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Building bridges
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A parallel qualitative study of The RECage Project

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The RECage Clinical Trial is a multicentric, multicountry study, carried out in existent SCU-Bs with some common features, but with not little differences and, above all, embedded in different healthcare systems and social context.

The RECage project involved eleven memory clinics and SCU-B in six European countries: Italy, Switzerland, Norway, France, Germany, and Greece.

These countries have health and Long Term Care (LTC) systems differently organized. All health systems are funded on universality, solidarity, and equity. The differences between them reside, above all, in how the different services are financed and operated.

The RECage project proposes a transversal analysis of experiences coming from three different care regimes: familistic care regime (Greece and Italy), mixed care regimes (Germany, Switzerland), and universal Nordic care regime (Norway).

While actively enrolling and following the patients, we realized that the future results of the study would not be correctly interpreted without a concomitant qualitative study exploring the different centers' social contexts.

This study aims to explore the SCU-B units to describe their main characteristics related to different implementation contexts and to identify the characteristics of his replicability.

Moreover, the qualitative investigation wants to examine the elements of the social innovation promoted by SCU-B.

The results presented in this work emerge from a qualitative study conducted from 2019 to 2021

Article

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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in press

Local research teams are responsible for conducting the qualitative study in their country, supported by methods experts.

The research work is composed of two steps:

a) redaction of country form
b) realization of qualitative study by interviews and Focus groups.

All participating centers filled out a detailed form on each country's socio-political context and regulatory framework to clarify the LTC and health context in the countries involved.

The contextual data module also collects the technical requirements of the SCU-B if it is operating. This form was mailed to the principal investigator of each center, who produced a written response.

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The main topics discussed in the FGs or the Interviews are:

- To highlight strengths, weaknesses, opportunities, and threats of the SCU-B (SWOT analysis);
- To identify the social innovations (SI) promoted by the SCU-B;
- To identify the scaling up characteristics of the SCU-Bs.

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The total number of participants in the FGs varied from 5 to 12 in each group section. In eight of them, "external" stakeholders were involved. The total number of FGs performed was eighteen involving altogether 140 participants. The number of expert and stakeholders' interviews (either in the presence or by phone) was about 250.

Target	Profiles
Internal professionals	Physicians (neurologists and geriatricians); Psychologists; Neurophysiologists; Nurses; Rehab technicians; Educators and occupational therapist
Local stakeholders	Social and health authorities; NG0s (e.g., Alzheimer Association, family support associations); Private care providers; Informal caregivers of relatives with Dementia

Characteristic	Description
Ward special unit	A specialized ward for the treatment of BPSD that houses the SCU-B, independent from the other wards
Informal caregivers support group (ICSG)	Support groups offer a space for caregivers to share their experiences. Such interaction can provide emotional support, allow better stress management, and reduce a sense of frustration and isolation in caregivers. The support groups are usually facilitated by professionals, though some peer-led groups exist.
Follow up (every six months)	Regular and scheduled check-ups for clinical and pharmacological re-evaluation
Managing case at home after discharge	Contact and support caregivers, also by phone, to help them manage the return home and the BPSD with environmental interventions.
Personalized care	Identify the most appropriate and effective treatments based on the characteristics of the patients and their disease.
Psycho-social therapy (Kitwood)	Psycho-social interventions refer to different therapeutic techniques, usually classified as non-pharmacological

Characteristic	Description
Rehabilitation therapy	Physiotherapy, speech therapy, occupational therapy
Multidisciplinary team (MDT)	A group of health care workers and social care professionals who are experts in different areas with different professional backgrounds, united as a team for the purpose of planning and implementing treatment programs for complex medical conditions.
Active Local network	The different health services in the area are in contact and collaborate for the shared care of the patient and caregivers.

Strengths	Weaknesses
. Well-trained, expertise, multidisciplinary team . Continuous education of the staff . Person-centered approach . Goal-oriented treatment philosophy . Psychosocial intervention . Possibility to optimize medical treatment . Dementia care network . No restraint policy	. Not integrated dementia care network . private healthcare structures . Lack of resources . Lack of ward space . No follow-up visits after discharge . Too high concentration of patients with solid needs
Opportunities	**Threats**
. Presence of Dementia-Friendly Communities . Possible admission directly from the emergency rooms . Good cooperation with outpatient services and nursing homes . Involvement of the caregiver during the stay and the preparation for discharge . Continuous training of the staff, debriefing sessions . Presence of many specialized services potentially available to the new collaboration	. Social stigma due to hospitalization in an Alzheimer's ward and ageism . Stigma related to mental health facilities . Organizational difficulties within the hospital structure and in the cooperation with other hospitals . Stressful job, the need for workers turnover . Service is not known enough to families/caregivers and stakeholders . Unrealistic family expectations

Table 4. Replicability of SCU-B's elements

Elements	Level and agreement %
Ward special unit	High 100%
Informal caregivers support group (ICSG)	High 75% - low 25%
Follow up (every six months)	High 75% - low 25%
Managing case at home after discharge (also by phone)	High 75% - low 25%
Personalized care	High 50% - low 50%
Psycho-social therapy (Kitwood)	High 25% - Medium 75%
Rehabilitation therapy	High 25% - Medium 75%
Open Multidisciplinary team	High 25% - low 75%
Active Local network	Low 75% - Medium25% - High 25%
All system	Low 75% - Medium 25%

"I think the old way of thinking about being old still exists. You are placed in an institution when you do not manage things at home. You are not worth anything anymore. You should just be kept safe and you are done with your life." (FG, O)

"The fragments of care pathways and global taking in charge of the person and caregivers also contribute to the stereotype that considers residential structures for the elderly as a last resort" (FG, P)

"SCU-Bs could play an important role in the dementia care network, as they seem to be a missing part of the puzzle.

"it is essential that caregivers become an integral part of the therapeutic process. It's impossible not to include them because at the discharge; they will be caregivers, spouses of, child of, etc. (FG, GE)

"Stigma of Dementia and mental illness and its impact on staff need to be actively Addressed" (FG, A)

"We understand that it can be difficult, but at the same time we have to suggest the ideal. We cannot say, OK and reduce what we mean the patient should have" (FG, O)