THE MEANING OF RECEIVING HELP FROM HOME NURSING CARE

Aud Moe, PhD- student, MH, BN (Corresponding author) is a lecture at the Faculty of Health and Science, Nord-Trøndelag University College, N-7600 Levanger, Norway; Department of Health Sciences, Mid Sweden University, SE-851 70 Sundsvall, Sweden; email: aud.moe@hint.no

Ove Hellzén, RN, PhD, is a professor at the Faculty of Health and Science, Nord-Trøndelag University College, N-7800 Namsos, Norway; Department of Health Sciences, Mid Sweden University, SE-851 70 Sundsvall, Sweden; email: ove.hellzen@hint.no

Ingela Enmarker, PhD, RNT, is a Associate Professor in Faculty of Health Science Nord-Trøndelag University Collage, N-7800 Namsos, Norway; email: ingela.enmarker@hint.no

Correspondence to:
Aud Moe
Faculty of Health Science
Nord-Trøndelag University Collage
Serviceboks 2501
N-7729 Steinkjer
Phone: +47 911 31 163
Fax: +47 74022501
E-mail: aud.moe@hint.no
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ABSTRACT

The aim of this study was to illuminate the meaning of receiving help from home nursing care for the chronically ill, elderly persons living in their homes. The study was carried out in Norway. Data were collected by narrative interviews, analysed by phenomenological hermeneutic interpretations. Receiving help from home nursing care sometimes meant, “Being ill and dependent on help”. Other times it meant “Being at the mercy of help”. It could also mean, “Feeling inferior as a human being”. Sometimes help was given by nurses who were respectful and proficient at caring for an elderly person, while at other times nurses seemed to be incompetent and worked with a paternalistic attitude without respect for privacy. Receiving help also meant the elderly wanted to be regarded and approached as equal human beings, supported in the courage to meet challenges in life.

Keywords: autonomy, dignity, elderly, home nursing care, phenomenologic hermeneutic
INTRODUCTION

The population of elderly people is rapidly increasing in the Western world and in Norway. Being elderly means facing challenges such as risk of functional impairment and chronic disease (1). As age and illness advance, one’s need of help from others increases (2, 3), and it is expected that professional help will be necessary in their homes (1). Becoming dependent on help might result in an asymmetric relationship, which threatens the person’s dignity (4). Anderberg et al. (5) describe dignity as common for all humans and, at the same time, unique to each person.

According to the Norwegian nurse philosopher Martinsen (6) the ethical question is how the society combats suffering and takes care of those who need help. The patient’s suffering and vulnerability appeal to the nurses professional care ethics to help the patient instead of interfere or master the patient. This means how to take care of persons’ eternal meaning and the individual’s unending worth. This is the underlying importance of the relationship between nurse and patient (7). This relation should support autonomy as a part of dignity (8).

Philosophers have for a long time emphasised the importance of relationships between human beings (9, 10, 11), this has also been confirmed empirically (12, 13). The relationship between nurses and the patients of home nursing care unfolds in the latter’s home, and it is important to remember that the home is a central place in the lives of elderly people (14). Lindal, Lindén and Lindblad (15) created a meta-synthesis of research to describe the relationship between patients and health professionals in the home care setting and found that when professionals entered people’s homes, the private arena became a place and space for professional care. Thus, Tønnesen Førde and Nortvedt (16) found that working in patients’ homes requires nurses to remain aware of their patients’ privacy as part of their dignity.

After reviewing extant literature about preserving dignity while caring for elderly people, Gallagher, Li, Wainwright, Jones & Lee (17)
found four themes for dignity-promoting factors; the environment of care, the culture of care, the performance of specific care activities, and the staff’s attitudes and behaviour. However, the knowledge about the ways that home care nurses influence a patient’s daily life from the perspective of the elderly persons is still limited. Therefore the aim of this study was to illuminate the meaning of receiving help from home nursing care for the chronically ill, elderly persons living in their homes.

DESIGN AND METHOD

This qualitative study focused the meaning of human experiences (18) through narrative interviews with elderly patients of home nursing care to understand the influence of this help in their daily life (19).

