GAMLEC
LEARN TO PLAY – PLAY TO LEARN

Gaming for
Mutual Learning in Elder Care
GAMLEC

European compendium on criteria for the quality of life of care home residents: National report for Germany

Document information

This document contains research results on long-term care in Germany, 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)

Karin Stiehr and Jesper Schulze

Version

V01.02

Status

Final

Delivery date

13rd April 2020

The results of the Erasmus+ project GAMLEC consist of this national report (part of the Compendium), a Compendium, of the rules of the learning board game for the game version without Game Coach, of the rules of the learning board game with Game Coach, of the guide to the design of format of the card content, of the learning game cards for adults about the quality of life of nursing home residents, the learning goals, and objectives of the learning board game, an instruction manual for the game version with Coach, an Educational Framework, Guidelines for the learning board game, and an interactive E-learning platform. The results are available in English, German, Italian, Dutch and Lithuanian at www.gamlec.eu.

Table of contents

GAMLEC
LEARN TO PLAY - PLAY TO LEARN

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

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 Germany. 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 German 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?

GAMLEC
LEARN TO PLAY · PLAY TO LEARN

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

- 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?

In accordance with the research plan, seven expert interviews were carried out. Four interviews were performed face-to-face, two interviews by telephone and one interview by email. The interview partners were comprised by a municipality counsellor for older people and their relatives, a head of social services, a social worker and a volunteers in care facilities, and a volunteer committed to various projects for and by older people. Besides these experts who reported from a more hands-on perspective, we discussed the topics with two employees from two lobby organisations: the Heimverzeichnis, publishing care homes with proven life quality for their residents on the internet, and BIVA-Pflegeschutzbund, an associations to protect persons in need of care.

3.   Summary of research results for the topics under study

3.1   Context of long-term care

How to ensure healthy ageing and long-term care also with view to the future are essential challenges in Germany and Europe. In its report "Global Strategy and Action Plan on Ageing and Health", the WHO states that the massive problem of an ageing society must be addressed (WHO, 2017). On one side, due to innovations and improvements in the area of

healthcare services, the expected number of healthy life years has constantly increased in the EU, between 2010 and 2017 for women from 62,6 to 64,0 and for men from 61,8 to 63,5 years. Nevertheless, persons aged 65 or over are frequently facing long standing illnesses or health problems that may reduce their life quality. This ratio has been quite stable over the past years at approximately 61% and can be considered a function of age. While this ratio in the age group 64-74 in 2017 amounted to 56,9%, it is 66,9% in the age group 75-84 and 72,5% for people 85 or older (Eurostat, 2019, p.60).

With the rising life expectancy, chronic and dementia-related diseases will increase in all European societies and lead to specific demands. Big hope is placed in technical solutions to solve existing practical and financial problems. However, health care currently will always include a high demand for human attention and manpower.

When the definition of the Germany Nursing Insurance Act is applied, about 2,6 million people in Germany were in need of care in 2013. The nursing quota (dependent persons in per cent relative to the respective age group) increases strongly with increasing age. Only one in twenty persons between 70 and 75 years is in need of care, compared to almost two-thirds of persons 90+. Women have a higher life expectancy but experience more years of multi-morbidity and dependency than men. Also the proportion of long-term care in-patients is significantly higher for old and very old women than for men of the same age (Robert-Koch-Institut).

A particular challenge for patients, their families and the health care system in general is the high number of dementia cases. About 1.4 million people in Germany live with dementia (Robert Koch Institute, 2015, p.413). Care for dementia patients is extraordinarily labour-intensive. An average care time of 6,5 to 10,5 hours per day is assumed (Robert-Koch-Institut, 2015, p. 442). Usually, the disease cannot be cured with the condition continuously worsening over time. The Federal Ministry of Health writes about therapy options: "A variety of treatments aim to train the patients' remaining abilities and strengthen their self-esteem. These include music and art therapy, movement exercises or sensory and perception exercises such as 'kim games' in which players are blindfolded and have to guess objects by touch or smell. It is important to focus on the patients' existing abilities and needs, take into account their life history background and avoid pressure to perform. Occupational therapy tailored to the specific situation of the patient can also help patients with mild to moderate dementia to maintain their everyday functions" (Bundesministerium für Gesundheit, 2020).

As of November 2019, new measures to assess and document the quality of care, also in residential settings, became effective. Public reporting will be based on 1) general information about the facility, 2) quality data collected by care homes on pre-defined criteria, 3) random quality checks by the Medical Service of Health Insurance Funds. Inpatient care facilities will have to collate the data every six months and forward them to an evaluation centre. Data is also provided on topics that are relevant not only for the quality of care but also cover aspects of the quality of life of care home residents.

