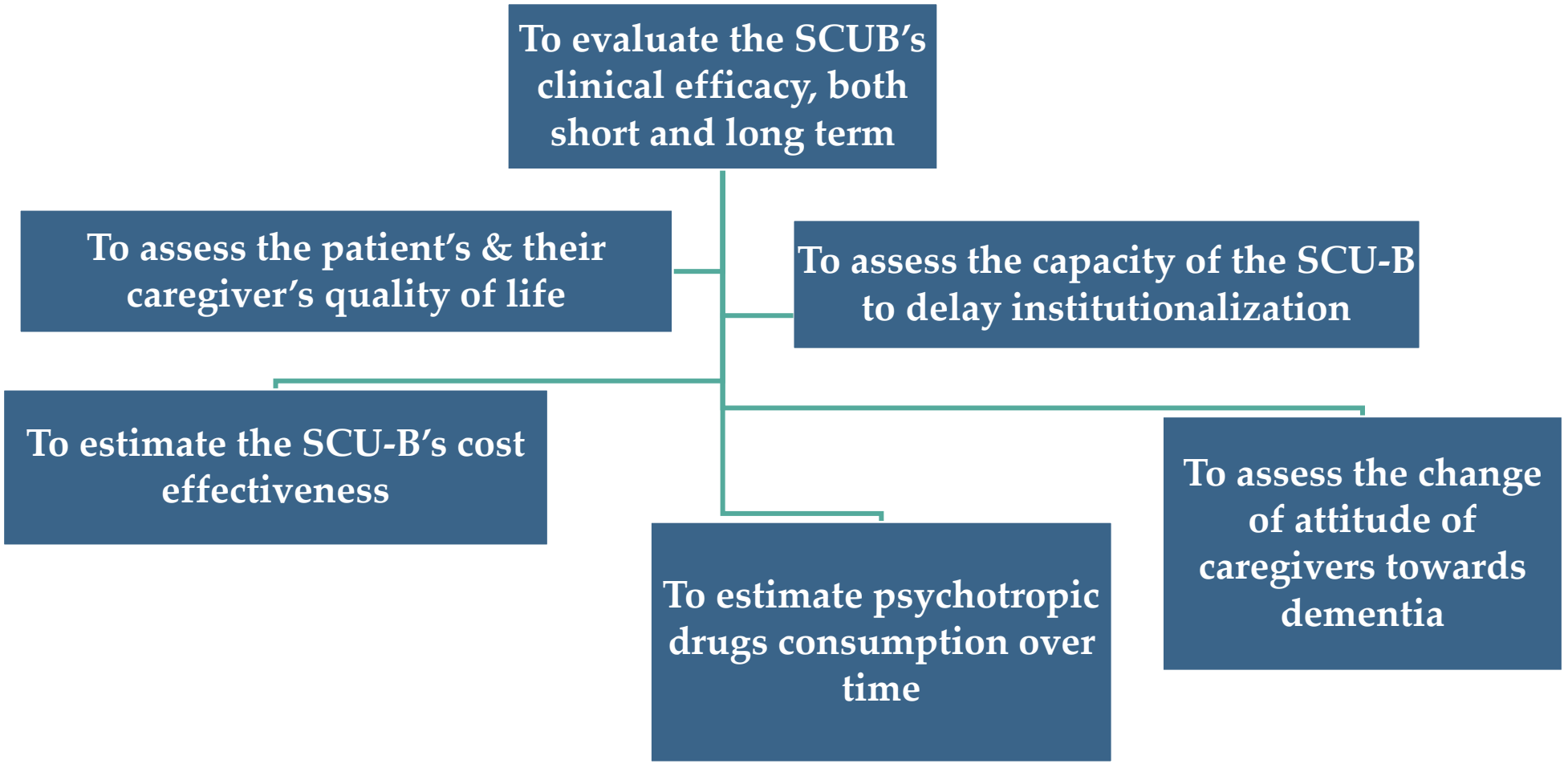
5 centers with SCU-B

	"Fondazione Europea di Ricerca Biomedica (FERB)" Gazzaniga, **Italy**
	"Azienda Unita Sanitaria Locale di Modena (AUSLM)" Modena, **Italy**
	"Universite de Geneve (UNIGE)" Geneve, **Switzerland**
	"Zentralinstitut fur Seelische Gesundheit (ZI) Mannheim, **Germany**
	"Innlandet Hospital trust (SI) Ottestad, **Norway**

