Research article

Severe behavioral and psychological symptoms of dementia: A clinical ethics study of cognitive-behavioral units in France

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Abstract

Background: In the last 20 years, cognitive-behavioral units (CBUs) have been opened in various countries to provide care for patients with Alzheimer's disease and related dementias who experience severe behavioral and psychological symptoms of dementia (BPSD).

Objective: This study examines the perspectives of relatives and healthcare professionals caring for patients in three CBUs in France and highlights key issues in clinical ethics.

Methods: Using the commitment model (a qualitative methodology in clinical ethics), we conducted 154 semi-structured interviews between March 2019 and March 2020, which were subsequently analyzed thematically. The study focused on three CBUs: one in a public hospital and another in a private hospital in the Paris region, and one in a public hospital in the Hauts-de-France region. We interviewed 62 individuals, including 25 relatives and 37 healthcare professionals. Some of the professionals were interviewed several times about their experience with the 30 patients included in the study (18 men and 12 women, average age 79 years).

Results: Three key themes emerged from the interviews: 1) general appreciation for the relational approach adopted in the CBUs, 2) concerns regarding the limitations of care, and 3) distress regarding restrictions to patients' personal freedom.

Conclusions: CBUs are a promising and welcome initiatives but would benefit from a reconsideration of cultural approaches to care for older people with BPSD. End-of-life care, interprofessional collaboration and respect for autonomy need to be more thoroughly discussed. In doing so, CBUs could act as catalysts for public debate on the accommodation of people with BPSD.

Keywords

Alzheimer's disease, behavioral and psychological symptoms of dementia, ethics

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Introduction

People with Alzheimer's disease often experience behavioral and psychological symptoms of dementia (BPSD) which include agitation, irritability, aggression, unusual motor activity, disinhibition, and hallucinations.[1,2] Such symptoms pose a challenge for patients, their families and healthcare professionals, as they may vary in form and severity and can be disturbing, disruptive and even dangerous for both the patients themselves and people living with them.

In the last 20 years, specialized care units for people with Alzheimer's disease and severe BPSD have been introduced in several countries, including France, Norway,

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Switzerland, Germany, and Italy.[3] The units can vary widely in their approaches and facilities across Europe. France has a widespread network of such units, known as *unités cognitivo-comportementales* (cognitive-behavioral units, CBUs), set up as part of the National Plan for the Care of Patients with Alzheimer's and Neurodegenerative Diseases introduced in 2008 (National Solidarity Fund for Autonomy CNSA, 2008–2012).[4] Specific requirements are established for CBUs in terms of referral criteria, the type of care provided, architectural and material standards, and human resources, with the aim of providing a conducive environment and an optimal patient-to-staff ratio.

CBUs are integrated into the so-called "follow-up care and rehabilitation" services (SSR from the French *soins de suite et de réadaptation*) and are part of the care continuum in France, sitting between acute/short-term hospital care and the patient's return to full autonomy, whenever possible (at home or in other environments). The aim is to help the patients return to a way of life as similar as possible to what they had prior to their illness.[5] Referral to SSR or a CBU is generally by a hospital physician following the acute phase, although it might be made by a general practitioner if the patient is seen at home or in another care institution. While some geriatric SSR centers may receive similar patients, CBUs are specialized units for rehabilitation targeted at patients whose BPSD makes it impossible for them to remain in their own homes or usual dwelling, such as a nursing home.

Along with the standard staff of the SSR unit, CBUs also require care and support specialists (such as physicians with experience or training in cognitive behavioral rehabilitation; psychologists; rehabilitation professionals such as psychomotor and occupational therapists; and paramedical staff. As the qualification of gerontology assistant has not yet been established, this role may be performed by a medical-psychological assistant or nursing assistant who has received appropriate training). CBUs also require architectural and material considerations. They need to be in or next to the department to which they belong. The technical equipment used in rehabilitation for activities of daily living should be adapted to the therapeutic activities and cognitive rehabilitation facilities. Patients should also be provided with specialized technical examinations and rehabilitations programs, single rooms, a walking area, a safe and reassuring environment, and a common area for social interaction and activities. There is currently no regulation on whether admission to CBUs requires consent. French legislation on involuntary hospitalization only applies to psychiatric patients and does not include people with cognitive disorders, even if they have psychiatric symptoms.