Data provided by care homes include:

1. Maintained mobility
2. Maintained independence in everyday activities
3. Preserved independence in the design of everyday life and social contacts

GAMLEC
LEARN TO PLAY - PLAY TO LEARN

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

4. Development of pressure ulcers
5. Serious fall consequences
6. Unintentional weight loss
7. Conducting an integration discussion
8. Use of belts to fix residents
9. Application of bed side parts
10. Timeliness of the pain assessment

Data by external random checks are provided on:

1. Mobility and self-sufficiency
1.1 Mobility support
1.2 Support for eating and drinking
1.3 Support for loss of continence, promotion of continence
1.4 Personal hygiene support

2. Illness and therapy-related requirements and stress
2.1 Assistance with taking medication
2.2 Pain management
2.3 Wound care
2.4 Support for special nursing needs

3. Support in shaping everyday life and social contacts
3.1 Support for impaired sensory perception
3.2 Support in structuring the day, employment and communication
3.3 Care at night

4. Special needs and supply situations
4.1 Support for the familiarization phase after the move
4.2 Transfer during hospitalization
4.3 Supporting residents with challenging behaviour
4.4 Application of deprivation of liberty

5. Accompaniment of dying residents and their relatives

In addition to the compulsory checks by the Medical Service of Health Insurance Funds, the Heimverzeichnis gGmbH, an associate partner of the GAMLEC project, is offering the assessments of the quality of life of care home residents by trained volunteers. As this evaluation is subject to charges and voluntary, only a small minority of care homes (currently approx. 7%) is making use of this offer.

The unanimously shared guiding principle for nursing is to ensure the greatest possible autonomy and quality of life. Problems, however, arise in its realization.

3.2 Quality of life of old people in need of care

In the scientific discourse, a widely shared understanding of quality of life in old age is that it is realized in the interaction between a person and his or her environment, depends substantially on the resources and potentials of the person concerned and can be promoted by positive framework conditions.

GAMLEC
LEARN TO PLAY - PLAY TO LEARN

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

The influence of age on the quality of life, however, is issue of debates. Compared to personal independence and social relationships, Kratzer (2011) considers age as ineffective factor. Wiese (2015) on the other hand, described self-sufficiency in contrast to depression and multi-morbidity as important factors influencing quality of life, whereas marital status, socio-economic status, education, nutrition and ethical affiliation tend to play a subordinate role. A consistent orientation towards the paradigm of active aging takes place in studies and projects that focus on aspects of learning and commitment to the community - the right to engage in meaningful activities - also in old age and in the event of functional limitations.

Although quality of life can be experienced at any age, advanced age not only increases the risk of partner loss but also favours the onset of age-specific functional limitations and disease. Dementia is the most common chronic disease in persons of old age. It not only reduces the quality of life of the person concerned, but also the family environment. Numerous studies and projects (see, inter alia, Menzi-Kuhn 2006 and Adler et al. 2009) deal with the topic of how dementia patients and their relatives perceive quality of life and how it can be maintained.

According to Gonzales-Salvador et al. (2000) people with dementia have a higher quality of life in people in sheltered housing than in nursing homes. Another study identified the presence of depression, neuropsychiatric manifestations such as aggression, apathy, irritability and anxiety, as well as limitations in the ability to perform daily activities and a poor physical health as the most important factors influencing the quality of life for people with dementia (Seeberg 2014). In this context, Schneekloth and Wahl (2007) arrived at the conclusion that medical or non-medical intervention targeting at non-cognitive symptoms, such as depression, agitation, apathy and lack of drive, has a positive effect on the quality of life of people with dementia.

The results of the research project „Möglichkeiten und Grenzen selbstständiger Lebensführung in stationären Einrichtungen" (Possibilities and Limitations of Independent Living in Residential Institutions) suggest a suitable therapeutic milieu and the special qualification of all staff in direct contact with dementia patients. Further, an increased involvement of relatives and volunteer work is recommended to promote mobility and independence (Schneekloth/Wahl 2007). The project "ReduFix" dealt in this context with the reduction of freedom-restricting means such as immobilization by psychotropic drugs, body fixation, and unneeded bed lattices, as this a massive intervention in representing human rights (Klie et al. 2008 and 2010); in addition to that, the concept of the DEMIAN project aims to provide emotional support to people with dementia (Berendonk et al. 2011).

Motel-Klingebiel et al. hinted already in 2002 to the need for supportive mixes for the realization and maintenance of quality of life in old age. The realization of quality of life in old age and in need of care crucially depends on how individual potential can be realized in the context of structures and processes in service provisions. These potentials are different in people with care and nursing needs due to physical, sensory or mental impairments. Consequently, they also require different framework and environmental conditions in order to unfold.

