



Gaming for Mutual Learning in Elder Care GAMLEC

O1: Compendium on criteria for the quality of life of care home residents, National report for Italy



Co-funded by the
Erasmus+ Programme
of the European Union



Document information

This document contains research results on long-term care in Italy, the quality of life of people in need of care, and aspects of the autonomy, participation and human dignity of care home residents.

Organisation name of lead partner

ISIS GmbH

Author(s)

Laura Annella
Carla De Lorenzo

Contributing partner(s)

Version

V01.02

Status

Final

Delivery date

07.04.2020

The European Commission's support for the production of this publication does not constitute an endorsement of the contents, which reflect the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.



Table of contents:

1. Aims of the national report	4
2. Methodology and proceedings	4
3. Summary of research results for the topics under study	6
3.1 The aging of the population in Italy: some data	6
3.2 National and regional long-term care systems and quality assessment	6
3.3 Quality of life of old people in need of care	7
3.4 Autonomy, participation and human dignity of care home residents	10
3.5 Examples of good practices and suggestions	17
4. Quotes	19
4.1 Autonomy	19
4.2 Social Participation	19
4.3 Human dignity	20
4.4 Other aspects	21
5. Sources	22

Annex: Revised draft thematic grid

1. Aims of the national report

In the debate of long-term care, a paradigm shift from quality of care to quality of life has been made over time. The perception of quality of life is subjective and based on both biographical and environmental factors. Unlike quality of care, which can be assessed by measurable indicators, quality of life is characterized by soft factors with individually varying importance. The WHO defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. Against this background, long-term care is defined in this project as a system by which a person with care and nursing needs can maintain the highest possible quality of life, ensuring self-fulfilment through independence, participation and human dignity.

The Intellectual Output of the research phase is a compendium on standards for the quality of life of care home residents that intends to serve as a basis for transferring know-how and create awareness among paid staff in direct contact with people in need of care, volunteers and committed relatives. The compendium reflects the state-of-the-art in theory and practice on these three dimensions with corresponding themes, criteria and indicators for the quality of life of care home residents.

Research on the current state-of-the-art in research and the public debate in each partner country provided the basis for the compendium. This national report describes the research activities and summarize the main results for Italy. Together with results of other national reports, they are integrated into a European compendium on standards of quality of life in care home settings.

2. Methodology and proceedings

In order to achieve the above-mentioned aims, the following methods were applied:

- Desk research in each country concerning the state-of-the-art and public debate on ensuring autonomy, social participation and human dignity of care home residents;
- Face-to-face or telephone interviews with relevant experts or stakeholders in fields relevant for the quality of life of care home residents.
- Revision of the draft thematic grid for the compendium by the lead partner of IO1 with preliminary examples for criteria, their rationales and exemplary indicators.

During desk research, key words for the internet search, cross-linking themes and target groups were applied in Italian and English. Themes included terms for quality of life, autonomy, participation and human dignity; as regards target groups, terms for care home residents, old people in need of care and not self-sufficient persons were used.

Lead questions for interviews with experts and stakeholder were agreed upon in the kick-off meeting; they were altered and adapted corresponding to the functions, expertise and personal background of the interviewees. The lead questions embrace the following topics:

- What influences, according to your opinion, the quality of life of old people in care homes?
- Let us at first discuss matters of the personal autonomy of care home residents. Autonomy includes personal independence and freedom of will in one's actions.



- In which way - separate from health issues - may the personal autonomy of care home residents be restrained?
- Why is this the case?
- How can the personal autonomy of not self-sufficient people in care homes be promoted by nursing staff?
- How can their personal autonomy be promoted by volunteers or relatives?
- The social participation of care home residents is another crucial area for their quality of life.
 - In which way - separate from health issues - may the social participation of care home residents be restrained?
 - Why is this the case?
 - How can the social participation of not self-sufficient people in care homes be promoted by nursing staff?
 - How can their social participation be promoted by volunteers or relatives?
- Human dignity is an overarching issue of high relevance for care home residents.
 - In which areas may the human dignity of care home residents be at risk?
 - Why is this the case?
 - What can and should nursing staff do to ensure the human dignity of care home residents?
 - What can and should volunteers and relatives do to respect their human dignity?
- Do you know about examples of good practice how the quality of life of care home residents was improved? If yes, please describe them.
- Are there any further recommendations how paid staff, volunteers and relatives can contribute to the quality of life of care home residents?

According to the research plan, seven expert interviews were carried out. Two interviews were performed face-to-face, five interviews by e-mail.

In order to analyse different perspectives, stakeholders and experts were selected as follows:

- 2 old people residents in care homes managed by ASP Città di Bologna;
- 1 certified activities director (in Italian “animatore sociale”) in a care home;
- 1 geriatrician active in care homes;
- 1 representative of ARAD (Association for Research and Assistance of Dementia) association active in Bologna and promoting projects on healthy and pathological aging;
- The General Director of “Santa Clelia Barbieri”, foundation that provides residential and day-care services for older people and disabled in need of care;
- The Health and Welfare Councillor of Bologna Municipality.

Desk research was performed by CADIAI while interviews were conducted by ASP Città di Bologna.

3. Summary of research results for the topics under study

3.1 The aging of the population in Italy: some data

Population aging is one of the main social transformations of our time. In Italy the older adults' population is constantly increasing along with many related diseases and disabilities. Among EU countries, Italy has one of the oldest populations with the highest life expectancy, while non-healthy life expectancy has recently increased (Tediosi and Gabriele, 2010). Data from the National Institute of Statistics (Istituto Nazionale di Statistica, ISTAT) reveal that in 2019 in Italy individuals aged 65 and older represent 23.1% of the population (equal to 13.9 million people). This figure is expected to grow to 34.3% by 2050. In the same way, the so-called *Ageing index* will also grow, i.e. the percentage ratio between older population (aged 65 and over) and the younger population (aged 15 and under). This value, which today is 173.1%, will reach 283% in 2050, therefore indicating that there will be almost 3 people aged 65 and older for each young person up to the age of 14 (ISTAT, 2019; 2020). The consequences of this progressive aging of the population are giving a new structure to the Italian population and its needs, with effects that affect most of the sectors of society. Among the most significant consequences of aging is the growth in the health and social-care needs of frail individuals, with around 4 million non-self-sufficient older people present in Italy. This rate is expected to reach 6.3 million of people in 2028 (Osservasalute report, 2018).