The average length of stay in CBUs is four weeks, the primary goal being to alleviate the BPSD by reducing psychotropic drugs use while fostering social interaction and cognitive stimulation.[5] CBUs provide an innovative approach to the care of BPSD patients through personalized cognitive and behavioral rehabilitation programs based on medico-psycho-social assessments.[6,7] They are intended to be a temporary solution, helping patients to return to their home environment or, if not possible, assisting both patients and families to transition to long-term care settings, such as nursing homes or other specialized hospital units.

Previous research on CBUs has evaluated their effectiveness in improving patients' clinical symptoms and quality of life and their success in achieving the CBU objectives (such as enabling patients to return home or reducing psychotropic drug use).[3,8–11] While most studies have reported encouraging results, they do not address the specific ethical issues raised by CBUs. Although these institutions are not exempt from the ethical challenges in Alzheimer's disease care (such as promoting relational expressions, supporting and assessing decision-making capacity, and preventing harm[12–15]), they also face the additional challenge of managing crises associated with severe BPSD and adopting *ad-hoc* interdisciplinary approaches for patients. Over the years, the Clinical Ethics Center (Cec) of the Greater Paris University Hospitals has conducted various clinical ethics consultations in CBUs, highlighting the need for more thorough research into the specific ethical challenges they face. While the consultations were primarily concerned with professionals' ethical issues regarding administering deep and continuous sedation until death, this paper aims to provide an in-depth examination of how both relatives and healthcare professionals experience the patient care in the CBUs, with particular emphasis on the various ethical challenges arising from their perspectives and first-hand experience.

Methods

This study examines the perspectives of relatives and healthcare professionals involved in the care of 30 patients in three different CBUs. The research protocol was submitted to the research ethics committee of the University of Paris Cité and received approval before fieldwork began (approval number: 2018–102). As this is a clinical ethics study, a qualitative design was adopted, as this allows for a thorough exploration of arguments, values, and experiences that cannot be adequately achieved through quantitative approaches. Ethical challenges in care are often complex, context-dependent, and intertwined with personal and cultural perspectives. A qualitative methodology permits in-depth analysis of these dimensions and provides a better understanding of how they are articulated by the actors involved.

From among the various methods proposed in clinical ethics research in different countries, we selected the commitment model, which was developed in the Cec.[16–18] We consider this model to be particularly appropriate for our study as it reflects our understanding of ethics as patient-oriented, dialogue-based, and relevant to practice. The

model is grounded in collegial, multidisciplinary deliberation, and ensures that a variety of perspectives are included in the analysis. It uses an ethical grid as a theoretical framework for building the guide for the interviews, which helps structure the inquiry around key ethical principles while leaving room for the participants' own reasoning to emerge. Furthermore, the model explicitly aims to associate empirical findings with the broader public debate, thereby ensuring that the insights obtained are not only academically rigorous but also socially and ethically meaningful.[17]

The commitment model draws on established traditions in bioethics and clinical ethics. It is informed primarily by principlism,[19] which provides a structured yet flexible framework for considering values such as autonomy, beneficence, non-maleficence, and justice, and by casuistry,[20] which highlights the importance of concrete cases and practical reasoning. Taken together, these traditions enable the inclusive adoption of principles and their analysis on a case-by-case basis, without assuming a predetermined meaning.

To carry out the fieldwork in line with the committed model, the interviews were always conducted in pairs, by a physician and a non-physician (a psychologist or an occupational therapist specializing in psychiatry, a psychiatrist, or a philosopher), depending on Cec staff availability at the time of the interview. All the Cec researchers had at least two year's training in clinical ethics. One CBU had previously requested clinical ethics consultations from the Cec, after their healthcare professionals contacted the Cec regarding ethical issues around the care of elderly patients with behavioral disorders and what they considered to be persistent suffering. The team was concerned about issues related to the legitimacy of administering deep continuous sedation until death, even though their condition was not immediately life-threatening. The other two CBUs were selected to ensure diversity among the types of institutions included in the study. One unit was located in a public hospital and another in a private hospital in the Paris region, and the third in a public hospital in the Hauts-de-France region. The units were comparable because they met the specifications for designation as a CBU, as established by the French Government,[5] such as having between 10 and 12 beds. The only notable difference between them was that two had an outdoor garden while one did not.

