

Personal stories improve standard of care and resident wellbeing

Getting to know the life experiences and wishes of older people can help staff provide more meaningful experiences for residents and improve their quality of life. Josanne Huijg discusses the results from a pilot project on using residents' narratives in the provision of care

Caring for older people is much more than just managing comorbidities and ensuring their physical needs are met; for example, an older lady with Parkinson's disease received the best possible care in her nursing home in the Netherlands. The staff did all they could to ease her pain and provide her comfort, but to no avail. It was only when they got to know her better, that they realised why the lady was so sad: she had an unfulfilled desire and that was to see her grandchildren again before she would pass away. The contact with them was sadly lost after her son's divorce. With the help from the nursing home staff, contact was established and her grandson came to visit. They shared valuable moments together. A few days later, the lady passed away.

Care home standards

In the Netherlands today, the long-term care sector mainly focuses on the diseases, disabilities and needs of nursing home residents. As a result, 'good care' is defined as care that reduces symptoms and complaints and responds to people's needs. Consequently, evidence-based medical care guidelines shape the everyday life of residents and guide staff's way of working. This leads to a high standard of nursing home care that is based on values such as justice, equality, autonomy and safety. Care should be uniform and evaluated by predetermined indicators. This normative perspective has played a defining role in the regulation of healthcare and the institutionalisation of vulnerable older people during the 20th century. In this way, the normative perspective has contributed to the reduction of social inequality and has improved health and care. But to what extent does it take into account the

quality of life of older people and their loved ones, and the job satisfaction of nursing home staff?

Towards person-centred care

The Dutch care sector is now shifting from a traditionally strong focus on health, protocols and standard practice to more emphasis on wellbeing, relationships and person-centred care. In 2017, the Dutch National Healthcare Institute published a quality framework on the care and support for nursing home residents and their significant others (Zorginstituut Nederland, 2017). The document provides guidelines on the quality and evaluation of care. Within the framework, person-centred care is one of the main principles. Personal narratives are defined as an important element of person-centred care, but the framework does not describe how these can be explored, nor how these narratives can guide daily routines. Further, the framework provides guidelines for the evaluation of care to feed into an internal continuous learning process and external audits. However, the framework lacks direction on how to evaluate care in which personal narratives play a significant role. To provide guidance on how to provide and evaluate person-centred care by the use of narratives, knowledge institute Leyden Academy on Vitality and Ageing initiated the 2-year pilot project *Enjoying life*. Supported by the Ministry of Health, Welfare and Sport, the project aims to develop a narrative approach to both the delivery and the evaluation of care.

A narrative approach

In the *Enjoying life* project, we worked in close cooperation with nursing home staff and examined how to achieve a sustainable change towards an increased focus on residents' personal wellbeing and desires. We aimed to develop a narrative approach that meets the wishes of staff, residents and their significant others. An approach that is not based on guidelines, protocols and checklists, but on the narratives of people on what is important to them, about their individual experiences, and about what touches them in the last phase of life.

Piloting the new approach

From April 2017 to March 2019, we piloted the approach in 11 nursing home organisations in the Netherlands. We used participatory action research to develop a training on narrative care delivery and evaluation, and to co-design the *Enjoying life plan*: a tool that helps staff to structurally pay attention to residents' narratives while delivering care and support and to use narratives on personal experiences to evaluate quality of care.

In each organisation, we started off with training teams of 10 staff members. We introduced the *Enjoying life plan* and taught staff how to use this plan in their daily routine. Simultaneously, the approach, training and plan were evaluated and adapted based on observation and staff members' feedback. The progress, gains, pains, sustainability, and future of the narrative approach, including the *Enjoying life plan*, were discussed with directors and managers of the organisations, often with the active participation of trained team members. Questionnaires were administered before, during and after the project, to map staff's perceptions on and experiences with the approach, training and plan. Face-to-face interviews were conducted with staff, residents and their significant others to examine different perspectives on personal wellbeing, desires and roles.

In our view, the narrative approach on the delivery and evaluation of care should include four elements, these are discussed below. A training on the approach should focus on these four elements and they should be part of a resident's *Enjoying life plan*.