3.2 National and regional long-term care systems and quality assessment

The Italian national health-care system is public and universal: it covers all citizens independently from their economic and social conditions. Italian regions and autonomous provinces differ in economic, social and demographic terms. Long-term care in Italy is therefore characterized by a wide variation among regions and areas in both funding levels and the structure of the services provided. In Italy, rather than one national long-term care system, there are many regional long-term care systems (Tediosi and Gabriele, 2010).

The legal framework defining minimum standards and requirements for running care homes or other long-term services are under nation responsibility in Italy. The Italian Ministry of Health defines the "*essential levels of assistance*" that National Health Service must guarantee, and then the Regions have the responsibility for the organization and administration of health-care financed through public funds by the local health authorities. In Italy a unique national framework legislation was adopted "to realize an integrated system of health and social care" (L.328/2000). This resulted in a partnership of most regions, which had to adopt and implement this regulation, to coordinate issues of quality and accreditation in social and health care, and in the development of criteria concerning the management of care paths, discharge management, training and quality assurance (Di Santo and Ceruzzi, 2009). Italian regions and autonomous provinces use programs such as accreditation, a form of external assessment of quality and safety, to assess, promote and maintain high quality and safe services. Minimum standards for the authorization and accreditation of care homes includes requirements such as accessibility, the employment of a coordinator and qualified professionals (specified by regional authorities in terms of staffing levels), individual care planning



and publication of a Service Charter. Regional variations are therefore inevitable but they result in relatively similar regulations. As an example, in Emilia Romagna's care homes staffing ratios were set at 1:3.1 persons with a moderate degree of disability, 1:2.6 persons with a severe degree of disability, 1:2 persons with high health and care needs or serious behavioural disorders; single rooms must have at least 12m², while double rooms at least 18 m² (Dgr 514/2009; OECD/European Commission, 2013).

Local health authorities promote systematic audit activities to enhance self-assessment of professionals and improve clinical practice. "Audit" activity for aged residential facilities is a widely used tool for assessing and improving quality and effectiveness of social-health care services. It consists in: comparison of specific outputs/result indicators to international standards, identification of critical issues that may hinder the achievement of these standards and implementation of specific interventions, final assessment of the obtained results. Many of such auditing activities follow the Italian Dementia National Plan, formulated in October 2014 by the Italian Ministry of Health in close cooperation with the Regions, the National Institute of Health and the three major national associations of patients and carers. The Plan provides directive indications for promoting and improving interventions in the dementia field, not limiting to specialist and therapeutic actions, but particularly focusing on the support of patients and families throughout the pathways of care. Four main objectives are indicated: promote health- and social-care interventions and policies; create/strengthen the integrated network of services for dementia based on an integrated approach; implement strategies for promoting appropriateness and quality of care; improve the quality of life of persons with dementia and their families by supporting empowerment and stigma reduction (Di Fiandra et al., 2015).

Since quality services mainly depends on well-trained professionals, regional accreditation system requires to provide continuous training of care workers and all paid staff. CADIAI provide specific educational programs held by experts, about all relevant and updated interventions in dementia care and management. At least 12-15 hours of training per year are provided (and paid) to each worker. The "audit" activities proposed by the local health agencies are also considered additional training opportunities in which our organizations are required to participate.

This national report has been realized by CADIAI and ASP Città di Bologna, providers of personal care services both operating in Emilia Romagna according to the quality standards defined by the regional law on the accreditation of social and health services (Dgr 514/2009).

3.3 Quality of life of old people in need of care

The research community has accepted no definitive theoretical framework of quality of life but there is a strong agreement on its multifactorial structure that takes into account both subjective and objective dimensions whose importance varies according to the wishes and needs of the individual and the stages of its existence (Cantarella et al., 2019).

There is also no consensus on a definition of quality of life in older age, whether among the younger, fit elderly population or among the frailer elderly population. Arnold (1991) pro-



posed that quality of life assessment in frailer, older people should include physical functioning and symptoms, emotional, behavioural cognitive and intellectual functioning, social functioning and the presence of social support, life satisfaction, health perceptions, economic status, ability to pursue interests and recreation, sexual functioning, energy and vitality. Darnton-Hill (1995) also emphasized the importance of income in determining life expectancy and quality of life in older age.

Lawton (1983) offers a conceptual model of well-being in older people (later changed with the term “quality of life”) as a complex collection of four interacting domains: *behavioural competence* (e.g. measured by indicators of health, cognition, time use and social behaviour), *perceived quality of life* (e.g. measured by the individual’s subjective evaluation of each domain of life), *psychological well-being* (negative and positive affect) (e.g. measured by indicators of mental health, cognitive judgements of life satisfaction, positive-negative emotions) and the external, objective (physical) environment (e.g. housing and economic indicators). Such models acknowledge the importance of the individual’s own sense of performance and well-being, in addition it is still popular and remains firm over more than 20 years.