The healthcare professionals were recruited by presenting the study objectives and methods in meetings with the unit personnel and discussing the informed consent forms and participation options with those who expressed an interest. To recruit relatives, we asked professionals to contact those of the last two patients admitted to the unit each month and included those whose cases involved specific ethical concerns. The relatives were informed of the study by the referring physician in the CBU and the Cec physician then phoned those interested in participating to explain the study and sent them a letter providing information. Consent was signed during the in-person appointment after reviewing the information on the study. From March 2019 to March 2020, we conducted semi-structured interviews to identify themes that were relevant to the participants. The interviews were conducted in the wards, in a quiet room, along with the patient and/or their relative. The interviewers had no previous relationship with the families and had only had previous contact with CBU staff who had requested an ethics consultation from the Cec. Each interview lasted approximately one hour and was not recorded.

Clinical ethics interviews are primarily used to understand individuals' positions on ethical matters. Verbatim transcripts are only used to help go over the exact wording used, but they do not reproduce the situation, the tone in which participants express or other non-linguistic factors. In line with the commitment model, we believe that verbatim transcriptions are insufficient for truly understanding a person's ethical position. It is the interview as a whole, as human interaction, that provides us with better understanding. To ensure that the interpretation work was not biased by a single individual perspective, two researchers with different backgrounds participated and carefully took notes during the interviews. These were then reviewed by the two Cec researchers in the days following the interview. As established by the commitment model, the results were also presented orally to the interviewees in an open session to initiate a dialogue with them about the findings and include their feedback and considerations.

Once saturation was reached, the interviews were concluded. The authors (a philosopher and an MD) conducted a thematic analysis[21] which was discussed on several occasions with the Cec team that conducted the interviews. A key aspect of the commitment model is its focus on patients and individual cases, so the analysis of the interviews were concentrated on specific patients. This meant it was also important for us to meet the patients themselves, in addition to their relatives, despite the severity of their symptoms. We approached only patients whose relatives had previously given their consent, verbal assent was then requested from the patients themselves. We told them that we were conducting qualitative research, explained the aims and objectives, and then asked whether they would agree to answering some questions. We conducted the interviews only with patients who clearly expressed their agreement. We sat with them in their room and asked them to tell us about their daily life and their thoughts about the units.

Participants

We conducted 154 semi-structured interviews with 62 individuals: 25 relatives and 37 healthcare professionals, including 11 doctors (9 geriatricians and 2 psychiatrists), 18 nurses and 8 clinicians involved in the units, such as psychologists, art therapists and psychomotor therapists. Some

of the professionals were interviewed several times about their experiences with the 30 patients included in the study (18 men and 12 women, average aged 79, 3 of whom were under conservatorship). In 11 cases, the relatives gave their consent for the patient to participate in the study, but the interview could not go ahead, either for logistical reasons (for instance, the patient was discharged, transferred, or died before the interview; n = 7), lack of interest (n = 3), or, in one case, when the patient said it was too difficult for him (n = 1).

We met all 30 included patients, but only 17 communicated and entered into dialogue with the interviewers about the study. Symptoms and overall health conditions varied: 19 patients had been diagnosed with dementia and 5 with psychiatric conditions, while 6 had not been diagnosed. All the patients were admitted to the CBU following a deterioration in health characterized by symptoms whose management had become challenging for caregivers (e.g., unusual motor activity, agitation, screaming, hallucinations, refusing care). In some cases, the deterioration followed a specific episode (such as surgery, a fall or conflict), while in others, no precipitating event was identified. Prior to admission to their respective CBUs, 9 patients had been living at home, 9 had been admitted to other hospital units (geriatrics or other medical specialties) and 12 had been residing in nursing homes. We collected demographic information available on the participants from the data provided by the referring doctor, after obtaining consent. All names mentioned in this manuscript are pseudonyms.

Results

Due to severe BPSD, forms of Alzheimer's disease or related conditions, the exchanges we had with the 17 patients were not analyzes, but an overall idea of their experience at the unit was obtained. All of them expressed their impressions and feelings regarding hospitalization and appeared to be fully aware of and concerned about their surroundings. They asked questions or made comments about their current daily routines, the care they received, and life within the community. Some patients expressed positive sentiments, for example, Lucien (aged 82) stated he liked being in the CBU because it provided a calm environment. Others expressed dissatisfaction, for example Adrienne (89), who complained about being treated like a child. Many also frequently commented on "the others". For instance, Justine (70) described her difficulty in forming friendships, as she believed that people in the unit were "false", while Clément (75) said it was difficult to find interesting topics of conversation, and he easily became bored.

