

Forgotten Vision

The perception of elderly living in a nursing home on the personal treatment by caregivers

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Samenvatting

Achtergrond en doel: Alhoewel het belang van de perceptie van ouderen op bejegening en kwaliteit van zorg in verpleeghuizen door alle betrokkenen wordt onderkend, blijft wetenschappelijk onderzoek naar dit onderwerp schaars. Tot op heden is er in Nederland nog geen wetenschappelijk onderzoek verricht naar de perceptie van ouderen in een verpleeghuis op bejegening door zorgverleners. Het doel van deze studie is een beschrijving van de perceptie van ouderen op bejegening door zorgverleners in een verpleeghuis.

Studie design en methode: Een kwalitatief onderzoek, data werd verzameld door middel van semigestructureerde interviews.

Setting: Een representatief verpleeghuis in een middelgrote stad in Nederland.

Studie populatie: Ouderen zonder cognitieve beperkingen in een verpleeghuis. Uit deze populatie zijn door middel van een doelgerichte steekproef 15 ouderen geselecteerd.

Resultaten: Ouderen willen dat hun zorgverlener; vriendelijk, kalm, begripvol, respectvol en betrokken is. De belangrijkste bevinding is de aannames die ouderen doen in relatie tot communicatie en contact met zorgverleners. Door deze aannames zijn ouderen terughoudend om hun wensen en behoeften te delen met zorgverleners. Dit beperkt de relatie tussen oudere en zorgverlener en is daardoor van invloed op de bejegening in deze relatie.

Conclusie: Resultaten van dit onderzoek geven inzicht in hoe ouderen in een verpleeghuis bejegend willen worden door zorgverleners in termen van gedrag maar nog belangrijker onthullen de invloed van ouderen op de bejegening. Door de terughoudendheid van ouderen veroorzaakt door de aannames wordt een extra claim gedaan op de opmerkzaamheid van zorgverleners. Het is belangrijk dat zorgverleners hieraan kunnen voldoen. Dit heeft praktische gevolgen zoals het aanpassen van het verpleegkundig systeem en het onderwijs van zorgverleners in een verpleeghuis.

Sleutelbegrippen: ouderen, ethiek, bejegening, perceptie, verpleeghuis en attitude

Abstract

Background and objectives: Although the importance of perceptions of elderly on personal treatment and quality of care in nursing homes is acknowledged, research regarding this subject remains scarce. To date no study has investigated the perceptions of elderly living in a nursing home in the Netherlands about the personal treatment given by caregivers. The aim of this study was to provide a general description of the perception of elderly in a nursing home on the personal treatment by caregivers.

Study design and method: A qualitative survey, using semi-structured interviews for data collection.

Setting: A representative nursing home in a middle large town in the Netherlands.

Study population: Elderly without cognitive impairments living in a nursing home. From this population a purposive sample was drawn consisting of 15 elderly.

Results: Elderly expressed the need for their caregiver to be: friendly, calm, understanding, respectful and involved. The most important finding is the assumptions made by elderly in relation to communicating and connecting with caregivers. Due to these assumptions elderly were reluctant to share their wishes and needs with caregivers. This is limiting the relation between elderly and caregiver and therefore of influence on personal treatment within this relationship.

Conclusion: Findings from this study give insight in how elderly in a nursing home want to be personally treated by caregivers in terms of behavior but more importantly reveal the influence of elderly on personal treatment. Because of the reticence of elderly due to the assumptions an extra claim on the attentiveness of caregivers is made. It is important that caregivers are capable to fulfil this claim. This involves practical implications such as adjusting the nursing system and education of caregivers.

Keywords: elderly, ethics, personal treatment, perceptions, nursing home, attitude.

