Respectful Caring for the Agitated Elderly
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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

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Abstract

For the past 20 years, the behaviors of people who live with dementia (PLWD) that others find challenging or problematic have primarily been ascribed to Alzheimer disease and related dementias and have been assessed through the biomedical lens of Behavioral and Psychological Symptoms of Dementia (BPSD). This has led to the root causes of these behaviors being overlooked, which in turn leaves them unaddressed. Further, using the artificial construct of BPSD has led to many PLWD being inappropriately prescribed (off-label) medications that are largely ineffective in resolving the behaviors because they do nothing to remedy the underlying psychosocial and environmental causes. The fact that many of the behaviors we call BPSD are normal human responses to particular sets of circumstances can be relatively easily demonstrated by directly observing the individual behaviors of PWLID, and putting them in context, as well as by asking ourselves how we would respond under similar conditions. Re-evaluating the use of the construct of BPSD, and replacing it with a person-centered rather than disease-focused approach will result in better care as well as healthier and happier long-term care residents and staff.

Keywords:
Alzheimer disease
BPSD
behavior
antipsychotics
The major objective of REspectful Caring for AGitated Elderly (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.
What is a Special care unit for BPSD (SCU-B)?

Our definition is: “a residential medical structure lying outside of a nursing home, in a general hospital or elsewhere, e.g. in a private hospital, where patients with BPSD are temporarily admitted when their behavioural disturbances are not amenable to control at home. The mission of the SCU-B is to improve patient’s behaviour and its goal is to permit, when possible, her/his coming back home”
How does a SCU-B works?

The therapeutic approach in most of the existing SCU-B is a mix of:

Cautious pharmacological treatments
Rehabilitative and non-pharmacological therapies (occupational therapy, physiotherapy, doll therapy, pet therapy…)
Appropriate environment

**Availability of a staff** (composed of doctors, psychologists, educators, occupational therapists, physiotherapists, nurses and health care professionals) **expert and trained**

*In some existing SCU-B patients approach is in line with the Gentlecare of Moyra Jones or the Person-Centered Care (PCC) of Tom Kitwood.*
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First phase of RECAGE: An *observational comparative cohort study*, during three years, comparing two cohorts of patients with severe BPSD, the first one followed by memory clinics endowed with a SCU-B (Gazzaniga, Modena, Ottestad, Genève, Paris, Mannheim, Bruxelles), the other followed by centres lacking this facility (Thessaloniki, Mantova, Bergamo, Perugia, Berlin)

Second phase of RECAGE: *To adapt the model in accordance with the results of the cohort study*, not only regarding the main endpoints, but also comparing the experience and the different ways to work of the participating centres and the different socio-political context in which they act.

Third phase: scaling up the intervention
Diagnosis of dementia

- Alzheimer: 57%
- Vascular Dementia: 6%
- Lewy Body Dementia (LBD): 17%
- Parkinson-Dementia: 7%
- Frontotemporal Dementia: 5%
- Dementia due to multiple etiologies: 1%
- Dementia non otherwise specified: 1%

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MEAN (SD) NPI- TOTAL SCORE

SCU-B (N=268) 52.81
Non SCU-B (N=252) 51.45
ALL (N=520) 52.15

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Rationale, Design, and Methodology of a Prospective Cohort Study for Coping with Behavioral and Psychological Symptoms of Dementia: The RECarege Project

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The Special Care Unit for people with Dementia and BPSD (SCU- B) in the context of the RECage project: A qualitative study

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The Project is still going on, but there have been considerable delays and **difficulties due to the present pandemic**. COVID hindered regular “in presence” visits and compelled the memory clinics to do **only or mostly phone visits (294 as for June 2021)**, with consequent

- loss of data,
- withdrawals from the study and delays of the visits,
- deaths due to the pandemic itself

For these reason we decided to ask for an extension of six month of the project, that has been accepted. Therefore the project will last 66 months instead of 60, end date 30/06/2023.

At the end of the project a **Final Conference** will be organized, during which we will present the results of the project in order to produce a **consensus document** on a model SCU-B
Milestones!

- Starting date: 01/01/2018
- Duration: June 2023 (66 months)
- Completion of 100% recruitment: Sept. 2019
- Completion of 100% follow up: Sept 2022
- Data Analysis completed: December 2022

- **Closing Conference: 14-15 Feb 2023**
- Scaling up of new SCU-B: Feb 2023-Jun 2023

let's stay in touch! sara.fascendini@ferbonlus.com