



Gaming for Mutual Learning in Elder Care GAMLEC

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



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De resultaten van het Erasmus+ project GAMLEC bestaan uit deze regels van het bordspel voor de spelversie met Game Coach, uit de regels van het bordspel zonder Game Coach, uit de handleiding voor het ontwerp van het formaat van de kaartinhoud, uit de leergame kaarten voor volwassenen over de kwaliteit van leven van verpleeghuisbewoners, een Compendium, de leerdoelen en doelstellingen van het bordspel, een handleiding voor de spelversie met Coach, een Educatief Kader, Richtlijnen voor het bordspel, en een interactief E-learning platform. De resultaten zijn beschikbaar in het Engels, Duits, Italiaans, Nederlands en Litouws op www.gamlec.eu.



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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.

This 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 The Netherlands. Together with results of other national reports, they are integrated into a European compendium on standards of quality of life in care home settings.

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 Dutch. Themes included terms for quality of life, autonomy, participation and human dignity; as regards target groups, terms for care home residents, older people in need of care and not self-sufficient persons were used.

Lead questions for interviews with experts and stakeholders 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 older 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 non-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?

List of interviewed experts

- Peter Aarssen, Team manager from older people care organisation Saffiergroep (Ouderenzorginstelling Saffiergroep)
- Marja Beemsterboer, Nurse from Patyna – Blauwhuis Friesland, housing and care organisation
- Corrien van Haastert, Policy advisor, Patients Federation (Patiëntenfederatie)
- Ingrid Meijering, Co-owner, GetOud Foundation (Stichting GetOud)
- Jannette Spiering, Director of Be the care concept and Founder of the Hogeweyk, dementia village



- Marianne Stadlander en Emi van Galen, Strategic and policy advisor, Dutch Healthcare Authority (Nederlandse Zorgautoriteit)



Introduction to the Healthcare System in The Netherlands

The healthcare system in the Netherlands is managed by the Dutch Government and supplemented by private insurance companies. All residents are required to take out health insurance coverage in order to access services (Buswell, 2019).

Primary healthcare in the Netherlands is delivered through primary care centers and GP services, while a network of hospitals delivers secondary and emergency services. The Ministry of Health, Welfare, and Sport is the Dutch Government department responsible for public healthcare in the country. Healthcare expenditure in the Netherlands is high. In 2016, the Dutch spent 10.3% of GDP on healthcare, the 8th highest out of EU/EFTA countries. The Netherlands is one of the 10 EU/EFTA countries that spends more than €4.000 per capital on health. In 2020, spending is expected to reach around €100 billion.

There are two main forms of health insurance in the Netherlands:

- Zorgverzekeringswet (ZVW) often called 'basic insurance', covers common medical care.
- Wet langdurige zorg (WLZ, Long-Term Care Act in Dutch) covers long-term nursing and care.

All residents and visitors in the Netherlands can access healthcare services provided that they have health insurance. Basic health insurance (ZVW) is mandatory for all Dutch residents, with some exceptions. Children aged under 18, who are covered by the insurance policy of their parent/guardian, are not required to take out ZVW. Temporary visitors and those with conscientious objections to health insurance are also exempt.

Dutch residents and employees are automatically insured by the Dutch Government for long-term nursing and care (as covered by the WLZ). The WLZ premium is a fixed percentage of income that is automatically deducted from wages or benefits.

Long-term Care in The Netherlands

Anyone who needs round-the-clock care or supervision is entitled to a place in residential care. These are facilities for people with high-level care needs, like vulnerable older people or people with severe mental or physical disabilities. Home care is also possible when determined to be practicable and cost-efficient. The high-level care system is set out in the Long-Term Care Act (WLZ).

Before entering a residential care or nursing home, one must apply to the Care Needs Assessment Centre for a WLZ care needs assessment. A representative from this centre will then check whether the individual meets the conditions set in the legislation.

In the Netherlands there are about 2.400 nursing homes and residential care homes providing long term 24/7 care to older people (Ministerie van Volksgezondheid, Welzijn en Sport, 2019). There are currently around 50.000 people living in a nursing home and 80.000 in residential care homes (Patiëntenfederatie Nederland, 2019).

Facts and Figures: Older People and Elderly Care in The Netherlands

The number of older people is growing in The Netherlands. In 2012, there were approximately 2,7 million people aged 65 and over; this number will rise to 4,7 million in 2041. An issue of concern is the relatively higher incidence of chronic disease in this population. Among people aged 65 and over,



70% have at least one chronic disease, and half of them have more than one chronic disease. Among people 75 years and above, 63% have two or more chronic diseases, and 32% have more than three.

