Results of the parallel qualitative study

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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

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Background

- Dementia is a priority for global public health.
- The management of BPSD needs new approaches
- These symptoms cause severe stress and can lead to early institutionalization
- Drug treatment appears to reduce the burden of caregivers

- World Health Organization. (2021). Global status report on the public health response to dementia. World Health Organization
- Bessey LJ, Walaszek A. (2019) Management of Behavioral and Psychological Symptoms of Dementia. Curr Psychiatry Rep.
- Gagliardi, C. (2022). The Burden of Caring for Dependent Older People and the Resultant Risk of Depression in Family Primary Caregivers in Italy. Sustainability.
- Kales HC. (2014). Management of neuropsychiatric symptoms of dementia in clinical settings: recommendations from a multidisciplinary expert panel.
- Schoenmakers B. (2009). Can pharmacological treatment of behavioural disturbances in elderly patients with dementia lower the burden of their family caregiver?.

Background

- Atypical antipsychotics in older adults → Side effect
- The American Psychiatric Association recommend reasonable use
- Multi-strategic psychosocial interventions reduce agitation and neuropsychiatric symptoms for PwD

- Rongen, S. (2016). Potentially inappropriate prescribing in older patients admitted to psychiatric hospital: Prescribing in older patients with psychiatric illness. Int. J. Geriatr. Psychiatry
- Livingston, G. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet
- Mühlbauer, V. (2021). Antipsychotics for Agitation and Psychosis in People with Alzheimer's Disease and Vascular Dementia; Cochrane Dementia and Cognitive Improvement Group.

In this scenario…

The SCU-B represents a new approach for addressing a growing population of people with dementia.

- The RECage project has been contributing to research on psychosocial interventions since 2019.
- The RECage project involved eleven clinical centers with memory clinics and SCU-B facilities in seven European countries. Health and long-term care (LTC) systems are organized differently in these countries.
- This study proposes a transversal analysis of experiences from different care regimes

… The evidence on the different social contexts of the centers is useful to interpret the results of the RECage Trial …

Aim of the study

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.

Methods

- The qualitative study was conducted in eleven clinical centers:

Gazzaniga (Italy)
Modena (Italy)
Geneva (Switzerland)
Ottestad (Norway)
Mannheim (Germany)

→ SCU-B

Bergamo (Italy)
Mantova (Italy)
Perugia (Italy)
Berlin (Germany)
Athens and Thessaloniki (Greece)

→ No SCU-B

- Redaction of a country form (survey), focus groups and expert interviews

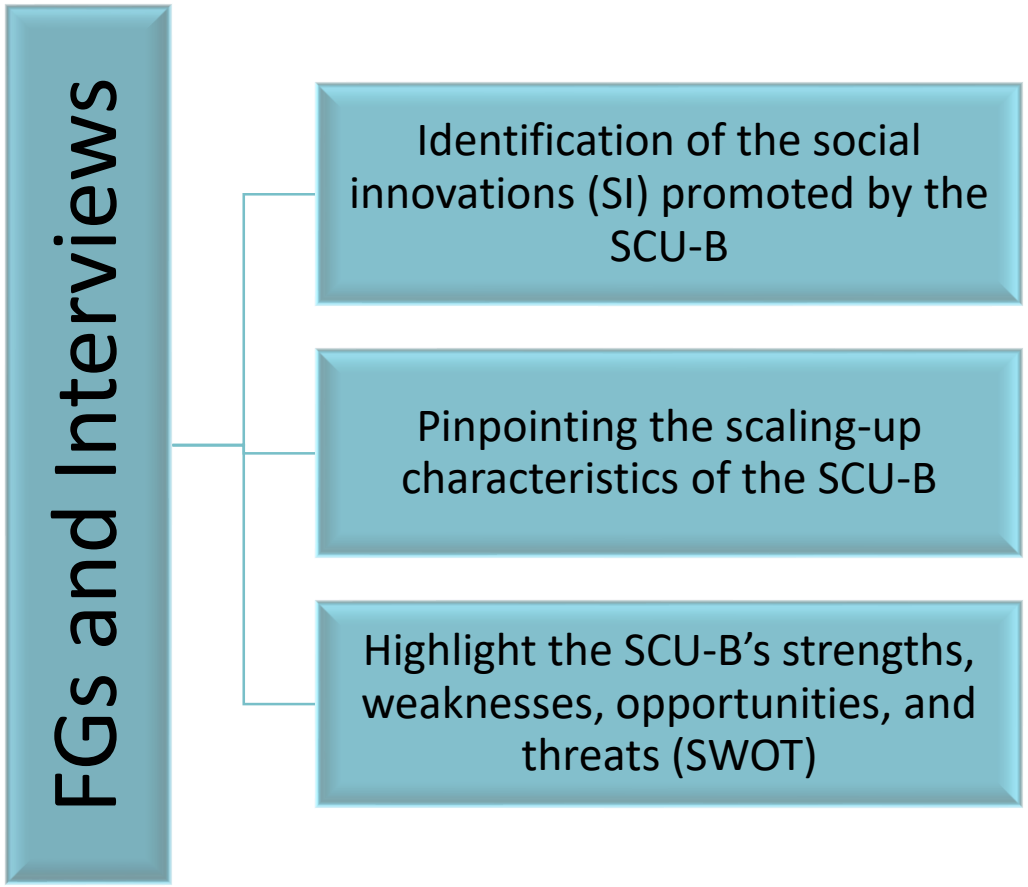
- Comparative qualitative approach based on content analysis and SWOT analysis

