

Nurses' and carers' appraisals of workload in care of frail elderly awaiting nursing home placement.

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ABSTRACT

Aim: The aim of this paper is to describe carers' and nurses' appraisals of workload in care of frail elderly awaiting nursing home placement.

Background: Carers' workload of care for frail elderly awaiting nursing home placement has been studied separately from that of nurses' workload. The literature has not addressed a comparison of carers' and nurses' appraisals of psychological and physical workloads nor the most strenuous factors common to the workloads of both nurses and carers in care of the same elderly person. The terms 'carers' and 'nurses' in this paper refer to informal caregivers and to both ENs and RNs respectively when no particular one is stated.

Method: The sample was comprised of 11 nurses and 11 carers paired based on care provided to the same elderly person awaiting nursing home placement in Norway. Data collected by a workload-scale was analyzed by descriptive statistics. Data collected by individual interviews was analyzed by qualitative content analysis. Carers' and nurses' appraisals of workload were compared and contrasted and most strenuous factors described.

Findings: The findings show that both carers and nurses rated workload levels maximum. Carers' highest ratings concerned psychological workload, while nurses' highest ratings concerned physical workload. The workload ratings concerning elderly with advanced dementia disease were most similarly aligned. Qualitative content analysis showed three categories that describe the most strenuous factors common to the workloads of both carers and nurses. These were feeling responsible, feeling burdened and feeling ambivalent.

Conclusion: This study reports carers' and nurses' appraisals of workload in care of frail elderly awaiting nursing home placement. The results show many similarities and some differences. These results may help guide policy development to address resource allocations to elderly care. Further research is needed to address workloads of care for elderly awaiting nursing home placement.

Keywords: Nurse, carer, elderly, workload, nursing home placement.

Nurses' and carers' appraisals of workload in care of frail elderly awaiting nursing home placement.

Introduction

Between 2001 and 2006 Norway was rated the best country in the world to live based on factors like life expectancy at birth and gross domestic product per capita (1). Almost 70 percent of women were employed, but 42 percent worked part time (2). Norway faces an increasing ageing population (3) and the national policy supports elderly living at home as long as possible, which reduces national health care expenditures, but poses great demands on informal care (4). Home care is government supported, but elderly pay 75-85 percent of their income for nursing home (NH) care (5). This can be an economic burden for families.

In Norway, when elderly become too frail (physically weak (6)) to manage living at home, community nurses or family members can request NH placement and then a community nurse and a physician assess the level of care needed. Often the decision is NH admission, but due to lack of beds (7), many are placed on waiting lists. During the waiting period, frail elderly have to manage with care from community nurses and carers. An Irish study showed that deciding NH placement could result in carers' feelings of failure, anxiety and guilt (8). In the Netherlands, high levels of carer burden were found for elderly with dementia disease on NH waiting lists (9).

In 1999-2003, most Norwegian elderly preferred adequate home care (10), many elderly desired more help than offered (11), and home services' resources had to be strictly prioritized (12). Nurses' and carers' assessments of elderly's needs differ. The fact that carers, with the exception of spouses, are often fulltime employed besides caregiving (2) can result in elderly not always receiving care they consider adequate. Most caregiving is unpaid, although it is possible to receive financial benefits for especially burdensome care (13).

Carers' workload ('the total energy output of a person performing a strenuous task over time' (14)) is well documented (15-17). We use the term workload instead of burden, because it appears more neutral. With some exceptions most studies focus on either carers' or nurses' perspectives. In Canada, nurses' and carers' responsibilities were reported changed over time. First, nurses provided and coordinated care while carers assumed supportive roles. Later,

nurses taught carers nursing skills and monitored their caring. Many carers accepted much caregiving responsibility, while feeling confused and abandoned. They had a heavy workload, and eventually became 'patients' themselves (18). A Canadian study showed that when carers and nurses assessed situations differently, carers risked becoming 'patients' due to insufficient respite care (19). Interviews with carers and nurses of elderly in England (20) showed that although carers undertook many complex and demanding tasks they were often uninvolved in care planning and decision making.

Carers' ability to provide care varies in relation to, e.g. their own health, age, family situation, working conditions and geographic location. These factors, as well as the health of the elderly, affect their workload. Elderly with physical, psychological and behavioural impairments impose high workload on carers (21-23).