Older people differ in their capacity, resources, and attitudes towards control and decision-making in care and self-management. A survey of people aged between 57 and 77 conducted by Nivel (Doekhie *et al.*, 2014) found that:

- 46% are pro-active: they find it is important to decide on their own living and care
- 28% are care demanding: they have enough social and financial resources, but they don't want to manage living and care themselves
- 10% are waiting: older people who have a bad quality of life, have low resources and act dependently towards others
- 16% are powerless: despite that they would want to, they are not empowered to fill in their own lives.

Political and societal developments in Nursing Home Care since 2014

Quality of nursing home care, autonomy, social participation and human dignity have been high on the political agenda over the past five years. Some particularly negative and well-publicized incidents brought attention to the bad quality of nursing home care. These include the mother of a Dutch minister who was left wearing a wet dress for a whole day; the organization of so-called "pyjama days" where people that did not get dressed due to lack of personnel; and other incidents concerning medication and falls. Improvement in the quality of life in a nursing home is, thus, a high priority, and issues of autonomy, participation and human dignity are an important consideration.

Action Plan: Quality of Nursing Home Care (2015)

An investigation by the Health Care Inspectorate (IGZ) has shown that the knowledge, skills, and availability of care workers in nursing homes are ill-matched to the care needs of residents. Additionally, the status of care in nursing homes has been a concern of the Dutch Parliament. In response, the Dutch Government has presented an action plan to improve the quality of nursing home care called *Dignity and Pride. Care with love. For our older people* (Ministerie van Volksgezondheid, Welzijn en Sport, 2015):

Quality of nursing home staff

According to the Dutch Government guidelines, nursing homes should be staffed by care professionals who take pride in their work and provide compassionate care. They should also have the right mix of training and experience to be able to give people the attention they need. Furthermore, older people should be able to rely on the fact that there is always someone around who knows them well. Since 2017, the Dutch Government has begun working to implement and enforce their establishment, which they hope will result in improved quality of life for nursing home residents.



Professional education and training

The health and education Ministries are currently working towards an action plan to bring education and training more in line with professional practice. Through training courses and other forms of education, they seek to ensure that care professionals have the knowledge and skills needed in nursing homes.

Improved transparency in quality of care

Improving access to information is one way that the Dutch Government is seeking to increase transparency in quality of care. Since 2017, reviews by care facility residents and their families have been available online. The websites kiesbeter.nl (in Dutch) and zorgkaartnederland.nl (in Dutch) provide information on the performance of nursing homes based on indicators like medication safety, communication with the resident and family members, staff qualifications, and quality-driven management. Such information will be helpful for people in making better choices when looking for a nursing home and may stimulate further improvements within these institutions.

Patients in charge of their own care and support plans

The goal for 2017 was for all nursing home residents or their representatives to be in charge of their own care and support plan. This includes people with dementia. A care and support plan sets out which care needs must be met in order for the resident to be able to live with dignity. The patient or their representative (informal carer or family member) are supposed to have control over the process of drafting the plan.

Manifest to Improve Nursing Home Care (2016)

In 2016, Hugo Borst, a well-known Dutch journalist, and Carin Gaemers, a representative of the clients council in a nursing home, met during a family meeting in the nursing home where Borst's mother lived. They shared the view that, in many Dutch nursing homes, frail and vulnerable older people did not receive the care that they need. They decided then to raise this issue in the media and Dutch Parliament and, in doing so, received considerable support. In response, the Dutch Minister of Health increased the budget for nursing home care to €2 billion for 2017.

Quality Framework for Nursing Homes (Kwaliteitskader verpleeghuiszorg) (2017)

The National Health Care Institute (Zorginstituut) released the Dutch Quality Framework for Nursing Homes in 2017 (Ministerie van Volksgezondheid, Welzijn en Sport, 2017). This framework provides the legal basis for the quality of nursing home care and describes what clients/residents and relatives may expect as basic nursing home care. The framework suggests that clients should take the lead in defining how caregivers and organisations support their quality of life. This approach is important because it is the client who values and is most impacted by the results and efforts of care institutions.

The model for the Quality Framework is based on the recommendations of the Dutch Organisation for the Rights of Human Beings (College voor Rechten van de Mens, 2016). This model has been integral in defining and garnering support for the quality of care in nursing homes.

