

Summary

Life in a nursing home

National overview of the life situation, perceived quality of life and care for older nursing home residents in the Netherlands in 2019

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Summary and discussion

S.1 Summary

Investments in nursing home care

The majority (92%) of older people in the Netherlands (aged 75 years or over) live independently in their own residential setting (De Klerk et al. 2019) and receive help from homecare services and/or their loved ones in the event of problems with their health. For a proportion of the older population, however, severe physical health problems or serious memory disorders, such as dementia, mean it is no longer possible to organise care in their home setting safely and responsibly. A move to a nursing home or similar protected residential setting can offer a solution for this group. Nursing homes provide 24-hour care and supervision, with all the care and support needed by the older person being delivered within the institution. A few years ago, nursing home care regularly featured in the news and in public debates, with many in the Netherlands expressing concerns about shortages of care staff and waiting lists in the elderly care sector (Den Ridder et al. 2019). A number of harrowing incidents in nursing homes also came to light via the media.

A great deal has been invested in nursing homes in recent years (TK 2017/2018a). The quality of life in a nursing home is a core focus of the policy, and more than 2 billion euros has been made available on a structural basis for improving the quality of care and quality of life in nursing homes. Based on the Nursing Home Care Quality Framework (Kwaliteitskader Verpleeghuiszorg) published by the Dutch National Health Care Institute (Zorginstituut Nederland 2017), in 2018 the Ministry of Health, Welfare and Sport launched the programme 'At home in the nursing home: Dignity and pride in every home' ('Thuis in het verpleeghuis: Waardigheid en trots op elke locatie'), which prioritises providing sufficient time, attention and high-quality care to nursing home residents (vws 2018). According to nursing home residents themselves, these were areas where there was room for improvement. In 2015 they reported that staff had too little time and attention for them, and that the provision of care was often rushed (Van Campen & Verbeek-Oudijk 2017). For the most part, however, the perceived quality of life of residents was good, and a majority felt happy and satisfied with their lives.

The Ministry of Health, Welfare and Sport monitors the impact of the recent investments on a number of key points: client satisfaction, sufficient number of motivated, qualified care providers, and innovation in nursing home care (see e.g. vws 2020). In this publication we present a general national picture of the quality of life and care in Dutch nursing homes as experienced by the residents themselves and – where residents were not able to share this information themselves – by those closest to them.

The central research question addressed in this study is as follows:

What is the perceived quality of life and perceived quality of care of nursing home residents in 2019, and how have these aspects changed since 2015?

In order to answer this question, we first describe the characteristics of nursing home residents in 2019 that are associated with both perceived quality of life and quality of care, and compare them with the characteristics of residents in 2015. This comparison sheds light on changes in the composition, care needs and available resources of nursing home residents. The most recent data on which this publication is based were collected in 2019 and therefore present a picture of life in nursing homes before the coronavirus crisis, which has clearly hit frail older persons both within and outside nursing homes hard (SCP 2020). Although the situation presented here has been overtaken by events, it still offers relevant insights into the state of nursing home care before the coronavirus pandemic overwhelmed us all. Moreover, this report is part of a series, and in that sense is relevant for future monitoring. In the discussion section (S.2) we devote attention to the consequences of the coronavirus crisis for the life situation of nursing home residents.

Experiences of residents themselves and their representatives

This publication draws on data from the Older People in Institutions survey (OII), which was carried out in 2019 by Statistics Netherlands (CBS) in collaboration with the Netherlands Institute for Social Research (SCP). Data for the OII survey were collected on 1,837 older persons during the calendar year 2019. The respondents were interviewed verbally. Where residents were not capable of answering the questions themselves, a portion of the questions were submitted in writing to the care provider with primary responsibility for the resident and another portion to a family member. Personal questions such as how happy a resident is or how they rate the quality of care are difficult for third parties to answer, and these questions were therefore only put to residents who were capable of answering themselves. The Qualidem¹ tool was also used for the first time to measure the perceived quality of life of residents with dementia (Ettema et al. 2005; Trimbos 2019).