A literature search in CINAHL and MEDLINE ADVANCED using the search words 'nurse', 'carer', 'workload', 'strenuous factors' and 'elderly' revealed no studies on both nurses' and carers' appraisals of physical and psychological workload of caring for elderly awaiting NH placement or in home care. Strenuous factors involved in care of frail elderly awaiting NH placement could impact workloads and carers' need for support and respite care. Illuminating these factors may lead to shared understandings of the workload and contribute to home health care policies.

Aim of the study

Our aim was to describe carers' and nurses' appraisals of workload in care of frail elderly awaiting NH placement.

Material and methods

Research design

This is a descriptive and comparative cross-sectional study using both quantitative and qualitative methods.

Sample/Participants

This study was conducted in a small municipality in Norway. The sample was 11 carers and 11 nurses paired based on care provided to the same elderly (three men, eight women; 71-99 years (Md=88); six with advanced dementia disease (ADD); seven lived alone) awaiting NH placement. Criteria for participation were: a carer or nurse providing care to an elderly on a waiting list for NH care and Norwegian speaking. Of the 11 carers, there were three wives aged 70-79, three sons aged 60-62 and five daughters aged 44-72. All were employed besides caregiving, except three wives and one daughter. Eleven participants were nurses (two men, nine women) employed in home care 1-17 years (Md=5). Seven were registered nurses (RNs), two were specialized in care of elderly. Four were enrolled nurses (ENs) (Table 1). The term 'nurses' in this paper refers to ENs and RNs when ENs or RNs are not stated.

Please, insert Table 1

Data collection

This study was based on workload-scale scores and on interviews. June-September 2005, the workload-scale, included in the Multi-Dimensional Dementia Assessment Scale (MDDAS) (24) was distributed to carers via post and to nurses from their charge nurse. The workload-scale rated levels of physical and psychological workloads (1 minimum -5 maximum) (Table 2). Completed workload-scales were returned to the first author.

September-November 2005, 11 carers and 11 nurses who completed the workload-scale were interviewed individually. Their ratings about workload were further elucidated and carers were asked to narrate their experiences with elderly care, daily routines, health services, what they learned and thought about the future. Most interviews were conducted in carers' home. The nurses were asked about their experiences caring for this elderly, focusing on the need of the elderly related to the amount of care given and their collaboration with carers. All interviews (n=22) lasted 50-60 minutes each, were audio-recorded and transcribed verbatim, including emotional reactions. Saturation was reached in nurse-interviews, but not in carer-interviews.

Please, insert Table 2.

Data analysis

Analysis of data from the workload-scale

The first author analysed data from the workload-scale by descriptive statistics. The question 'What are the characteristics of these elderly?' was used to divide the elderly into three groups: 'elderly with low physical function', 'elderly with multiple medical diagnoses' and 'elderly with ADD'.

Presentation of groups

The group, 'Elderly with low physical function', had two elderly men, 75 and 87 years, with some cognitive impairment, post-stroke hemiplegia, urinary incontinence and immobility. One lacked bowel control. Both received NH respite care every two weeks. Their wives were 74 and 78 years, both with impaired health. One wife managed to help her husband with personal care. Community nurses visited 3-4 times a day.

The group, 'Elderly with multiple medical diagnoses', had three elderly women, 85-90 years, who lived alone, yet were at risk for falls. They had several diagnoses, such as heart disease, degenerative joint disease and chronic urinary tract infection, and were functioning well psychologically. Two carers, a son and a daughter, resided in close proximity and assisted them daily. Community nurses visited 3-4 times a day.

The group, 'Elderly with ADD', had two men and four women with ADD, aged 70-99. One man lived with his wife, one man lived in his son's basement, one woman lived with her retired daughter, three women lived alone. Community nurses visited up to five times a day. The three women living alone received most frequent visits. All six elderly were physically well functioning. They were mobile; two needed a walker; three had urinary incontinence, one was incontinent of faeces. Three of these elderly, two who lived alone and one with his wife, refused home health care.