A periodic national survey on the quality of life, health and perception of services in old age, reveal that in Emilia Romagna region 42% of aged 64 and over (more than 1 million people) reports feeling well or very well, 47% fairly well and remaining 11% bad or very bad. At a national level the values are respectively: 37%, 50% and 13%. In line with the cited literature people reporting a better perceived quality of life are aged 75 and under, male, have no financial difficulties and good health conditions. In contrast, people reporting a worse perceived quality of life are aged 84 and over, female, have financial problems, are in frail conditions or in need of care. 17% reported being not satisfied at all with their lives, confirming as detrimental factors: female gender, serious economic difficulties and a state of frailty or disability (Passi d’Argento, 2016-2018). A comparative research between Turkey, Spain and Italy on the living standards of residential care centres show that dependency in daily life activities, chronic diseases (combined with the onset of cognitive impairments) may lead to institutionalisation more likely in Italy than in the other two countries (Canatan and Yildirim, 2015). In general, research tends to identify lower levels of psychological well-being and quality of life for older people residents in institutions compared to peers residing at home (for a systematic review, see Bradshaw et al., 2012). There is a wide-spread belief that people with dementia and a high level of physical and cognitive impairment cannot experience a good quality of life (Hoe et al., 2006); and it has been demonstrated that mood disorders and environmental factors could affect quality of life regardless of dementia severity (Hoe et al. 2005; 2006).

Within dementia research, it is also well known that when assessed by proxy raters (staff and relatives), quality of life is judged as lower than self-rated values (Hounsome et al. 2011). In fact, Griffiths and colleagues (2020) show that people living with dementia in care homes rated their quality of life higher than both relatives and staff. Moreover, Robertson and colleagues (2020) recently found that proxy ratings are influenced by the rater's own context and experience of caring. While all raters reported higher quality of life when the resident had fewer neuropsychiatric symptoms, staff judged a resident's quality of life to be



significantly higher than family members did. Staff were more likely to view quality of life as synonymous with 'quality of care'. Relatives, however, had a longstanding personal relationship with the resident, their own fears, understanding and sense of loss for themselves and their relative influenced their judgement of quality of life. Some relatives felt it was impossible to have a good quality of life whilst living in a care home.

The main goal of any socio-health system should be to maximize patient well-being (Lubkin and Larsen, 1990), especially in those situations where quality of life represents a primary value and is at risk, such as in people admitted to nursing homes. Moving into a care home involves life changes that significantly impacts on an individual's quality of life. These include substantial alterations in social interactions and adapting to issues involving privacy, dignity and independence (Kane R.A., 2003). Rosalyn Kane, one of the pioneers of the study of instruments for measuring quality of life in nursing homes, identified 11 domains of the quality of life of care home residents: *comfort, security, meaningful activity, relationships, functional competence, enjoyment, privacy, autonomy, individuality, dignity, spiritual well-being* (Kane et al., 2003). These objectives must be sought by means of the pursuit of quality of care and person-centred assistance/taking charge. A systematic thematic review found four key themes that affect good quality of life in care homes: *acceptance and adaptation, connectedness, homelike environment and caring practices* (Bradshaw et al., 2012). In addition, authors of an important study in New Zealand found that resident's quality of life was significantly related to: the quality of life of co-residents, the positivity of resident about entry to long-term residential care, lower depression, but more physical ability, family contact, and emotional support (Wilkinson et al., 2012).

Our interviewed experts stated that the personalization of care pathways from the definition of nursing and medical services to leisure activities, cannot be disconnected from the in-depth knowledge of the individual (including its biography). Care home residents have to be considered, first of all, unique human beings. Giving voice to the manifest needs, but also trying with the latent ones, is the basis for a person-centred approach. The quality of life of residents mostly depends on the professionalism of the staff, a homelike environment and the connectedness with care workers.

Our interviewed residents consider social integration as a key factor of their quality of life. According to their statements, even with health problems, social interactions, presence of family members, the opportunity to create and keep friendships and take part together with pairs in leisure activities, as opposed to loneliness, strongly influence the maintenance of quality of life in care facilities.

Systematic data collection of perceived quality of life in Italian care facilities from residents' view is meagre. One reason is the settled practice that general customer satisfaction is periodically rated by residents' families, on the other hand, there is lack of quality of life assessment tools that are translated and validated on the Italian population. Very recently, researchers from the psychology of aging and longevity laboratory of the University of Padua, validated the first and innovative Italian tool for measuring the quality of life of people living in institutions (from 65 to 105 years old), named *Quality_VIA* (Cantarella et al., 2019). The tool is an "easy-to-use" interview with 34 items exploring 7 different dimensions of quality

of life according to Maslow's hierarchy of needs (1962): *basic needs satisfaction and quality of care provided, satisfaction about physical environment, satisfaction about relationships established with care staff, satisfaction about the level of participation and stimulation, privacy and self-determination, connectedness and sense of belonging, spirituality and self-actualization*. Because of its simple and clear language, Quality_VIA can be administered directly to the resident even in case of cognitive impairment (score range 13 to 30 points in the Mini Mental State Examination, Folstein et al., 1975). This tool may add more knowledge about quality of life of care homes residents in Italy. In addition, it may help in assessing the efficacy of provided psychosocial interventions (included expected outcomes of individual care plans) and quality of care within the institutions.

Results of our interviews confirmed the multifactorial structure of the quality of life in care homes. The most relevant factors that emerged from experts' statements can be summarized as follows:

- Adequacy of architectural structure, the availability and suitability of outdoor spaces;
- Organizational model applied;
- Well-trained and motivated paid staff;
- Person-centred approach, the ability to define personalized care pathways involving family members (for example in defining individual care plan);
- Empowerment of residents: promotion of individual cognitive and social abilities;
- Participation in social life in a broader sense: balancing and integrating the social activities carried out inside the care home with those offered by the local community;
- Promotion of a "culture of respect" until the final phase of life.

3.4 Autonomy, participation and human dignity of care home residents

The European Union recognizes and respects the rights of older people who are more likely to come to depend on others for care, to lead a life of dignity and independence and to participate in social and cultural life (Charter of fundamental rights of EU, art. 25).

Even when moving to a care facility, people maintain the same rights and their autonomy, participation and human dignity must be guaranteed by the institution.

