Bewarende zorg

Vormgeving en opmaak: Trees Vulto DTP en Boekproductie, Schalkwijk
Afbeelding op omslag: Henry Moore, *Large Figure in a Shelter* (1985-1986), Perry Green, Much Hadham, Hertfordshire. Reproduced by permission of the Henry Moore Foundation.

ISBN 978-90-5931-534-1

www.boomlemma.nl

Bewarende zorg

Een visie voor verzorgenden en verpleegkundigen

Preservative Care

A Philosophy for Nurses
(with a summary in English)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag van de rector magnificus, prof. dr. J.C. Stoof, ingevolge het besluit van het college voor promoties in het openbaar te verdedigen op dinsdag 25 januari 2011 des ochtends te 10.30 uur

door Jan Seerp Jukema
geboren op 3 oktober 1967 te Sexbierum

Promotoren
Prof. dr. M.H.F. Grypdonck
Prof. dr. M.A. Verkerk

Dit proefschrift werd mede mogelijk gemaakt met financiële steun van:
- een schenking verkregen via bemiddeling van de Stichting Porticus;
- de Christelijke Hogeschool Windesheim, School of Health Care, te Zwolle;
- J.E. Jurriaanse Stichting;
- de Radboud Stichting te Nijmegen
  (tegenwoordig Stichting Thomas More te 's-Hertogenbosch).

Summary

Chapter 1 • A philosophy of good daily care for nursing home residents

Basic principles, aims and methods of this dissertation

This dissertation introduces preservative care as a philosophy of good daily care by nurses for persons residing in nursing homes. This particular quality of daily nursing preserves the personhood of residents in ways the person can recognize and accept. The moral test of preservative care is 'recognising the uniqueness of the other in this particular community'. That nursing home residents are cared for like this has considerable moral significance. Preservative care allows them to go on being the unique person they once were and still are, among other persons in the same situation. Being dependent and vulnerable may force them to live in a strange new way, one they might never have anticipated, but this new way of life can become recognisable and acceptable to the person concerned. Ultimately, it is up to the person to decide if this is the case or not. Even in a nursing home, the residents have the moral authority to lead their life in their own way. This fundamental right should never be forgotten or taken away from them.

The nursing home as a moral care practice

From a moral perspective, a nurse's caregiving is never neutral. Values may occasionally be at odds with one another, as there can be differences of opinion regarding what good care actually is and what ideals are worth striving for. The nursing home can be seen as a morally responsible care practice in which all concerned express themselves morally in word and deed. Is it more important to a resident that she is showered at a fixed time so she is fresh and clean, or is it more important from *her* point of view that today she saves her limited energy for a visit from her daughter? Is it more important to a nursing team leader that the 'work' is finished by 10 o'clock, or that the nursing home residents are left in charge of their own care? Care may be given with the best of intentions by the nurse or care facility, but in real terms it may not suit the resident at all.

Care accomplished through value-generating and expressive action

The daily care nurses give directly to nursing home residents involves far more than anything they may or may not do with their hands. Their care is not only aimed at, for example, keeping residents as physically healthy as possible (*value-generating acts*). At the same time it also emphasises that one vulnerable and

highly dependent person is as worthy of all the care and effort as any other person (*expressive acts*); attentiveness, little chats, and sincere attention all express values such as solidarity, security, and respect for one another. In the practical daily care nurses give, there is no clearly defined boundary between care that expresses explicit values and care as a form of value-generating action–both are interwoven.

A philosophy of care

In the field of professional care, nursing research continues to focus on the development of interventions, with means and methods usually targeted at cost effectiveness. In this approach, the more the professional actions of nurses contribute to the accomplishment of predefined aims and measurable outcomes, the better they are regarded. In a nursing home these outcomes would be, for example, 'functionality', 'autonomy', and 'self-sufficiency'. In contrast, another approach to nursing care not only strives to achieve and maintain certain levels of health and well-being for the person concerned, it also strives to sustain an existence that is as valuable and dignified for the person as it can be. The starting point is good care for this person in this situation and upholding the perceptions of the person as very important. Both the nature of the nurse's actions, then, as well as the common aim are determined in part by the nursing philosophy of care. In the view of this dissertation, however, existing philosophies of care do not offer nurses enough scope for them to be able to provide suitably caring answers and solutions to the questions and concerns of nursing home residents.