A nationwide survey on quality of life in old age and in need of care (Stiehr et al. 2016) gave a voice to older people with and without care needs in their home environment and care facilities. With regard to the factors influencing the quality of life, health in the sense of mental

GAMLEC
LEARN TO PLAY - PLAY TO LEARN

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

and physical well-being was considered by the majority of the survey participants as crucial. For a strong minority of nearly 40%, however, health was important, but not necessarily most important. Harmonic relationships with others, above all, with a permanent partner, spirituality, contentment and the feeling of being at peace with one another, are powerful influencing factors that can put the meaning of health into perspective. In particular, a higher level of education seems to lead to health not being considered the most important prerequisite for quality of life.

Other very important influencing factors for the realization of quality of life are self-determined decisions, independence, the respect of others, the preservation of dignity and a home that ensures well-being and privacy. With increasing age, being needed by others, having family around, being materially secure, finding rest, feeling safe, and leading a spiritual life appears to become more relevant for one's quality of life. Men who, more often than women, still live in a solid relationship in old age, emphasize the importance of a loving relationship; women on the other hand, seem to have adjusted their expectations to the low probability of finding a new partner in old age. While low-skilled people often focus on material security issues, meaningful activities are in many cases the key to quality of life for highly educated people.

As long as moving to a care facility can be avoided by assistance at home, the influence of these offers on one's own quality of life is positively assessed by the majority of respondents. The situation is different when need for help requires a life in an institution. Very positive comments on its impact on the quality of life are in contrast with many statements that it affects the quality of life negatively. The breadth of the assessment of identical aspects suggests that this reflects the quality differences in performance and that there is still considerable potential to improve structures and processes in care homes considerably.

Our interviewed experts overall agree with the findings from literature. According to their statements, fundamental factors influencing the quality of life in care homes can be summarized as follows:

- Architectural design: Single rooms with an own bathroom ensure privacy, and easy access to all community rooms should be possible for people with restricted mobility. Own furniture and personal items should be allowed.
- Person-centred care: The human being should be in the focus of care, not an efficient work flow. The time budget of paid staff should allow for personal relations, for an encounter at eye level. Personal preferences and aversions should be respected.
- Promotion of personal potentials: These potentials should be maintained and promoted by adequate therapeutic and social offers. Care homes offer many opportunities to make new friends and take on meaningful tasks.
- Active involvement of volunteers and relatives: Besides support which they can render within the care facility, they ensure relations towards the neighbourhood and the former circle of friends and acquaintances.

3.3 Autonomy, participation and human dignity of care home residents

The studies mentioned above refer to autonomy often in terms of independence, self-efficacy, and self-determination. Participation is described a result of personal and social

GAMLEC
LEARN TO PLAY – PLAY TO LEARN

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

relationships as opposed to loneliness. The following research results reveal the varying perspectives of different stakeholders.

Autonomy

In a recent US American research piece on factors influencing autonomy of nursing home residents with dementia, family caregivers were asked about conditions that may improve or impede autonomy. A person-centered approach, the ability to hold on to family traditions in the nursing home, the ability to bring personal belongings of the residents to the nursing home, and the resident being involved in meaningful activities, were considered important in maintaining autonomy. Barriers to autonomy that were mentioned by family caregivers were frequent changes in care staff, restriction in resident freedom of movement, lack of time for person-centered activities, lack of personal attention, having to adapt to the needs of other residents, and offering group activities that do not sufficiently suit resident interests (Hoek et al. 2018).

In another study, English care home managers were queried on their attitudes to balancing risk and autonomy for residents with dementia. There were three areas in which care home staff reported balancing safety and risk against the individual needs of residents. First, the physical environment created a tension between safety and accessibility to the outside world, which meant that care homes provided highly structured or limited access to outdoor space. Second, care home managers reflected a balancing act between an individual's autonomy and the need to protect their residents' dignity. Finally, care home managers highlighted the ways in which an individual's needs were framed by the needs of other residents to the extent that on some occasions an individual's needs were subjugated to the needs of the general population of a home (Evans et al. 2018).

Evidence suggests that healthcare personnel act in what they consider the best interest of older people but still exclude them from decision-making in everyday care. Against this background, interviews were carried out with Swedish nurses. From their perspective, the awareness of older people's frailty in nursing homes and the importance of maintained health and well-being were described as the main source for promoting autonomy and participation (Hedman 2017).

The need for a change in care homes culture was emphasized by a Swedish study based on older people's experiences. Three themes emerged showing how autonomy was not a reality for the residents. The first revealed an ambivalent mission, indicating ambiguity as to whether the nursing home was a place to live in or a place in which to be cared for. The second theme was symbolic power, which encompassed the staff's power embedded in the organization. The third theme was an ageist approach to care, which was noted in the way staff considered the residents to be old people who were unable and unwilling to strive for autonomy. The three themes were embedded in the organizational culture and were created and recreated in the interaction between residents and staff (Wikström and Emilsson 2014).