Service Charter of care homes managed by CADIAI and ASP Città di Bologna specify that they must protect and promote the following rights of each resident:

- *To maintain one's own individuality and freedom*
- *To express one's own beliefs, opinions, feelings and behaviour, as long as they are not harmful to the rights of others*
- *To be cared and supported to improve/recover one's own injured abilities*
- *To develop and maintain relationships*
- *To be protected from all forms of physical and/or moral abuse*
- *To be informed about one's own state of health and the available treatment and care options, as well as medical interventions and the supporting motivations. To participate and contribute as far as possible to the concerned decisions.*



- *To express opinions, suggestions and complaints about the services received.*

The above mentioned points are in line with the rights expressed in the recent *“European Charter of the rights and Responsibilities of older people in need of long-term care and assistance”* (Eustacea Project, within the framework of the DAPHNE III programme against elder abuse, 2010).

The quality policies of CADIAI and ASP Città di Bologna care homes have been developed on the basis of residents’ rights, needs, care preferences, consistent with their lifestyle, according to a person-centred care approach (Kitwood, 1997). Our model is based on practices that guarantee and support the maintenance and enhancement of the skills and competences still preserved, even in case of advanced dementia. An individual care plan is elaborated from a multidisciplinary team adopting global and integrated interventions, which respect each resident in all his dimensions and in his dynamic relationship with the environment (Service Charter of CADIAI care homes, 2018). Our care approach aims to achieve essential goals as recommended by national guidelines for care homes and literature (Guaita et al., 2005; Bertolini and Pagani, 2011; Pagani et al., 2016) such as: preserving self-identity, maintaining continuity with one’s own biography, preserving and respecting human dignity, maintaining control and making choices, engaging in pleasant activities.

Autonomy

It is well known that the sense of autonomy and self-determination influence perceived quality of life in care homes residents. A study by Ferrand and colleagues (2014) offer evidence that old age can be fruitful and show that autonomy and relatedness need satisfaction is positively associated with indicators of well-being such as purpose in life and personal growth, considered as essential components of optimal functioning.

Autonomy, as perceived from our experts, is the precondition for overcoming frailty.

Autonomy is strictly linked to the individual level of dependency: residents often face their physical limitations and depend on others, this may decrease their feeling of competence. The majority of Italian residents in care homes declared to be fully dependent (25.7%), this rate is drastically higher compared to other countries (Turkey, 13.2% and Spain, 15.7%). The rate of full independency is less than 10% in most of the daily activities in the case of Italy. Fully dependent residents or independent residents helped by a facilitative tool are more common in Italy. The dependency in activities such as using toilet and walking is very high with the approximate rate of 35% (fully dependent) and 20% (partly dependent). Physical living standards are also crucial for residents’ autonomy such as: size of the room, room per resident ratio, ventilation, WC/baths, stairs, elevators, ramps, thresholds and doors. When asked on these elements Italian scored a general satisfaction of 78.1% (Canatan and Yildirim, 2015). Accessibility (also by wheelchair) of the living areas and proximity with residents’ rooms, “walkability” (a measure of how friendly an area is to walking) of the environments, presence of green areas and outdoor spaces, are all elements supporting residents’ autonomy.



Progression of dementia may affect quality of life since it enhances the individual level of functional dependency. Studies show that residents with a higher dependency on staff generally have a lower quality of life (Jones et al., 2015).

Eating independency, for example, is crucial in promoting residents' autonomy (with or without dementia). An Italian multicentre descriptive qualitative study show that the maintenance of eating independence for as long as possible, is ensured by a set of interventions targeting three levels: i) *environmental*, by ritualising the mealtime experience by creating a controlled stimulated environment; ii) *social*, by structuring effective mealtime social interactions; and iii) *individual*, by individualizing eating assistance (Palese et al., 2018). Authors found that these interventions derived from tacit knowledge and were offered daily in assisting eating by healthcare professionals in nursing homes. It would be beneficial to raise awareness among staff in the interventions they provide.

Since the loss of independency impairs perceived quality of life, more and more is being invested on the so called "*prosthetic model*", widely accepted in dementia care. As said by Guaita and Jones (2011): "*it identifies deficits in function in the patient and builds a 'prosthesis of care' for each individual that is intended to compensate for the lost function(s). The main goal of the prosthesis is not to regain cognition or function, but to deal with the well-being of the person, to achieve the best status in absence of distress and pain*". Along this line, specially designed environments have been proposed in most of Italian care homes. The prosthetic environment is being adapted to meet people with dementia changing needs, enhancing safety, comfort, and access, rather than stimulation. They are also called "dementia-friendly environments". A good example could be the creation of circular corridors, indoor or outdoor walking paths, tailored on individuals who continuously need to walk ("wandering"). These environments ensure safety and don't prevent walking. Furthermore, residential facilities that are "homelike environments" help to facilitate residents' adaptation, allowing a better recognition of the living spaces and links with one's own biography.

Our experts also recommended to create an environment without constraints that does not limit the need for movement of people living with dementia. The same concept of "prosthesis" is mentioned by the interviewed certified activities director when she talks about finding activities that build on remaining skills and talents.

Autonomy also refers to the decision to enter in a home care. This choice is more positive if old people in need of care come to that decision themselves. Wilkinson and colleagues (2012), found that people who regarded their move as positive were more likely to have higher quality of life. This highlights that helping the older person to make their own decision about entry to long-term residential care, may enhance quality of life. Moreover, the quality of life of other residents is likely to be important in choosing a facility.

Among conditions that may affect their personal autonomy, residents mentioned the lack of freedom in maintaining some daily habits such as: to take a walk in the neighbourhood or to make small personal purchases by themselves, bring some personal belongings to the care facility. As highlighted by the interviewed care home manager, autonomy is more restricted in those organizational models which exclude residents from decision-making. In these models the care planning is more focused on residents' health needs, while their will, desires and



expectations are less likely to be considered. The possibility of being involved in the choices related to one's own care, plays an important role in strengthen perceived residents' autonomy.