With regard to the analysis of the interviews with the patients' relatives and healthcare professionals, while they generally appreciated the relational approach adopted in the CBU, they expressed concerns about the limitations to the care provided and restrictions on patients' personal freedom. See Table 1 for a summary of the three themes described as below.

Appreciation of the CBU relational approach

Most interviewees expressed appreciation with the CBUs, emphasizing their relational approach to care. For example, the wife of Antoine (73) said: "It's great, we need more of these interactions so people feel less lonely, less on their own, less rambling in their heads."

The focus is on maintaining patients' interactions with relatives, other patients and professionals to help them remain calm and feel relieved. With regard to Louise (83), her art therapist highlighted that: "The objective is to reduce the state of tension, to soothe the patients and facilitate encounters with other people… All this evokes positive feelings."

From the corpus of interviews, professionals identified three key strategies used to implement a relational approach:

1. Tailoring care to patients' specific needs and prioritizing non-pharmacological approaches, such as workshops and group activities;
2. Respecting patients' behavior and preferences, even if this requires adapting the way care is organized. For example, one nurse explained how she accommodates patients' wishes by postponing care if they are not compliant at a given moment: "You have to go back every hour to find the right time to provide care, and so it doesn't go too badly;"
3. Trying to learn more about patients' previous lives and placing importance on adapting their stay in the unit accordingly. In this respect, the psychologist of Charles (92) said: "It helps us to know what he likes so we can encourage him to participate in activities and understand his preferences for organizing meals, personal hygiene and daily life."

Additionally, the fact that CBUs are closed units was considered positive because it provides a secure, comforting environment. It ensures safety, as patients cannot easily leave, while, within the available space, patients are allowed a degree of freedom of movement and can come and go without constant supervision. Most relatives appreciated the fact that patients can walk around freely in the unit and have access to areas beyond their own rooms. A psychomotor therapist from the public CBU in the Paris region, during her interview about Marie (92), noted: "What is good for them is to be in a group, in a setting… And there is always someone here who is available, even at night".

We noted, however, that general appreciation for the relational approach taken in the CBU is not necessarily

Table 1. Summary of themes and subthemes.

Theme	Subthemes	Brief description
1. Appreciation of CBUs relational approach	– Relational focus (interaction, calm, relief) – Tailoring care & non-pharmacological approaches – Respecting patient behavior & preferences – Adapting to personal history – Secure but flexible environment – Ambiguity of care goals	Interviewees appreciate CBU strategies used to foster relational care, linking patient experiences, staff strategies, and unit environment. Appreciation, however, comes with a certain ambiguity in care goals and gap between relatives and professionals' expectations.
2. Limitations of care provided	– Diversity/complexity of symptoms – Non-pharma interventions: challenges – Temporary solution – Unappealing and inadequate post-CBU options – Difficulty of discussing end-of-life care	CBUs struggle with patient diversity, the limits of non-pharma care, the restricted options for transition after CBU, and ethical hesitation about death/end-of-life, which shape perceptions of care efficacy.
3. Restrictions to personal freedom	– Limited consent and respect of autonomy – Closed unit (environment & restriction of movement) – Use of physical restraints & moral distress	CBUs present some sources and forms of constrained autonomy. Closed-unit design causes mixed feelings and ethical debates around restraint practices. Patients' limited freedom issues is linked to staff and family experiences and moral distress.

synonymous with clarity or consensus regarding the care goals. Relatives generally expected an improvement in the patient's condition through accurate diagnosis and effective treatment. The wife of Paul (63), for instance, highlighted that CBU professionals make repeated attempts to identify the best treatment to manage her husband's "crises". She acknowledged that they were difficult to deal with, but her understanding was that CBUs specialize in such cases. This sense of specialization leads most relatives to believe that the CBUs have the resources to address the complexity of the patient's condition. However, the healthcare professionals indicated that their primary aim is to relieve and mitigate symptoms, rather than treat the underlying disease. One geriatrician, for instance, described his care goal for Marie (92) as "to get her cleaned up and agree to having her nails cut." Most geriatricians stated that they do not consider it important to establish the patients' psychiatric diagnoses or to work with psychiatrists, given their advanced state of deterioration. For instance, the geriatrician of August (89) clearly stated: "It's rare for us to get a diagnosis because we can no longer make one by the time they come to us. We're not that interested anyway".