1. Getting to know the resident's identity

Traditional care focuses primarily on nursing home residents' physical care needs. To define these needs, we collect information on diseases and disabilities, often by using standardised questionnaires. Consequently, the information is not distinctive between residents, and defining residents' needs is not dependent on the relationship between the health professional, the resident and their significant others. In our narrative approach, identity will emerge and will be recreated within a relationship. Getting to know this identity, including resident's wishes and desires is to us the starting point for person-centred care. What is important for this person? Which relationships does he or she cherish? And what person does the resident really want to be: a grandmother, a spouse, a caretaker for a beloved pet? This personal information can only be collected in a conversation between two people with a personal relationship (Brown Wilson and Davies, 2008). In the project, we trained staff in using the *Doodle me tool* (Slaets, 2017) to get to know residents' wishes and desires. The tool invites staff to have open conversations about what matters most to residents, in the here and now. Based on the information they gather during these conversations, staff members create a Doodle board as a visual summary (see picture below).

Before the start of the training, most staff indicated that they already knew their residents quite well. However, after finishing the training, they were surprised to find that working with the *Doodle me* tool had brought important new information on their



Resident Hanneke with her Doodle board

residents to the surface (see *Box 1*). Staff's responses to the questionnaires indicate that 87% of the respondents believe that they got to know the residents better (58.7%) or much better (28.3%) after the training. Residents responded very positively to the *Doodle me tool*. They enjoyed the dedicated attention and curiosity of the staff. Most of them beamed when receiving the Doodle board that was made especially for them and in which they recognised themselves. Significant others were also enthusiastic.

2. Using information on wishes and desires

Within our narrative approach, we believe that it is important to also take residents' wishes and desires as a starting point for the delivery of care and support. First, this information can contribute to positive and prevent negative care experiences. Second, knowing residents' wishes and desires can contribute to make the day more valuable for them, for example, by offering more personalised activities, facilitating important relationships and allowing space for fear, anger or sadness (see *Box 2*). Last, but not least, knowing wishes and desires and the corresponding personal relationship may help staff to be more sensitive and responsive to residents, which is important to be able to deliver person-centred care. During the training, staff were educated to develop an *Enjoying life plan* based on the Doodle board they made. Moreover, they were stimulated to create opportunities for an enjoyable life for individual residents and discuss these with residents' significant others.

During the training, many creative, personalised care plans were developed and staff created countless opportunities for enhancing residents' enjoyment of life. Further, we have seen beautiful examples, both big and small, on how staff and important others collaborated in initiating meaningful experiences. Staff's responses to the questionnaires indicated that they were actively working on creating opportunities for an enjoyable life during (62.2%) and after the project (76.6%).

3. Making dilemmas explicit

When providing care and support not only based on residents' physical needs, but also on their wishes and desires, dilemmas are inevitable. In our approach, a dilemma is defined as a difficult choice in which several options conflict with what is possible, allowed, expected, and/or what someone would like. For instance, choosing for freedom may conflict with health or safety. In case of a dilemma, it is important to look at the options from different perspectives. The 'best option' may vary from the perspective of the staff member, resident or significant other. Staff encounter dilemmas (big or small) every day, but they do not always make them explicit. Within the project, we taught staff to identify dilemmas, discuss the various options and perspectives and to make choices with regard to the 'best option' (see *Box 3*).

Box 1. Staff comments

'We knew that one of our residents was once an important person in Africa, but we never realised just how much he liked to talk about this. When I asked him about it, his face lit up. When he became frail, he returned from his mission back to the Netherlands. We think he would have preferred staying there.'

During the training, staff indicated that they found it really helpful to discuss dilemmas with one another and, related to this, that it is important to make time to actively work on dilemmas as a team. Further, they became more aware that registering dilemmas could support them in the delivery and justification of their work.

4. Using narratives to evaluate care quality

The registration of information on residents, as well as arrangements regarding their care and support is necessary for the evaluation of quality of care. In traditional care, what should be registered is mainly informed by a normative perspective. Quality of care is evaluated based on numbers and figures, with one reference point for everyone. Moreover, the evaluation does not take into account efforts to contribute to residents' enjoyable lives. In our narrative approach, we believe that the evaluation of quality of care should be based on the personal experiences of staff, residents and their significant others (see *Box 4*). Registering both positive and negative experiences in a care plan can guide staff in the everyday delivery of care and help them to keep learning and improving. It can also be used in the justification of quality of 'narrative care' to external parties.

During the training, we learned that sharing personal stories motivated staff to create more positive experiences and to communicate these with residents' significant others. Additionally, staff were highly motivated to

Box 2. Staff comments

'We have a sweet lady in our home who never really asks for anything. Every evening, we help her take off her compression socks. The other day, I asked her if she would like me to massage her legs with lotion afterwards. She told me she never experienced this and would really love it. We now do this every day.'