Our interviewed experts confirmed the above-mentioned Swedish findings when asked for reasons why personal autonomy in care homes can be restricted.

- Care homes not being places to live but being cared for: Especially modern care homes strive for technical perfection. Bath-rooms are oversized to allow for wheelchairs, but

space is saved in living rooms. Hence old people can only bring only a few personal items to the care facility. Further, as life in care homes is organised according to pre-set time schemes, personal preferences as regards times for sleeping, eating and personal hygiene are seldom respected.

- Attitudes of nursing staff: Staff in care homes is usually underpaid, overburdened and may lack the knowledge on how to deal adequately with dependent old persons. Help for self-help in order to increase autonomy requires time that is often not available, given the shortage of personnel in the care sector.
- Indifference of old people: Too often it is assumed that old people in need of care are not interested any more in their environment, in reading newspapers, socializing and activities for which they may need support.

Some of our experts conceded that nursing staff is principally ready to provide good care, also in terms of personal autonomy. But concepts and management procedures must provide the necessary framework conditions. Biographical data, including daily routines, hobbies, likings and aversions, should serve as an orientation to render support. In Germany, residents of care homes are represented by Home Councils; their members should be involved in all important decisions, including menus, events and other community actions. One basic prerequisite for all support measures is, however, that care home residents are considered adult persons whose opinions are taken seriously.

Relatives and volunteers also play an important role. They can strengthen the position of the old person in need of care, act as whistle-blower, if needed, or simply invest time that cannot be rendered by paid staff. Some experts highlight the necessity of trainings to prepare and accompany volunteers in care homes. Like paid staff they must be aware that they deal with people who suffer from certain restrictions but are adults entitled to full respect and esteem for what they have performed during their lifetime.

Participation

Social and democratic participation in residential settings for older people were investigated in England and Wales from the perspective of older people and nursing staff. Residents did not participate in deciding how the residential settings where they lived should be organised and managed, except for helping with simple domestic tasks. The authors conclude that there is a need to change both attitudes and practice to enable older people to participate more fully in these settings (Abbot et al. 2000).

The main focus of an Australian study was to investigate older peoples' perceptions and experiences of social interaction and leisure activities living in a residential care facility. Themes emerging from discussions about their social interactions included: importance of family, fostering friendships with fellow residents, placement at dining room tables, multiple communication methods, and minimal social isolation and boredom. Excursions belonged to the favourite activities. Participants commonly were involved in leisure activities to be socially connected. Poor health, family, the facility itself, staffing, transportation, and geography influenced their social interaction and participation in leisure activities. Through the use of new technologies and creative problem solving with staff the residents could enhance their social lives and remain engaged in leisure activities (Thomas et al. 2013).

Opportunities for meaningful and active ageing, including the target group of residents with dementia, were topics under study in Canada. Research was carried out against the background that loneliness and depression are serious mental health concerns across the spectrum of residential care, from nursing homes to assisted and retirement living. Psychosocial care provided to residents to address these concerns is typically based on a long-standing tradition of 'light' social events, such as games, trips, and social gatherings, planned and implemented by staff. Although these activities provide enjoyment for some, loneliness and depression persist and the lack of resident input perpetuates the stereotype of residents as passive recipients of care. Residents continue to report lack of meaning in their lives, limited opportunities for contribution and frustration with paternalistic communication with staff. Those living with dementia face additional discrimination resulting in a range of unmet needs including lack of autonomy and belonging—both of which are linked with interpersonal violence. Research suggests, however, that programmes fostering engagement and peer support provide opportunities for residents to be socially productive and to develop a valued social identity (Theurer, K. et al. 2015).

Our experts also hinted towards reasons why participation of care home residents in community life may be restricted. Usually scarce time does not allow for paid staff to encourage contacts and relations among the residents. As experience show, residents like to socialize, if they are animated to do so. Also mobility restricted or bed-ridden persons can participate in activity offers with adequate technical equipment. However, support is time-consuming and hence often not performed. The same applies even more to events outside the care facilities. The participation in sports, cultural or social events is especially important for the quality of life of people for whom this was a habit in younger years.

The situation could be improved by nursing staff that is well trained, aware of the problems and given enough time to support the participation of dependent old people. Care home managers are responsible to provide for that and develop concepts for joint activities. Each care home can organise events like singing, joint cooking, quizzes, Wii gaming or thematic parties. Cooperation with external stakeholders like churches, kindergartens or schools is important to connect to the social environment. One expert suggests to apply more telecommunication technologies and also encourage activities in online communities.

