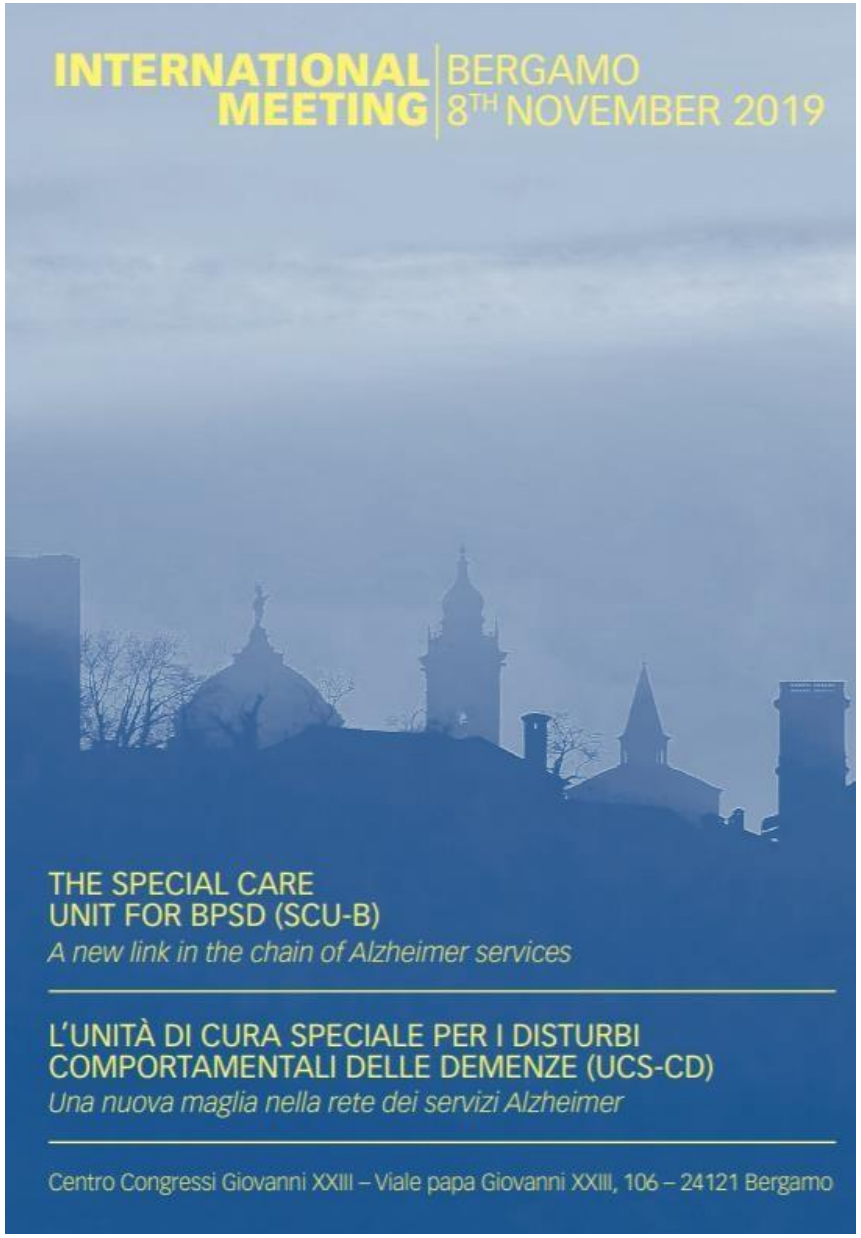

RECage

REspectful Caring for AGitated Elderly (RECAGE)

Focus Group in Greece

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Athens Alzheimer Association (AAADRD)

Greece

It is a non-profit organization founded in 2002 by carers of people with dementia (PwD) and health care professionals interested in Alzheimer's disease (AD). It aims at raising awareness of all forms of dementia and improving the quality of life of PwD and their families. Currently, it numbers 4.850 official members, has a staff of 56 health professionals and 53 active volunteers.