6 centers without SCU-B

	"Charite – Universitatsmedizin Berlin (CHARITE), Berlin, **Germany**
	"Universita degli Studi di Perugia (UNIPG)" Perugia, **Italy**
	"Azienda Socio Sanitaria Territoriale di Mantova (ASSTM)" Mantova, **Italy**
	"Cliniche Gavazzeni SpA (BG)" Bergamo, **Italy**
	"Assistance Publique Hopitaux de Paris (AP-HP)" Paris, **France**
	"Aristotelio Panepistimio Thessalonikis (AUTH)", Thessaloniki, **Greece**

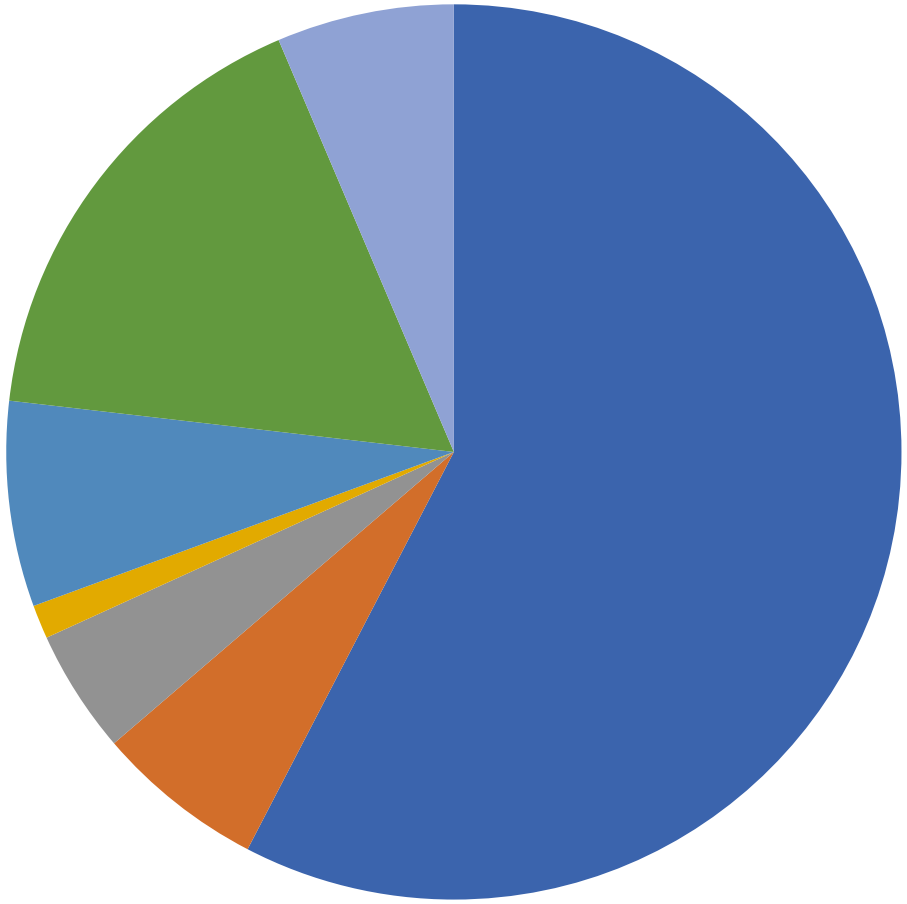
RECage study's objectives



Study hypotheses

1. BPSDs (measured through specific tools) will be mitigated via the SCU-B pathway compared to the no-SCUB one
2. The Quality of Life (QoL), both for patients and their caregivers, who are cared by centers endowed with a SCU-B, will be improved compared to the QoL of the patients followed by centers lacking a SCU-B
3. The attitude of caregivers toward dementia will be possibly improved, due to the psychoeducation they will have in SCU-Bs
4. SCU-Bs will be a cost-effective solution for both people with BPSD and their caregivers. People who will be admitted to SCUB will present diminished costs compared to the patients who will not be admitted in SCU-B.
5. People with BPSDs admitted in SCU-B centers will have less psychotropic drug consumption
6. People with BPSDs not admitted in SCU-B centers will be prone to earlier admission to institutions than people cared for in SCU-B centers