In order to ensure personal autonomy our experts stressed the importance of minimizing physical restraints, especially for people living with dementia. Residents' freedom usually may be affected by a tight organization that, although necessary, does not allow to meet individual desires. In care homes often the rhythms of the care routines are marked by fixed working time schemes and standardized interventions. Enhancing residents' autonomy is a challenging issue, it requires continuous staff training and more time devoted to the individual's care since all residents' needs change and evolve over time. The staff should be more careful when assessing residents' potential and should be more confident about their current abilities. At the same time, relationships of trust and collaboration with the family members could help the care workers to support and maintain the preserved abilities of residents. In addition our experts highlight the opportunity of training courses for family members and volunteers.

Participation

Old people in need of care may spend an important part of their life in care homes. The facilities have to become more and more resident-friendly environments, maximizing opportunities to have options and choices, the agency to make decisions and also promoting skills development and self-growth regardless of the residents' age and degree of frailty (Cantarella et. al., 2019; Baxter et al., 2019).

For the majority of older Italians the opportunity of living in an environment that encourages relationships, the sharing of common spaces and activities, the connection with the local community, is an essential quality feature of a residential facility. The analysis of some exemplars of excellence in Italian nursing homes, demonstrates the importance to create pro-relationships contexts, places, activities and projects, which are capable of generating social integration as well as providing quality services and caring practices (CENSIS national report, 2015).

Social integration, family contacts and emotional support promote positive well-being and quality of life in home care residents', this way they are less likely to be depressed (Wilkinson et al., 2012).

An active social life helps improve resident's mental health and quality of life. Meaningful activities give structure to the day for residents, which give them a sense of safety, helps with passing the time, and give a purpose to their life. There is a certain level of safety in knowing what exactly to expect from the entirety of the day. A stimulating activities program with tailored and manageable goals, encourage affirming self-identity, feeling of usefulness, adaptive and coping skills, use of technologies, cognitive and functional stimulation. It is therefore important to identify and remove the barriers to participation by clearly communicate daily activity options to all staff so they can remind residents and encourage them to attend. Encourage a feeling that the activity is useful or relevant by tailoring them on residents' desires and aptitudes. Some authors have pointed out that residents' participation in



leisure activities is influenced by their level of self-determination. (Ferrand et al., 2004). According to these findings, our institutions are periodically required to re-think and re-schedule the activities programs together with the best ways of inviting residents. Involving relatives, and volunteers could be very useful. For example, in our facilities all spiritual activities and needs are guaranteed by local church community which visit residents at least once per week.

An international project involving Australia, Norway and Sweden investigated cost-effective ways to help residents live fulfilling lives. Thriving interventions aim to help residents participate in society, enjoy a decent quality of life, and experience healthy, pleasurable activities and meaningful social participation. Findings have shown that resident thriving was associated with engagement in everyday activities in the facility, spending time outdoors, dressing nicely and spending time with people they liked. On the flipside, predictors of poorer resident thriving included a lower capacity for activities of daily living, cognitive impairment and behaviours of concern (Edvardsson et al., 2018).

Residents of our care home are given the opportunity to participate in local events, as well as in outdoor trips, and intergenerational programs. They are supported in participate in political events exercising the right to vote inside the facilities.

Our interviewed experts and residents generally agree with the idea of a close connection between the quality of care and social integration. As suggested by some of them, the individual care plan should include specific interventions aimed at maintaining social relations. Time and effort should be devoted to the social sphere of the individual as part of the care process.

From the point of view of care professionals, time constraints and staff shortages are at odds with the possibility of adequately addressing the social dimension.

The organisation of social events is challenging, and their success depends on the involvement and collaboration of all staff. Participation in social life can be limited in different ways: for example, by creating constraints such as limited visiting hours or lack of space to spend time with family, volunteers and friends.

Social participation can be improved through a real teamwork and better coordination and communication between all staff involved in care. Well-trained staff are needed to develop the most appropriate strategies. The activities must be meaningful and chosen by the participants, not just recruited as the right ones by the certified activities director. The personal skills of residents can be identified, considering their interests, wishes and past work, and the specific tasks entrusted to them, to promote their feeling of usefulness. Social interactions can be encouraged by promoting the participation of residents in the social life of the local neighbourhood, in close collaboration with external institutions and associations.

Gender differences must also be considered. Women particularly love to take care of themselves. Therefore, helping them in make-up and in dressing up for an event can promote their social participation. Men should also be encouraged to take care of their appearance and clothing. Isolation must be avoided by supporting, even in the most serious cases of ill-

ness, passive participation or by encouraging the use of technological tools to overcome physical and/or cognitive deficits.

Relatives and friends are often valuable allies in supporting the participation of even the most apathetic people. They can also take part in social life within the facility, encouraging residents to participate. Their expertise and hobbies can foster the exchange of knowledge and relationships with care home residents.

Human Dignity

“Human dignity is inviolable. It must be respected and protected”. This right is enshrined in article 1 of the Charter of Fundamental Rights.

A recent review analyzing dignity in care from both the nurses' and patients' perspectives support the idea of a multidimensional structure of human dignity (Šaňáková, Š. and Čáp J. 2018). Contrary to the general view in society that living in a nursing home always undermines one's dignity, good professional care and a supportive social network can preserve dignity as well. To support residents in their challenge of maintaining dignity, nursing home staff, relatives and society should pay more attention to the way they treat them (Oosterveld-Vlug et al. 2014). An Italian review indicate that residents and their families desire a personalized approach by health care professionals, within a relationship based on trust, respect, and sensitivity (Mignani et al., 2017).

The services charter of our care homes (CADIAI, 2018), for example, points out some obligations:

- *the staff is required to guarantee a respectful resident-centred communication to each resident regardless of the degree of cognitive or functional impairment*
- *residents are respected in their habits and privacy, compatibly with the residence co-existence rules, however they are helped and stimulate to social integration*

The personalization of one's own room is also encouraged in our care homes as stated by our Charter of Service. Each resident can bring small objects, photographs and everything that can contribute (without prejudice to the constraints imposed by the safety regulations) to characterize and personalize his new living space.