Developing a philosophy of care by means of a counterstory

A story is an apt way to display the meaning, dynamics, contextuality, and complexity of good daily care for nursing home residents. A story *represents* what people experience, *selects* what is represented in a narrative and *interprets* what is represented. It also *connects* the various elements within the story, and the story in turn connects with other stories. The philosophy of preservative care–a 'voice of opposition' raised against a rational, evidence-based and outcome-oriented approach to care–is here presented as a *counterstory* (as conceptualised by Lindemann Nelson) that resists the narratives explaining and justifying the rejected approach by depicting the problems of nursing home residents and suggesting solutions in terms of good care. The counterstory narrates the standpoint of the nurse in a way that differs from the usual, bringing to the fore things that otherwise would rarely or never be seen. It particularly highlights some of the moral dimensions of the direct daily care nurses give to nursing home residents, thus opening these dimensions to discussion. The story may help nurses to provide grounded support for existing nursing practices delivered to nursing home residents, to criticise or renew these practices, and to support development of new practices. Indeed, this philosophy of good care should be included in the education of both experienced nurses and nurses in training. Its aim is to motivate and inspire nurses to examine daily routines in nursing homes that they experience as simple and dull, and allow them to regard what they are doing as meaningful and

valuable, not only to the nursing home residents but to themselves as well. The quality of a counterstory is measured by its coherence, its credibility and its validity. This dissertation concentrates on accomplishing the first criterion–coherence. Systematic testing of the credibility and validity of this philosophy of care in practice, both by providers (nurses) and receivers (vulnerable nursing home residents) thus falls outside its scope.

The answers to the following research questions contributed to the development of the counterstory as a coherent philosophy, in that they functioned as building blocks. The central question is: *What is good daily nursing care for vulnerable nursing home residents?*

This question was formed on the basis of the following subset of questions:
- What holds a resident of a nursing home in their personhood?
- What is the character and meaning of the care that goes into holding a person in their personhood?
- What should nurses be doing in direct daily care to hold nursing home residents in their personhood?

Empirical data were collected through participant-observation and structured interviews in various care practices. Particular attention was paid to the ways in which professionals carry out the care, assuming that when caring for nursing home residents, nurses express in some way what, in their opinion, is morally good or not good. The theoretical insights derive from the literature on needs-led care and the ethics of care. Both accord a central position to care, to the context of caregiving and care-receiving, and to the interrelationships between those involved in the practice of care. In a spiralling research model, empirical data and theoretical insight are continually connected, compared, and tested against each other, and then merged step-by-step into a coherent whole.

Chapter 2 • Nursing home residents are vulnerable

How nursing home residents can be held in their personhood

Using several cases in illustration, Chapter 2 shows various vulnerabilities of nursing home residents and describes how they run the risk of not being recognized as unique persons–as is their right–or even the risk of having their personhood damaged as such. The cause, albeit unintentional, lies partly in the type of nursing care; however, the same nursing care practices also contain opportunities to sustain the identity of nursing home residents as unique persons.

Identity: embodiment, relationality, and narratives
Personal identity is the key to holding someone in personhood. To a great extent, a person is identified by bodily responses and physical appearance, their rela-

tionships with others, and the unique, ongoing story (narrative) of their life. The reciprocal relationships between embodiment, relationality, and narrative can be defined as follows: A person's identity is expressed by various narratives in which each thread may not be completely accurate on its own but is nevertheless bound up with such criteria as depiction, selection, interpretation, and connection. The identity of a person is relational or, to put it differently, it is partly constituted through relationships with others. The person is also embodied uniquely. In other words, when the unique person answers to the question 'who am I?' the 'who' refers to their narrative, and the 'I' to their embodiment and interpersonal relations with others. The person is dynamic, but has some constants (continuation), such as character traits, talents, or relationships. A dynamic person changes over time (becoming), accumulating more losses and achievements the longer they live.