Research context and participants

The selection of participants was completed through recruiting participants from a previous study of the elderly persons in Norway (20). In the present study, a sample of elderly women (n = 6) and men (n = 5) who were 80 to 92 years old (mean age = 88) participated. They were aged 80+ years, living at home with chronic diseases, receiving help from home nursing care, and with a capacity to be interviewed. The informants had a variety of diagnoses, such as diabetes, heart disease, cancer, musculoskeletal disease, and visual and hearing impairment. Living at home meant that they lived in traditional homes (n = 7) or in a sheltered household (n = 4) that is a concentration of apartments adapted to the needs of elderly persons. At the time of the interview, all participants were receiving help from home nursing care two – six times a day for general attention, personal hygiene, feeding, medication, wound care, and other kinds of treatment. The employees who were assisting the participants
were registered nurses, licensed practical nurses, or unskilled labourers.

Data collection

Data was collected by narrative interviews describing lived experiences (21). The first author conducted the interviews and asked the participants to discuss their experiences in receiving help from home nursing care, and what they wanted from their helpers. The narrative was performed in their homes. The researcher used an audiotape during all interviews, which lasted 45 – 90 minutes.

Ethical considerations

Permission to carry out the research was given by the Middle Norway Regional Committee of Research Ethics (4.2007/257). The home nursing care staff informed the participants of the purpose of the study, their ability to retire from the study at any time, the confidentiality, and the use of information from the interviews. All participants gave written, informed consent.

Data analysis

The tape-recorded interviews were transcribed. This life world interview (22) focuses on experiences, using interpreted narrative interviews to understand the meaning of receiving help from home nursing care for the elderly and chronically ill persons. Interpretation may be done using the hermeneutical circle, which shows movements between the understanding grasped by the reader and the meanings suggested by the text (23). The analyses that the authors applied to the transcriptions were similar to the ones developed by Lindseth and Norberg (24). In addition, they developed their method from Ricoeur’s “phenomenological interpretation”, which entails a first naïve reading followed by a
structural thematic analysis and comprehensive understanding. The authors then reached consensus by way of reflection and dialogue (19).

Naïve understanding: The authors subjected the text to an open-minded, naïve reading in its entirety several times to gain a sense of the whole and to understand the meaning of its content as articulated by the informants and formulated by the authors from a phenomenological perspective. The naïve understanding was validated using structural analysis.

Structural analysis: The text was read again and sorted into meaning units that were guided by the aim of the study and the naïve understanding of the text. Meaning units were condensed to units that were read fully, compared to reveal similarities and differences, and then sorted. Units with similar meaning were further condensed before being formulated into sub-themes and themes (Figure I).

Comprehensive understanding: The text was read once more as a whole using the understanding that was gleaned from the naïve reading and validated by the structural analysis, which reduced the uttered meanings of the text according to the phenomenon to be illuminated (25). This method combined phenomenological philosophy with hermeneutic interpretation in a dialectic process that moved back and forth between understanding and explanation, and it culminated in a comprehensive understanding (26) influenced by the authors’ pre-understanding and theoretical framework.
**Figure 1 Example of the analytical process from sub-theme to theme**

- Living a daily life with chronological illness
- Being in need of professional help
- Being a participant or a receiver of help
- Being a host or a guest in my home
- Being a burden to nurses
- Being an oldest old human being

**FINDINGS AND INTERPRETATIONS**

**Naïve reading**

The naïve reading showed that receiving help meant being ill and dependent on help from home nursing care. Some of the informants were satisfied with the nurses’ friendly manner of carrying out duties. Others missed help from competent nurses in treatment, caring, and individual adjustment of help. The help they received influenced their participation and experiences of being at home. Some of the nurses took time for a talk, and others did not talk at all,
because they were busy with duties and made the informants feel inferior. On the other hand the elderly felt consideration for the nurses. Still, many of them had thoughts of enjoyment of life.

**Structural analysis**

The structural analysis resulted in three themes that exist in aspects of receiving help from home nursing care: “Being ill and dependent on help”, “Being at the mercy of help”, and “Feeling inferior as a human being”. These themes will be presented with their sub-themes.