Relatives and volunteers are a valuable resource in the context of participation, too. Care home residents enjoy to spend time and especially joint outings with relatives and friends. Personal accompaniment and training offers help family members and volunteers to cope with problems that may arise in biographically critical situations. One expert reports on volunteers who do not meet the personal preconditions because they need own support. Other volunteers do not want to work according to time schemes but prefer to help spontaneously, e.g. in events. These individual characteristics need to be coordinated.

Human dignity

Human dignity forms an overarching category that needs to be defined and can cover various topics. Again, the perspectives of different stakeholders vary.

In a meta-analysis conducted by the Palacký University Olomouc and the Comenius University of Bratislava, a total of 306 papers were retrieved. From the residents' perspective, six main themes of dignity in care were synthesized: autonomy and control, privacy,

relationships, care and comfort, communication and identity. While residents highlighted relations, nurses underlined the working culture and environment (Šaňáková, Š. and Čáp, J. 2018).

Findings for the residents' perspective were confirmed by a qualitative analysis from the UK. The most prevalent themes were: independence and privacy, followed by comfort and care, individuality, respect, communication, physical appearance and being seen as human. Residents and their families also described incidents where a resident's dignity had been compromised (Hall et al. 2014).

The dignity of people with dementia is at special risk as pointed out by a Norwegian study. The results build on participant observation combined with qualitative interviews with relatives. The most important issue for relatives was that their family member with dementia was confirmed as a relational human being. However, relatives experienced lack of resources and task-centred care to be threats to relational care and the dignity of dementia patients. Findings from participant observations confirmed this (Heggestad and Nortvedt 2013).

Human dignity is a topic not only in research but also for associations and lobby groups as well as for training institutions. Available are, among others, the Resource Guide "Dignity in Residential Care" in the United Kingdom Homecare Association with examples of good and bad practices. Exemplary indicators for good practice are given for the domains of communication, privacy, autonomy, social inclusion, personal hygiene, personal care, eating and nutrition, pain control, end of life care. Part of the framework of providing dignified care are respect, diversity and equality. Awareness is also given to abuse and whistle blowing (United Kingdom Homecare Association 2009).

Our interviewed experts commented also on reasons for compromising human dignity in care homes. Again, scarce time budgets of paid staff, financial aspects and a lack of training and awareness lead to a number of deficiencies and flaws. Examples are missing respect in intimate care, fixations of unruly or aggressive persons, and deprecating or belittling ways of addressing old people. The violation of ethical rules and norms of conducts is not necessarily grounded in evil attitudes, as put by one expert, but more likely embedded in the work culture of a care facility. While staff may be astonished at the beginning, they take it as common practice after a while and start to practice it themselves. Persons with dementia or other challenging behaviour are at special risk of being denied their dignity.

Formation and further training of managers and nursing staff is, according to our experts, key to improve the situation. If dignity is ignored, it is usually grounded in a misguided mindset. Humanity, human dignity and my idea of man and woman should be much more in the centre of training measures than this is currently the case. Many measures that ensure dignity do not cost much, like blinds in double rooms; agreements how people are addressed are free of charge.

The need for information and training also applies to relatives and volunteers, especially if the dependent old person is behaving in a way that is hard to bear and needs expertise. The opportunity to share experiences and to discuss adequate solutions is also helpful for improving the situation. As representatives of the external world, however, family members

GAMLEC
LEARN TO PLAY - PLAY TO LEARN

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

and volunteers can also influence and correct nursing staff in order to promote empathy and avoid organizational blindness.

Examples of good practice

A comprehensive collection of more than 300 good practice examples including detailed descriptions and photos is published by the Heimverzeichnis, an associate partner of the GAMLEC project. They cover various themes including events, opportunities of volunteering for residents and external persons, living with animals, cooking projects, cooperation with organisations in the neighbourhood, environmental protection and many other activities.

Also our experts mentioned existing good practice or suggested ideas for further-development:

- A village for persons with dementia that was perfectly adapted to their special needs
- A farm with animals that was run in connection with a care home
- Person-centred care as opposed to task-centred care
- Involvement of as many volunteers as possible
- Neighbourhood relations, like regular visits from children from the kindergarten
- An open communication climate in which suggestions for improvements are welcome
- Joyful activity offers, like singing in a choir or organizing excursions
- Champaign and salmon for breakfast on Sundays

GAMLEC
LEARN TO PLAY - PLAY TO LEARN

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

4.   Quotes

Autonomy

„People are not regarded as individuals in a nursing home. The daily routine is determined by the tight organization of care. The one who is cared for has little influence on it."

Volunteer working with and for older people, Offenbach, Germany

„There should be more flexibility. Not everyone should always be woken at 6:00 a.m. because the shift begins. The biorhythm of the people should be respected."