Analysis of interviews

The first author analysed the interviews (about 110,000 words) by qualitative content analysis (25). To ensure trustworthiness, the co-authors audited data analysis. The interviews were divided into 11 pairs, consisting of one carer and one nurse who both provided care to the same elderly. These paired interviews were analysed comparing appraisals. Each interview was read, summarised, and divided into meaning units (a constellation of words that relate to

the same central meaning) that were coded and condensed. Through answering the question 'What feelings or experiences is this about?' 13 sub-categories were created (Table 3) and grouped into three categories: 'feeling responsible', 'feeling burdened', and 'feeling ambivalent' (Table 4).

Please, insert Tables 3 and 4.

As we wanted interviews to be as close together as possible because situations are quickly changeable with frail elderly we performed all interviews before we started the analysis. Thus we could not ask nurses more questions concerning carers' workload, and probably obtain more comparable data. The most strenuous factors were not directly asked about in the interviews, but were interpreted from the text. Although all elderly were on a NH waiting list, some carers did not want NH placement, which made comparison difficult.

Ethical considerations

The study was approved by the Head of the Social Welfare Unit at the municipality and the National Committees for Research Ethics in Norway (57/2004).

The participants received an explanatory letter from the head nurse in their home services area inviting their participation. They were promised confidentiality, assured that participation was voluntary and informed they had the right to withdraw at any time without stating a reason. Before data collection began, written informed consent was obtained. To secure anonymity, biographical details, such as name and age, were changed for reporting findings.

Findings

There was a high level of complexity and both similarities and differences between carers' and nurses' appraisals of workload in care of frail elderly awaiting NH placement. Carers seemed in despair and expressed stronger feelings of responsibility and worry. Giving care up to 24 hours a day made them more exhausted and isolated, too. Nurses too worried about the elderly. Nurses were frustrated about the lack of NH beds, lack of enough resources in home health care to do an appropriate work and lack of directions for how to handle situations when elderly refused care. We present findings from the workload-scale and then from the interviews.

Findings from workload-scale

For elderly with low physical function, carers rated both physical and psychological workload maximal. One EN rated physical workload high and one RN rated it maximal. Both rated psychological workload minimal. Both carers' and nurses' ratings of physical workload were highest for these elderly (Figure 1).

For elderly with multiple medical diagnoses, two carers rated physical workload high-maximal. One carer who shared the workload with two siblings rated it low. Carers rated psychological workload high-maximal, while nurses rated physical workload low-medium and psychological workload minimal-low (Figure 1).

For elderly with ADD, carers rated physical workload minimal-medium and psychological workload medium-high. Nurses rated physical workload low or minimal, except one unit where it was rated medium. Three nurses rated psychological workload minimal-low, and three other nurses rated it medium or maximal (Figure 1).

Please, insert Figure 1

Findings from interviews

Three categories were found, namely 'feeling responsible', 'feeling burdened', and 'feeling ambivalent'. The following presents the categories with sub-categories and examples of quotations from each sub-category. All sub-categories did not include contributions from nurses' interviews. For some sub-categories nurses only confirmed carers' feelings. For other sub-categories they described their own feelings.

Feeling responsible

The category 'feeling responsible' had four sub-categories: 'expressing love', 'expressing duty', 'experiencing overwhelming responsibility' and 'feeling alone with the responsibility'.

'Expressing love'

One wife expressed warm feelings for her husband and contentment with her life. When he was at respite care, she visited friends and family, and, in this way, was able to manage the situation. She hoped to be able to provide care as long as possible; she did not want NH placement for her husband until it was necessary. She narrated: "*As long as I can manage, I*

want to have him at home. After all he is my husband. We have been married for almost 50 years. We have had a very good life". According to his EN, this elderly would receive fulltime NH placement whenever his wife requested it.

'Expressing duty'

Some carers living with elderly having ADD described being on duty 24 hours a day. One wife said she had promised to care for her husband and never place him in a NH. She felt strongly bound by that promise, but she made clear it was not because of love, only for duty. She said: "*It has nothing to do with love. It is more that I am a kind of person easy getting troubled conscience*". One daughter said: "*Because I am her only daughter, I have both an assignment and a duty to help her*". Nurses' feelings of responsibility were described as their professional duty.