**Being ill and dependent on help**

The theme “Being ill and dependent on help” was interpreted from the sub-themes “Living a daily life with chronic illness” and “Being in need of professional help”.

**Living a daily life with chronic illness**

Living a daily life with illness meant that the informants needed help on both good and bad days. Most of the informants were satisfied with the help coming to their homes. Some felt busy with many visits during the day because of illness and they became exhausted. Illness with pain, infections, and shifting periods of chronic illness could cause bad days, and they wanted to stay in their homes. Some participants were not satisfied with the lack of continuity with many different nurses visiting them. This was expressed by a man, 85 years old:

Never the same (nurse). Do not know how many different persons they are? I do not know who is coming you know.

With foreign nurses caring for the elderly persons, they were unable to get to know them and that made it difficult to have conversations. Limited continuity could lead to information failure such as the case of one woman who talked about the safety alarm that did not function when she had a heart attack; unfortunately, the battery had drained on the device. Previously the porter regularly changed the
batteries, but the porter no longer had this job, and the woman was not informed about this change.

Living a daily life with illness could also mean good days with possibilities to participate in social activities, have visits, and enjoy short journeys. They were satisfied with help from nurses who could invoke positive feelings when visiting them.

**Being in need of professional help**

Being in need of professional help meant the informant’s age combined with disease demanded competence in treatment and care. Some nurses were experienced and clever, whereas others were not even competent in the basic tasks that they were sent to do, such as observing the patient’s condition. On occasion the incompetent ones did not notice cues that they needed to heed, as one woman explained:

*They do not see anything when I sit there ill, they do not look at me and discover what I need.*

Woman, 92 years old

On the contrary, competent nurses observed and discussed the patients’ bad appetite, urinary incontinence, musculoskeletal disease, worries, etc., and then their needs were met.

A man was anxious about his next shift of catheter à demeure because the last shift resulted in life-threatening bleeding but none of the nurses talked to him about this problem before the next shift and he spent a considerable amount of time thinking about this. In contrast a woman told about nurses helping her to contact a priest to clarify her rights in connection with her death and funeral. Then she did not worry any more.

Being in need of professional help meant competence in technological skills, such as injections, and manual dexterity in carrying out physical assistance like movements when getting up in the morning. A woman reported, “It hurts when they rotate me; they are not careful” and this made the movement painful for her. Caregivers also showed their level of competence through their attitudes. One helper demonstrated a lack of empathy by making the
remark, “You can manage this if you just have the will to do it”. The woman felt hurt by this statement that placed the responsibility on her.

Being in need of professional help could mean competent nurses treating them with respect such as calling the elderly person if they were too late for the visit. These nurses were vigilant on the patients’ conditions, and gave qualified treatment and care.

**Being at the mercy of help**

The theme “Being at the mercy of help” was interpreted from the sub-themes “Being a participant or a receiver of help” and “Being a host or a guest in my home”.

**Being a participant or a receiver of help**

Patients were living in the tension between being a participant or a receiver of help since there were times when some were able to participate in helping but also times when they were merely receivers of help, or sometimes just left alone. The recipients told about limited participation in discussion about their need of help and some nurses did not make individual adjustments to the help they were providing. This frustrated the informants. A woman living in a drafty house told about a lack of care during a very cold and windy winter:

> I was lying in my bed and freezing. I rolled up a towel to put under my bed to keep cold air away. I said to the nurse, “Would you please lay this under my bed”? She wanted to leave and said, “There are several of you needing help. It is not only you”. The nurse repeated this several times.

Woman, 91 years old

At last the woman threatened to complain and then she received help. There was no flexibility to ask for more duties than those that were already decided.

This woman also told about participating in her own morning care:

> Yes, they wring the face cloth for me and I wash my face. Before I reach to dry my face, they have taken the towel away
In this case the woman was a participant in washing her face but because nurses were in a hurry she did not have time to complete her self-care. The nurses took charge and thus transformed the woman into a receiver of help.