1.The Recage Clinical Trial



Mean NPI score: 52,15

Patients:
- First in: 19/04/2018
- Last out: 22/09/2022

(db lock: 30.09.2022)

Patients:
- Screened 520
- Enrolled: 518 – 508 ANALYSED
- Completed: 211 (/ 508 = 41.53% -
  192 (37.8%) with all 7 visits.
- Drop-out: 307

RECage

RECage study results according to the hypotheses #1

The main hypothesis of superiority of the care pathways of patients by centres with SCU-B regarding the change of BPSD over time, was not confirmed

01

No significant differences were noticed regarding functional status, quality of life, and caregiver's burden

02

The caregivers of people with dementia who lived in SCU-B improved their attitude because of psychoeducation that they had, compared with the non SCU-B cohort

03

RECage study results according to the hypotheses #2

There were higher costs in the intervention group (SCU-B). Therefore, it seems that the SCU-B isn't cost-effective.

04

There were more accesses to emergency rooms in the no SCU-B cohort, and a hint to increased use of psychotropic drugs was found

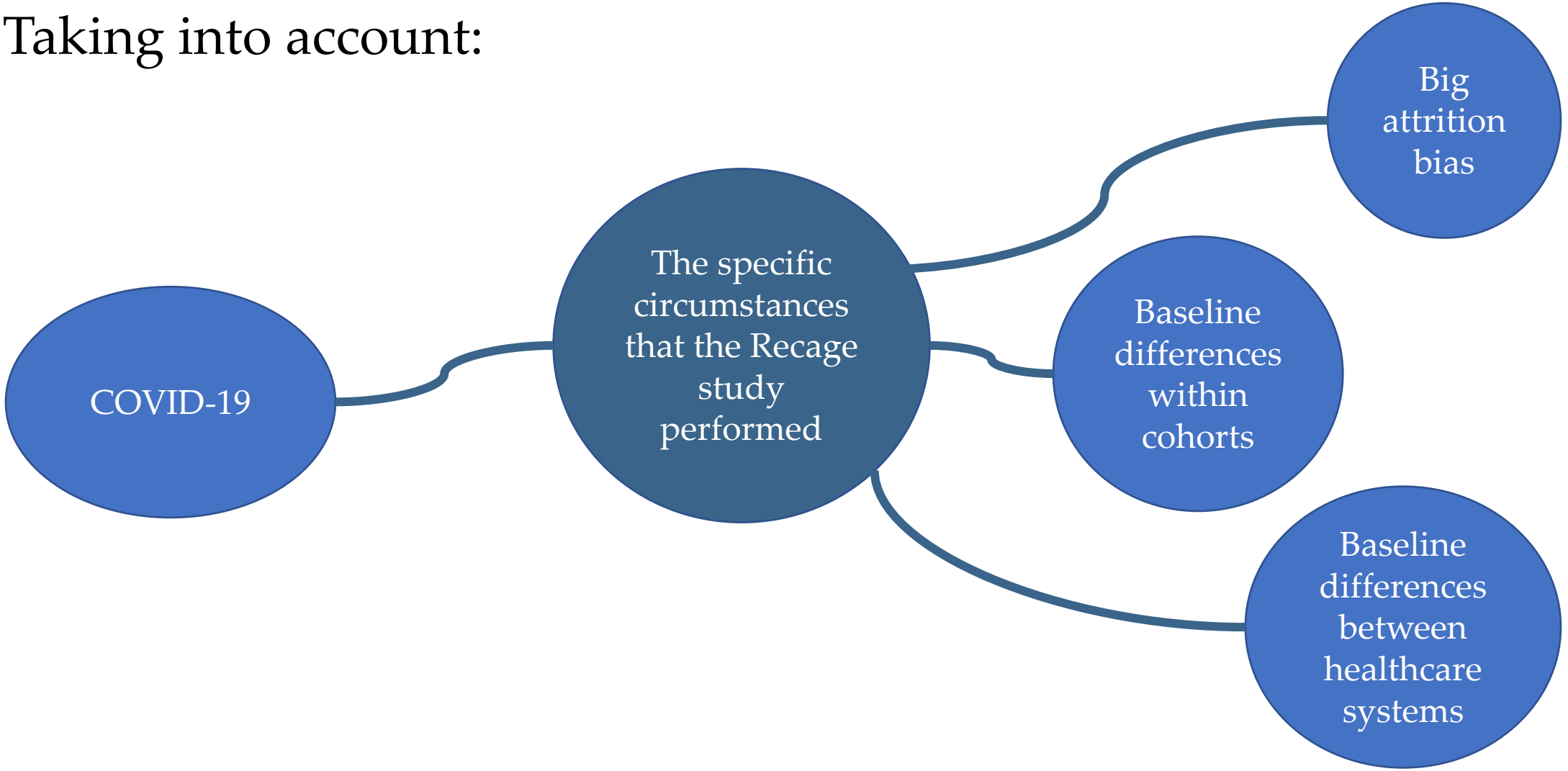
05

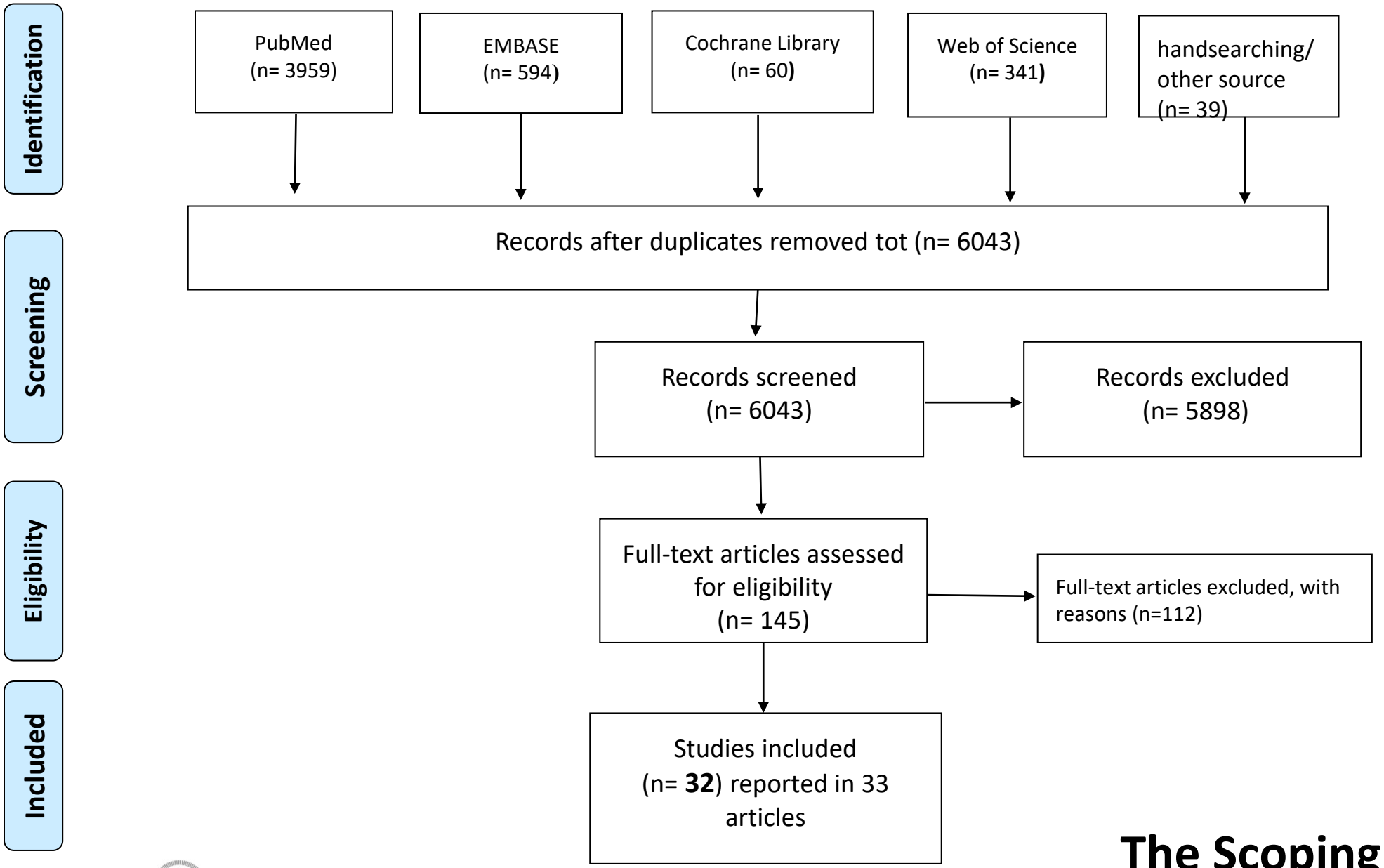
There was no significant difference between SCU-Bs and no SCU-Bs in terms of NH placement