The quality of care is described from the perspective of three levels:

- Micro-level: daily interaction between client and caregivers
- Meso-level: conditions for care organisations to support micro-level care
- Macro-level: supervision, defining responsibilities, and support for learning and improving

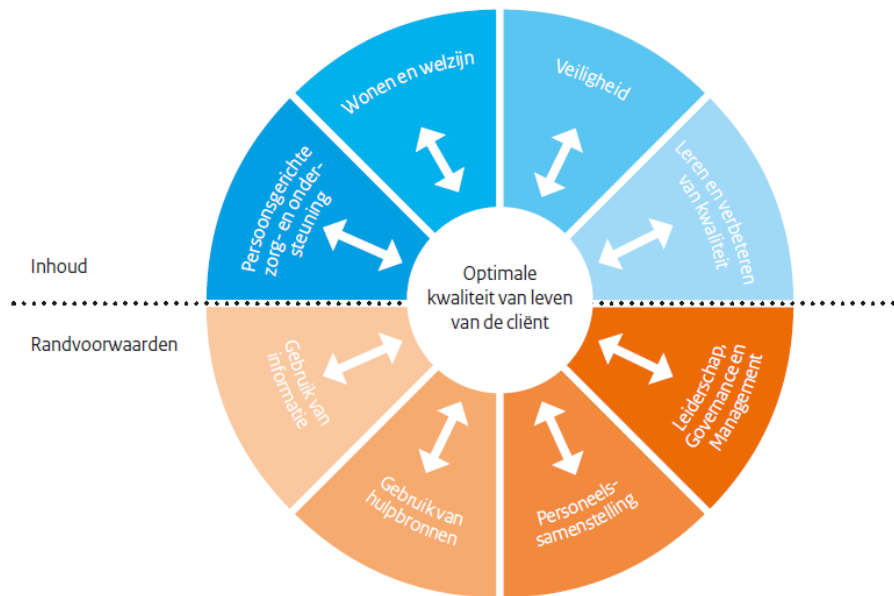


Figure 1: Integral model for dynamic improvement of nursing home care

Focusing on the quality of life of the client, the model addresses the following domains:

- Care-related content: client centred care and support, housing and wellbeing, safety and quality improvement.
- Organisational conditions: use of information, use of resources, composition of staff, leadership, governance and management.

Each piece of the circle is further elaborated in the Quality Framework. This national report focuses on the conditions of the following domains.

Client centred care and support: conditions

- The themes for quality improvement are: compassion, unity, autonomy, and care targets.
- Every nursing home provides information in quality plans and reports on how to deliver these themes.
- Every client has a personal care plan that addresses issues such as medication, diet, primary needs, and their contact person.

Housing and wellbeing

- The themes are: meaningfulness, useful daily activities, clean and cared body/clothing, family participation, volunteering, and comfortable living.



- Every care organisation provides information on how to fulfil these themes.
- Special attention is given to the adaptation of living environments to the specific needs and possibilities of different target groups in nursing homes.

Safety

- The basic safety themes are: medication safety, preventing bedsores (decubitus), policies around measures for restricting movement, and reducing the need for emergency hospital care.
- Indicators on basic safety are recorded and delivered to the Public Database of the Dutch Healthcare Institution.
- Every nursing home organisation has access to a committee for handling and reporting incidents.

Learning and improving quality

- Every nursing home organisation has a quality plan and a quality management system.
- Every nursing home organisation provides a quality and liability report.
- Every nursing home organisation participates in a learning network with at least two other organisations.
- Every five years the professional sector organisation visits each nursing home organisation.

At Home in the Nursing Home: Dignity and Pride in Nursing Homes (2018)

After the general elections in 2017, the newly appointed Minister of Health launched the action programme: *At home in the nursing home: dignity and pride on every location (Thuis in het verpleeghuis: waardigheid en trots op elke locatie)* (Ministerie van Volksgezondheid, Welzijn en Sport, 2018). This programme is the successor of the action plan from 2015. Based on the Quality Framework that was released in 2017, it aims to improve the quality and measurability of nursing home care. Sufficient time, attention and qualitative good care to every older person staying in nursing home care is the main objective of the programme.

The Quality Framework is the base for this governmental action programme. The Dutch Government requires every nursing home to comply with the Quality Framework by 2021.