Redaction of Country Form

All participating centers filled out a detailed survey concerning each country's sociopolitical context and regulatory framework in order to clarify the long term care (LTC) and health contexts in the countries involved.

The contextual data module also gathered the SCU-B's technical requirements. This form was mailed to each center's principal investigator, who then provided a written response.

The Qualitative Study's Implementation



Participants

Table 1. Targets and profiles included in the sample.

Target	Profiles
Internal professionals	Physicians (neurologists and geriatricians); psychologists; neurophysiologists; nurses; rehab technicians; educators and occupational therapists.
Local stakeholders	Social and health authorities; non-governmental organizations (for example, the Alzheimer's Association and family support associations); private care providers; informal caregivers of relatives with dementia.

FGs and interviews were conducted by the centers from 2019 to 2021.

Table 2. Number of focus groups in each center and number of participants involved.

	Interview	No. Focus Groups	Tot. No. Participants
Gazzaniga (Italy)	3	2	22
Berlin (Germany)		1	5
Geneva (Switzerland)		1	5
Ottestad (Norway)		3	17
Mannheim (Germany)	9	2	26
Mantova (Italy)	4	2	18
Perugia (Italy)	1	1	12
Modena (Italy)	2	4	27
Bergamo (Italy)	3	1	11
Athens (Greece)		1	11
Thessaloniki (Greece)		1	10
Total	22	18	164

Data Analysis

- The interviews and focus group discussions were recorded and transcribed verbatim.
- The reports from each center were translated in English.
- National reports were subjected to a content analysis by the authors, who also post-categorized the data.
- Participants' comments were listed using abbreviations linked to their regions *(G—Gazzaniga; Ma—Mantova; Ge—Geneva; O—Ottestad; M—Mannheim; Be—Berlin; Mo—Modena; B—Bergamo; P—Perugia; A—Athens; T—Thessaloniki)* and the user data collection channel *(FG = Focus Group; I = Interview)*

The LTC Context and Specialized Services: Results from Context Forms

Three main themes potentially influencing the implementation of the SCU-B

LTC Strategy:

- General practitioners as the focal point of the evaluation and care path.
- in Germany, social care for people with dementia is graduated by the level of dementia and is specifically designed to cover the related care need.
- Dementia care in central and Nordic countries is managed as a social issue and local institutions provide support services for families and caregiver.

Residential care:

- Is a crucial component of the dementia care system in all countries.
- In Norway, the full public funding of the cost of residential care results in a high percentage of persons with BPSD entering a nursing home.
- In other countries, families must contribute at least in part to cover the overall cost (Greece).

Memory Clinic:

- Are widespread across the countries.
- It grants diagnostic assessment, pharmacological treatment, and follow-up.
- According to the general rules of cost cover in these countries, access to these clinics may be free or may require co-payment (depending on income and age).

Results: Technical Requirements for a Model SCU-B

Table 3. Summary of how these SCU-Bs are set up.