In both 2019 and 2015, more than half the selected older persons answered the questions themselves, while for just under half the information came from a family member and a caregiver. The presence of advanced cognitive impairments and/or dementia was often the reason for older persons not being able to participate. In seven out of ten cases, the questionnaires were completed by a child of the resident, while in one out of ten cases this was done by the partner; the remainder were completed by another family member or loved one. These family members often visited the residents once a week or more, and will therefore generally have a good idea of the life situation of their older relative.

The description of the different characteristics of nursing home residents incorporates the data of all respondents. We then go on to describe and compare the perceived quality of care and perceived quality of life. Only residents who were able to answer these questions themselves were included in this part of the study.

1 This is a validated instrument for measuring the quality of life of people with dementia, which is suitable for use with nursing home residents aged 65 and over with mild to very severe dementia. The questionnaire is completed by two caregivers who were able to observe the residents concerned at all times of the day, after an observation period of a week.

Number of nursing home residents declining, number of caregivers increasing

Under certain conditions, nursing home care can also be provided in the recipient's home, provided it is suitable and the care can be provided efficiently (De Klerk et al. 2019). The number of people receiving this care at home has risen sharply since 2015 (CBS 2019; ActiZ 2020). Older people are thus increasingly living independently for longer, even those with a high care need. That is reflected in a fall in the number of nursing home residents, to around 115,000 in 2019 (CBS StatLine) – some 2,000 fewer than in 2015 (Verbeek-Oudijk & Van Campen 2017) and 43,000 fewer than in 2008 (Den Draak 2010). The reduction in the number of nursing home residents has thus levelled off somewhat in recent years, probably due to an increase in the number of (very elderly) older persons. Residents sometimes spend a long period living in a nursing home: half of all clients spend more than 18 months living in a nursing home (Zorginstituut Nederland 2017), and the period of residence can rise to around six years (Verenso 2019).

A shift has also taken place in the care profile received by nursing home residents. The introduction of the Long-term Care Act (Wlz) in 2015 meant that new nursing and care clients were no longer referred for lighter forms of care. In 2015, 16% of nursing home residents were still receiving lighter forms of care (based on earlier referrals), while in 2019 this applied for only 3% of residents. The share of residents with more intensive care indications (sheltered accommodation with intensive dementia care) has seen a particularly marked increase, rising from 32% in 2015 to 41% in 2019.

At the same time, the number of nursing home care staff has increased according to the progress report 'At home in a nursing home' (*Thuis in het verpleeghuis*) (vws 2020). Between 2017 and 2019, around 36,000 additional employees (22,000 FTE) began working in nursing home care, an average of sixteen extra workers per site. Care providers appear to have focused primarily on recruiting extra staff at grades 1 and 2 (residential assistants, hosts/hostesses, helpers) and relatively less at grade 3 staff (e.g. caregivers and activity supervisors). It is unclear whether this was a deliberate decision by nursing homes to ease the burden of their care staff or whether it was necessitated by the situation on the labour market.

Nursing home residents more often have severe physical disabilities and dementia

Nursing home residents are mainly women aged 80 years and older: three-quarters are women and more than 60% are aged 85 or over. Roughly one in five residents still have a partner, who in more than half the cases still lives independently. Four out of ten residents have attained no higher than an elementary education level. This was no different in 2019 than in 2015, albeit the education level of women was slightly higher in 2019 than four years previously. Compared with their peers living independently, nursing home residents are relatively frequently low-educated. Older people with more resources, thanks to a higher education level or more financial means, also have more opportunities to continue living independently for longer, and when they do move into an institution, this is more often a private residential care facility (Plaisier & Den Draak 2019).

Virtually all nursing home residents have physical disabilities plus one or more chronic illnesses. They are accordingly almost all taking medication. A quarter of nursing home residents also suffer pain, and the same proportion have difficulty sleeping. Many of them also have cognitive impairments, with more than a quarter suffering moderate memory problems and over four out of ten having been diagnosed with dementia. The proportion of residents with very severe disabilities was higher in 2019 than in 2015 (41% versus 37%), and a dementia diagnosis was more common (44% versus 40%). This suggests that the care needs of nursing home residents may have increased slightly over recent years. This is in line with the trend for older people to continue living independently for longer, only being admitted to a nursing home when their care needs become severe.