Introduction

When elderly move into a nursing home it becomes their home and influences how care is perceived. However, the medical model of care is often used in nursing homes which focus on the diagnosis and not the patient. This care model contributes to the objectification of elderly living in nursing homes (1; 2). From literature it becomes clear that an important factor on the quality of life and care in nursing homes is how caregivers personally treat elderly (3; 4). Care with dignity and integrity is important for elderly. If it is lacking it makes them feel that they are not seen as a unique individual (5-7). To preserve this individuality, elderly must be recognized as a person with a life story (8-10). Independence can be increased by letting elderly exert control over the daily routine. Depriving them of this decision making makes them vulnerable and this vulnerability impedes them to raise objections against decisions of caregivers (6; 7; 11). If caregivers listen and communicate with elderly, they feel heard and compassion from caregivers which contributes to feeling someone (6; 10; 12-15). Care can be made more personal and perceived positive by adjusting personal treatment by caregivers to the wishes and needs of elderly (4).

In this study the term personal treatment is used because there is no exact translation of the Dutch word 'bejegening'. Personal treatment is the behavior towards someone or something (Dale van, 2010). According to Fishbein and Azjen (1975), behavior is determined by the *intention* to treat. This intention is formed by, someone's *attitude*, the view of others and the assessment of the individual capabilities in order to carry out the behavior (17). In addition to the intent to the desired behavior, personal treatment calls for abilities such as, correct and congruent verbal and non-verbal *communication, nursing skills* to perform technical and instrumental proceedings in regards to the nursing profession and possession of the necessary relevant *knowledge* (18).

Problem statement

Currently, quality of life and care in long term care institutions is measured by the experience of elderly (19). Experience with and perception on personal treatment are not necessary the same (20). By solely focusing on experience, perceptions of elderly living in a nursing home are omitted, while it is the perception on the quality of care that can be used as a starting point for improving (long-term) care (21).

Much scientific research is carried out on quality of life and care and how care should be executed. This has resulted in different nursing systems. These nursing systems have in common that they are patient centred.

This means care, which corresponds to the needs and wishes of the patient. In light of the latter it is remarkable that there is so little research available on the perception of elderly on care and personal treatment (22-24) To date, no study has investigated the perception of elderly living in a nursing home, on the personal treatment given by caregivers in the Netherlands. By focusing on the perception of elderly in a nursing home on personal treatment given by caregivers, care can be shaped according the needs and wishes of these elderly.

Research Question

Guiding in this study was the following research question; "What is the perception of elderly (aged >65) living in a nursing home on personal treatment given by caregivers?"

Aim

The primary objective of this qualitative survey is a description of perceptions related to experiences of elderly living in a nursing home on the personal treatment by caregivers. A secondary objective is providing recommendations for caregivers to improve quality of care by using the obtained insight in the experience and perception on personal treatment of the elderly living in a nursing home.

Method

This study was designed as a qualitative survey. This method is suitable to explore the variety in nature of features, behavior or cognitions (25). According to the Dutch law, (WMO, 2011) no approval by an ethics committee was required to conduct the interviews. The study was approved by the management of the nursing home.

Setting

The study was conducted in a nursing home that offers care and treatment to over 200 residents. It was located in a green residential area in a middle large town in the Netherlands. The home consisted of two wards for somatic care, two wards for rehabilitation and two wards for psycho geriatric care. The target population is elderly without cognitive impairments who are permanent residents of the nursing home. Therefore, the two wards for somatic care were chosen for this study. A total of 58 residents lived in these wards. Their age, social background and physical and cognitive abilities varied. Staff on both wards consisted mostly of nursing aids and volunteers, under supervision of a licensed practical nurse.

Sample

A purposive sample was used. Residents eligible for participation were 65 years of age or older, permanently living in the nursing home for at least six months and cognitively able to understand and take part in an interview in Dutch. Cognitive abilities were assessed by the recruiting care coordinator and graded with a yes or no for participation. The usage of the Mini-Mental State Examination (MMSE) was considered, but rejected because of time restrictions. The literature also indicates that it may offend elderly that their cognitive capacity is assessed by questions (26). Furthermore, elderly with slightly reduced or variable cognitive capacity are able to give their views and perceptions (27). Consequently, it was not considered necessary to exclude residents according to the outcome of the MMSE, if they were clinically judged to be cognitive capable to participate in the study.

Of the 58 residents, 21 elderly met the inclusion criteria. Thirteen women and two men between 68 and 94 agreed to participate in the study. Six elderly refused, mainly because they are unfamiliar with research and participation would cause too much anxiety.

