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An Innovative Model of a Home-Like Environment for People in Vegetative and Minimally Conscious States

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Abstract

Background and Purpose: Many forms of assisted living have been proposed for people who have a loss of autonomy in activities of daily living. Despite the increasing prevalence of vegetative and minimally conscious states, no dedicated residential accommodation has been implemented for patients with chronic disorders of consciousness (DOCs). **Methods:** This is a descriptive study addressing an innovative model of in-house assistance, named Casa Iride, which has recently been implemented in the attempt to ensure health, safety, and well-being for people with DOCs and their families. **Results:** Our findings show that Casa Iride enables severely disabled individuals to live with dignity within a customized domestic environment. At the same time, it provides support for caregivers from both a practical and a psychological point of view. **Conclusions:** The results so far indicate a virtuous cycle that brings health, social, psychological, ethical, and economic advantages: the individuals receive all the assistance needed; the families share a place with other people with similar challenges, become more aware of their situation, and learn to cope with it and to maintain their productivity at work; and the care flow of patients through intensive care units and intensive rehabilitation wards is not delayed by a lack of post discharge services.

Keywords

neurohospitalist, trauma, nervous system, outcomes

Assisted Living for Special Populations: Historical Perspective

Assisted living and supported housing are the terms generally used to indicate the many forms of residential accommodation for specific types of population known as special populations .[1-5] The latter includes older adults with age-related cognitive impairment, patients with end-stage neurodegenerative diseases (such as Alzheimer or Parkinson disease), young people with severe disability as a consequence of widespread brain injury, patients with terminal illnesses, particularly cancer, and children with genetic diseases or with severe general developmental disorders.[1-5] The shared characteristic of these populations is a lack of autonomy in activities of daily living (ADLs). As a result, they need assisted living accommodation within residential care facilities where they receive continuous monitoring and assistance.[1] Apart from this, assisted living facilities are extremely heterogeneous with respect to infrastructures and services, admission criteria, and the degree of medicalization.[6] In light of this heterogeneity, some have suggested labeling the kaleidoscopic panorama of residential care facilities with the deliberately generic term "housing with services."[1] There is an evident need worldwide for more accurate and homogeneous classification of these services to allow better rationalization of their supply and demand.

Patients With Disorders of Consciousness: A Special Population With Growing Prevalence and Needs

The growing population of adults who sustain traumatic brain injury (TBI), stroke, or hypoxic brain damage, combined with advances in emergency treatments, has led to an increasing

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number of patients with disorders of consciousness (DOCs) or severe disability. The spectrum of DOCs includes coma, vegetative state (VS), and minimally conscious state (MCS).[7-9] Patients with DOCs are initially admitted to intensive care units (ICU) because of instability of vital functions. After stabilization, they are transferred to postacute care (PAC) units for rehabilitation. Patients who recover consciousness carry on with rehabilitation outside the PAC unit to then go home once maximum benefit has been achieved. Patients with a chronic VS or MCS, on the other hand, need continuing medical or nursing care and may be managed either at home or in residential care facilities, depending on their resources and opportunities.

Casa Iride: A New Organizational Model of Care for People in VS and MCS

Here we describe an innovative model, recently developed in Rome, of assisted living for people in VS or MCS. Casa Iride is a nonmedicalized cohousing community, which allows severely disabled people to live with dignity within a domestic environment. These individuals should no longer be considered inpatients, as they are commonly in a condition of medical stability allowing survival with in-home assistance. Nevertheless, they are severely disabled with a complete loss of autonomy and need personal assistance for all ADLs. Currently, in Italy, these individuals are commonly discharged to their own homes, where they are provided with integrated home care. The person's return home also involves a series of interventions on the house itself in order to remove any architectural obstacles and to equip the home with the aids necessary for hygiene, mobility, and sustenance. Indeed, the person's return home, although charged with expectations on the part of the family members, becomes for them a moment of enormous responsibility and often generates feelings of inadequacy and fear. This is especially the case for low-income working families who have to face both an economic and a psychological burden which until then has been shared with the hospital and rehabilitation staff. This burden of responsibility often ends up threatening the psychological well-being of the whole family who, resigned to such a dramatic chronic condition, can lose hope for the future. In the most serious cases, they compromise their own everyday lives and productivity and are at risk of remaining isolated from the world with all the accompanying psychological, social, and economic consequences.[10,11]

The development of Casa Iride started from the attempt to prevent this vicious circle and to protect the right to a dignified life and to physical integrity for people with a chronic disorder of consciousness. As the name suggests, Casa Iride is a home, where the most disadvantaged and severely disabled individuals and their families have their own living space, share common areas, and benefit from general support services including nursing assistance and physical therapy. A centralized home facilitates family reunion, with integration according to each person's skills, values, and way of life. The individuals receive all the assistance they need, and the families share a place with other people facing similar challenges, thus learning to cope and to maintain their well-being and productivity at work. It is also designed to enable the best possible results with contained costs. The result is a positive cycle from a health care, social, psychological, and economic point of view (Figure 1).