Limitations to the care

A central characteristic of CBUs is their aim of providing a calming and comfortable setting for patients. In this respect, relatives stressed the importance of fostering a sense of belonging within the unit but often expressed concerns when this does not occur. The wife of Antoine (73), for example, described how differences in patients' symptoms affect her husband, noting that he fears being around people so unlike himself: "While he is calm and reserved, many of the others are agitated and loud most of the time. He gets scared."

The diversity and complexity of diagnoses and symptoms among hospitalized patients is also seen as problematic by healthcare professionals. For instance, the geriatrician of Raphaël (78), working in the private CBU, suggested specialized units were needed for at least three categories of patients with BPSD: those with acute behavioral disorders, those with early-stage behavioral disorders and those who are bedridden and screaming.

Another key characteristic of CBUs is their focus on reducing psychotropic drug use and prioritizing non-pharmacological interventions. However, this approach is seen as challenging for two reasons: the combination of drugs is not always effective, and non-pharmacological interventions are sometimes described as futile due to the severity of the patients' cognitive impairment. Some physicians expressed concern over the ineffectiveness of different approaches and the lack of alternative options. A gerontologist described how Henri (76) had such severe symptoms that the only feasible approach was what he termed "palliative care for behavioral problems." Additionally, some relatives questioned the purpose of non-pharmacological interventions. The daughter of Marcel (74) stated: "We didn't really understand the point of the therapy

in the workshops. He can no longer focus. He can't do that!"

A related challenge is that CBUs are designed as a temporary solution and the long-term care options are often perceived as unappealing or inadequate. The clinicians interviewed stated that an important part of their role involves organizing patients' healthcare pathways after their stay. They take time to assess and provide recommendations on the best available options for each patient after discharge. In most cases, the interviewees recommended institutionalization in nursing homes. After their stay at the CBUs, 5 of the 30 patients we met returned home, 13 were institutionalized in nursing homes for the first time (5 in a dedicated Alzheimer's unit) and the remaining 12 returned to the nursing home where they had previously resided (6 of whom were transferred to a dedicated Alzheimer's unit). Some relatives had a positive view of the support provided by the CBU professionals, as it provides a period of respite from the demands of managing a loved one's deteriorating health. Temporary hospitalization was described as an opportunity to come to terms with the patient's decline in health and the prospect of the institutional care that might follow. The son of Hector (89) stated: "I'm not saying you have to do it for everyone, but this rite of passage before the nursing home is good, if only to make the decision to institutionalize. It gives a medical justification to the act [of institutionalization]. It also reduces relatives' feeling of guilt."

Most interviewees expressed concern that nursing homes provide poorer care and living conditions than the CBUs. A psychomotor therapist stressed that it is often difficult for patients in nursing homes to adapt well and express themselves. Similarly, the sister of Jeanne (86) said: "If she goes back to the nursing home, she won't eat. If I'm not there, they leave her to do everything by herself, but she can't… In the CBUs they are very attentive."

Many relatives expressed a sense of impasse and worry regarding the care after the CBU. The son of Jules (73) expressed this very clearly: "For me it's heartbreaking, though. None of the situations are satisfactory. At home, organizing safety and care is complicated. In the nursing home he would have those, but as family we wouldn't be there for him, especially since, given our economic situation, he won't be able to access a high-quality nursing home… Innovative options between nursing homes and home should be available."

A final concern relates to the difficulty of openly discussing end-of-life care. Although most of them hospitalized patients were nearing the end of their lives, the interviewees described a certain reluctance to discuss this topic among the various actors in the CBUs. In discussing his interview with Antoine (73), a psychologist from the public CBU in the Paris region explained how difficult it is for professionals to broach the subject: "Caregivers are uncomfortable with the question of death and are reticent about palliative care, especially when patients are suffering psychologically and not physically, like in the onco-geriatric unit next door."

Relatives who had tried or considered raising the issue believed the healthcare professionals are not receptive, as they tend to focus mainly on treatment. Conversely, most professionals said they did not talk about the subject because it would be too hard for the relatives. They also believed that it was not part of their role as CBU professionals. As the geriatrician from the public Parisian CBU caring for Germain (91) explained: "They come here because of behavioral problems, not due to an illness that will kill them. If there is a serious accident, we can provide palliative care. Otherwise, we don't talk about it."