06

Are the results disappointing?

Taking into account:





The Scoping Review

RECage

BMJ

BMJ 2013;347:f4132 doi: 10.1136/bmj.f4132 (Published 2 July 2013)

Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial)

Sarah E Goldberg *research associate*[1], Lucy E Bradshaw *statistician*[1], Fiona C Kearney *consultant geriatrician*[2], Catherine Russell *research nurse*[2], Kathy H Whittamore *clinical researcher*[1], Pippa E R Foster *research associate*[1], Jil Mamza *clinical researcher*[1], John R F Gladman *professor of geriatric medicine*[1], Rob G Jones *associate professor of old age psychiatry*[3], Sarah A Lewis *professor*

wood

Conclusions: Specialist care for people with delirium and dementia improved the experience of patients and satisfaction of carers, but there were no convincing benefits in health status or service use. Patients' experience and carers' satisfaction might be more appropriate measures of success for frail older people approaching the end of life.

International Journal of
Environmental Research and Public Health

MDPI

Article

The Special Care Unit for People with Behavioral and Psychological Symptoms of Dementia (SCU- B) in the Context of the Project "RECage-Respectful Caring for Agitated Elderly": A Qualitative Study

Anna Giulia Guazzarini [1], Georgia Casanova [2,3,*], Friederike Buchholz [4,5], Mahi Kozori [6], Sara Lavolpe [7], Bjørn Lichtwarck [8], Eleni Margioti [9], Aline Mendes [10], Marie-Louise Montandon [10,11], Ilenia Murasecco [1], Janne Myhre [8], Elena Poptsi [6,12], Valentina Reda [13], Dorothea Elisabeth Ulshöfer [14] and Sara Fascendini [15]

1. Describe the main characteristics of SCU-B in relation to different implementation contexts
2. Identify the characteristics of their replicability.
3. Look at the social innovation elements promoted by SCU-Bs.

FGs and Interviews

SWOT Analysis

3.The Qualitative Study

RECage Consensus Conference

21st – 22nd February 2023

In person - University Foundation (Fondation Universitaire)

Rue d'Egmont 11, 1000 – Brussels

- A specific way of producing definitions/statements/recommendations through a **formal consensus process** between different stakeholders
- It revolves around a **public debate** in which clinical experts and other stakeholders exchange views
- **Purpose**: to provide patients with the best quality of care in relation to available resources
- Appropriate in specific situations:
  → **Controversial topic requiring public debate**
  → **Scanty evidence, no evidence**

Definition: to explain
Statement: to express a position
Recommendation: operational indication

- Summary of the available evidence (systematic review of scientific literature or surveys)
- Panel of renowned experts (multidisciplinarity with respect to the topic) synthesize the available evidence and develop a report for each topic
- The panel listens to the reports and discussion with the public and develops recommendations/statements