The programme describes in greater detail what can be done to meet the conditions of the Quality Framework. For example, the Minister provided an overview of the chapters that must be part of the quality plan:

- Profile of the organisation
- Overview of staff and measures to maintain or acquire personnel
- Current situation and/or plans to implement person-centred care in meal provisioning, wound care, mouth care, bedsores (decubitus), and daily activities



- Reducing administrative burden
- Improving locations
- Learning and improving quality of care
- Budgeting

The words 'autonomy' and 'participation' are not to be found in the document of the Minister. The word 'dignity' is mentioned once outside of the title in relation with the loss of dignity that people experience due to their disease or disability.

From 2018 to present

Debates on the necessary improvement of the quality of nursing home care have continued. Currently, much concern is about the number of vacancies in health care, which threatens the quality of care in every health care domain. In November 2019, this discussion led to a unique occasion in Dutch healthcare: nursing and caring staff organised a strike for the first time ever. Their primary demand was for more money to employ more people.

Research organisation Nivel (Wiegers and de Veer, no date) evaluated the effects of the extra financial resources of nursing homes to provide more qualified staff, meaningful daily activities and better cooperation and dialogue between the board, employers' representatives, nursing and carers' board and clients board in healthcare organisations. To improve the quality of staff, organisations mainly use courses, workshops, trainings, and clinical courses. Since 2015, the results in quality improvement have been mixed: one third of staff thinks that they have improved, and meaningful daily activities seem to have improved slightly. A third of staff report that they have less time and space to address quality improvement. Overall, almost half of staff report lack of time and opportunity as the key barriers for quality improvement.

Other societal initiatives

Institute for Positive Health

The Institute for Positive Health (IPH) has been active in the Netherlands for the past couple of years. It was established by researcher Machteld Huber. In a 2011 article in the British Medical Journal, she and her colleagues argued that the WHO definition of health as complete wellbeing is no longer fit for purpose given the rise of chronic disease (Huber *et al.*, 2011). They proposed changing the emphasis towards the ability to adapt and self-manage in the face of social, physical, and emotional challenges. One tool the IPH uses is the *dialogue tool*, a spider web-like diagram, which can be filled in by the targeted individual themselves. This tool can be used to start a discussion with older people on what goes well and where additional support may be needed. The tool and concept have been attractive for many Dutch municipalities, which are responsible for delivering community support to older people.

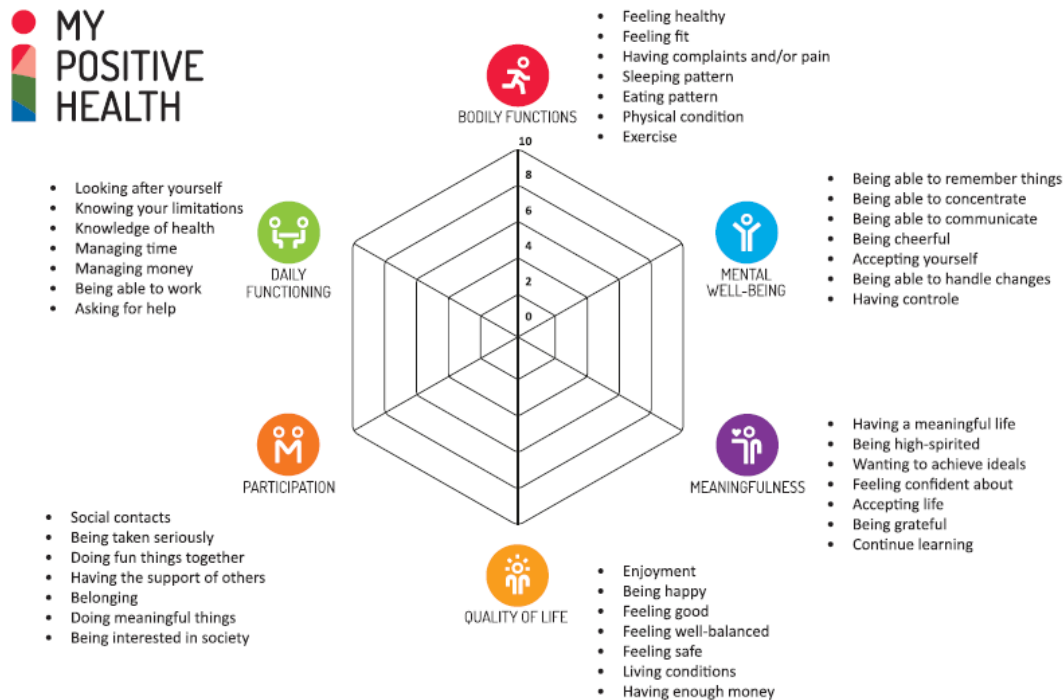


Figure 2: Institute for Positive Health: dialog tool

GetOud: Dignity in elderly care

In 2019, Foundation GetOud from the Netherlands published the booklet “Dignity in elderly care”, a report from 70 interviews (GetOud, 2019). In this booklet the authors described, at first, what workers, managers and residents define as dignity. Best description would be: To be seen, appreciated and recognized. Attention for and understanding of what the resident is concerned with. Be as you are.