Counsellor for older people and their relatives, Neu-Isenburg, Germany

"Many nurses would like to take more care of the individual concerns of the residents. It is the task of the facility manager that their time budget allows for that. A good duty-roster is the first step to make it possible."

Employee of the Heimverzeichnis gGmbH, Frankfurt am Main, Gernany

Social participation

"If, for example, if a person who has loved to go to the theatre all of his or her life is no longer able to do so due to health conditions and the need for care, it would be an increase in quality of life to enable this person to attend theatre plays."

Social worker in care facility, Neu-Isenburg, Germany

"Quality of life is when you feel joy. When you observe the looks of participants in activity offers in care homes, there is little joy. Many were probably persuaded to visit the event, although they would have preferred to do something else. "

Employee of the Heimverzeichnis gGmbH, Frankfurt am Main, Germany

"Everything that gets the residents outside is particularly important. If you look at your own four walls all the time, you feel like you are in prison at some point. "

Employee of the Heimverzeichnis gGmbH, Frankfurt am Main, Germany

"Quality of life is primarily about participation in one's community and not about focussing in body care, like personal hygiene."

Social worker in care facility, Neu-Isenburg, Germany

Human dignity

„When moving into a nursing home, people lose their human dignity to some extent. Unfortunately, you cannot deny that. "

Volunteer in care facility, Hanau, Germany

"Human beings are not only bodies, they are minds, souls, and that is actually what defines human existence. And this part, this big important individual personal part, is often simply no longer taken into account."

Counsellor for older people and their relatives, Neu-Isenburg, Germany

„It is important that those in need of care are seen as adults. Professional carers and people in need of care should meet at eye level."

Volunteer working with and for older people, Offenbach, Germany

„There should be blinds around the bed when nursing is performed in double rooms. I find it inhumane to be washed in the room and watched by others. "

Counsellor for older people and their relatives, Neu-Isenburg, Germany

"Human dignity can be violated very quickly, for example, by being touched where you don't want it. Some women don't want men involved their intimate hygiene, but they are told we don't have any other staff, you have to go through that now. Or someone who is restless is fixated in a wheelchair or prevented from getting out of bed, which is of course not allowed."

Head of social services, Maintal, Germany

„You have to work on everyday situations and actively shape them. A respectful tone and something nice being said is often enough. This influences the atmosphere in the facility."

Volunteer in care facility, Hanau, Germany

Other aspects

„An in-depths exchange with the relatives is very important. Then you often understands the preferences and desires of the residents much better."

Volunteer in care facility, Hanau, Germany

"Voluntary work only works if it is coordinated by paid staff. Without this, it usually doesn't work, unless the old person knows the volunteer from his or her own context."

Head of social services, Maintal, Germany

GAMLEC
LEARN TO PLAY - PLAY TO LEARN

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

5. Sources

Abbott, S.; Fisk, M. and Forward, L. (2000). Social and democratic participation in residential settings for older people: realities and aspirations. In: Ageing and Society, 20, 2000, p. 327-340. [Online] Available from http://openaccess.city.ac.uk/id/eprint/465/2/Social_and_democratic_participation_in_residential_settings_for_older_people.pdf [accessed 28.11.2019].

Adler, G. et al. (Ed.) (2009). Seelische Gesundheit und Lebensqualität im Alter. Depression – Demenz – Versorgung. Schriftenreihe der Deutschen Gesellschaft für Gerontopsychiatrie und -psychotherapie (DGGPP), Bd. 7., 1. Aufl., Stuttgart Kohlhammer.

Becker, S. et al. (2005). Heidelberger Instrument zur Erfassung von Lebensqualität bei demenzkranken Menschen. In: Zeitschrift für Gerontologie & Geriatrie 38 (2), p. 108-121. [Online] Available from http://www.gero.uniheidelberg.de/imperia/md/content/fakultaeten/vekw/ifg/forschung/hildekongress/becker_etal_2005.pdf [accessed 27.11.2019].

Berendonk, C. et al. (2011). Biographiearbeit in der stationären Langzeitpflege von Menschen mit Demenz – Potentiale des DEMIAN-Pflegekonzepts. In: Zeitschrift für Gerontologie und Geriatrie 44, S. 13-18.

Brandenburg, H. et al. (2011). Pflegeoasen: (K)ein Lebensraum für Menschen im Alter mit schwerer Demenz!? POLA-SD. Abschlussbericht. Vallendar. [Online] Available from http://www.pthv.de/fileadmin/user_upload/PDF_Pflege/Projektberichte/PFLEGEOASE_Abschlussbericht_Veroeffentlichung.pdf [accessed 26.11.2019].

Bundesministerium für Gesundheit (2020). Diagnose Demenz: Krankheitsbild und Verlauf. [Online] Available from: https://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-demenz/krankheitsbild-und-verlauf.html. [Accessed: 7th February 2020].