Activities

- 4 Day Care Centers providing psychosocial interventions for PwD in Athens
- 2 Home Care Services
- Memory clinics
- 43 Dementia Counseling Centers in collaboration with municipalities all over Greece
- Training, counselling and support services for carers
- Training of healthcare professionals
- Dementia screening and prevention programs in the community
- Research - European projects (FP7: LLM, Sociable Horizon: RECAGE, Erasmus+: GYMSEN, iDO, Dem@entoring, ERALYDEM, Super Lingo)
- Publication of newsletters, factsheets and booklets

www.alzheimerathens.gr

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World Alzheimer Month 2019

World Alzheimer Month 2019

National Observatory for Dementia & Alzheimer's Disease in Greece

It is an independent strategic public institution, authorised by law which:

- Engages doctors and other health professionals, lawyers, health economists, caregivers and other members with specific expertise.
- Ensures the implementation and subsequent updates of the National Action Plan.
- Promotes a permanent dialogue between the PwD organizations, the clinical and research community and the public authorities.
- Provides guidance for organizing the national policy in research and education.

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AAADRD in the RECAGE project
WP 5 Scaling up the intervention

Objective: promote the implementation of new SCU-Bs

- Advocating SCU-B implementation with policy-makers, ministries and other government officials, EU representatives, managers of the hospitals and other medical & care facilities, influential individuals, private and public institutions, academia, NGOs.

- Assessing the current normative context and the changes required to introduce the intervention into the Health and Social Care Systems. Factors promoting and hindering the intervention implementation, such as normative and organizational contexts, reimbursement systems, personnel needs, competences required, will be evaluated through surveys and semi-structured interviews.

REspectful Caring for AGitated Elderly (RECAGE)

The objective of **RE**spectful **C**aring for **AG**itated **E**lderly (RECAGE) is to adapt and upscale the implementation of interventions aimed at controlling Behavioral and Psychological Symptoms of Dementia (BPSD), **the special care units for persons with dementia and BPSD (SCU-B).**

It is 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.

http://www.recageproject.eu/

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Doll therapy

16th April 2018 - Gazzaniga, Italy

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Focus Group
October 16, 2019 – Athens, Greece

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Focus Group
October 16, 2019 – Athens, Greece

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Focus Group - Questions

1. **What are the key elements of a SCU-B, in your view?**

- The health care professionals working in the SCU-B and also the carers should be well trained in the recognition and management of BPSD.
- Person-Centred Dementia Care approach.
- Specialized training of all clinical staff is, of course, essential. Standardized assessment is needed to identify causes of agitation and other challenging behaviors.
- For the effectiveness of the project, the SCU-B should organize training programs for carers. The carers should also be well trained for providing psychosocial interventions at home, setting a care plan and managing crisis at home probably with the remote support of the SCU-B personnel.
- An other finding was that the SCU-B must set a mentor that will be in contact for the PwD and his/her carer.
- Follow-up and interface with other services i.e. Daily Day Care Centers

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Focus Group - Questions

2. **Does a SCU-B need a care philosophy, and, if yes, how is it implemented?**
   - SCU-B does need a care philosophy. Clear methodology and a sense of purpose for the unit must underlie all interventions. Dignity and human rights of the PwD is paramount. Care must be person-centered, and inclusive of family/carers with whom the PwD will eventually live.
   - Follow-up and networking with other services i.e. Daily Day Care Centers
   - Mobile Unit

3. **What are the risks and the benefits of a SCU-B?**
   - **Benefits:** The benefits of SCU-B are potentially great (Psychological, Social, Financial). It might facilitate the delivery of the highest possible quality of care and quality of life for all concerned. In addition, health care costs might be reduced due to fewer accidents, infections, need for medication, hospitalizations etc.
   - **Risks:** The risks for abuse of this vulnerable population are huge, especially if the person-centered is not universally embraced. In addition, setting exclusion and inclusion criteria for the successful return home of PwD, the perspective of the placement in a Long-term care setting should also be considered.