Demographic characteristics of the participants are described in Table 1.

<Table 1>

Procedure

The care coordinators of the participating wards were verbally informed about the study by the researcher. When the inclusion criteria were met, the residents were informed about the study in writing and verbally by a care coordinator. They received an information letter and informed consent form. Before the interview started the researcher emphasized that participation was voluntary, and that they could withdraw without any consequences for their care and treatment. Participants were ensured of confidentiality and told that their personal details were only known to the researcher. The researcher emphasized that she did not belong to the staff of the nursing home.

Data collection

Data collection took place from January till April 2011, by semi-structured interviews. The interview started with two general questions: Since when are you living in this nursing home? and; What was the reason that you had to move to the nursing home? Subsequently, the overarching question was asked: How do you like your life in the nursing home? A topic list was used to ensure that the following aspects of personal treatment by caregivers were addressed: *attitude, communication skills, nursing skills* and *knowledge* of caregivers.

Because the answers of elderly were often short, follow-up questions were used to allow participants to elaborate on their experience based perception. This led to more extensive data but not to long descriptions. The researcher then interpreted their views and returned it as a question to stimulate elaboration, as done in the study of Bergland (2006). The interviews were carried out on the included ward in a separate, private room, lasted for 30 to 60 minutes and were tape recorded and transcribed verbatim. Participants were assigned a study code and all personal identifiers were sealed. The clean transcripts were used for analysis. The mentor (MJ) read the transcribed interviews and compared them with the analysis procedure and results. The researcher (EZ) and mentor (MJ) discussed differences in person until agreement was reached.

Analysis

The analysis was conducted in four phases (Table 2). The first step consisted of reading the transcribed material integral to become familiar with the data and so that statements can be seen in the correct context. In the second step significant statements were extracted from the interview related to the sensitizing concepts *attitude*, *communication skills*, *nursing skills* and *knowledge*. These significant statements were given a so called in-vivo code in MAXQDA. Some statements could be placed under two in-vivo codes. Significance was determined by integral reading the material and with the matrix of code frequencies, an application in MAXQDA. In total 46 in-vivo codes were appointed. These in-vivo codes were also exported into different MS Office Word files. In the third step the researcher read and reread the different in-vivo code files to identify what was important in the perception of elderly on personal treatment by caregivers in a nursing home. In this stage the assumptions made by elderly and their effect on personal treatment emerged as an additional category related to the sensitizing concept, *communication skills*. The in-vivo codes were connected with the initial concepts which came from the literature on personal treatment. After this transformation the statements were compared to determine the degree of variation or agreement. Theoretical and methodological memos were kept and inventoried in MAXQDA.

<Table 2>

Results

Each interview started with elderly making a general statement about the personal treatment by caregivers, which were primarily positive. They all expressed loyalty by understanding that caregivers in the nursing home were doing their best under conditions of time pressure.

As soon as they referred to situations they wanted to see differently, they almost immediately wanted to modify their statement. But on several moments in the course of the interview they reverted to these situations which indicate their importance.

Based on the data obtained, two main categories of personal treatment were extracted by analysis, *attitude* of caregiver and *communication* related to personal treatment. Both categories will be elucidated and discussed further in this paper. The remaining sensitizing concepts, *nursing skills* and *knowledge* appeared only relevant for elderly in case of a student caring for them. Elderly assumed that the nursing skills and knowledge of the regular staff was sufficient. When asked for examples of their skills and knowledge, following statements were given: 'they *just* know what I need' and 'they must know, all my pills are neatly besides my plate'.

Attitude

Attitude refers to how the caregiver behaves and carries him or herself in relation to elderly. Understanding and respect of the caregiver was stated important as well as being treated as an individual and ability to exert control.

Understanding and respect. Understanding from caregivers was related to the situation of elderly in the nursing home. When caregivers showed understanding, elderly expressed that this made them feel acknowledged as an individual. These meaningful encounters were seen in short daily contact moments when caregivers inquire how elderly experienced the day or activity, or showed interest in their past. However, elderly would like to see caregivers inquire more often how they feel or how they want to be cared for. The feeling of being respected was intensified when caregivers behave and act according the set of values of elderly. Elderly can feel offended when values were not respected.