Sincere attention to the resident can be improved by taking care of the following aspects:

- External care of the resident: cloths, hair, make-up, nails
- Daytime activities: volunteers, relatives, informal caregivers to take people out, organise activities at the ward/living room, garden
- Life storytelling: ask people who they are, where they come from, what they did in life
- Cultural background: information about religion, culture and cultural habits.

The attitude of workers is very important. Do workers only work in elderly care to have a living, or do they the work from their heart, with passion. In the interview, Ingrid Meijering, suggested that residents should have a say in the staff that is to be hired.

Examples of serious games in residential care homes



With the support of Actiz (branch organisation of employers in elderly care and home care) following examples have been identified:

- *Spel-maker*: for elderly care organisation, Noorderbreedte, Spel Maker made the game “Dialogoog”¹ (dialogue) that will start in April 2020. The game aims to support the learning and mutual communication about core principles of workers. During the game, the players enter into a dialogue with all parties involved whether they provide appropriate care, in which the core values are incorporated in the game in a logical manner. During the debriefing, some situations that have arisen in the game are further elaborated in order to emphasize the learning objectives again.
- *The home of the vision* (Het Huis van de Visie): To support the dialogue on the vision on quality of care, Gemiva-SVG Groep (care organisation for people with mental disabilities), developed a game on eight key principles.²
 - Self-management
 - Respect
 - Appreciation
 - Empathy
 - Support when needed
 - Living together
 - Talents
 - Be as you are at home
- *Pluszen*: Guide and reflection method for teams of workers to learn how to improve quality of life³. The guideline makes use of cards with reflective questions, such as: how well do we cooperate, do we feel supported, do we pay enough attention to the residents?
- *Care to improve* (Zorg voor Beter), A platform for nursing, care, home care and primary care. On this platform good practices are shown for daily care (such as medicine, hygiene, food and drinks, fall prevention), wellbeing (such as dementia, coercion in healthcare, intimacy and sexuality, diversity, depression), and transformations in care (such as dialogue, informal care, change management, cooperation, voluntary work).

¹ <https://www.spel-maker.nl/dialogoog/>

² <https://www.kennispleingehandicaptensector.nl/ontwikkelingen-gehandicaptenzorg/visiespel>

³ <https://pluszen.team/wp-content/uploads/2018/12/Pluszen-Instructiekaart.pdf>

Additional search on keywords in the Netherlands

Table 1: Keywords in English and Dutch

English	Dutch
Quality of life	Kwaliteit van leven
Autonomy	Autonomie
Social participation	Sociale participatie
Human dignity	Menselijke waardigheid
Dependent old people	Kwetsbare oudere(n)
Care home residents	Verpleeghuisbewoners
People in need of care	Zorgafhankelijk(en)

Autonomie – verpleeghuisbewoners:

Two articles Van Hoof et al, 2016, and Rijnaard et al, 2016, related to sensing at home in nursing homes have been identified. Fifteen factors influence the feeling at home of people living in a nursing home:

- Psychological factors: respect and recognition, maintaining own habits and values, autonomy and control, coping with the situation
- Social factors: interaction and relationships with professionals, other patients, family, friends and pets and to continue activities and
- Built environment: private rooms, personal belongings, technology, looks and feel of the building and surroundings.