'Experiencing overwhelming responsibility'

For some carers the responsibility and caregiving were described as overwhelming, taking all their time and resources. A daughter narrated: "*I spend a lot of hours helping her. It feels like having double work. I should have double wages (laughing)*". Nurses confirmed many carers took much responsibility. Some carers narrated that due to work and other obligations, they could not spend so much time with the elderly as they wanted to do. A daughter said: "*This is my mother, and I have to live with the fact that I cannot take care of her. I am not able to help her as much as I want*".

'Feeling alone with the responsibility'

Most carers narrated they felt alone with their responsibility. Some spouses narrated the children could have contributed more to the care. When carers were siblings, it seemed to be common that one of them got more involved in the caregiving than the others and some of these carers considered this as unfair. One daughter said: "*My siblings could have done more. I have to say that, but I suppose they feel they have enough to do with their own families*".

Feeling burdened

The category 'feeling burdened' had seven sub-categories: 'feeling exhausted', 'feeling worried', 'feeling helpless', 'feeling depressed', 'feeling isolated', 'feeling bitter' and 'feeling troubled conscience'.

‘Feeling exhausted’

One wife sometimes felt very exhausted. She had developed a technique to assist her husband by herself with toileting. When he was at respite care, nurses used a mechanical lift. The EN said she could easily understand the wife’s feelings, but there was no way to relieve the workload as long as the wife wanted her husband home: *“It is hard for her, and she is really exhausted. He cannot be alone, so if she surrenders, he will be placed in a NH”*. One wife narrated a difficult situation. She said she felt unhappy, exhausted and in despair due to the couple’s poor finances and health problems. Her husband received regularly respite care every two weeks. Then she felt lonely and isolated because she could not visit him due to her own poor health.

‘Feeling worried’

Many carers worried that something dangerous would happen to the elderly when left alone. Carers were afraid the elderly might fall, be unable to get up or call for help. They worried about food intake, safety, loneliness, sadness and that they could be sitting for hours possibly in urine and faeces. They also worried about wandering outside alone. Their worst worry was the elderly freezing to death. One daughter on the brink of tears said: *“This is hard... I am prepared that one day they might call and tell me she is lying in the roadside ditch frozen to death. I have been living with this for a while, but I cannot do anything to prevent it”*. Nurses confirmed that carers’ worries were understandable, because many elderly were alone most of the time. They had an alarm system, but when they got upset, they sometimes forgot the alarm, or resisted using it to ask for help. Most nurses were worried too; some even worried about patients in their leisure time. One RN said she considered finding another job: *“I am often thinking about patients in my leisure time, worrying about them. How much easier it would be to work in a hospital, in a surgical ward, to be able to leave and know the patients were taken care of”*.

‘Feeling helpless’

Some carers expressed feelings of helplessness. A daughter narrated: *“I do not know what to do. Nothing is happening. I feel like butting in a wall”*. The RN said she knew this, but she felt helpless, too. During this particular time, her area of home services did not have resources to relieve the situation. She said: *“We have tried to get them a respite stay for a long time now, but we have so few respite beds”*. A wife described how helpless she felt about her husband’s depressive symptoms: *“I think he has given up; always talking about he is dying. I*

find it hard. Some days he is so depressed, I do not know what to do. I just want to go out and scream”.

‘Feeling depressed’

Some carers said they were depressed, and one daughter cried frequently during the interview. A son described how difficult he found the situation: *“A psychic consequence of the situation is I am feeling very exhausted and depressed. Everything is sad and bad. I am not feeling well, and it does not feel all right at all”.*

‘Feeling isolated’

Many carers said they felt very isolated. Some helped the elderly daily, and could not leave for a holiday, or even a weekend. One son narrated that fellow workers could invite him to their cottage in weekends, but he always had to refuse. He could not leave his mother alone for a whole night. Most nurses understood carers’ feelings of isolation, and said they would prioritize the elderly for a NH respite stay.