Reason for moving to a nursing home is often physical deterioration, but family concerns also frequently play a role

Three-quarters of residents were living independently before their admission to a nursing home; the remainder first spent time living in another institution or in a sheltered housing facility. A variety of considerations played a role in the ultimate decision by residents to move to a nursing home. Concerns on the part of their family were the most commonly mentioned factor (77%), followed by a decline in physical health (73%) and the fact that family or friends (72%) or homecare services (61%) were no longer able to provide the required care in their home setting. When respondents were asked to state the most important reason for moving to a nursing home, the decline in physical health was the most frequently mentioned reason (39%).

Majority of residents receive visits and help from loved ones, but 13% rarely or never do

People's social networks are important in offering support and companionship. Physical and cognitive decline make it more difficult for older people to maintain existing contacts. The majority of nursing home residents (two-thirds) rarely or never visit others. Around two-thirds of residents do however receive visits on a weekly or more frequent basis, mainly from children or grandchildren. The older residents (aged 85 and over) not only more often have children/grandchildren, but also receive more visits from them than younger residents. There were no significant differences in frequency of visits in 2019 compared with 2015, which means that more than one in eight residents rarely or never receive a visit. Residents have little telephone contact with their children or other relatives. When family and loved ones visit nursing home residents, they also frequently offer help to them; the majority of residents (almost 80%) receive help from family on a daily or weekly basis. This often takes the form of help with administration, transport or the household. Almost half of nursing home residents also receive help from volunteers, often for trips out, with eating or with their personal appearance. The demands on family members and volunteers appear to have increased between 2015 and 2019, with residents receiving help significantly more often in 2019. This is in line with the trend towards placing ever greater reliance on informal carers and volunteers (De Boer et al. 2020).

Residents go out more often and are generally satisfied with the activities they undertake

Their (daily) activities are also important for older persons. These activities not only create opportunities for social interaction, but can also be a valuable way of filling their day and potentially slowing further decline (Meijering & Duimel 2019). It is of course important that the daily activities are tailored to the wishes and capabilities of nursing home residents (Möhler et al. 2018). Most people feel better if they are able to go out regularly (Van den Berg 2013). The majority of nursing home residents go out daily (around 30%) or several times a week (around 40%). On the other hand, almost one in five residents rarely or never go outside, usually because their health prevents them from doing so, though lack of accompaniment or transport is also cited as a reason. The proportion of residents who almost never go out fell from 25% in 2015 to 20% in 2019, a positive trend which argues for continuation of the efforts in this regard.

Most residents participate in (daily) activities in the nursing home, and this was unchanged in 2019 compared with four years earlier. Almost three-quarters of residents regularly drink tea or coffee together, and around half regularly visit a garden or park within walking distance. A third of residents regularly make their own sandwiches, around one in five regularly go shopping within or outside the institution, or visit a cafe, restaurant or community centre. A large majority of the residents in our survey (84%) say they are satisfied with the activities they do, though around half (51%) say they would like to be more physically active than they are at present. That is significantly more than in 2015, when the figure was 45%. It is unclear whether the activities on offer do not fully match the wishes of residents, or whether residents would like to take more exercise than they are physically capable of. This could be ascertained in discussions between nursing home staff and residents.

Residents more often satisfied with the care they receive, though they feel the care is often rushed

More than nine out of ten residents feel that the care staff make proper allowance for the capabilities of the residents and feel that they are taken seriously. In addition, three-quarters of residents have a caregiver in whom they can confide, and almost two-thirds feel that the nursing home staff have sufficient time and attention to devote to deep questions that concern the resident. A number of positive changes have taken place compared with 2015. According to residents, for example, the care they receive is less rushed (33% in 2019 versus 40% in 2015), residents more often feel that the staff have enough time and attention to discuss deep questions (64% versus 58%), and residents more often have a caregiver in whom they can confide (74% versus 68%). Although things have improved, the time pressure under which care staff have to work still appears to be a problem: a third of residents report that the care they receive is rushed.