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Focus Group - Questions

4. **Could the change of environment worsen the cognitive state of the PwD?**
   - Taking under consideration the impact of BPSD to PWD they will already experience cognitive decline and fluctuations in their cognitive status.
   - The change of environment could worsen the cognitive state of PwD. All changes increases uncertainty and anxiety, but especially so for those with impaired cognition. For this reason, it is essential that the SCU-B is well planned and operated, with appropriate physical design and well-trained and appropriately disposed personnel. They should, ideally, be well trained, respect and appreciate the importance of their work.

5. **What about the use of restraints?**
   - Physical restraints should not be used. They are an assault on human dignity. Chemical restraints, pharmaceuticals, might extremely rarely be needed for an emergency situation.
   - The Focus group concluded that the use of restraints should follow a clear and strict protocol, including a review of what initiated the need, other interventions tried, responses to those interventions, people involved, what chemical restraint was used, in what dose, and the response of the PwD.

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Focus Group - Questions

6. **What about PwD consent?**
   - It is necessary to have PwD consent from mild to moderate stages or the consent of the legal representative.
   - The project should focus on the engagement and the empowerment of PwD.
   - A panel of experienced health care professionals should deal with reviewing difficult situations and making decisions.

6. **When, and why, to admit PwD to a SCU-B? Discuss the criteria for admission/exclusion.**
   - BPSD and crisis management
   - Reducing the burden of carers

   Inclusion Criteria
   - Dementia diagnosis
   - Referral from a treating physician

   Exclusion criteria
   - Mentioned psychiatric disorders from the medical history

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Focus Group - Questions

8. **How and by whom are PwD referred to a SCU-B?**
   - Family doctor - treating physician
   - Formal/informal carers
   - Social care professionals (nurses, social workers, nurse aids) in elderly care units.
   - Even the PwD might, hypothetically, at an early stage, self refer

9. **Who decides about admission/discharge?**
   - The multidisciplinary team of the SCU-B will decide the admission or discharge of the PwD, after complete assessment.
   - PwD and carers should be encouraged to participate in the procedures.

10. **How is the discharge prepared?**
    - Appropriate environment on discharge is essential for a successful intervention.
    - Ideally, behavior of PwD will be stabilized and carers competent to deliver appropriate care.

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Focus Group - Questions

11. **What would you think of an admission to the SCU-B of a PwD/family member of yours?**
    - The focus group was very positive for the possibility of admitting a PwD in a specialised unit for the management of BPSD.
    - Specialised mobile unit for transporting the PwD from their home to the SCU-B.

12. **Does the admission to a SCU-B entail a social stigma?**
    - Stigma is a huge issue for the diagnosis of dementia and impacts many, PwD, their carers, even health care professionals.
    - The Focus group believe that the admission to an excellent SCU-B would, in general, be a secondary stigma. The support given should include addressing stigma. If the SCU-B is not well run, then there would be additional negative stigma.
    - The key is to have high standards of function & quality.

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Focus Group - Questions

13. **How do you see the role of the SCU-B in the general dementia network?**
    - SCU-Bs are a very positive hypothetical component of the dementia network. Behavioral issues are presently dealt with on an ad hoc basis, with very mixed results.
    - A standardized approach, including extensive assessment, would enhance quality of life for PwD who have challenging behaviors and for their carers who need support.

14. **Is delay in admission to a NH a valuable goal?**
    - From a financial perspective, care at home is less expensive both for the insurance systems & the families. **Cost-effectiveness** analysis
    - It depends on the quality of care delivered either at home or in a Nursing Home.

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Focus Group - Questions

15. **Is staff training periodical refreshed and how?**
    - Staff training must be ongoing.
    - In addition, the personnel of the SCU-Bs must feel that their work is important and appreciated.
    - A key element to these direction is Mentoring.

16. **What about staff burn out?**
    - Staff burn out occurs when the personnel is not stimulated or feel they are not valued.
    - Stigma of dementia and mental illness and its impact on personnel need to be actively addressed.
    - Work 4 days/week, more breaks, e.tc.

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Dementia Alliance International

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Thank you for your attention!