EUROSTAT (2019). Ageing Europe: Looking at the Lives of Older People in the EU. [Online] Available from: https://ec.europa.eu/eurostat/documents/2995521/10163480/New+publication+%27Ageing+Europe+%E2%80%93+looking+at+the+lives+of+older+people%27/43eb8f07-e498-d587-0dc2-73427589dfb7 [Accessed 26th February 2020]

Evans, E. A. (2018). Care home manager attitudes to balancing risk and autonomy for residents with dementia. In: Aging Ment Health. 2018 Feb; 22(2): 261-269. [Online] Available from https://www.ncbi.nlm.nih.gov/pubmed/27768393 [accessed 28.11.2019].

Gabriel, Z.; Bowling, A. (2004). Quality of life from the perspectives of older people. In: Ageing & Society 24 (5), S. 675–691. [Online] Available from http://discovery.ucl.ac.uk/1648/1/qualityof-life.pdf [accessed 27.11.2019].

Gonzales-Salvador, T. et al. (2000). Quality of Life in Dementia Patients in Long-Term-Care. International Journal of Geriatric Psychiatry 15 (2), S. 181-189.

Hall, S.; Dodd, R. H. and Higginson, I. J. (2013). Maintaining dignity for residents of care homes: A qualitative study of the views of care home staff, community nurses, residents and their families. [Online] Available from https://www.researchgate.net/publication/258700262_Maintaining_dignity_for_residents_of_care_homes_A_qualitative_study_of_the_views_of_care_home_staff_community_nurses_residents_and_their_families [accessed 28.11.2019].

Hedman, M. et al. (2017). Caring in nursing homes to promote autonomy and participation. [Online] Available from https://journals.sagepub.com/doi/abs/10.1177/0969733017703698?journalCode=neja#abstract [accessed 28.11.2019].

Heggestad, A. K. and Nortvedt, P. (2013). Dignity and care for people with dementia living in nursing homes. [Online] Available from https://journals.sagepub.com/doi/10.1177/1471301213512840 [accessed 28.11.2019].

Heimverzeichnis gGmbH. News und Erfahrungsberichte. [Online] Available from https://www.heimverzeichnis.de/index.php?id=99 [accessed 11.02.2019].

Held, C.; Ermini-Fünfschilling, D. (2004). Das demenzgerechte Heim. Lebensraumgestaltung, Betreuung und Pflege für Menschen mit leichter, mittelschwerer und schwerer Alzheimerkrankheit. 2., vollständig erneuerte und erweiterte Aufl., Karger Basel.

Hoek, L. et al. (2018). Factors influencing autonomy of nursing home residents with dementia: The perception of family caregivers. In: Innovation in Aging, Volume 2, Issue suppl_1, November 2018, p. 722. [Online] Available from https://academic.oup.com/innovateage/article/2/suppl_1/722/5170384 [accessed 28.11.2019].

Klie, T. et al. (2008). Abschlussbericht zum Modellvorhaben: Reduktion von körpernaher Fixierung bei demenzerkrankten Heimbewohnern. [Online] Available from http://www.redufix.de/html/img/pool/redufix_Abschlussbericht_Ministerium_Entfixierung.pdf [accessed 27.11.2019].

Klie, T. et al. (2010). Beispiele für eine gute Praxis bei der Vermeidung von körpernahen Fixierungen in Einrichtungen der stationären Altenpflege. Best-Practice-Bericht zum Projekt ReduFix Praxis. [Online] Available from http://agp-freiburg.de/downloads/ReduFix_Leitfaden_Vermeidung_koerpernaher_Fixierungen_2010.pdf [accessed 27.11.2019].

Kratzer, M. (2011). Lebensqualität im hohen und höchsten Alter im städtischen Bereich. Eine Untersuchung von 75- bis 95-jährigen Wiener und Wienerinnen in Privathaushalten und Altersheimen. Dissertation. Universität Wien, Wien. [Online] Available from http://othes.univie.ac.at/18629/1/2011-10-11_0348574.pdf [accessed 25.11.2019].

Lang, G. et al. (2007). Well-being in the nursing home - A methodological approach towards the quality of life. In: Journal of Public Health 15 (2), S. 109-120. [Online] Available from https://www.researchgate.net/publication/225312965_Well-being_in_the_nursing_home_-_A_methodological_approach_towards_the_quality_of_life [accessed 28.11.2019].

Menzi-Kuhn, C. (2006). Lebensqualität von Menschen mit Demenz in stationären Langzeitpflegeeinrichtungen. Universität Maastricht. [Online] Available from http://www.humanrights.ch/upload/pdf/090304_Demenz_Langzeitpflege.pdf [accessed 25.11.2019].