Description of the House

Casa Iride is a smart building with 350 m^2 of floor space, planned to foster a sense of belonging and togetherness following the principles of social contact design (Figure 2). There are some social areas (both indoors and outdoors) for the use of residents and their families and a number of individual rooms for the residents. Of the 7 bed spaces available, 6 are allocated as stable residence for individuals who, at the time of being discharged from the recovery unit or from intensive neurorehabilitation, find themselves in socioeconomic conditions that do not enable them to return to their own homes. The remaining bed is allocated as temporary accommodation for people transitioning from an inpatient facility to their own home or for respite. The shared areas include the residents' hygiene room, equipped with specially designed waterproof stretchers, which enables washing in a supine position; storage rooms for medications and disposable equipment provided for each resident (such as catheters, gloves, mattress protectors, and so on); and various recreational spaces for the use of residents and their families, including a living area with kitchen and table and an outdoor garden.

Selection and Admission of Guests

The selection of residents is made according to preestablished criteria, with particular attention being paid to the social and health needs of the individuals and their families. Priority is given to low-income individuals with small dwellings and quantitatively or qualitatively limited family support or to families with young children. If the socioeconomic situation of the resident improves, he or she can return to the family home, leaving a place for someone else. To date, 9 individuals have been permanent residents at Casa Iride (mean $\pm$ standard deviation length of stay, 20.2 $\pm$ 9.7 months), while 4 have been temporarily admitted to enable a respite period for their relatives (Table 1).

General Management of Residents

As mentioned previously, individual residents of Casa Iride are no longer considered inpatients but simply residents, as they have overcome the most critical phase and have reached a condition of clinical stability, which allows normal home care. In this way, Casa Iride has been created in the true spirit of housing with services. Services include all of the