Nursing home residents have been confronted by drastic changes–usually including loss of physical faculties–which have resulted in their becoming dependent on nursing home care. Relational changes also involve loss, often the loss of relationships and contacts, certainly in their original form, and these are seldom replaced in the new nursing home situation. This places the relational fundamentals of the person's 'continuation' and 'becoming' under pressure. Life in a nursing home interrupts a person's familiar narratives. Now other people's stories, about what they think should be important and valuable to the person concerned, partially determine who that person is, often without acknowledging that person as a unique person. Many stories are borrowed from or relate to stereotypes that are common property in a particular culture or subculture, in this case the nursing home. These *master narratives* are largely archetypal and function as a summary of socially shared understandings of who people are or should be. They are at odds with recognising and accepting that persons are unique, and go against their leading an authentic life in the enforced community which now houses these unique persons.

Causing harm to a unique person

Perhaps due to illness or other physical ailments, nursing home residents often have neither the strength nor ability to protect themselves from psychosocial or physical harm. This, combined with pressure from their surroundings, means that in practical terms they cannot defend themselves against immutable and occasionally compulsive nursing routines ('everyone here gets a shower once a week'). The high pace of nursing practice far exceeds the pace of the elderly resident. In the worst case this reduces the person to little more than a care object to be fed, cleaned, and shunted around. Another example, injurious in the narrative sense, is labelling a person's behaviour as virtually pathological ('neurotic and obsessive'), even if this person has herself been tidy her whole life, just because she would rather have ornaments put back in their own place in her room. The above examples, and many others in this dissertation, illustrate how nursing home resi-

dents are not recognised or acknowledged for either who they used to be or who they have become now: particular persons in a situation of dependence.

Preservative care holds residents in their personhood
The situation of nursing home residents demands, as it were, a special kind of protection. Nurses, like no others, are in a position to offer this protection by continually attuning their care to this unique person in this unique situation. In so doing, they are sustaining or holding in personhood the unique person in the context of nursing home care. This expression of protection is thus a special kind of preservative care, a moral practice. The practice of holding someone in personhood is not something static. Preservative care involves creating a situation whereby the person experiences a sense of recognition and acknowledgement as an individual. Sustaining continuity in personhood may sustain a person's right to their 'known' identity, but it may also have the painful effect of accentuating that which has been lost forever. Conducting preservative care purely in terms of 'continuation' could do more harm than good. Therefore, preserving someone as a unique person should also entail keeping the door to 'becoming' open, starting from this person is this situation.

Chapter 3 • Preservative care

How preservative care is distinguished as a quality of direct daily care

Chapter 3 analyses preservative care according to real situations in *direct daily care*. Everyone needs to sleep, eat, drink, go to the toilet, wash, get dressed and undressed. Direct care is simultaneously universal yet personal and can on occasion be intimate as well. So, how can one distinguish preservative care as a *quality* that transforms daily nursing practice into 'good care'? Put differently, bearing a nursing home resident's personhood in mind, what does 'good direct care' mean, and how does this meaning get reflected in actual nursing practice?

Four phases of care
Tronto's model for an ethic of care (1993) is used to establish four phases of good direct nursing home care: (1) ascertaining the care needs (caring about), (2) organising the care (taking care of), (3) caregiving, and (4) care-receiving. Facility directors and supervisory boards are associated with phase 1, managers with phase 2, nurses and all other health professionals with phase 3, and nursing home residents with phase 4, but as we see in Chapter 4, nurses exhibit all four phases as they practice preservative care. The wider context of care as a moral practice is formed by politicians and others in power who establish and define the societal care needs (phase 1), and by managers and policy makers who are responsible for its organisation (phase 2). These four phases of care and their associated interpretations influence one another in a continual cyclical process. An ethical ele-

ment is linked to each phase of care: (1) *attentiveness* to ascertaining care needs, (2) *responsibility t*o organising the required care, (3) *competence* to giving care properly, and (4) *responsiveness* to care-receiving. The quality of the direct daily care offered by nurses is partially determined by the availability of resources and the way in which the care is organised. Nurses carry the responsibility of tangible practical care (phase 3), but the third moral quality–competence–is the most important. A person's care requirements can be ascertained and suitable care can be organised, but if those involved do not give the care with any competence then the requirements are ultimately left unsatisfied.