All birthdays are celebrated, with a party for all the people born in the current month or according to the wishes/needs of the guest of honour and his family.

The concept of dignity is commonly debated in end-of-life care issues, because the majority of older people who die each year do so in a care home. In Italy palliative care legislation (L.38/2010) stated treatment of pain and palliative care to be extended to all care settings, including long-term care facilities. Within this legislative framework, thematic “audit” activities on pain treatment in care home facilities have been proposed from local health authorities. Every residential institution has been required to guarantee pain management (assessment and treatment) even in case of advanced dementia and to adopt internal protocols



about appropriate care in the last phase of life. CADIAI and ASP Città di Bologna comply with current legislation.

Some studies have investigated the residents' view about their death and last phase of life. Results show that residents think about dying and/or death, and have desires for their dying and are also willing to talk about it. Residents expressed, for example, some of following wishes: not to receive life-prolonging measures, not to have pain, not to be in need of care or bedridden, to receive affection while dying and to find forgiveness and reconciliation as well as to die peacefully in the residential and/or nursing home (Kurkowski et al. 2018). Even *Advance Care Plan* is considered a welcome intervention for the majority of Italian interviewed residents (Ingravallo et al. 2018). This evidence encourages organizations to promote an end-of-life culture and the training of employees.

The results of our interviews confirmed the multidimensional structure of human dignity as emerged by literature. From residents and the experts' perspective: privacy, respect for behaviour and ideas, being listened to and considered as adults, as well as the management of pain, are priority issues.

The human dignity of residents can be violated when attention is not paid to individual needs and preferences, when there is a lack of listening or when the staff is distracted. This, unfortunately, happens when rigid timeframes, work shifts and tiredness force the staff to a high pace, which can compromise motivation and lead to shortcomings in the quality of care.

Training of staff should be more focused on communication and meta-communication skills with the aim of preserving the dignity of the individual. How to deal with and communicate with residents should be part of the care culture. As suggested, the presence of a psychologist on staff is strongly recommended in order to stimulate the ability of care professionals to recognize and respect the different physical and psychological needs of residents. At the same time, a cohesive working group in which members help and support each other may enhance the quality of care. According to our experts, knowing the past biography and lifestyles, as well as the tastes and desires of the residents are all elements that preserve their dignity as unique individuals. From the manager's point of view, it might be useful to gather this information at the beginning of the residents' stay in the care home, and then schedule moments to discuss how their wishes change over time.

Our interviewed stakeholders argue that relatives and volunteers should work together with staff to give voice to the residents and combat prejudices about the quality of care in nursing homes.

3.5 Examples of good practice and suggestions

Our interviewed experts mentioned existing good practices that can be summarized as follows:

- Encouraging Non-Pharmacological therapies, such as pet therapy
- Continuous training on innovative methods and use of new technologies
- Person-centred care as a synergy between professionals, family members and volunteers
- The "*Socializing circle*": space and time devoted to listen to residents' opinions about the services and activities offered by care home
- Participation in local cultural initiatives such as cinema, theatre, museums
- Activities promoted by local institutions and active ageing associations: such as bingo, reading, personalized gifts for residents' birthday
- Intergenerational projects, promoting activities and exchanges between old and young people of the community
- The "*Community tells itself*": volunteers and family members tell stories about local cultural heritage
- The "*Charter of responsible rights of frail older people*", an ongoing activity in which ASP Città di Bologna is involved. The charter arises from the debate between different stakeholders on the issues of fragility and safety of frail older person.

Examples of projects aimed at improving the quality of life of residents carried out in care homes managed by CADIAI from 2000 to date:

- *Capelli d'Argento*, music festival with live concerts held in nearby town squares and in the care home gardens
- *Concorso di poesia de "Il Corniolo"* - Literary contest for poetries and short stories written by both residents and older people from the local community
- *Pet Therapy* at the San Biagio day care center
- *Simplified Memory Training* for persons with moderate cognitive impairment
 - *San Biagio Alzheimer Café*: care home staff providing support, information and education for persons with dementia and their family members living in the community
 - *Pet Therapy* for older people– research project in association with the Emilia Romagna regional administration
- *Il clown in RSA*: Clown-therapy activities in care homes – in association with the University of Bologna
- Pain assessment and management for persons with advanced dementia
- Simplified and ecological Augmentative/Alternative Communication for older people with cognitive impairment
- Research project in association with the University of Bologna aimed at defining an explanatory model for the assessment of dementia caregivers psychosocial needs
- Implementing the "Water Swallow Test" for a quick and reliable dysphagia screening in care homes
- Adoption of the *Nurturing Touch*, gentle body contact techniques for residents with advanced dementia



- New technologies in care homes: implementing telepresence technology to enhance communication with families
- *Le immagini raccontano*: art therapy project for care homes residents
- An action-research intervention to improve fall detection using an adapted version of the Morse Fall Scale
- Advance care planning: giving a voice to care homes residents, in association with the University of Bologna
- Granarolo *Dementia-Friendly*: building a dementia-friendly community to improve participation and social engagement of people living with dementia
- Liberi dalla contenzione – AUDIT activity proposed by the Health Local Agency of Bologna in order to avoid unnecessary use of physical restraints in care homes
- Active participation in the european project IMPACT (IMplementation of quality indicators in PAlliative Care sTudy), in association with the University of Bologna
- A retrospective study on the usefulness of bedside ultrasound ecography for residents with severe cognitive impairment
- *Valorizzare la Qualità di Vita*: using “Photovoice” techniques to improve expression and communication about residents’ perceived quality of life
- *La persona al centro*: applying a Shared Decision Making approach to involve residents in defining their individual care plan
- Sensory stimulation using *snoezelen rooms* and tactile paths in the care home

Experts also suggested some ideas for further developments:

- Pain assessment should evolve as a tool to better observe and learn more about residents, moreover pain management may help to reduce agitation of patients, and avoid pharmacological and physical restraints
- Increase staff training on relational, communicative, motivational aspects rather than just technical skills
- Investing in interventions that improve the quality of life of both residents and staff in order to overcome prejudices about care homes.