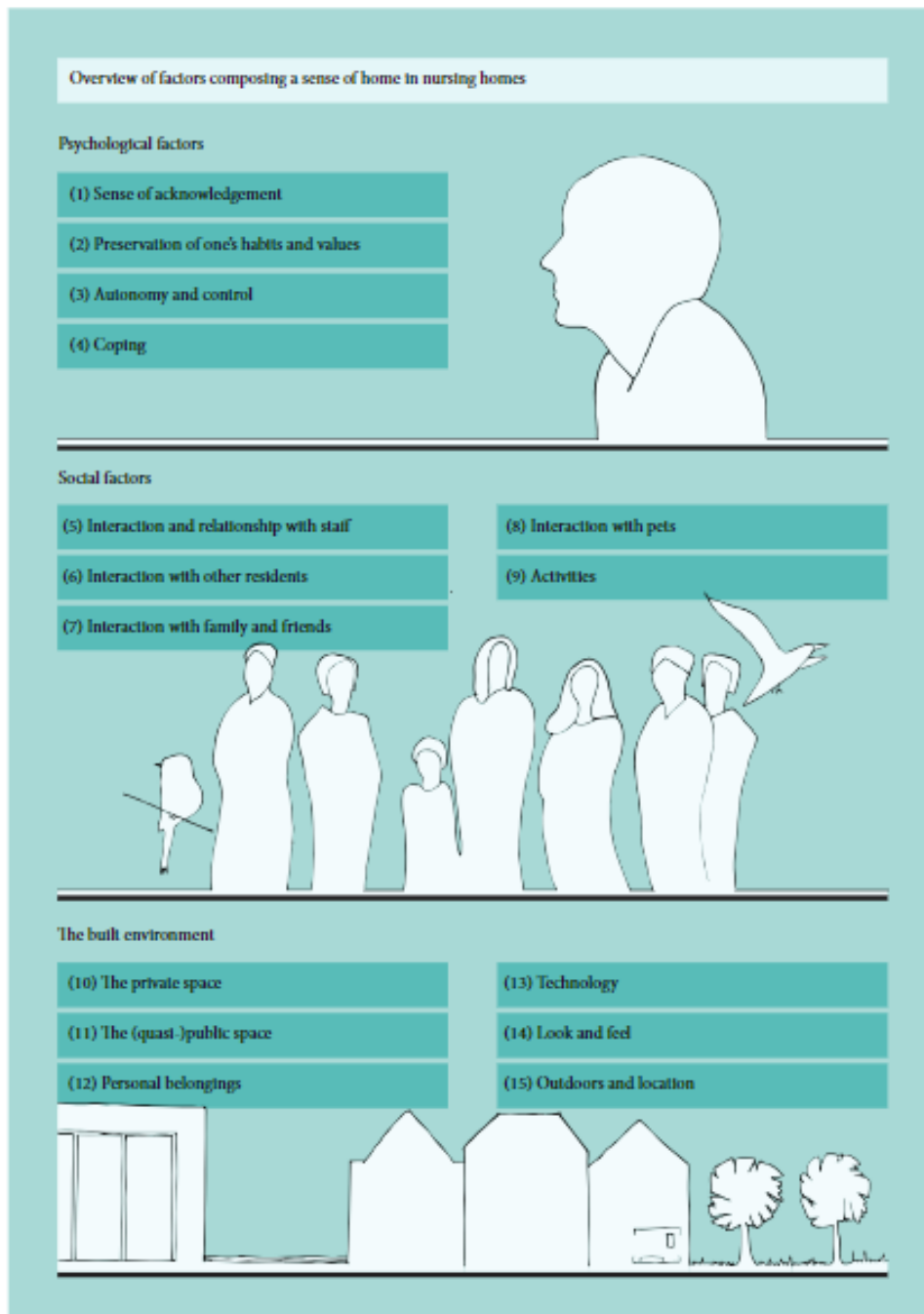


Figure 3: Sensing at home in the nursing home, M.D. Rijnaard et al. 2017

Waardigheid – verpleeghuisbewoners

Research on dignity, autonomy and human interaction in nursing homes was performed in 2015 in assignment of the Netherlands Board on Human Rights (*College voor de Rechten van de Mens*) (Wijngaart and Witte, 2015). From the human rights perspective, human dignity is the core theme as base and aim of human rights. Although a uniform definition of human dignity doesn't exist, it includes autonomy and human interaction. Autonomy is related to the right to freedom and self-determination. Human interaction is about the way people interact with each other in a respectful



way. The researchers approached the autonomy and human interaction by focusing on personal care, food and drinks, and daily activities.