Name	Role, Affiliation
Iva Holmerová	**Gerontologist, University of Prague, Panel Chair**
Maria Do Rosário Zincke Dos Reis	Chairperson of Alzheimer Europe
Ninoslav Mimica	Psychogeriatrician, University of Zagreb
Francesco Nonino	Methodologist, Institute of Neurological Sciences of Bologna
Pierre Jean Ousset	Geriatrician, University of Toulouse
Frans Verhey	Psychiatrist, University of Maastricht
Marco Canevelli	Neurologist, Istituto Superiore di Sanità, Sapienza University, Rome
Katalina Tudose	Psychiatrist, University of Bucharest

Domain	Research Question	Questions for the panel
Description and technical characteristics of SCU-B (including description of target population, architectural, organizational, legal aspects)	What kinds of SCU-B are there? With special regard for the SCU-Bs: what about architectural features, staff compositions, activities, criteria for admission?	**1. Which types of SCU-B can be identified ?** **2. What are the characteristics of different types of SCU-B in terms of target population, structural and organisational aspects ?** **3. What are the main ethical issues to be addressed by the staff of a SCU-B?**
	What are the main issues related to the SCU-B (informed consent, restraints, "benevolent" coercion …)	
Effectiveness of SCU-B	What is the evidence of clinical effectiveness of the SCU-B vs usual care?	**4. What are the recommended effectiveness and safety outcomes to be considered when assessing/auditing a SCU-B?**
Costs and economic evaluation of SCU-B	What is the evidence of cost-effectiveness of the SCU-B vs usual care?	*(see question 4 – Effectiveness component of cost-effectiveness)*
Safety of SCU-B	What are the safety issues of physical restraints and neuroleptic treatments?	**5. What are the main safety issues to be addressed by the staff of a SCU-B in relation to restraint measures?**

CONSENSUS CONFERENCE
ON THE SPECIAL CARE UNIT FOR BPSD (SCUB)

Brussels, 21st – 22nd of February 2023

The Consensus Conference on the RECage Project was convened in Brussels, 21st - 22nd by the Fondazione Europea per la Ricerca Biomedica (FERB), Coordinating Centre of the Project. The venue of the meeting was the Fondation Universitaire, rue d'Egmont 11 – 1000 Bruxelles.
The goal of the Conference was to evaluate the results of the RECage clinical trial (first phase of the Project) and to ask an International Panel to express an opinion on the object of the study, that is the Special Care Unit for patients with dementia and BPSD (SCUB).

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 779237

FERB FONDAZIONE EUROPEA RICERCA BIOMEDICA ONLUS

Recommendations

1. During acute phases SCU-Bs can tackle challenging clinical situations not easily amenable to solution at home

2. Significant role of SCU-Bs in the management of people with dementia and severe BPSD

3. Implementation of new SCU-Bs in countries which lack them completely or have only a few can be recommended, at least in experimental way. In any case, the SCU-B must be only a component of a comprehensive network of dementia care.

Recommendations

4. An international standard definition of this kind of units is lacking. There is great need to provide a definition flexible enough to comply with different healthcare systems

5. More research is recommended toward exploring alternative different crisis interventions, as well as towards the cost-effectiveness of SCU-Bs

6. The SCU-B can be regarded as socially innovative insofar as it satisfies a social need that is largely unmet; the unit provides patients and their families with strong crisis support from a skilled team and is a privileged place for the training of health workers and caregivers.

7. The SCU-B model received positive feedback from experts in the different countries. The lack of resources is the main barrier to implementing the model, therefore, a political commitment to putting the SCU-B into practice is essential.

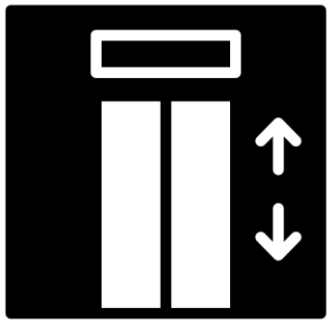
Recommendations - The main characteristics of SCU-B

- Person-centred approach of caring
- Focusing on the person's needs and preferences
- Surveillance and appropriate environments
- A flexible team approach
- Dialogue amongst staff members
- Respect for patients' needs and rights