VV11: They all bring it with a joke and that is fine with me, but not to people who are 80 or 90, that is crossing the line and then I say to them you can't do that, it is very disrespectful.

Also respect regarding their physical being was notified as important. Elderly need caregivers to be gentle and careful during caring moments. When caregivers are rough and hard in handling them, they feel uncomfortable and can feel violated.

VV03: Then two of them storm in my room, start pulling my arms and legs, it isn't going that soft, not that it hurts but it doesn't feel right.

Individuality. Elderly expressed that being treated as an individual is often lacking in personal treatment.

They are daily confronted with the fact that they are one of many, this usually happens when they ask for help and caregivers reply with: 'I first have to go help Mrs. X.' or 'You know you are not the only one on the ward that needs help'. The experience of often waiting for help was reported by all elderly in this study. This waiting and asking for help makes some feel powerless and small.

VV08: I ask them please help me, but they are too busy. Then I think where am I? I feel pushed in the ground sitting there waiting.

Some felt that they weren't kept informed about their treatment or with the routine of the ward. Most of the elderly accepted this fact as part of the institutionalized life but some stated that this made them feel belittled.

VV12: They said to me you can't stay here and I knew that, but then one week to another they said you are going to another ward next week. I didn't know anything and said that is no way to go, you're suppose to take it easy...that really hurt me.

Furthermore, elderly who were cognitively intact didn't experience equality amongst themselves. Especially living with residents with behavioral problems due to beginning dementia was perceived as uncomfortable. This resulted in withdrawal which made it more difficult for them to connect with caregivers.

Exert control. Being able to exert control over necessities of life was perceived by elderly as important and contributes to the experience of individuality and independency. Yet, most of the elderly expressed that they are fine with leaving caregivers in control and that they no longer felt the need to have full control.

VV08: I adapt to the rhythm of the ward, of course sometimes that's difficult but you take it, I don't think I can change that, and to be honest I don't want to, its fine like it is.

Communication

Elderly in this study expressed basic needs related to communication; caregivers should be friendly, respectful and involved.

VV01: Love and kindness, that is important.....The only thing I need is a warm and kind word. What also was expressed as being important was the ability of caregivers to listen and the effect when this was lacking.

VV15: I stopped saying what I think or want, they don't listen to it so why bother? I just let them tinker.

Elderly perceive the caregiver that listens as calm, soft and able to explain things in a simple and clear manner. This contributes to feeling an individual who is taken seriously.

It is perceived offensive when caregivers are curt. According to the elderly this curtness usually occurs when caregivers are in a hurry due to time pressure and staff shortage.

VV07: Then they are curt with everything you ask them...it makes you walk on eggs. But they are so terribly busy, I know I am not the only one.

Acceptance. Elderly in this study showed a lot of acceptance with the limitations of life in a nursing home, by frequently using words like; 'being realistic' or 'learn to appreciate'. Elderly lowered their expectations and valued their lives before the nursing home as best, but regarded as history. They expressed that the nursing home would never feel like home, it is merely seen as a necessity. Although elderly regarded their previous life as history most of them still act on their own set of values. What was perceived important is that one should be 'grateful' and 'not criticise'.

VV14: Gee, you have ears and eyes don't you, if you see that the nurses are busy, you don't start calling, first of all that is really rude.

However, elderly did expect caregivers to behave in a certain way. In most situations these set of values were related to their personality, past or upbringing with typical statements like; 'I am just that way' or 'that is how we did things at home'.

If elderly felt that the caregiver had similar values a connection was more easily established because they felt more inclined to share their thoughts and feelings with those caregivers.

Assumptions. Almost all elderly made assumptions during the interview related to connecting with the caregiver. These assumptions ranged from; don't want to be seen as a burden, to be seen as being difficult when expressing their feelings.

VV11: Look the girls already got their hands full; I am not going to burden them even more with my wishes, which they probably can't fulfil anyway.