Country	Location	SCU-Bs	N° of Beds	Staff
Gazzaniga (Italy): Center of Excellence for Alzheimer's Disease	In a general public hospital run by a private foundation	2	23 beds each	Geriatricians, neurologists, and psychologists
Modena (Italy): Hospital Unit dementias with High-Intensity Care (NODAIA)	Private hospital	1	25 beds	Geriatricians, neurologists, psychologists, nurses, occupational therapists, and social workers
Geneva (Switzerland): SOMAtic DEMentia unit (SOMADEM)	Specialized geriatric hospital	1	18 beds	Physicians, nurses, psychologists, neuropsychologists, speech therapists, physical and occupational therapists, nutritionists, and social workers
Ottestad (Norway): The Research center for Age-related Functional Decline and Disease	Psychiatric hospital	1	5 beds	Psychiatrist and psychologist
Mannheim (Germany): The Central Institute for Mental Health (CIMH)	Psychiatric hospital with a geropsychiatric department	1	24/22 beds	Multi-professional team

Several features are common to all descriptions…

Results: Technical Requirements for a Model SCU-B

Homelike environment:

Architectural features, such as a dementia-friendly design, are necessary to create a safe environment

Composition of the staff:

The team should be multidisciplinary

Personalized care approach:

“one size does not fit all” is especially true in the case of an SCU-B because the more tailored an intervention is, the more effective it becomes

Physical restraint policy:

The physical restraints should generally be reduced to a minimum. The SCU-B is a place where staff can explore alternative solutions for the safety of the patient.

Pharmacological therapy policy:

The approach involves a mix of psychosocial interventions and drug therapies, favoring the first.

Results: Technical Requirements for a Model SCU-B

The analysis of the technical requirements of the SCU-B experiences made it possible to identify the elements that characterize the SCU-B model.

Table 4. Elements characterizing the SCU-B.

Characteristic	Description
Ward special unit	A specialized ward for the treatment of BPSD that also houses the SCU-B independently of the other wards.
Informal caregivers support group (ICSG)	Caregivers are provided the opportunity to share their experiences in support groups. This interaction helps caregivers feel less isolated and frustrated while also providing emotional support and better stress management. Although some peer-led groups do exist, support groups are usually led by professionals.
Follow-up (every six months)	Regular and scheduled check-ups for clinical and pharmacological re-evaluation
Managing cases at home after discharge	Contact and support are provided to caregivers over the phone to help them manage the return home and the BPSD by means of environmental interventions.

Results: Technical Requirements for a Model SCU-B

Table 4. *Cont.*

Characteristic	Description
Personalized care	The most appropriate and effective treatments are identified based on the characteristics of the patients and their medical conditions.
Psychosocial therapy	Psychosocial interventions refer to different therapeutic techniques, usually classified as non-pharmacological
Rehabilitation therapy	Physiotherapy, speech therapy, and occupational therapy
Multidisciplinary team (MDT)	A group of healthcare workers and social care professionals, who are experts indifferent areas and have different professional backgrounds, are 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 maintain contact and collaborate for the shared care of the patient and caregivers.

Results: SWOT Analysis for the SCU-B

Table 5. SWOT Matrix.

Strengths	Weaknesses
Well-trained, skilled, multidisciplinary team Continuous staff education Person-centered approach Goal-oriented treatment philosophy Psychosocial interventions Possibility to optimize medical treatment Dementia care network No restraint policy	Non-integrated dementia care network Private healthcare structures Lack of resources Lack of ward space No follow-up visits after discharge Concentration of patients with solid needs is too high
Opportunities	**Threats**
Presence of dementia-friendly communities Possibility of admission directly from the emergency rooms Good cooperation with outpatient services and nursing homes Involvement of the caregiver during the stay and preparation for discharge Continuous training of staff and debriefing sessions Presence of several specialized services that may be used by 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 leading to employee turnover Families/caregivers and stakeholders are not sufficiently aware of the service Unrealistic family expectations

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Strenghts

- The person-centered approach and personalized style of care are seen to be part of the unit's culture

"We were considering how to better respond to challenging symptoms when we came across the Kitwood approach, and we decided to try it out" (I, G).

- The service's mission is defined by the ability to respond promptly and flexibly to highly critical situations, avoiding improper hospital admissions.

- High pharmacological competence permits drug wash-outs to put an essential drug therapy in place that is better suited to patients' needs.

"Offers the possibility of optimizing medical treatment and medication under close surveillance, communicating with caregivers to find common treatment goals, and transferring knowledge and ideas for the period following discharge" (FG, M)

- The involvement families is another significant strength of the SCU-B. Families are welcomed in the ward and are invited to participate in activities to acquire strategies suitable for managing the patient at home.

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Weaknesses

➢ There is a common concern about the suitability of the SCU-B's environment.

"The ward space is similar to a standard hospital ward unit, and certain areas are not suited for supporting psychosocial protocols (. . .), e.g., the doors or the room area, the bed (. . .); many aspects of the ward are similar to those in other hospitals" (FG, G).

"Mirroring behaviors can be another risk (. . .). The patient may be confronted with other very agitated patients or patients with advanced dementia; that kind of situation can be morally difficult for the patient" (FG, GE).