Recommendations – The SCU-B structure

Architectural features

- **Dementia-friendly design** (provides both a prosthetic & safe environment)
- Markings at key points of the facility for disorientation avoidance
- Both virtual and in writing signs to find their room
- Utilization of capitals & lowercase letters
- Large, simple fonts along with recognizable symbols or images
- Existence of color contrast between the marking and the background
- Avoiding abstract / funny markups
- Automated lighting
- Reduce excess noise
- Safe flooring
- Dementia-friendly items



Architectural features

- Restrained access to and exit from the ward
- Enough room for walking (wandering) - a circular corridor
- Two beds per room (some rooms with single beds in case of agitated/hyperactive patients)
- Large seating area for patients / extra room for meeting with relatives
- Direct access to an outdoor area and indoor kitchen
- Direct access to occupational and physical therapy
- Access to gardens

Recommendations – The SCU-B structure

Architectural features

Exposure to **gardens** in the yard of SCU-Bs and gardening

- Multisensory stimulation and contact with nature
- Stimulation with color, smells, touch and sounds
- Promote feelings of calmness
- Reduce stress and lower blood pressure
- Relieve tension, frustration, aggression
- Reduce agitation, confusion and aggression

Recommendations – The SCU-B structure

Staff number / Nursing model

- Composition of the SCU-B's staff
- Multidisciplinary team

1) Physicians (geriatricians, neurologists, psychiatrists)
2) Nurses
3) Psychologists/neuropsychologists
4) Speech therapists
5) Physical and occupational therapists
6) Nutritionists
7) Social workers

Recommendations – The SCU-B structure

Staff number / Nursing model

- Person-centered approach to caring (dementia-informed system implemented by culture and specific training)

Employers have to be:

- Informed about the patients' preferences and aversions
- Educated to implement the aforementioned features into their interventions

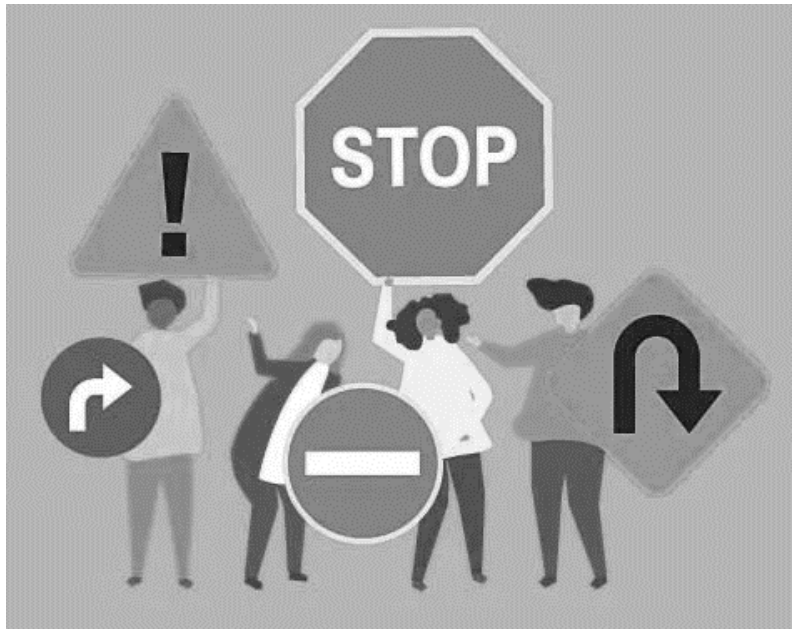
Receive specific training on:

- Dementia and BPSD
- Ethical and legal aspects, included those related to physical restraints
- Appropriate use of psychotropic drugs
- To be familiar with person-centred care
- To be familiar with evidence-based non-pharmacological interventions

"one size does not fit all"

Physical restraints

- To be reduced to a minimum and limited in time as a medical/nursing intervention in dementia
- Physical restraints only in exceptional situations of immediate danger for the person's health
- When and only whether all other measures of containment failed
- Physical containment should be done according to predefined procedures
- According to the guidelines, for the shortest time possible, after identifying a specific objective and with regular and close re-assessment



Conclusion

Disappointing results of the RCT because of bias and methodological issues (differences between healthcare systems-different cohorts etc.)

But

Other studies show that

SCU-B are a safe solution for behavioural difficulties

A solution that respects the Person's with dementia rights

Let's go on and talk about it!