Preservative care

The same model is now deployed to analyse and describe the quality of preservative care in the typical context of nurses providing direct daily care to a special group of people. Preservative care is not a new skill or a new method; rather, it implies a *quality*: a specific *way* of carrying out responsibility. Preservative care is expressed by the caring behaviour of the nurse during the actual interaction with a nursing home resident (phase 3). The remaining three phases (noticing in passing new or different care needs, organizing or adapting care on the spot, and reciprocal communication during care-receiving) can also be discerned in this third phase. The core dimensions involved are attunement and responsibility. Instead of using broad narratives that apply to everyone in general, case descriptions based on the four phases and their associated moral qualities are better for visualising the many and various manifestations of tangible preservative care: no two people and no two moments in time are the same. The continuity and maintenance of 'becoming' can be given valuable form by allowing residents, for example, to take their daily baths in a style adapted to their physical limitations or by giving them the leeway to assist in their own care, and in so doing to acknowledge their helpfulness (in accordance with phase 4). In cases where the value-generating action of preservative care is virtually impractical–when a person is incapable of expressing her wishes or his suffering is so great that even the most competent care no longer eases the burden–then simply signalling the desire to take the person's wishes into account gives that person the feeling that she or he is still valuable. Even if care is given only in the form of an expressive act, it is still preservative care. Preservative care is hard to describe unambiguously. The categories and criteria mentioned above can help bring its facets more sharply into focus, but its moral test remains 'this person in this context feels that this care holds him in his personhood.'

Chapter 4 • Preservative care as a moral practice

How preservative care takes form in the context of the nursing home

Chapter 4 uses dynamic cases to examine in detail the four phases of preservative care and show their interrelationships. This chapter also demonstrates how the material and relational context of the nursing home care are often at odds with these phases and, indeed, with the practice of preservative care.

Explaining the four phases of preservative care

In phase 1 of preservative care, the nurse expresses the quality of *attentiveness* in such behaviour as listening, taking time, asking questions, and making eye contact. Attentiveness draws on both personal knowledge and specialist knowledge of the care needs of the person. At the same time it requires an open yet pragmatic attitude focused on what is needed now, in these circumstances, for this person to flourish. Interpreting a situation correctly not only depends on the competence of the nurse, but also on the openness and responsiveness of the resident. In phase 2 of preservative care, *responsibility* is the central moral quality. The nurse is usually the closest professional, the obvious one to organise the actual care. Success depends on *well-established* responsibility in the nursing team, with a team leader who may or may not take personal responsibility for the required conditions, and colleagues whose tangible actions can be measured by reflection and evaluation. Ultimately nurses are responsible for their own motivated choices and the results of these.

In phase 3 of preservative care, *competence* is the central tenet. Here the direct concern is the actual provision of the established care needs. Being merely attentive and responsible is not enough; competence is crucial. The more competent the nurse, the larger his or her repertoire of actions, and the better the care can be. A sensitive attitude and the empathy to attune to the person in context play important roles in competence. With this approach the content and form of preservative care can never be prescribed fully *beforehand*. Only in actual practice does the tangible form of caregiving become clear. Even when routines are developed on the basis of experience with a person, they may have to be changed on the spot to create space for 'becoming'. Phase 4 of preservative care is characterised by *responsiveness*. Judging by the responses of the care recipient, the nurse can renew observations and take responsibility for reorganising or adapting established care routines–perhaps suspending or scrapping certain elements. The moral quality of responsiveness is bound to the nursing home resident as the active recipient of preservative care, and to the nurse as giver of this care; both are responsible for this. Responsiveness is necessary so that the preservative character of the care can be tested and to answer the critical question, Does this care meet what is needed to preserve this resident as a unique person in this specific situation?