Some professionals, however, argue that palliative care should be considered for certain patients. For example, one team discussed the possibility of terminal sedation for bedridden patients with severe cognitive impairments who exhibit signs of unbearable suffering. Some relatives consider death as the option closest to the patient's perceived or expressed wishes. The cousin of Adrienne (89) said: "I think the best thing for her is to die as soon as possible, for her to be relieved and free. She wants to die. She has asked for a gun so many times, to kill herself. She asked a woman to take her to Switzerland when she was no longer well. I'm all for it. When you reach that point, is it worth living? I don't believe it is."

Restrictions to personal freedom

Most of the interviewees expressed concern about restrictions to patients' personal freedom. This encompasses various issues, such as obtaining free and informed consent, the freedom to come and go and the use of physical restraints. Some patients were admitted to the units although they could not provide informed consent, while others explicitly refused hospitalization, treatment or even personal hygiene on various occasions. Most of the interviewees believed that hospitalization is in the patients' best interest, but different forms of refusal create distress. They wondered, for example, whether patients are aware of their condition and if their refusals are genuine. A psychologist had this to say about Justine (70): "It's more difficult because she doesn't recognize her impairment… She thinks everything was fine when she was living at home. She experiences this hospitalization as an injustice."

Additionally, the CBUs inherently restrict patients' freedom as they are closed units. Most professionals felt uneasy about such confinement, as it is not regulated by law in France, unlike in psychiatric units. Some professionals adopt strategies to mitigate this limitation, such as one geriatrician who said he often allows special leave, for instance on weekends, for this reason.

The relatives shared similar concerns. The son of Charles (91) stated: "He has lived all over the world. He has always enjoyed freedom and wide-open spaces. Here, he has the opposite of what he has always loved." Similarly, the daughter of Marcel (74) remarked: "No, we didn't see this as being lucky. It's more like flying over the cuckoo's nest (Reference to the movie called *One Flew over the Cuckoo's Nest.*). We felt like we were in a madhouse: white walls, a code at the door, people trying to kiss you… with 10 people walking around, it's weird sometimes."

Physical restraint is also commonly used on patients and is justified either for safety reasons or to facilitate essential care, such as sitting long enough to eat a minimum amount of food. Concern was raised regarding cases of physical restraint (abdominal belt on a chair during meals to prevent falls, temporary immobilization by several professionals in cases of acute behavioral disorders, and, on exceptional occasions short periods of immobilization by tying down limbs) or chemical restraint (injections of psychotropic drugs in cases of acute episodes). Unlike some psychiatric wards, there are no isolation rooms in the CBUs. These practices evoke mixed emotions: it is not pleasant to see patients constrained, yet it is often deemed necessary by professionals and relatives alike. The daughter of Julia (69) said that she thought it was sometimes necessary to restrain her mother because "it's intolerable to think we would let her starve to death." Similarly, the wife of Antoine (73) said that it was sometimes better to insist on certain things: "It is still necessary to maintain a minimum level of decency, to make him put on underwear or to take him back to his room."

Both the professionals and relatives who were interviewed justified the use of restraints, viewing it as an inevitable measure to prevent greater harm. However, this sense of inevitability does not spare them from moral distress. Some interviewees questioned whether it is beneficial for the patient, while others clearly described it as an abusive and disrespectful procedure, reminding them of the well-known and controversial practices by psychiatric services. The gerontology care assistant of Julia (69), working in the public hospital in the region Hauts-de-France, stated: "Restraint to prevent falls at night shocks me. It's true that it's necessary, but it's barbaric. Even just the sound of the magnets—*click click click*. We had a patient who had to have his limbs tied. […] We felt so bad."

Discussion

The interviewees recognized and appreciated that the CBUs strive to provide an innovative approach to the care of individuals with BPSD, with a focus on fostering relationships. However, they also expressed concerns about certain aspects that might cause harm. They questioned the benefits of these units, particularly with regard to their limited ability to accommodate the patients' diverse symptoms, the lack of evidence to support the non-pharmacological therapies used and the need to transfer patients despite the absence of satisfactory options. These reservations are echoed in the literature, which highlights the scarcity of robust evidence for many non-pharmacological interventions and the challenges of individualizing care for people with BPSD.[22]