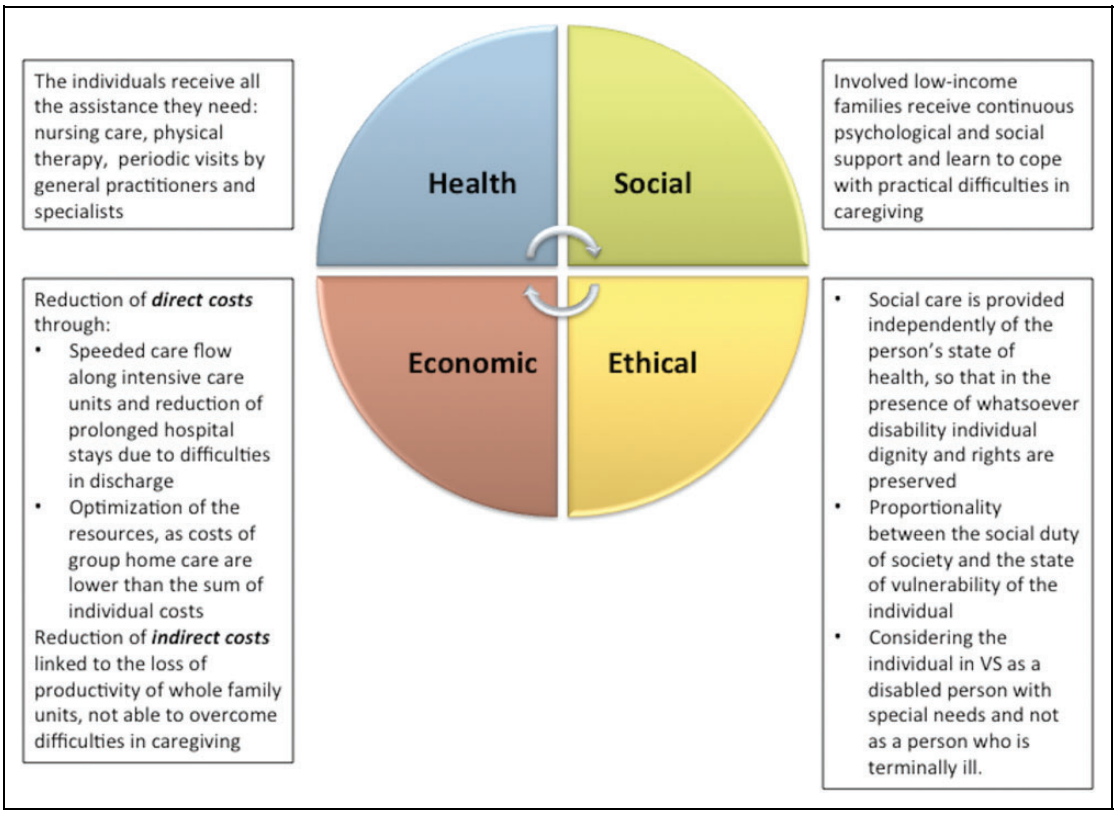

Figure 1. The virtuous cycle of Casa Iride: health, social, economic, and ethical implications.

Figure 2. External view of Casa Iride.

interventions aimed at guaranteeing sensible and dignified management of the resident without hospitalization. Nighttime surveillance of patients is also provided. As in the classic model of home care, periodic visits are made by general practitioners to observe the resident's state of health and make any adjustments to the therapeutic schedule. Whenever necessary, the home care center ensures the intervention of specialists and the carrying out of any laboratory or instrumental examinations.

Person-Centered Care

The residents and their families play the leading role inside Casa Iride. Active training of family members, carried out

Table 1. Demographic and Clinical Characteristics of Patients Admitted at Casa Iride.

	Sex	Age	Primary Injury	Diagnosis	Time From Injury to Admission, months
Permanent residence	M	26	TBI	VS	15
	M	33	TBI	MCS	39
	M	44	TBI	VS	23
	M	34	TBI	VS	23
	M	57	Stroke	MCS	18
	M	22	TBI	VS	23
	F	52	TBI	MCS	31
	F	38	AE	VS	19
	F	56	AE	VS	15
Temporary residence for a respite period	F	53	TBI	MCS	49
	M	36	TBI	MCS	63
	M	22	TBI	VS	55
	F	40	TBI	VS	11

Abbreviations: TBI, traumatic brain injury; AE, anoxic encephalopathy; VS, vegetative state; MCS, minimally conscious state; M, male; F, female.

within Casa Iride, in the tasks involved in managing the resident's care allows first-hand involvement in providing for the physical and emotional needs of their loved one. At the same time, the family can dilute the daily workload by availing the services of trained care workers. The concept of person-centered care is also reflected in the organization of the temporal rhythms which mark out the resident's day, with particular attention to the strengthening and maintenance of circadian rhythms to help the resident's biological clock return to a healthy cycle.[12-14] Finally, person-centered care aims to guarantee the resident constant observation through the presence of the staff and family members. This facilitates the identification of particular signs and behaviors, which might suggest a transition in the state of consciousness and which, as such, should be noted and investigated.[15-19]

Support for Relatives and Caregivers

The *Associazione Risveglio* promotes services of tutoring and guidance for the families of residents at Casa Iride. The tutoring aims to train caregivers in the practical management of the resident, including management of tracheostomy tubes and gastrostomy tubes, and this action begins even before the individual is transferred from the hospital to Casa Iride. The guidance services for the family members also include psychological support. Family members often find it hard to accept a condition such as VS, which can seem like a poorly defined state of limbo not destined to evolve either in one direction or in the other. Depending on individual factors, this can give rise to feelings of resignation, detachment, and aggressiveness or can foster attitudes of denial, with a tendency to incubate false hopes and illusions. Preliminary data on the level of satisfaction of caregivers at Casa Iride show that they have an acceptable quality of life and a good mental well-being. Using the Burden Scale for Family Caregivers (BSFC),[20] 9 caregivers of patients at Casa Iride were surveyed, and their score was lower (BSFC score 18) than that found in 20 caregivers of patients with similar disability and managed in a traditional long-term care unit (BSFC score 26). Although these data are too preliminary to draw definite conclusions, they suggest that caregivers may be more likely to cope with dramatic conditions of their relatives when psychologically supported. Future studies on larger samples of caregivers are needed in order to establish the real benefits associated with the diffusion of structures like Casa Iride.

Economic and Resource Allocation Implications

The Casa Iride model generates a virtuous cycle also from an economic point of view. Its main strengths can be summarized in the following points: (1) reduction in direct costs linked to unjustified prolonging of hospital stay due to a lack of suitable services in the area; (2) optimization of resources through the creation of a communal facility where the costs of group home care support are lower than the sum of those incurred at an individual level; and (3) reduction in indirect costs linked to the loss of productivity of family members where there is not sufficient support from society in the onerous tasks of caregiving. As shown in Table 2, the comprehensive costs for care at Casa Iride amount to approximately a third of the estimated costs for the care of those same individuals in ICUs and a half of the estimated costs for care in long-term care units. While the direct costs of home care are lower compared to care at Casa Iride, it is possible the reduction in indirect costs due to maintenance of family and caregiver productivity may offset this difference. Moreover, home care does not provide 24-hour monitoring and assistance like Casa Iride.