To guarantee the autonomy of a person in nursing home care, important instruments are the scope of the organisation on delivering care, the intake of the person, personal care plan and care plan meetings. These instruments, but also barriers, were found during the performed research:

- Real person-centred care is being questioned, because in many cases only the professionals decide what the norms and values are. Also, the physical environment can act as a barrier to provide person-centred care due to small rooms or more persons sharing one bedroom. Outdoor facilities are limited as well.
- The voice of the older people in nursing homes is rather limited. Agreements on the care delivery don't guarantee real voice and self-determination.
- Guaranteed autonomy is limited in case the person can't tell anymore what he/she wants. Also, it is not always clear if relatives know what the person really wants.
- Regarding respectful human interaction, the research showed a varied picture of respectfulness and disrespect. Especially privacy is an issue: personnel walks in and out of the rooms without regarding the privacy of the older person.
- Despite the grand offer of central daily activities, the opportunities for participation are limited especially for persons who have severe physical or mental problems. These persons receive a too limited offer of activities in the form of attention, variety, stimulus of the senses or involvement in the household activities.
- Lack of time – pressure on the job. Most workers in long term care are struggling to provide enough attention to the people they care for.
- Many temporary personnel and many different staff limit the provision of dignified care, because they don't know the persons (and their family) they are dealing with.
- Different attitudes and competencies of professionals: some have themselves a natural respectful attitude; others will not ever learn it. There is a lot to learn for professionals. For example, to become aware of the fact that they are responsible for an adequate and meaningful life of the people they care for. This can be easily realised by simple games, stimulating the senses by aroma, taste, touch, see and hear. Other thing they can learn is to respect the personal living environment of the people they are caring or and not to walk in and out their private space freely without respect.

Conclusions

To develop the grid as base for the serious game, we will make use of the above described findings on national policy, societal initiatives and experiences and knowledge. This will be largely enriched with the experts' views that we received in the interviews.

A priori

Before moving to the concrete measures concerning quality of life, autonomy, participation and human dignity, it is important to emphasize some important conditions before building the GAMLEC game.

At first, from the experts and from literature we learn that the quality of care or medical quality must be as good as to provide at least good quality of life. If the quality of (medical) care is poor, this will immediately affect the wellness and wellbeing of the resident. Good quality of care is therefore a *conditio sine qua non*.

Secondly, it is essential to consider that the elements that create quality of life are interconnected. Decentralized preparation of meals can improve quality of life, but then food safety might be more at risk. People will be happy if they can walk freely, but to prevent them from falling, many nursing homes fix people with their chair at the table. The game should be designed in that way that it allows to make choices between a happy life according to the resident's needs (or family) and taking risks. Also, it would have added value if the game would become available for residents too.

Thirdly, based on the experience of one of the interviewed experts, board games in elderly care are not well received, due to the time it will take to play them. On the other hand, other experts were interested to help to develop the game and to try it. Time consumption is a relative issue.

Finally, there are other initiatives on the Dutch market to support the dialogue between caregivers, relatives and residents. We must avoid adding 'just another one'.

Quality of life

Quality of life of care home residents is an important issue of nursing homes and policy makers. Many good initiatives are developed to improve the quality and to start the dialogues on values and attitudes. As mentioned before: elements of quality of life are interconnected and lead to the choice between a happy life or taking risks.

To make quality of life more concrete, the Dutch research comes to the following:

- Sincere attention and respect for the resident and his/her life story, demands and wishes
- Continuous dialogue to understand, define and act according to what it is important for the resident
- Freedom to move
- Autonomy to choose (meals, sex, smoking, decoration, etc.)
- Support self-management of the resident



- Tailor made facilities to address, as much as possible, the wishes and demands of the resident

Autonomy

Autonomy of the residents is mentioned in literature and by the experts as an important asset to maintain or improve their quality of life. Autonomous decision-making by the resident should be the basis. As one expert explains, people should go on to live their own life and nursing homes support in what cannot be done anymore on their own.

Sincere attention and listening well to the wishes and needs of the resident is essential. It is important to consider that when a resident moves to the nursing home, he/she (or family) is hardly able to express his/her needs and wishes. It is important for the staff to continue the dialogue with the resident and the family. Two experts also recommend to always visit the upcoming resident at their home, to better understand the background and lifestyle of the new resident. The life style groups of Hogeweyk is a good example of housing residents in groups according to their needs and wishes.

To meet the needs and wishes of the resident, staff has sometimes to be **creative**. Such as the case of a resident who wants to eat the whole day and feels happy; when he does so, he is then less aggressive. The staff doesn't correct him in his eating habit but provides him with very small portions during the day to avoid that he grows fat. In the meantime, the resident feels happy. Or the case of a resident with a lot of energy who wants to clean everything; bring this resident and the cleaning person together and provide the resident with small tasks of cleaning.