Additionally, CBUs raise ethical issues regarding restrictions to patients' liberty and respect for their rights. Healthcare professionals may resort to physical restraint, non-consensual hospitalization and restrictions to patients' freedom of movement. These ethical issues are not unique to CBUs, as similar concerns have already been highlighted in other institutions, such as nursing homes and psychiatric settings. Restraint itself has been identified as an ethical strain as, among other reasons, it may compromise person-centered care.[23] If not assessed carefully on a case-by-case basis and with appropriate consideration, these practices risk leading to forms of abuse or neglect.[24,25] However, previous research shows that, despite limited evidence on the adequacy of physical restraint, there is a common perception among relatives, patients and professionals that it is needed to avoid greater harm to the patient.[26–28] These issues are particularly relevant in the ethical analysis of CBUs, as they appear to contradict the innovative approach to care they aim to promote. The fact that the organization of care of CBUs involves restraint and restricting freedom clashes with the idea that these units are designed to adapt to the individual, as they do not offer an alternative to problematic approaches adopted in other units.

Our analysis shows that CBUs are pioneering institutions. However, they operate within institutional and cultural knowledge and practice frameworks regarding elderly care. If not critically examined, these frameworks may hinder CBUs from realizing their full potential. One particularly controversial aspect is the uncritical approach to care when it comes to expressing the role, functions and aim of the CBUs. Given the absence of in-depth consideration, three issues require further ethical reflection: end-of-life needs and expectations, the collaboration among specialists and the respect for patients' autonomy.

End-of-life care

We found that relatives and professionals view the care goals in CBUs quite differently: while relatives expect some form of treatment, professionals focus on symptom management. The latter explicitly strive to "de-medicalize" certain aspects of care by, for instance, reducing the use of medication. However, they do not address the ethical significance of expanding the care for individuals with BPSD beyond the strictly medical realm. There is little dialogue and reflection on a broader view of "care" beyond the pursuit of a "cure", despite the severity of most patients'

symptoms and the fact that geriatricians admit that they are unable to cure their patients. The lack of open reflection on these matters is even more striking in France, where, since the 1980s, trends in medicine and public health have tended toward expanding the concept of medical care to a more open idea of "*accompagnement*" (which may be translated as "accompaniment", "support" or "assistance").[29] Recent regulations and recommendations on end-of-life care are not limited to palliative care but also encompass other possible approaches and forms of accompaniment. In this context, Gaille[29] states: "Real accompaniment begins by not avoiding the subject of death and end of life" (p.45, our translation).

From the Catalan perspective, Esquerda[30] similarly underscores the importance of talking about death, beyond the medical context, to counter cultural resistance and discomfort. While reticence in discussing end-of-life issues is common in cases of dementia,[31] we noted that 40% of the patients we met had died within a year of our last interview. Including conversations about death and end-of-life arrangements in the CBU relational approach could benefit these patients. This does not mean that palliative care should be prioritized in CBUs over other aspects of their organization, but it could be worthwhile to create space for all stakeholders to freely discuss all available options, including concerns about death.

Previous literature highlights that end-of-life care for people with dementia and related diseases is sub-optimal as it may include aggressive treatments, low rates of palliative care referrals and poor pain and symptom management.[32] Not only has the implementation of palliative approaches been lacking in long-term care homes, there is also a limited understanding among professionals and families regarding death and bereavement.[33] Our analysis confirms the need for education regarding the identification and symptoms of people with dementia at the end of life, early integration, and the best options for palliative care in CBUs, as in other settings.[34–36] Not considering palliative care as a form of care represents a cultural barrier that clashes with the declared mission and scope of CBUs.

Interprofessional collaboration

Broadening and critically examining the meaning of care could also strengthen collaboration and knowledge-sharing between the specialties of geriatrics and psychiatry. While CBUs are meant to adopt an interdisciplinary approach, the interviewees reported unclear and inconsistent integration of psychiatric and geriatric care in diagnosis and treatment. The geriatricians interviewed openly stated they were not interested in such an exchange, and psychiatrists are not regularly present in the units, as they are generally only consulted by geriatricians for advice on treatment strategies. These findings highlight our interviewees' difficulty in fostering interprofessional practices, which include collaborative learning and cooperation to provide the optimal care for patients. The findings also contribute to the literature by demonstrating that only a minority of professionals establish reciprocal collaborative relationships, suggesting both uneven distribution of influence and ambiguous role boundaries in psychogeriatrics teams caring for people with Alzheimer's disease.[37] Closer collaboration between psychiatrists and geriatricians could facilitate further exploration of the etiology and pathophysiology of patients' conditions and improve pharmacological and non-pharmacological interventions. Lack of collaboration can also lead to higher costs and less effective diagnoses and therapeutic management.[38] Cooperation should therefore be promoted both internally in CBUs over a continuum with institutions providing care for patients over time.[39]