Being a participant or a receiver of help could mean feeling left alone. One woman said the visit from home nursing care lasted only ten minutes, so she thought the purpose of the visit was to see if she was alive, nothing more, and she felt left alone. Another woman recounted an experience with taking a urine test. The home care nurses had given her equipment and left her with a message to carry out the urine test on her own, which was difficult for her to do with her stiff fingers, lack of mobility in her legs and hips, and with problems visiting the toilet on her own.

Being a participant or a receiver of help could imply nurses who had positive attitudes and who asked the elderly persons in a friendly manner whether they could do more to help them. “It is what they do – they who are the right persons ... they do something extra. They have learned to treat us as we want”. A woman told about a nurse calling a pedicurist for her when it was difficult to manage this. Then she was happy to be a receiver of help. Some of them also described nurses coming for a special visit when they thought there was a need for talk or that the elderly person needed more help. These nurses made them feel safe by inviting a phone call if they wanted to talk to them.

The desire to be a participant or a receiver of help could mean wishes of supporting help carried out in equal cooperation between the nurse and the patient. One respondent described this cooperation through her wishes for a good visit:

Sometimes, I have hypoglycaemia and then I feel unsafe and wonder about the doses of insulin I dare to set today, and I wonder if there was a nurse with some experience. Then she (the nurse) could say, “I think you should have only a half dose today”. And then I would think it is good support.

Woman, 92 years old
This woman felt unsafe when she had to decide the doses of insulin when her blood sugar was too low for the normal doses. She wanted support from nurses discussing the doses with her. Then she would feel comfortable setting the injection herself.

**Being a host or a guest in one’s home**

Being a host or having a guest in one’s home could mean that the recipients were satisfied with the nurses who visited them in their home with an attitude of being a guest letting the elderly person be a host. Other informants were unsatisfied with the way the nurses behaved, especially their lack of respect for the recipient’s private home. One man told a story about a cupboard in his kitchen where the nurses stored their equipment.

“…And I said to a nurse that there is a terrible mess in this cupboard. I have to tidy up because there is nobody else to do it, I said. Then she got angry”.

Man, 82 years old

This man wanted to help the nurses to keep his cupboard clean and tidy but when he suggested his help the nurses got angry and he felt the nurses became the host in his kitchen.

A few recipients even complained of the phone calls that the nurses made while they were visiting them. One woman remarked:

*They are using my sitting room as a telephone exchange ... I am sitting on needles during the visit and am not looking forward to the visit.*

Woman, 92 years old

The woman wanted visits from nurses focusing on her. Instead the nurses used her time and home for phone calls. She regarded the nurses as stealing her time for the visit and turning her home into a workplace. This made her feel like a guest in her own home. There were also positive experiences in which the homeowners felt as though as they were hosts to nurses who had respect for their private zone and underlined their home as a part of their identity.
Feeling inferior as a human being

“Feeling inferior as a human being” was interpreted as “Being a burden to nurses”, and “Being an elderly human being”.

Being a burden to nurses

Being a burden to nurses was expressed as busy nurses who “do not care for me and my illness; the help is impersonal”. The latter types of nurses were described as coming into the home and immediately asking where the equipment was. They would start to work at once and did not answer when the informant talked to them. This could cause the informant to hurry with their own care, because they might worry that they were troubling the nurses.

Being a burden to nurses could mean they did not dare to talk about difficult thoughts. One woman with experiences of illness and death of two of her children often thought about her loss and grief:

Thinking about those who have passed away ... If I start to think of that I cannot leave this though ... I do not have more tears left, but then there are flowing tears of blood in my heart.

Woman 91 years old

When she felt like a burden to the nurses she could not speak about such a serious subject. The informant needed a good relationship with nurses who were willing to make individual adjustments on bad days.

Being a burden to nurses could lead to consideration for the nurses. One woman felt displeasure about the busy visits. Afterward, she felt sorry for the nurse, admitting:

I get in a bad mood, get sorry for what happens then. Maybe she (the nurse) was not happy when she left. They need encouragement when they leave to continue in this job.