‘Feeling bitter’

A daughter who lived with her mother made some bitter statements, like: *“I have been a pensioner for some years, but I have not had a pensioner way of life. No trips to the South... I get more and more angry year by year. I am not grateful. I have paid for this”.* The EN, who knew them well, described this daughter as a bitter woman: *“She cannot make the decision to send her mother away, not even for a respite stay. It looks like she is just holding out, sacrificing her own life. How bitter can that taste!”*

‘Feeling troubled conscience’

Both carers and nurses reported troubled conscience. Most carers narrated they struggled constantly with troubled conscience. Some sacrificed their own needs. Others tried to set limits, continue their ordinary routines and pursue personal interests, but troubled conscience was difficult to escape. One son, whose father lived in his basement, felt troubled conscience because sometimes he became angry with his father. He narrated: *“You should not get irritated with old parents, but when he is nagging me, shouting that I have to come immediately, I can get really angry. It is foolish, but also human, I think”.* A common feeling was being inadequate. A daughter said: *“I have not been there as much as she needs, but I am too exhausted. I have not been able to spend enough time with her”.* Most nurses understood

that the situation could fatigue carers. One RN said she considered starting a support group for carers. Some nurses described how they, too, could have troubled conscience when they had to leave the elderly, knowing they were lonely and afraid. One EN narrated: *“It is hard to leave when you realize they need you to stay, but what can you do? You just have to leave. That is the hardest part of it”*.

Feeling ambivalent

The category ‘feeling ambivalent’ had two sub-categories: ‘feeling ambivalent about NH placement’ and ‘feeling ambivalent about use of coercion’.

‘Feeling ambivalent about NH placement’

Some carers were ambivalent about NH placement. On one hand, they felt the elderly would have better quality of life and be safer in a NH. On the other hand, they knew that many NH patients have ADD. If the elderly they cared for were functioning well psychologically, they were afraid it could be depressing to be with others who could not communicate. One carer said: *“I am ambivalent about it. Intuitively I would have been happy if she was in a NH, because I would feel much safer. But I really do not know if I want her to sit there.... I would not welcome it for her”*. Some carers living with elderly with ADD considered when to give up and place the elderly in a NH, which seemed closer on some days. They expressed concern about quality of care in NHs, and a feeling of betrayal. Simultaneously, one wife felt she had forsaken her grandchildren by never being able to visit them. The nurses were aware of carers’ ambivalence, and said that some of the elderly would have NH placement when carers wanted it. One wife did not want permanent NH placement because if her husband moved into a NH, she would lose his retirement pension without which she could not afford rent, and perhaps she would have to leave their home. She was in bad health and exhausted. In between, she was about to give up caregiving, but because of the economy she felt she had no other choice than to continue. The RN said this man ought to live in a NH, to have more continuous care, and he would quickly be admitted if his wife changed her mind. The RN felt she had to respect and support the wife’s decision. She said: *“Because of her opinion we have never put him on the priority list, although he would benefit from NH placement”*. While the RN was patient, she felt in a dilemma about priority of carers’ needs over elderly’s needs.

‘Feeling ambivalent about use of coercion’

Another situation, which provoked ambivalent feelings, was when elderly refused nursing care, resulting in hygienic deterioration, especially when incontinent of faeces. Yet, in the case of faeces incontinence, the carer was very sceptical about use of coercion, saying: “*I think it is wrong to use coercion against her. I strongly doubt it*”. The elderly’s EN was clear, too: “*She has the right to decide herself, so we cannot force her*”. Some nurses said this was a very difficult situation to handle: “*It is very difficult. It is a typical dilemma, which we discuss a lot without finding any solution*”. Some carers said that nurses were weak, and they should use more force when elderly resisted help.

Discussion

This study described a high level of complexity in workload for elderly awaiting NH placement. More quotations were included from carers’ than from nurses’ perspective, which is understandable because many carers gave care 24 hours a day.

Appraised workload levels by workload-scale

For all groups of elderly carers rated physical workload somewhat higher than nurses. This may be due to nurses visiting the elderly 3-4 times a day, while most of the time carers helped elderly or elderly were alone. Carers, providing care to elderly with low physical function rated physical workload maximal. Carers of patients with stroke in poor physical health can be at risk of burn-out (26). Perhaps this was the case with one wife who expressed she was unhappy and exhausted. Concerning psychological workload, we found greater differences between carers’ and nurses’ appraisals. When elderly with ADD lived with a daughter or wife, nurses knew somebody was with them, and they rated psychological workload lower than when elderly were living alone. Carers’ average ratings of psychological workload were lower for elderly with ADD than for the two other groups. This was somewhat surprising because carers of elderly with ADD expressed they had most strenuous care. Yet, some of them had not rated their psychological workload as higher than medium, probably because they knew the situation could become even worse.