4. Quotes

4.1 Autonomy

“We have to take in consideration resources of people. The attempt is to encourage and develop residual skills by trying to be "prosthetic" without replacing.”

Certified activities director (“animatore sociale”) in care home, Bologna, Italy

“I don't like going to sleep so early. In the summer at 7:00 pm there are still many hours of light and we have to stay in bed until morning.”

Care home resident, Bologna, Italy

“I would like to have the possibility of a single room, to have more space. I had to bring a whole life into one closet.”

Care home resident, Bologna, Italy

“Architectural barriers are limiting. For example: the absence of internal places suitable for wandering for people with dementia, severely limits their need for movement.”

Representative of ARAD, Bologna, Italy

“As for relatives, it is important to involve them in a therapeutic alliance with the staff, establishing a relationship of mutual trust. The same for volunteers”

Geriatrician in care home, Bologna, Italy

4.2 Social participation

“Encouraging participation in social activities requires a close coordination. For example: to allow a non-self-sufficient person to attend an event outside, it is necessary to collaborate with the doctors and nurses so that there are no other health commitments on that day, inform the social and health workers in that shift, collaborate with the nurses to discuss any problems related to the consumption of certain foods, inform family members and involve them in the event ... in short, there has to be real teamwork!”

Certified activities director (“animatore sociale”) in care home, Bologna, Italy

“Even if I do not have children or a husband, there are my relatives for all my needs. Furthermore, I am lucky because I have many friends who come to spend time with me”

Care home resident, Bologna, Italy

“The quality of my life is good, I would be alone at home. I like this place because there is a nice garden, the bar gives me the opportunity to see people, animation activities are fun.”

Care home resident, Bologna, Italy

4.3 Human dignity

“Relatives should involve residents in decisions related to the actions that are taken, explaining them clearly. It should never be assumed that the ‘person does not understand’...”

Certified activities director (“animatore sociale”) in care home, Bologna, Italy

“The thing that hurts my dignity most is to be infantilized. A few years ago my situation was more serious and I needed everything, just like a new-born baby. It is difficult to get used to being cared for. Now the staff don't make me feel uncomfortable even in moments of most intimate care.”

Care home resident, Bologna, Italy

“Human dignity for me is first of all privacy, for example, closing doors when doing hygiene care. I feel not respected in my dignity when I express problems and I am not believed.”

Care home resident, Bologna, Italy

“People are known from the point of view of what they ‘lack’, but not for their whole life. This is a limit in the humanization of the care relationship.”

Representative of ARAD, Bologna, Italy

“When you take the place of the resident to do something or stop him/her in taking an initiative, the dignity of the individual is offended. People must also be respected when they engage in atypical and uninhibited behaviours.”

Representative of ARAD, Bologna, Italy



“Favouring anonymous suits or clothes simply because they are more practical - thus also disrespecting a person's will or taste in clothing - is a serious violation of human dignity.”

General Director of “Santa Clelia Barbieri” Foundation

“Healthcare professionals work for the well-being of people in their care. This is not repetitive work, it should rather be a comprehensive form of assistance to an adult in a state of frailty. Staff should see the person before the task to be performed.”

Health and Welfare Councillor of the Municipality of Bologna.

4.4 Other aspects

“Human closeness with the staff means a lot to me. I would like to have more time to spend together just to talk.”

Care home resident, Bologna, Italy

“The goal of all staff must be the well-being of each resident. The path we are walking with our residents can be a challenging one and we must be mindful of this. On this path, failure is a possibility. Nonetheless there is help and guidance, and we must sometimes give up our professional roles to become more welcoming. We aim at creating a “soft” prosthetic environment that can stimulate (and help maintain residual abilities) while not being over-stimulating (so as to avoid disruptive inputs in some cases). We need to make use of our professional and pharmacological expertise, while using a whole range of non-pharmacological treatments when necessary, and aiming at a person-centred approach.”

Geriatrician in care home, Bologna, Italy.

5. Sources

- Arnold, S. (1991). Measurement of quality of life in the frail elderly. In: J.E. Birren, J.E. Lubben, J.C. Rowe (eds). The concept and measurement of quality of life in the frail elderly. San Diego CA: Academic Press, 1991.
- Baxter, R., Sandman P.O., Björk, S., Lood, Q., Edvardsson, D. (2019). Illuminating Meanings of Thriving for Persons Living in Nursing Homes, *The Gerontologist*, gnz142
- Bertolini, L., Pagani, M. (2011). Qualità della vita o qualità della cura? *Psicogeriatrics*, 2:71-80.
- Canatan, R. and Yildirim, D. (2015). Rights of Elderly People and Care Services: A Comparative Study between Turkey, Italy and Spain, YÖRTÜRK Foundation, Ankara.
- Cantarella, A., Borella, E., De Beni, R. (2019). La valutazione del benessere psicologico e della qualità di vita nelle residenze per anziani. Franco Angeli ed.
- CENSIS (2015). L'eccellenza sostenibile nel nuovo welfare. Modelli di risposta top standard ai bisogni di tutela delle persone non autosufficienti. Il piano della cultura sociale e collettiva. Analisi socio-economica e istituzionale del fenomeno. Rapporto Censis.
- Darnton-Hill, I. (1995). Healthy ageing and the quality of life. *World Health Forum*, 16:335-343.
- Di Fiandra, T., Canevelli, M., Di Pucchio, A., Vanacore, N. (2015). Italian Dementia National Plan Working Group. The Italian Dementia National Plan. Commentary. *Ann Ist Super Sanita*, 51(4):261–264.
- Edvardsson, D., Sjögren, K., Lood, Q. et al. (2017). A person-centred and thriving-promoting intervention in nursing homes - study protocol for the U-Age nursing home multi-centre, non-equivalent controlled group before-after trial. *BMC Geriatr*, 17, 22.
- European Union, Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02. <https://www.refworld.org/docid/3ae6b3b70.html>
- EUSTACEA Project, Daphne III Programme (2010). European Charter of the rights and responsibilities of older people in need of long-term care and assistance. Age Platform Europe. https://www.age-platform.eu/sites/default/files/European%20Charter_EN.pdf
- Ferrand, C., Martinent, G., Durmaz, N. (2014). Psychological need satisfaction and well-being in adults aged 80 years and older living in residential homes: Using a self-determination theory perspective. *J Aging Stud*. Aug;30:104-11.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189–198.
- Griffiths, A.W., Smith, S.J., Martin, A., Meads, D., Kelley, R., Surr, C.A. (2020). Exploring self-report and proxy-report quality-of-life measures for people living with dementia in care homes. *Qual Life Res*. 29(2): 463–472.
- Guaita, A. (2005). Linee guida della SIGG per le RSA. Società Italiana di Geriatria e Gerontologia. Reperibile sul sito <http://www.sigg.it/>