Residents feel they have sufficient privacy, autonomy and say in their care

The majority of residents (90% or more) say they primarily determine the course of their day themselves, feel able to express their views, are able to determine for themselves when they go to the toilet, are able to decide for themselves what they wish to do, or are

able to ask for help when needed, and also that they have sufficient privacy. Compared with 2015, satisfaction with the way that residents feel they have in their care, in particular, has increased, but their perceived autonomy in 2019 appears to have declined slightly. The surveyed residents thus appear to have seen a positive development in person-centred care, but there is still room for improvement. Residents are generally satisfied with the degree to which agreements are adhered to and the way they have in their care.

Roughly one in ten residents treated disrespectfully in the past year

One in ten nursing home residents sometimes feel unsafe within or outside the nursing home, a comparable figure to 2015. A proportion of residents have experienced disrespectful treatment on one or more occasions during the past year, and especially situations where they did not receive help when they needed it, or situations in which someone shouted at the resident or tormented, insulted or threatened them (13%). That proportion was the same in 2019 as in 2015.

Residents satisfied with their physical living environment

A majority of nursing home residents are satisfied or very satisfied with their physical living environment. A small proportion (around 5%) are dissatisfied or very dissatisfied with the building, their room or the outside space. That figure is comparable with 2015. Residents are also generally satisfied with the atmosphere and the activities that are organised in the institution; around 90% of residents say there are enough activities.

Residents generally happy and satisfied with life, but also regularly lonely

Care in a nursing home is in most cases not about the treatment, recovery or healing of a disease, but about achieving and sustaining quality of life in the final phase of life.² Almost two-thirds of nursing home residents surveyed say they are happy or very happy. They are also generally satisfied with their lives. One in ten residents say they are unhappy or very unhappy and rate their life satisfaction with a score of less than five out of ten. At the same time, feelings of loneliness are relatively high among the surveyed residents: almost six out of ten report that they are lonely, with 43% saying they are moderately lonely and 14% very lonely.

Nursing home residents assess their mental health more positively than their physical health: almost 60% of residents rate their own physical health as moderate or poor, while a quarter assess their mental health as moderate or poor. It is striking that older residents rate their physical health as better on average than younger residents; acceptance of physical limitations in advanced age may play a role here.

2 Where residents were able to answer the questions themselves, we asked them both general questions about happiness and satisfaction with life and also more specific questions, such as perceived mental and physical health and feelings of loneliness. We also asked a number of questions about lust for life and end of life. The quality of life of residents who were unable to answer these questions themselves because of advanced dementia was measured using the Qualidem questionnaire.

Around one in three nursing home residents derive insufficient meaning and pleasure from life

Roughly a third of residents say they have slightly less lust for life. Four out of ten say they have difficulty finding meaning in their day-to-day existence; three out of ten say they have few goals; and a third say there is nothing which they can genuinely enjoy. One in eight residents say they are regularly bored and that life has too little to offer. Despite this, a majority of residents do feel their lives have sufficient meaning and derive pleasure from life.

Quality of life of nursing home residents with dementia also reasonable to good

A proportion of residents were unable to participate in the survey themselves, often due to limited cognitive ability and the presence of dementia. In order to measure the quality of life of these residents, care staff were asked to observe their behaviour. These residents achieved reasonable to good scores on most aspects, scoring particularly highly on 'feeling at home', 'positive self-image', 'positive affect', 'care relationship' and 'social isolation'. One notable negative outlier is the aspect 'having something to do'. This aspect of quality of life for nursing home residents with dementia therefore warrants extra attention.

Need for better alignment of care, activities and personal interaction with personal preferences

The picture that emerges of nursing home care in 2019 shows that much was going well. Generally speaking, both the residents and their loved ones were satisfied with the safe and pleasant residential setting and the good quality of care provided. Satisfaction with the attentive care, the amount of say they have in that care and the trust in the care staff have all increased slightly. The measures to improve quality in the sector thus appear to have had an impact in these areas. Despite this, a substantial proportion of residents see room for improvement and feel that the care is still too often rushed. If we look more closely at the suggestions for improvement put forward by residents and their loved ones, there is a striking absence of 'luxury' requests, but rather above all a desire for a better match with residents' personal preferences, both as regards activities and in the personal interaction with staff.