Some stated that if they expressed their wishes or needs, a form of punishment would follow. As soon as these types of statements were made, participants tried to make excuses for the behavior of the caregivers or smooth out their statements.

VV05: No, I know that they dislike you because you say something, then they take a dislike to you, that becomes clear because they don't help you right away at night but leave you lying there for a while. But that's their decision, because then they have to work till late, I don't care.

Ideal situation

Social contacts from family or friends were valued as the utmost important, it was described as; 'the link with the outside world'. Elderly stated that this is what makes life in the nursing home bearable.

When social support was available, elderly expressed less need to connect with caregivers. However, all the interviewed elderly stated that, if it was possible, they would like to have more personal chats or attention with caregivers.

VV01: I would like to have more contact with the nurses if they would have the time. I would discuss my thoughts and feelings with the nurses if they have the time for it.

Besides the extra time to talk to caregivers about their thoughts and feelings, elderly didn't express to have other wishes directly related to personal treatment.

Discussion

The aim of this study was to describe the perception of elderly on personal treatment by caregivers in a nursing home. Although there were some differences in personal circumstances, there was an agreement on how elderly want their caregiver to be; friendly, show understanding, respectful and involved. These findings are consistent with what is already known in the literature on how elderly want to be cared for (6; 7; 13; 14; 28).

Especially in caring situations, where elderly can feel vulnerable and dependent, it is important to feel understood and respected. This corresponds to the main theme in the study of Harrefors (2009); maintaining the self and being cared for with dignity to the end.

In our study this is concretized in describing caregivers characteristics and behavior; being calm, soft spoken and able to explain in a simple and clear manner.

Acceptance. Elderly who accept life in a nursing home are more able to adapt to live in a nursing home. When they hold on to their previous life with the hope of returning to living independently, it limits the possibility to build a life within the nursing home and connecting to caregivers and other residents. This supports the concept of thriving within a nursing home as an emotional state, where balance between expectations and environment need to exist (13). Most of the elderly showed a high level of acceptance in combination with loyalty towards the caregivers. They were reluctant to criticize the behavior and actions of caregivers. In first instance this loyalty can be ascribed to the personal relation developed between elderly and caregivers. But on a deeper level it may be a result of the dependency of elderly on caregivers, best symbolized with the phrase: 'you don't bite the hand that feeds you'. Due to the dependency of elderly on caregivers, there is an uneven balance of power in the relation between them.

Assumptions. What was remarkable and not yet emphasized in other studies is the influence that the assumptions of elderly have on the level of communication and therefore the personal treatment by caregivers. All interviewed elderly continuously made assumptions which not only limits their attempts to connect to caregivers but also disables caregivers to establish a connection with elderly. As a result of those assumptions, elderly withheld information from caregivers such as; how they felt, what they needed and wished for.

It is possible that this behavior is a form of dealing with the situation, where elderly hedge against negative encounters with caregivers. Its origin remains unclear; it can be due to previous negative experiences or to expectations of life and caregivers in a nursing home. However, due to these assumptions a greater claim to the attentiveness of caregivers is made. Caregivers then have to be attentive enough to notice the needs of elderly. Staff shortage, time pressure and the level of education of caregivers in nursing homes can form impediments to fulfill this claim.

Limitations

Although this qualitative survey was conducted according a rigorous methodology, it is not without limitations. The first limitation is the focus on perception instead of experience which distinguishes this study from many other studies, but proved to be difficult. Elderly had a hard time reflecting on their situation or to picture the ideal situation. Only when the researcher sketched a situation where there was enough time and personnel, elderly confirmed that they would like to talk with caregivers and share what their wishes and needs are. A pitfall of this approach is that it can lead to controlling the interview which limits the objectivity of the study.

A second limitation is that the included nursing home was situated in a middle large town. The findings maybe different if the study had been conducted in a nursing home in a large city, due to variation in ethnicity in the population. It is possible that the needs and wishes of elderly with a different cultural background with personal treatment by caregivers differ. Generalizing results of qualitative research should be done with caution and with consideration of setting and population under study.