Respect for autonomy

As the last point with regard to the critical examination of the approach to care in CBUs, our analysis highlights the need to develop a critical understanding of respect for patients' autonomy. The interviewees placed great emphasis on patient autonomy as a central component of the CBU relational approach. However, interpretations of autonomy vary significantly and shape the relationships professionals establish with patients. As mentioned above, some professionals seek to learn more about patients' previous lives so they can better adapt their care. This approach suggests that professionals are concerned about patients' authenticity: aligning their present values and beliefs with those they held in the past.[40] However, others state that they focus on patients' behaviors and desires at any given moment, using an approach termed "immediate autonomy". This seems to overlook broader considerations regarding the individual's authenticity and continuity in personal values and beliefs. Focusing on the current moment may affect how care is provided by, for example, limiting opportunities for patients to participate in their own care, to the extent that they are able.[41]

Another perspective on autonomy that emerged from the interviews focuses on patients' ability to understand their situation and make decisions. This view emphasizes rationality and informed consent, although it neglects other important considerations, such as patients' emotions, bodily sensations, relationships and surroundings—all of which were important in our observations with patients. It is not surprising that rationality plays a crucial role, given the influence of Western biomedicine, shaped by the Cartesian view of the body as separate and independent from the mind.[42,43] According to this view, autonomy is equated with informed consent and is deemed sufficient for moral deliberation.[44] However, this idea is challenged

by Merleau-Ponty, who suggests replacing the body-subject dualism with the notion of "embodied subjectivity". He emphasizes that one's experience of the world is only possible *through* the body.[45] The concept of embodied subjectivity has informed, among others, relational approaches to autonomy, which highlight the importance of context and intersubjectivity.[46] Relational autonomy has been characterized in various ways by different authors: for example, Gómez-Vírseda et al.[47] argue that it should not be seen as a one-time decision made by the patient as an isolated individual, but as a process subject to changes and fluctuations, in which healthcare professionals and other relational factors play a fundamental role. Reflection on how autonomy is understood in BPSD patients could help healthcare professionals strengthen the relational approach to care they strive to achieve.

Conclusion

> "If our goal is to point to a set of 'culture change practices' and satisfy ourselves that we are 'doing it,' there is a real danger that nothing very meaningful will change".[48]

CBUs are promising and welcome initiatives. However, they would benefit from a reassessment of cultural approaches to the care provided for older people experiencing BPSD. In particular, end-of-life care, interprofessional collaborations and respect for autonomy should be discussed. In doing so, CBUs could become catalysts for public debate on accommodating people with BPSD. While CBUs aim to manage crisis situations, their temporary nature and limited resources often result in patients being redirected to other institutions that offer less than ideal solutions. Prioritizing patients' rights and freedoms should encourage society as a whole to explore alternatives to nursing homes. Some inspiring examples are provided by "dementia villages" or small care homes. CBUs could play a pivotal role in communicating the needs of hospitalized individuals and encouraging a broader public discussion on how to extend the principles of care practiced in these units.

This study has some limitations. One of the CBUs included in this study had had prior contact with the Cec after detecting certain ethical concerns. However, this may not be representative of all units. Additionally, patient recruitment was conducted through professionals, potentially excluding the perspective of other patients and relatives. We also acknowledge that, while our findings show an unclear relationship between geriatrics and psychiatry, such collaboration may function more effectively in some other units. Although the results of the analysis are not representative of all CBUs in France and may reflect recruitment bias, they are valuable due to the exploratory nature of this study.

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Ethical considerations

The research protocol was submitted to the research ethics committee of the University of Paris Cité and received approval before fieldwork began (approval number: 2018–102).

Consent to participate

All participants provided informed consent to participate in this study.

Consent for publication

Not applicable

Author contribution(s)

Maria Cristina Murano: Data curation; Formal analysis; Investigation; Writing – original draft; Writing – review & editing. **Nicolas Foureur:** Conceptualization; Formal analysis; Methodology; Supervision; Writing – review & editing.

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Data availability statement

The datasets analyzed during the current study are not publicly available but are available from the corresponding author on request.

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