➢ Some units concern about the facility's isolation, both geographically and in relation to the network of local services. Some units, complained about the lack of resources and the non-optimal ratio between the number of healthcare professionals and beds.

➢ Is common the difficulty of providing follow-up visits after discharge, including by telephone, the brevity of the hospitalization period observed by the Geneva center, and the length of the waiting lists for admission found in Gazzaniga.

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Opportunities

- The majority of experts expressed hope for a higher level of involvement from general practitioners, both in the pre-admission phase to improve family and patient compliance during the stay and just before discharge to get the home ready for the patient's return.

"As soon as the patient is hospitalized, it is important to prepare for discharge by thoroughly understanding both the patient's and caregiver's circumstances at home. The caregiver must be contacted for this purpose within 24 h of admission" (FG, GE).

- Psychological support to caregivers improve personal, relational, and environmental dynamics that prevent the onset of BPSD. In addition, these activities ensure that the benefits of hospitalization in the SCU-B are maintained after returning home.

"It is essential that caregivers become an integral part of the therapeutic process. It is impossible not to include them because, once the patient is discharged, they will be the caregivers, the spouses, the children, etc." (FG, GE).

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Threats

Sometimes the families have unrealistic expectation on treatments.

Another significant threat that was discussed is the high staff turnover. Which reduces the time required to ensure that new team members get the supervision and training they need for their work.

"We sometimes need to respond to a string of emails about pharmacological therapy to alleviate a patient's situation. However, this approach is not structured; it is based on the individual's goodwill" (FG, B).

An important social threat is a stigma associated with residential facilities for the elderly, which are considered to be a "last option"…

"The fragmentary care pathways (..) also contribute to the stereotype that considers residential structures for the elderly as a last resort" (FG, P).

"The stigma surrounding dementia and mental illness and its impact on staff need to be actively addressed" (FG,A).

Potential of the SCU-B's Social Innovation

The European Commission defined SI in 2013: *"any new idea—including products, services, and models—that simultaneously meet social needs—more effectively than alternatives—and creates new social relationships or collaborations, i.e., it is both good for society and enhances society's capacity to act"*

The recent literature applied the SI concept to LTC

The SCU-B can be regarded as socially innovative insofar as:

- It satisfies a social need that is largely unmet in participating countries
- The unit provides patients and their families with strong crisis support from a skilled team
- The SCU-B is also a privileged place for the training of caregivers
- There is also a potential to share and expand knowledge about the disease

- *European Commission. (2013) Social Innovation Research in the European Union: Approaches, Findings and Future Directions: Policy Review; Publications Office of the EU: Luxembourg.*

The SCU-B's Replicability

The SCU-B's replicability was discussed during the data collection process in four Italian centers (Gazzaniga, Mantova, Bergamo, and Perugia) and the German center (Mannheim).

Table 6. Replicability of an 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 cases at home after discharge (by phone)	High 75%–low 25%
Personalized care	High 50%–low 50%
Psychosocial therapy (Kitwood)	High 25%–Medium 75%
Rehabilitation therapy	High 25%–Medium 75%
Open multidisciplinary team	High 25%–low 75%
Active local network	Low 75%–Medium 25%–High 25%
All systems	Low 75%–Medium 25%

The SCU-B's Replicability

In general, the SCU-B model received positive feedback from experts in the different centers, but doubts emerge about the replicability of the complete SCU-B system in other regions.

The lack of resources is the main barrier to implementing the ward unit or complete system, which is deemed to have "low replicability".

Therefore, a financial commitment to putting the SCU-B into practice is essential.

Discussion

The SCU-B represents a new approach

It promotes social innovation in the long term care sector

It promotes a personalized care strategy and prioritizes the dignity of the patient and caregiver

It offers an alternative solution to permanent institutionalization as a result of BPSD

However

Low investments in the LTC and health sectors for specialized residential units in Mediterranean countries would impede an SCU-B implementation in that territories.

The lack of resources is the main barrier to implementing the SCU-Bs.

The SCU-B model's high level of complexity reduces its capacity to be replicated as a whole.

Conclusions

- The specific characteristics of the LTC systems in the countries involved and the organization of specialized units are the determinants of success for the SCU-B model

At the same time

- The improvement of existing units through single support services (e.g., informal caregivers support groups or periodic follow-ups) or internal organizational changes (multidisciplinary teams) is seen to be applicable.

Indeed

The qualitative study's results advocate the gradual implementation of SCU-B.

Thank You!

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