The physical condition and **built environment** of the nursing home is also of importance. For example, to have a patio where people can freely move in and out. "Buiten komt voorbij" (outside passes) is an example of a project where people sitting inside the nursing home can see the world (pedestrians, cars, busses) passing by. The dementia village of Hogeweyk allows people to freely move around the whole village and to undertake the activities they wish. The only restriction the people have is not to go outside unaccompanied.

Autonomy of residents is limited by:

- Hospitalization attitudes and vision of the staff, resident and family.
- Lack of sincere attention and dialogue.
- Lack of time by staff and shortage of staff.
- Inspection rules, such as hygiene restrictions. An example was mentioned of a bin that was placed at the ward and where people in wheelchairs could throw away things themselves. The bins had to be replaced by bins that could only be opened by foot.
- Single solutions can be provided, such as having your own train playground, but if many more residents ask the same, the building is limiting these requests.
- Wrong expectations from the family, such as hospital tells that as soon the resident moves to the nursing home, much more time will be spent on the resident. This is in many cases not feasible.



Social participation

Activities inside and outside the nursing home, social networks, are elements to enable nursing home residents to participate.

An offer of daily activities that the resident can choose to participate in is provided by every nursing home. Staff needs to be proactive to provide social participation activities. The activities must be provided according to the wishes and needs of the resident.

Besides the usual offer of exercises, bingo and singing, nursing homes could also think of more innovative offers and other ways to improve social participation of the residents:

- Silent disco (headphones with personal favourite music)
- Nursing home robots (such as Zora) are very expensive. In toy stores you easily can find robot toys that are useful too for nursing home residents
- Dolls or toy animals are supportive to have
- Child puzzles to be played by residents
- Volunteers taking residents out to visit family, cultural events, etc.
- Children visiting the residents. For example, children from primary schools.
- Family has to be informed or trained that their valuable input for the resident or the nursing home is needed.

Social participation is limited by:

- Social networks are gone due to the behaviour of the resident (in case of brain damage patients)
- Paid staff is too much occupied by delivering good quality of care instead of having time to spend on social participation activities.
- Lack of volunteers, family and friends to undertake social participation activities.
- Budgetary issues; lack of money.
- Stigmatism.

Human dignity

Human dignity is an overarching issue of high relevance for care home residents. Human dignity is presented in the following ways:

- Respectful treatment: Mr., Ms. or Mrs.
- Sincere attention and dialogue
- Respect the privacy of residents (knock before entering the room)
- Respectful clothing of the resident and external care (hair, nails, make-up)



- Well-dressed staff and volunteers
- Give eating in a separate room and not in presence of other residents
- Accept people as they are and don't have prejudices

Good examples

Experts mention many good examples:

1. Hogeweyk⁴: dementia village where people can move freely and have activities according to their interests and they live in lifestyle wards
2. Tante Louise⁵ – Bergen op Zoom, location Vissershaven: people with dementia are free to leave the nursing home and carry tags in case they get lost
3. Personal budget for residential care
4. Outside passes⁶ by Buiten komt voorbij⁷
5. Foundation NiKo⁸: Newly built 2-room or single room units for residents with physical impairments, whereby the neighbourhood inhabitants make use of the same facilities. NiKo provides many activities, such as ball games, (classic) music and reading
6. De Hoven⁹: residential care where residents define the policy

⁴ <https://hogeweyk.dementiavillage.com/en/>

⁵ <https://tantelouise.nl/zorg-wonen/dementie/>

⁶ <https://www.youtube.com/watch?v=jOa2XAquPt4>

⁷ www.buitenkomtvoorbij.nl (at the time of edition of this report, the website is being replaced)

⁸ <https://www.dehoven.nl/>

⁹ <https://www.stichtingniko.com/>



Quotations

“Good quality of (medical) care is essential to provide good quality of life to nursing home residents”.

“Elements of quality of life are interconnected; choices in the game are necessary to choose between a happy life against taking risks”.

“It is important to visit a new resident at home, to see what the background is”.

“Continuous dialogues between resident, family and caregivers are needed to provide the best conditions for quality of life”.

“Sincere attention for the resident as a human being, is the most important thing. Look and see the resident and provide trainings to caregivers to achieve this”.

“Respect the resident by communicating with Mr. or Mrs. and being well dressed”.

“As a worker in nursing homes, I keep myself informed on topics relevant to my work by reading and by attending workshops. Knowing what is normal for the resident or the families helps to communicate with them about what to expect”.



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