Ethical Implications

Chronic DOCs are the dramatic result of severe acquired brain injury, the incidence and prevalence of which is progressively increasing in the general population.[21] These pathologies often affect young people and are the biggest cause of disability and

Table 2. Residential Costs Per Patient Per Year for Casa Iride as Compared to Costs for Intensive Rehabilitation Care Units, Long-Term Care Units, and Home Care Assistance in Italy.[a]

	Casa Iride[b]	Intensive Rehabilitation Care Unit	Long-Term Care Unit	Home Care and Assistance
Assistance availability	24-hour monitoring and assistance, 7 days per week	24-hour monitoring and assistance, 7 days per week	24-hour monitoring and assistance, 7 days per week	3 hours per day 6 days per week
Costs	42 057 €/year	171 550 €/year	80 409 €/year	17 066 €/year

[a]Expenses include costs for medical and nursing assistance, physical rehabilitation, swallowing and speech therapy, and maintenance of structures and medical devices.
[b]Costs for the maintenance of Casa Iride are covered by the region of Lazio together with the Municipality of Rome. Moreover, the families of the residents contribute to the maintenance costs of Casa Iride through a boarding fee, which is comparable to the amount they receive in support from the State for the care of their family member.

loss of autonomy in the first 40 years of life. For these reasons, as highlighted by the Italian Ministry health guidelines in 2011,[22] the search for social solutions for patients in VS and MCS has become urgent and should be based on the following principles and necessities:

- The guarantee of social care which conforms with the ethical concept of personhood independently of the person's state of health so that in the presence of whatsoever pathology and disability, the dignity and rights of the person are preserved.
- Proportionality between the social duty of the society and the state of vulnerability of the individual: the more extreme the state of vulnerability, the stronger the social duty should be.
- Considering the individual in VS as a disabled person with special needs and not as a person who is ill, let alone terminally ill.
- The recognition and proper management of any source of pain for these individuals.[23]

The model of Casa Iride is structured according to these principles. Patients are not considered terminally ill and receive medical and nursing assistance as well as rehabilitative treatments able to encourage even small recoveries. Moreover, every effort is made to ensure the dignity of patients and to preserve the quality of life of caregivers and their mental well-being.

Report of a case

The first resident to arrive at Casa Iride was a young man who was 19 years old and had a severe head injury in a motorbike accident. He had spent several weeks in intensive care and neurosurgery, where he had undergone several surgical interventions including the insertion of a ventricular-peritoneal shunt. The patient recovered wakefulness without any signs of consciousness and recovered normal respiratory function. He was discharged with a diagnosis of VS as a result of severe TBI. The patient was then admitted to an intensive care and rehabilitation unit to undergo further clinical stabilization and to begin a course of rehabilitation. Unfortunately, after 2 years in a neurorehabilitation unit, the patient remained in a VS and would have had to return home, where he would have been provided with home care for 3 hours a day and 6 days a week. However, the socioeconomic circumstances of the family did not allow for structural changes to the house, which was unsuitable for the accommodation and care of the patient due to many architectural barriers. Moreover, the family situation was fragmented as the patient's parents were separated and had always alternated in managing their son. The principal mentor for this patient was an uncle who at the time of admission had been named his support administrator. This patient is currently still resident at Casa Iride. He has not shown any variation in his neurological and rehabilitation profile, and he continues to receive all the necessary medical, nursing, and rehabilitative care. He has frequent visits from his father and uncle and is considered a member of the family at Casa Iride, where he receives much attention from all of the personnel. They are always careful to safeguard his dignity and to maximize any chance, however small, of improvement.

Conclusions

Casa Iride is the first Italian experience in creating a home-like environment in the community for patients with chronic DOCs. We believe it represents a paradigm shift in the care of these individuals by providing a collaborative style of living, which fosters interdependence, the development of support networks, sociability, and safety for individuals with DOCs and their families. It is hoped that this prototype will be followed by a diffusion of other similar care homes in the area with the same characteristics and objectives.

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Authors' Note

This article has been written according to the Declaration of Helsinki and every precaution has been taken to protect the privacy of research subjects and the confidentiality of their personal information. No investigations on new treatments or new diagnostic methods have been performed on patients.

Declaration of Conflicting Interests

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