Feeling responsible

All carers expressed they strongly felt responsible giving care to the elderly. They stated love and duty as reasons for giving care. A Finnish study concluded it was fair to describe the

work of carers as largely altruistic, and many carers felt caregiving was a way to show their love (27). Gates (28) conducted a phenomenological study in Canada to uncover the meaning of caring for a loved one. For many spouses, caregiving was regarded as a 'natural' continuation of a lifetime together, and many children regarded caregiving as reciprocity, because their parents had nurtured them when they were young (28). In this study, most carers providing their parents' care expressed feeling alone with their responsibility. Some whose siblings did not share the workload felt it was unfair. This is in accordance with the findings of Almgren *et al.* (17) that many carers of elderly with ADD in Sweden experienced family conflicts, because they received little or no family support. In the USA, about a third of siblings collaborated and distributed caregiving responsibilities by taking turns, and the distribution of caregiving tasks was perceived by all siblings to be equal or fair. Nevertheless, for two thirds it was perceived as unequal and unfair (29). Another study showed that children's willingness to provide parent care was reduced in proportion to their number of sisters (30). Some nurses expressed a strong feeling of responsibility for both elderly and carers. The shortage of NH beds frustrated nurses. Their resources for giving sufficient care to elderly, and less to carers, were scarce. Yet, one RN considered starting a support group for carers of elderly with ADD.

Feeling burdened

Both carers and nurses felt burdened. Nurses were mostly aware of carers' burdensome feelings, and tried to support carers as much as possible. Both carers and nurses reported feelings of helplessness and worry. One spouse described how helpless she felt when her husband talked about his dying. Previous studies have concluded that patients' depressive symptoms can be very burdensome to carers (31-32). Some nurses, too, described a sense of helplessness, not being able to give the care they wanted to relieve carers' exhaustion. Research showed that helplessness was a usual feeling among nurses, because of their constant pressure from management to 'cut costs' by finding the least expensive home-care service or reducing the frequency of home visits (33). A hermeneutic study showed that when nurses experienced the total workload, i.e. the intensity of care needed by the patients and external and internal factors of the care situation, as too high, they felt unable to provide good enough care to patients, resulting in feeling 'not being' a good nurse. Over time, the result of this stress can be burnout (34). As described earlier, many carers and nurses worried a lot. Worry and guilt have been described as common companions to caregiving (35-36). Most carers in this study felt troubled conscience because they could not spend more time with the

elderly. One carer said he felt guilt-ridden because at times he became angry with his father, although he considered these feelings human. Experiencing anger and irritation is understandable given the many stressors involved in the caregiving role. These can be habitual feelings, often experienced as burdensome for carers (37). The carer who seemed bitter was immersed in the caring process, sacrificing her own needs to help her mother. Sanders and Adams reported this as a widespread phenomenon and labelled it 'personal sacrifice' (38, p 291). Many carers described serious problems leaving the elderly, and often felt isolated. Carers' feeling of being isolated has been previously reported (38-39). We find it striking that carers sometimes will not institutionalize their spouses because, due to losing the spouse's retirement pension (5), they fear losing their own home when they cannot afford rent.

Feeling ambivalent

Carers and nurses felt ambivalent about NH placement of elderly and use of coercion. A daughter was ambivalent about NH placement, because she worried about the quality of NHs. An English study (40) showed that elderly living in NHs received poorer care than those living at home in terms of medication management and monitoring chronic diseases. A wife felt very exhausted because of her husband's paranoid behaviour, but she would not place him in a NH because of earlier promises. Cognitive impairment (41) and dementia-related behaviour (23) are factors known to precipitate NH placement. Both carers and nurses were sceptical about use of coercion when elderly refused help. Yet, some carers said they wanted nurses to use more force or manipulation. Although in Norway use of any kind of restraint, such as physical restraint, force or pressure in medical treatment and Activities of Daily Livings (ADL) (13), is illegal, in 2000, in some NHs use of force or pressure in ADLs was widespread (42). The incidence has not been explored in home health services.