(Clinical) Implications

The assumptions made by elderly are of influence on the level of communication and connection with caregivers. This finding is not yet been emphasized in literature and is relevant if personal treatment must be geared to the wishes and needs of elderly. A practical implication is related to the extra claim on the attentiveness of caregivers due to the assumptions made by elderly. Because lower skilled caregivers work in nursing homes it is possible that this extra claim can not be met. Therefore, it may be important to include this finding in the education of caregivers working in nursing homes so they can correspond accordingly. First, more research is needed to uncover the influence of elderly on personal treatment and the underlying processes in the relation between elderly and caregivers. The second practical implication is linked to the curtness of caregivers. Currently, staff in nursing homes have to work according time schedules, this means that each task can only take up a fixed amount of time.

In this study all of the elderly experienced caregivers lacking time. This resulted in the perception of caregivers as curt when they are in a hurry and busy. It is possible these time schedules causes caregivers to focus more on working efficiently and this has a negative influence on personal treatment. This corresponds with the fact that residents then become instruments to meet bureaucratic requirements which leads to objectification of nursing home residents (1; 29).

In social context it is important to realize how significant contact with family members and friends are for elderly in a nursing home and how this influences their lives within the institution. Social awareness to this need must be stimulated.

Conclusion

This study provides a general description of the perception of elderly in a nursing home on the personal treatment by caregivers. This description corresponds with results from other published studies. Findings from this study give insight in how elderly in a nursing home want to be personally treated by caregivers in terms of behavior but more importantly reveal the influence of elderly on personal treatment. Elderly continuously make assumptions in connecting with caregivers. Therefore, caregivers must be aware that elderly can show behavior that can easily be misinterpreted. It matters to understand the relation between elderly and caregiver because of the impact this has on personal treatment.

At last, caregivers must be able to provide care that is adjusted to the wishes and needs of elderly even when those wishes and needs aren't literally expressed. As a consequence it is imperative that policy of nursing homes and education of caregivers are adjusted, enabling caregivers to provide the best care, as perceived by elderly.

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Author contributions

Esther Zwart and Michel Jansen were responsible for the design of the study. Esther Zwart collected and analysed the data and is also the primary author of the article. Michel Jansen participated in the data analysis and supervised the study. Both authors, Michel Jansen and Janneke de Man supervised the writing of the manuscript.

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Table 1 Participants' demographic data (N=15)

<i>Variables</i>	<i>N (%)</i>
Gender: Female	13 (89%)
Age (years)	2 (13%)
- 65-74	2 (13%)
- 75-84	11 (74%)
- 85<	
Length of stay (mean, months)	26
Disease/illness:	
- CVA	6 (40%)
- Immobility	2 (13%)
- Other	7 (47%)
Living conditions prior to admittance:	
- independent living together without assistance	2 (13%)
- independent living alone without assistance	8 (54%)
- independent living alone with assistance	5 (33%)
- institutionalized	0
Social support available	13 (87%)
Level of mobility*:	
- No limitations (0-4%)	0
- Slight limitation (5-24%)	0
- Moderate limitation (25-49%)	3 (20%)
- Severe limitations (50-95%)	4 (27%)
- Complete limitations (96-100%)	8 (53%)
Level of self care*:	
- No limitations (0-4%)	0
- Slight limitation (5-24%)	0
- Moderate limitation (25-49%)	3 (20%)
- Severe limitations (50-95%)	4 (27%)
- Complete limitations (96-100%)	8 (53%)

* based on the WHO 'international Classification of Functioning, Disability and Health' (ICF)

Table 2 Analysis example of step 2-4

Step 2: Extraction significant statement	Step 3: In vivo codes	Step 4: Sensitizing concept
There are some that are nice, but some are very curt, you know, well I don't accept that, I am not a little child, if so they can just leave...	The effect on elderly when caregivers are curt	Communication
It wouldn't relieve me to talk to nurses what bothers me.....they don't understand.... They say; "Oh don't whine it is wonderful here". So no.....	When caregivers lack understanding, elderly will not discuss their feelings or thoughts	Attitude