Mollenkopf, H.; Walker, A. (Ed.) (2007). Quality of Life in Old Age. International and Multi-Disciplinary Perspectives. Social Indicators Research Series (31), Springer Dordrecht.

Motel-Klingebiel, A. et al. (Ed.)(2002). Lebensqualität im Alter. Generationenbeziehungen und öffentliche Servicesysteme im sozialen Wandel. Reihe Alter(n) und Gesellschaft, Bd. 4, Springer Fachmedien Wiesbaden.

Robert-Koch-Institut (2015). Gesundheit in Deutschland. Wie gesund sind die älteren Menschen? [Online] Available from https://www.rki.de/DE/Content/Gesundheitsmonitoring/Gesundheitsberichterstattung/GBEDownloadsGiD/2015/08_gesundheit_in_deutschland.pdf?__blob=publicationFile [Accessed: 9th December 2019].

Šárka Šaňáková, Juraj Čáp (2018). Dignity from the nurses' and older patients' perspective: A qualitative literature review. [Online] Available from https://journals.sagepub.com/doi/abs/10.1177/0969733017747960?journalCode=neja [accessed 28.11.2019].

Schenk, L. et al. (2013). Quality of life in nursing homes: results of a qualitative resident survey. In: Quality of Life Research 22 (10), S. 2929-2938.

Schneekloth, U.; Wahl, H. (Ed.) (2007). Möglichkeiten und Grenzen selbständiger Lebensführung in stationären Einrichtungen (MuG IV) – Demenz, Angehörige und Freiwillige, Versorgungssituation sowie Beispielen für „Good Practice". Forschungsprojekt im Auftrag des Bundesministeriums für Familie, Senioren, Frauen und Jugend. Integrierter Abschlussbericht, München. [Online] Available from http://www.bmfsfj.de/RedaktionBMFSFJ/Abteilung3/Pdf-Anlagen/abschlussbericht-mug4,property=pdf,bereich=bmfsfj,sprache=de,rwb=true.pdf [accessed 27.11.2019].

Seeberg, G. (2014). Krankheitskosten, gesundheitsbezogene Lebensqualität und Versorgungssituation bei Patienten mit kognitiven Defiziten, Marburg. [Online] Available from: http://archiv.ub.uni-marburg.de/diss/z2014/0749/pdf/dgs.pdf [accessed 25.11.2019].

Stiehr, K. et al. (2016). Lebensqualität im Alter: Kriterien für eine zielgruppengerechte Verbraucherinformation. Bericht an das Ministerium der Justiz und für Verbraucherschutz, Berlin. [Online] Available from: http://bib.heimverzeichnis.de/bibliothek/ [accessed 26.11.2019].

Tesch-Römer, C. (2012). Active aging and quality of life in old age. United Nations New York. [Online] Available from http://www.dza.de/fileadmin/dza/pdf/2012_Active_Ageing_UNECE.pdf [accessed 27.11.2019].

Theurer, K.; Mortenson, B.; Stone, R.; Suto, M.; Timonen, V. and Rozanova, J. (2015). The need for a social revolution in residential care. In: Journal of Aging Studies, Volume 35, December 2015, pp. 201-210. [Online] Available from https://www.sciencedirect.com/science/article/pii/S0890406515300347# [accessed 28.11.2019].

Thomas, J. E.; O'Connell, B. and Gaskin, C. J. (2013). Residents' perceptions and experiences of social interaction and participation in leisure activities in residential aged care. In: Contemporary Nurse, Volume 45, 2013 - Issue 2, pp. 244-254. [Online] Available from https://www.tandfAvailable from.com/doi/abs/10.5172/conu.2013.45.2.244 [accessed 28.11.2019].

United Kingdom Homecare Association (ed.) (2009). Dignity in Residential Care, Resource Guide. [Online] Available from https://www.dignityincare.org.uk/_assets/microsoft_word_-_dignity_in_residential_care_resource_guide.pdf [accessed 28.11.2019].

Wiese, C. (2015). Einflussfaktoren von Lebensqualität im Alter: eine systematische Übersichtsarbeit. Dissertation, Staats- und Universitätsbibliothek Hamburg, Hamburg

Wikström, M. and Emilsson, U. M. (2014). Autonomy and control in everyday life in care of older people in nursing homes. In: Journal of Housing For the Elderly, Volume 28, 2014 - Issue 1, pp. 41-62. [Online] Available from https://www.tandfonline.com/doi/abs/10.1080/02763893.2013.858092 [accessed 28.11.2019].

WHO (2017). Age-Friendly Environments in Europe: A Handbook of Domains for Policy Action [Online] Available from: http://www.euro.who.int/__dataassets/pdf_file/0011/359543/AFEE-handbook.PDF?ua=1 [Accessed 27th February 2020]