Preservative care and the inherent dilemmas of its institutional context
Preservative care is part of a complex institutional context. A number of factors are characteristic of care and, to some extent, determine it. These are the material factors (building and layout, aimed at both communal and individual needs); the many different people involved in the care of an individual; and the fundamental inequality of power between institutional routines and habits, on the one hand, and the nurses and the care-dependent residents who have to cope with them, on the other. And last but not least, the lack of time, resources, and staff. In short, preservative care is carried out in a context in which it can easily come into conflict with what is needed to hold this unique individual in personhood in this unique situation. In managing the diverse dilemmas of preservative care, it would be helpful for nurses to reflect critically on their own actions and discuss their views with their peers. Mutual exchanges are a way of justifying choices, their impact, and possible alternatives, and to judge whether the care provided is suitable or not. On these grounds, and using the moral test of preservative care as another criterion (see Chapter 3), the selected method of care can be continued, adjusted, or discontinued.

The meaning of preservative care
The practice of preservative care is both value-generating (it allows people to sustain the value of personhood) and an ethical expression (it is good to abide with vulnerable, dependent people). In relational terms, preservative care has meaning for both the individual nurse and the nursing home as a whole, because by providing preservative care, nurses hold not only residents but also the nurses themselves in personhood. A nursing home that delivers expressive preservative care can count on the recognition and appreciation of society at large.

Chapter 5 • The future of preservative care

How preservative care can contribute to good nursing home care

To answer the central question of this dissertation–*What is good direct daily care for highly vulnerable nursing home residents?*–the preceding chapters narrated a counterstory about preservative care. The story's very composition is the first step in the development of a philosophy of good care. Chapter 5 places this philosophy in the caring tradition to which it belongs and which it also reflects: what *distinguishes* preservative care? Preservative care is an interpersonally oriented approach to professional care that belongs to the tradition of needs-led care and the ethics of care. This approach includes value-led care (Pool), meaning-giving care (Van der Kooij), professional loving care (Van Heijst), and 'presence and care' (Baart & Grypdonck), also emphasizing the relationships, experiences, and meaning of the unique circumstances of all those involved. Preservative care strongly emphasises the life the person led both before and after landing in her

current vulnerable context, which ideally should sustain the person's personhood. Awareness of the moral context of giving care to nursing home residents may help nurses determine what counts as good actions to undertake in the circumstances and the manner in which they should carry out these actions. Preservative care is distinguished by five characteristics that make specific contributions to a person-centred approach of professional care:

- It gives nurses a fitting answer to the question of how attuned and responsible they are in holding someone in personhood whilst caring for particularly vulnerable and dependent nursing home residents.
- It has the potential to *transform* situations in direct daily care so that the nursing home residents feel that they are sustained in their unique personhood even in the midst of their dependence and vulnerability.
- It provides a *normative test* for good care, in which the response of nursing home residents is the measure of whether their personhood is acknowledged and sustained.
- It takes as its starting point the nature and meaning of tangible behaviour in direct daily care, whereas other approaches are aimed more at psychosocial and verbal dimensions.
- It enhances care-receiving by the nursing home resident as well as care*giving* and thus pays due recognition to nursing home care as a moral practice in a civilised society.

It is up to the reader to judge the coherence of the counterstory presented, and up to the nursing profession and nursing home residents to judge its credibility, but the ultimate test of the story is how well preservative care is received and valued by the nursing home residents themselves. Only that test can determine the validity of this philosophy. The chapter concludes with a proposal outlining a programme of further research to test the validity of preservative care. It suggests using case studies and qualitative methods (interviews, participative observation) to map in detail the reception of preservative care by nursing home residents and their context. This study should deal with the more or less helpful characteristics of the context, and the optimal professional characteristics of the nurse that would best support preservative care. Given the crucial role that nursing attitudes and skills play in the accomplishment of preservative care, and also taking into account its relative complexity, this dissertation closes by suggesting that future nurses should be given a thorough grounding in the philosophy of preservative care during their training.