Woman 92 years old

She felt her bad mood was a burden to the nurses and after the visit she was sad because she wanted to be nice and support them in their job. The informants expressed sympathy for the nurses and emphasised that it is not the person but the system with which they were dissatisfied.
All informants talked about busy nurses but they also said the nurses mostly were patient and friendly. One informant receiving help four times a day talked about nurses as a part of his family. Even if the nurses were in a hurry they took time for a talk once a day.

**Being an elderly human being**

Being an elderly human being could imply thoughts about the end of life; several of them stated that they did not wish to be held alive artificially. Other thoughts were about wishes for death:

*Thinking about death, I hope I do not have to be alone … to have somebody with me, not being alone the last days and nights. I am not pleased by these thoughts.*

Woman 91 years old

She did not expect the nurses to stay with her during her last days and nights and that made her worry for what would come in the end of life.

Being an elderly human being could mean feeling unworthy, accepting negative attitudes toward their age, thoughts about end of life or contrary to that; enjoying life despite being ill and very old. Some participants told about equality in relations between themselves and the nurses whom they described as fantastic and like friends. One woman said:

*They (nurses) are coming every morning … I have two human beings coming, one in the morning and one in the evening.*

Woman 88 years old

She was very happy because every morning and night nurses visited her and these visits confirmed her as a human being meeting other human beings. Others told they rarely received this confirmation in their old age. A woman said that she was so lucky to be very old and still alive, but she also thought that she got in the way of others. Being an elderly person could encourage one to criticise him or herself as being old-fashioned and having difficulty adjusting.
Being an elderly human being could mean positive situations, such as staying in their homes with small souvenirs from a long life as well as with something to anticipate. They also expressed enjoyment of life and possessing the courage to meet a new day. The courage was connected to their will to get up in the morning and to pressure themselves to participate in activities they could manage. They felt good when they were supported in the courage to meet challenges in life.

Comprehensive understanding

Being a receiver of help from home nursing care meant being ill and dependent on help. The help was concretized as physical help, but as far as the informants knew, it did not tell about continuity, flexibility, competence, nurse attitudes in completing the visit, or the consequences of time pressures for the nurses. Daily life sometimes was influenced by a great variety of nurses carrying out help-oriented duties instead of individual caring. Being at the mercy of help made them sometimes feel like a participant, other times like a receiver of help. The help given in their homes made them sometimes feel like a host, other times they became guests in their homes. Some nurses worked in a paternalistic way, their homes became working places without a sense of privacy. Other nurses were friendly, took care of the integrity of the informants, and confirmed them as human beings in a respectful way. These visits were bright spots in daily life. However feeling inferior as a human being could make the recipients feel like a burden to busy nurses but they also cared for the nurses who they wished to meet as fellow humans. Being confirmed as a human being in need of help was for them to be seen, met, and supported in the will to live and the courage to meet challenges in daily life as elderly and chronically ill.
DISCUSSION

The aim of this study was to illuminate the meaning of receiving help from home nursing care for the chronically ill, elderly persons living in their homes. Being a receiver of help from home nursing care could sometimes be restraining, other times promoting dignity as being elderly in need of professional help.

Gallagher et al. (17) formulated four themes that might promote dignity in care; the environment, culture of care, performance of specific activities, and staff attitudes and behaviour. The environment, e.g. the context, was in this study the elderly person’s home where they sometimes were the host yet other times guests for the nurses. Homes are sometimes influenced by the professionals who transformed a private space into a place of professional care (15). In this study homes became a working place for nurses and the informants were at the mercy of this help. Elderly persons living at home value getting sufficient information, having the ability to reach nurses by phone, and getting an extra visit (27). The informants of the present study expressed a desire for flexibility, but they claimed that phone calls caused a disturbance in their relations with nurses visiting them. Specifically, elderly persons then feel uncertainty within the encounter, low esteem, and loss of privacy (4). Opposite to being a guest the informants sometimes were hosts for nurses who brought bright spots in their daily life.