5.2 Discussion

This study presents a national and general picture of nursing home care in the Netherlands, and explores whether any changes occurred between 2015 and 2019. Our data do not enable us to study individual nursing homes, which means the wide differences that may exist between individual homes are not apparent in the national averages presented here.

Recent investments in nursing homes mainly visible in a slight improvement in perceived quality of care

Concerns among the Dutch public about the quality of elderly care, and a number of harrowing incidents in nursing homes which emerged in the media, sparked off a public debate about the quality of nursing home care, culminating in recent investments in the sector. The negative image that many people have of nursing home care is much less apparent in the responses of residents themselves. Earlier research has shown that the perceived quality of care and quality of life of nursing home residents is generally very reasonable, but also identified a need on the part of residents for more personal attention and showed that pressure of time meant the care provided was too often rushed (Van Campen & Verbeek-Oudijk 2017). Since that study, major investments have been made in the sector, aimed mainly at boosting the numbers of hands-on care staff. The general observation from our study is that there has been a slight improvement in the quality of care as perceived by residents in 2019 compared with four years earlier. However, the perceived quality of life remained unchanged over that period. The recent investments in nursing home care thus appear to be bearing fruit mainly in terms of residents' experiences with the care they receive, but not for their quality of life. In the remainder of this section, we reflect further on the key developments observed between 2015 and 2019 and address a number of focus areas for both policymakers and nursing homes themselves.

Perceived quality of life stable, despite slight increase in care needs

Broadly speaking, no change can be observed between 2015 and 2019 in the quality of life of nursing home residents. For various reasons, the lack of improvement in the average perceived quality of life of the nursing home population should come as no surprise. In the first place, as stated, the majority of residents already rate their own lives fairly positively; the majority feel happy and rate their satisfaction with life as fairly high. In addition, the desired quality boost in the nursing home sector was sought mainly through increasing staff numbers. This is likely to have had a positive impact on perceived quality of care – we shall return to this later – but not by definition on the perceived quality of life of residents, which depends on much more than the number of available care staff in the nursing home. Earlier research has found no scientific evidence for a relationship between the deployment of more care and nursing staff and increasing quality of life (Hamers et al. 2016). We also observe a slight increase in the health problems and care needs of nursing home residents since 2015. The share of residents with severe physical disabilities increased slightly over the four-year period studied, as did the share of residents with dementia. Residents thus face an increase in health problems which make it more difficult for them to maintain social contacts and perform day-to-day activities – precisely the aspects which play a key role in maintaining physical well-being, and by extension quality of life. The finding that residents' perceived quality of life remained fairly stable between 2015 and 2019 and has not diminished despite their increasing health problems, can thus be seen in some senses as a positive development.

Loneliness and pain still a problem

At the same time, it is clear that there are still gains to be made in the perceived quality of life of nursing home residents. Earlier research has shown that moving to a nursing home reduces the risk of loneliness: nursing home residents experience less loneliness than older persons living independently in the community (Van Campen et al. 2018). Despite this, loneliness is still a problem and the majority of residents do experience feelings of loneliness. Resolving this issue is not a straightforward matter: loneliness does not have one single cause. In order to develop a more coherent approach to tackling loneliness, greater insight is needed into the dynamics and interaction between the factors that can cause loneliness, as well as possible interventions that could reduce loneliness.

Pain is also a problem for frail older persons. We also know that the majority of older people do not spontaneously say that they are suffering pain, or else they use different words for this, such as ‘uncomfortable’ or ‘an unpleasant feeling’. Guidelines and treatment plans have been formulated to help recognise and address the pain suffered by these older persons (Verenso 2020). This study shows that a large proportion of residents still suffer problems with pain and sleeping which impact negatively on their perceived quality of life. Investing in knowledge on how to identify, resolve or reduce pain could further improve the quality of life of nursing home residents.