- Guaita, A., Jones, M. (2011). "Prosthetic" approach for individuals with dementia? *JAMA*;305(4):402-3
- Hounsome, N., Orrell, M., & Edwards, R. T. (2011). EQ-5D as a quality of life measure in people with dementia and their carers: Evidence and key issues. *Value in health*, 14(2), 390–399.
- Ingravallo, F., Mignani, V., Mariani, E., Ottoboni, G., Melon, M.C., Chattat, R. (2018). Discussing advance care planning: insights from older people living in nursing homes and from family members. *International Psychogeriatric*, 30, pp. 569 – 579.
- Istituto Nazionale di Statistica ISTAT. (2018), Il futuro demografico del paese. Previsioni regionali della popolazione residente al 2065 (base 1.1.2017)
- https://www.istat.it/it/files//2018/05/previsioni_demografiche.pdf
- Istituto Nazionale di Statistica ISTAT (2020), Indicatori demografici anno 2019
https://www.istat.it/it/files//2020/02/Indicatori-demografici_2019.pdf
- Istituto Nazionale di Statistica ISTAT (2020). Rapporto Annuale 2019. La situazione del Paese.
<https://www.istat.it/storage/rapporto-annuale/2019/Sintesi2019.pdf>
- Jones, R.W., Romeo, R., Trigg, R., Knapp, M., Sato, A., King, D., et al. (2015). Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: the DADE study. *Alzheimer's & Dementia*. 11(3):280–290.
- Kane R.A. (2003). Definition, Measurement, and Correlates of Quality of Life in Nursing Homes: toward a reasonable practice, research, and policy agenda. *The Gerontologist*; 43 Special Issue II: 28-36.
- Kane R.A., Kling, K.C., Bershadsky B., Kane R.L., Giles K., Degenholtz H.B., Liu J., Cutler L.J.(2003). Quality of life measures for nursing home residents. *J Gerontol A Biol Sci Med Sci* 58(3):240-8.
- Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham.
- Kurkowski, S., Heckel, M. & Volland-Schüssel, K.(2018). [Wishes of nursing home residents for their dying]. *Z Gerontol Geriat* 51 (8): 912-920.
- Lawton, M.P. (1983a). Environment and other determinants of well-being in older people. *Gerontologist*, 23: 349-357.
- Lubkin I.M., Larsen, P.D. (1990). *Chronic illness impact and intervention*. Jones and Bartlett Publishers, 1990.
- Maslow, A. (1962). *Toward a psychology of being*. Van Nostrand, New York.
- Mignani, V., Ingravallo, F., Mariani, E., Chattat, R. Perspectives of older people living in long-term care facilities and of their family members toward advance care planning discussions: a systematic review and thematic synthesis. *Clin Interv Aging*. 2017;12:475–484.
- OECD/European Commission (2013), *A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care*, OECD Health Policy Studies, OECD Publishing.
<http://dx.doi.org/10.1787/9789264194564-en>



- Osservatorio Nazionale sulla Salute nelle Regioni Italiane (2019), Rapporto Osservasalute 2018. Stato di salute e qualità dell'assistenza nelle regioni italiane. Report, <https://www.osservatoriosullasalute.it/wp-content/uploads/2019/05/ro-2018.pdf>
- Palese, A., Bressan, V., Kasa, T., Meri, M., Hayter, M., Watson, R. (2018). Interventions maintaining eating Independence in nursing home residents: a multicentre qualitative study. BMC Geriatr. Nov 27;18(1):292.
- Pagani, M., Grillo, A., Franchini, R., Ivaldi, C. (2016). La Residenza Sanitaria Assistenziale. Psicogeriatrics. 3: 69-77.
- Regione Emilia Romagna: "I dati Passi d'Argento 2016-2018 in Emilia-Romagna" <http://salute.regione.emiliaromagna.it/sanita-pubblica/sorveglianza/passi-dargento>
- Tediosi F., Gabriele S., (2010). The Long-term Care System for the Elderly in Italy, ENPRI Research Report N. 80, June 2010.

Legal references

- L. 328/2000: Legge quadro per la realizzazione del sistema integrato di interventi e servizi sociali. Gazzetta Ufficiale della Repubblica Italiana n. 265 del 13 novembre 2000 - Supplemento ordinario n. 186. <https://www.gazzettaufficiale.it/eli/gu/2000/11/13/265/so/186/sg/pdf>
- Dgr 514/2009: Primo provvedimento della Giunta regionale attuativo dell'art. 23 della L.R. 4/08 in materia di accreditamento dei servizi sociosanitari. <http://salute.regione.emilia-romagna.it/normativa-e-documentazione/leggi/regionali/delibere/dgr-514-2009>
- L. 38/2010: Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore. Gazzetta Ufficiale della Repubblica Italiana n. 65 del 19 marzo 2010. <https://www.gazzettaufficiale.it/eli/gu/2010/03/19/65/sg/pdf>