Dignity can be promoted by the culture of care, e.g. ward philosophy (17). In this study the participants being ill and dependent on help received help from many performers of help. This is in accordance to other studies that found nurses visiting many patients resulted in limited continuity (27, 28). The culture of care sometimes made the informants be participants while at other times they were receivers of help, or just left alone. Some nurses in this study focused on carrying out tasks from a perspective of a given framework, not on how they carried out the help. Studies have found that nurses did not show respect for the patient’s situation when they focused on only a few aspects of the patient’s needs (12, 16). Values
such as respect and solidarity are threatened by a shortage in resources (16) limited continuity, little involvement, and lack of holistic or individualised care (17). However, some informants received help from a few respectful nurses treating them as family who took responsibility to observe their changing needs for help.

The performance of specific care activities has the potential to promote or thwart dignity in actual procedures or actions (17). In this study being ill and dependent on help meant nurses with limited competence in caring for elderly persons. Caring demands competence in three broad areas: knowledge and science, skills and clinical proficiency, and ethical attitudes and formation (29). To promote dignity competent nurses in this study used their competence in a supportive way letting them be a participant but also a receiver of help when they did not manage the activity. One important support is to be understood and confirmed in illness through supportive relations (30).

The staff attitudes and behaviour in actual procedures and actions can promote or thwart dignity (17). The recipients’ feelings of being confirmed or violated in relation to caregivers depend on the latter’s influence on the performance of the care and services (31). In this study informants sometimes felt at the mercy of help, unable to yield any influence. They also sometimes felt inferior as a human being by being a burden to nurses who did not see them as human beings and met them with attitudes of ageism (32). Ageism is one of the major sources of the ethical issues that arise for nurses caring for elderly people (33). Nurses can threaten the patient’s dignity through the misuse of power, such as not attempting to respect the patient, not providing enough privacy, and taking control of the patient’s life (34). Other times nurses in this study met with their patients, confirming them as human beings simply by behaving as a fellow human.

To promote dignity in care has to be another consideration with respect for the dignity of others (8, 35, 36). When nurses objectify a patient and treat the patient as another number in the working day, they establish a connection with the patient characterised by the “I–
It” relationship (37). The participants in this study sometimes experienced the relationship as not being seen as a whole person. According to the French philosopher Marcel (38), the inter-subjective context of “being with” presents us with “I – You” rather than “I – It” - relationships. Dignity through the “I – You” relationship is to take responsibility for, not from, the patient (11). In this study, I and You sometimes changed place. The participants expressed that they could “see the other” by “being with” busy nurses from whom they sometimes experienced disrespect. Disrespect has the potential to diminish the possibility of flourishing relationships, and it can make persons more vulnerable (37). Opposite to disrespect is to give patients the courage to live (10, 39) on both good and bad days. In the context of caring for the elderly it is to take care of the elderly person’s eternal meaning with her or his unending worth (7). This will promote autonomy and dignity as a human being.

CONCLUSIONS

Promoting dignity for elderly persons’ demands is influenced by those who care for their needs as they shift between good and bad days. There is a requisite to maintain continuity, and improve nurses’ attitudes. While receiving help from caring staff, elderly persons wish to be seen and met as human beings. The worth of a human being is unique and nurses can engender respect or disrespect depending on their attitudes, their knowledge about ill elderly persons, and possibilities for this practice. It is then important that expert knowledge is used to support the will to live and the courage to meet challenges in life. Nurses’ working days are busy and there is no indication that this is going to change. Therefore having leaders who are willing to provide a culture of care will be very important. A culture of care should be coloured by respect for the elderly person and her or his privacy, and should result in focusing on the person for the few minutes that the visit lasts. This can promote a feeling of dignity as they will be seen as an individual, met and confirmed as a human being.
METHODOLOGICAL CONSIDERATIONS

The participants were vulnerable persons and had great dependency on others. The research interview is a professional conversation with a distinct asymmetric power between the researcher and the respondent; the researcher needs to reflect on this power during the production of knowledge (22). The participants could easily provide inferior information by answering with what he or she thought was the right response or because of a poor dialogue that gave the wrong information. The researcher tried to let the participants speak freely and thus balance the power in the conversations.

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