'One of our residents really loves classical music. When I saw there was a classical concert planned in town, I immediately called the resident's wife and asked if we could take him there. She thought it was a great plan, but was a bit anxious about lunch, as her husband usually only eats liquid food. We went to the concert, the three of us, and had a blast! The resident even enjoyed his chips.'

Box 3. Staff comments

'Before ending up in a wheelchair and losing his speech, a resident lived together with his girlfriend. At home, he could obviously be more intimate with her than in this nursing home. Here, everyone walks in constantly to check in on him. When we discussed this desire for intimacy, we arranged a *Do not disturb* sign. His girlfriend hangs it on his door when she is with him, so no one enters the room. As staff, we trust his girlfriend to take good care of him.'

Box 4. Staff comments

'We had a lady living in our group with a daughter who was always grumpy. When her mother passed away, she showed me how much she appreciated me. I never knew. She gave me a keychain that said "You were always my rock". I shed a tear.'

share (negative) experiences and how to deal with similar situations in the future. Staff's responses to the questionnaires indicated that 60.6% of the respondents was working more actively on identifying, registering and sharing experiences after the training.

The *Enjoying life plan*

The four elements of the narrative approach also shaped the *Enjoying life plan*. This plan was developed

collaboratively with staff members while they applied the plan in their everyday practice. As the pilot progressed, the *Enjoying life plan* took shape and started to include more of what staff indicated as crucial to know and register. An important consideration is that a reduction of the normative approach in the delivery and evaluation of care is an important step in the integration of a narrative approach in nursing home care. In this way, an accumulation of what should be done and registered can be prevented, as this does not contribute to personal relationships, person-centred care, or quality of care (Van de Bovenkamp et al, 2017). To balance the normative and narrative approach, we organised sessions in which staff discussed which normative information was relevant to register.

Staff indicated that the *Enjoying life plan* is simple to use, meets their objectives in work and helps them to focus on what matters most to their residents and to make choices that enhance their wellbeing. In addition, they indicated that the narrative approach contributed to their own happiness at work. For most of them, providing personal care based on wishes and desires was one of the main reasons to start working in care in the first place.

Conclusion

In the *Enjoying life* pilot-project we aimed to contribute to a sustainable change towards a focus on nursing home residents' personal wellbeing and desires by introducing a narrative approach to the delivery and evaluation of care into 11 nursing homes. Staff were enthusiastic



A resident bathes the baby of one of the nurses

and actively participated in the further development of the approach, training programme and the *Enjoying life plan*. Moreover, the project was received very well by the residents and their significant others, as well as directors and managers of the organisations. As a consequence, we believe that the introduction of this scalable narrative approach in nursing home care is a successful first step in really putting wellbeing first, and fundamentally changing the way we observe and evaluate quality of nursing home care.

Our ambition is that all nursing homes in the Netherlands will work with an *Enjoying life plan* (or a similar plan), containing relevant normative and narrative information. To this end, we have started several follow-up projects. We are developing training materials and videos to help organisations make the transition. We are also upscaling the initiative to two complete locations of two care organisations to explore how the plan can be best implemented in the present systems and ways of working, and what issues or challenges may be encountered. Besides the Ministry of Health, other parties that supervise the quality of long-term care in the Netherlands are closely involved in this follow-up project, such as the Health Inspectorate, the National Health Care Institute, the Dutch Healthcare Authority, and two leading health insurers. The involvement of all these parties is crucial to make the transition succeed. We all share the same objective: to make a positive change for the older people entrusted

Key points

- At present, care is organised to be uniform and focuses on managing symptoms and conditions, standards are normative rather than narrative
- A recent pilot project trained care staff to get to know their residents' personal stories and integrate these in the care they provided
- This led to increased resident wellbeing and a greater job satisfaction among care staff
- When providing care and support not only based on residents' physical needs, but also on their wishes and desires, dilemmas are inevitable; during the pilot staff were trained to decide on a 'best option' when presented with dilemmas

to our care and make sure their last phase of life is as enjoyable as possible. **NRC**

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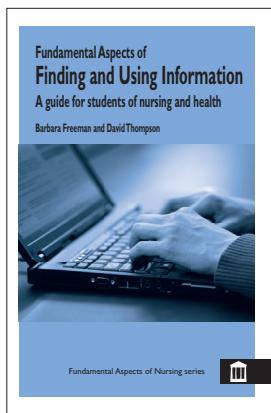
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Fundamental Aspects of Finding and Using Information

By Barbara Freeman and David Thompson

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