Attracting more care staff as important as ever

In this study we observe a number of positive developments in the quality of care as experienced by nursing home residents between 2015 and 2019. For example, a smaller share of residents feel that the care they receive is too often rushed, and a bigger proportion of residents feel that staff have enough time and attention to discuss deep questions with them. The increased staff numbers in nursing homes and the rise in informal carers and help provided by volunteers appear to have increased the scope to give more personal time and attention to residents. However, there is more to be done: a third of residents feel that the care they receive is rushed. The extra staff recruitment was focused less on care and nursing staff, and frequently involved residential assistants and hostesses who help with things such as meals and activities. Earlier research has shown that bringing about real improvements in the quality of care requires an optimum mix of staff with different skill sets (Hamers et al. 2016). Other research shows that the general level of satisfaction among staff has increased slightly, the perceived pressure of work has reduced slightly and staff take a more positive view of working in the nursing home care sector (vws 2019). With only a limited reduction to date in the number of nursing home residents, a projected increase in the near future due to ongoing population ageing, and an intensifying care need, this means that a great deal of care still needs to be provided by a limited number of people. Recruiting more care staff could conceivably reduce the pressure of work, but vacancies for these roles in nursing homes take an increasingly long time to fill (Monitor Woonvormen Dementie (‘Monitor of residential models for dementia’ – forthcoming).

Ongoing coronavirus crisis putting pressure on positive developments in nursing home care

The data used in our study were collected in 2019. However, the outbreak of the coronavirus pandemic in early 2020 has changed everyone's lives. The virus has clearly hit frail older persons both within and outside nursing homes hard. Nursing homes proved to be virus hotspots, with many residents becoming infected and the number of deaths rising sharply. In a bid to protect older residents and their frail health, nursing homes locked their doors, preventing informal carers, volunteers and loved ones from visiting and providing help. Activities from which residents derive a great deal of enjoyment also became virtually or completely impossible. This affected many residents. Before the coronavirus crisis, roughly two-thirds of residents received one or more visits each week. Although creative solutions were found to facilitate some form of contact, such as waving at the window, 'over the fence' visits and special visitor pods with a glass partition (SCP 2020), this does not appear to be a complete alternative for the emotional and physical contact which means so much for these older persons who are in frail health and in the last phase of their lives (see e.g. Pols et al. 2020). Residents, relatives and care staff reported in an online questionnaire that they observed a decline in the health of residents during the visiting ban (Van der Roest et al. 2020). Research among older persons living independently in the community found that they were also suffering more loneliness as a result of social distancing, personal losses and worries about the pandemic (Van Tilburg et al. 2020; De Klerk et al. 2020). That will have been no different for older persons living in nursing homes. Unsurprisingly, therefore, the media reported the great relief when the ban on visiting was lifted. Although there are no indications that this period has had a permanent negative effect (Heyblom 2020), the impact at the time was considerable. Researchers and the sector itself accordingly recommend that, in the future, a national ban should be avoided, but that instead scope should be created for a regional approach, with nursing homes and residents themselves involved in the decision-making (see e.g. NOS 2020). Administrators, academics and prominent figures also published a manifesto in the autumn of 2020 in which they argue that quality of life must prevail over safety. Closing the nursing home doors strips away much of what makes the life of residents worthwhile (see e.g. Van de Wier 2020). The undiminished raging of the coronavirus pandemic, the rising number of infections in nursing homes and the second lockdown that was issued in december 2020, is bearing down on the quality of life in nursing homes. At the time of writing, there is no end in sight to the coronavirus crisis, and it is therefore unclear what the consequences will be for nursing home residents in the longer term.

More customisation and person-centred care and activities desirable

The picture that emerges in this study is that, according to residents themselves, life in a nursing home is generally better than many people imagine. Given the increased financial envelope that has been created for the sector over the coming years, some of the money could be used to meet the wishes of residents better and align more closely with their personal preferences. Extra attention is also needed for the growing group of residents with

dementia, who do not always have enough to keep them occupied. The growing numbers of staff in the sector could possibly also create more scope for customised care. Most of the efforts at present consist of small-scale initiatives which adopt a broad interpretation of the provision of integrated custom care for frail people and which involve actions such as expanding the combined package of accommodation, care and support to include elements such as art and culture in order to give residents more enjoyment and happiness in their old age (Bakker et al. 2019). The question, of course, is how to find the right match for each resident. Further research could shed more light on which groups would benefit from a more customised approach. Space must be created to engage in that dialogue and thus support older people and increase the satisfaction and meaning they get from life, including in the final phase of their lives (Van Campen 2020).