Limitations

The quantitative findings from this study give a visual picture for these participants. While the context was a community in Norway, these findings may be transferable to similar settings. The sample was diverse in terms of context and participants, why the findings from interview gives a broad picture of possible reactions when caring for an elderly on waiting list for NH placement. Both carers' and nurses' appraisals of workload seemed influenced by the carer residing with or in close proximity to the elderly. This study includes no objective appraisals of the workload, only carers' and nurses' subjective appraisals.

The main limitation of the study is that the elderly were neither interviewed nor observed. Recommendations for further research are to implement an observational study to deepen the understanding of workload in home care and to accomplish interviews with elderly being cared for at home to illuminate their experiences.

Conclusions

Based on the UN's selection of Norway as the best country in the world to live (1), one might expect it is a good country to grow old in, too. Findings from this study show this may not be the case for some frail elderly. Many similarities and differences are apparent in the carers' and nurses' assessments of physical and psychological workloads of providing care for frail elderly awaiting NH placement. Further research is needed to explore life-conditions for carers and frail elderly, as well as work conditions for nurses working in home health care.

Author contribution

All listed authors have contributed directly to this study and this article. Data collection, analysis work and drafting of manuscript were performed by AMSF. KN, NH, AN and FG contributed to critical revisions of manuscript. KN and NH regularly met with AMSF for discussion, support and supervision throughout the complete process.

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Table 1 Description of participants

Elderly		Ages
Women	8	71 – 99
Men	3	74 - 88
Living alone	7	
Living with spouse	3	
Living with child	1	
Low physical function	2	
Multiple medical diagnoses	3	
Advanced dementia disease (ADD)	6	
Carers		
Wives	3	70 – 79
Sons	3	60 – 62
Daughters	5	44 - 72
Nurses		
Registered nurse	7	30 – 45
Enrolled nurse	4	24 - 36
Women	9	
Men	2	
Years worked in home care	1 – 17 years (median 5)	

Table 2. Presentation of scale to assess workload

For the patient who you have assessed, attempt to estimate the degree of workload, from minimum to maximum workload, both physical and psychological.

1. Physical workload

1	2	3	4	5
Minimal				Maximal

2. Psychological workload

1	2	3	4	5
Minimal				Maximal

(1 = minimal, 2 = low, 3 = medium, 4 = high, 5 = maximal)

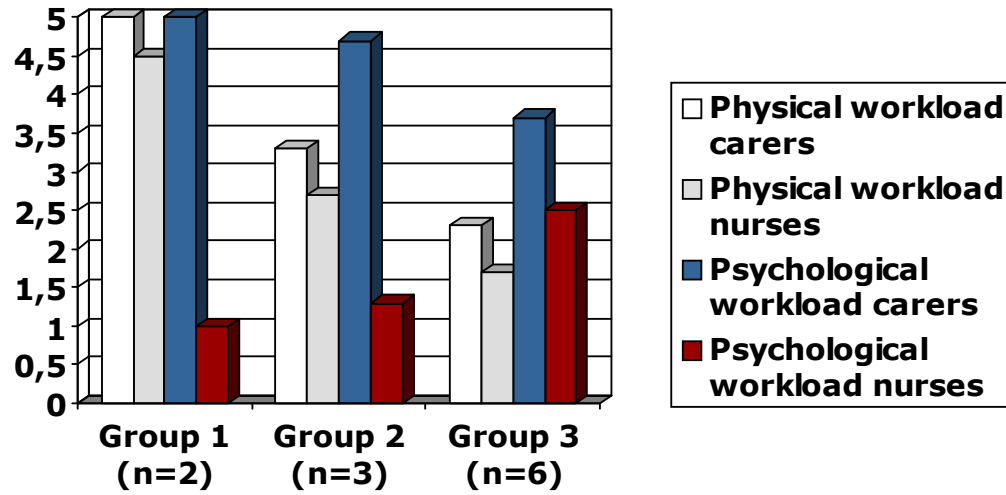
Table 3 Example of the process of qualitative content analysis

Meaning unit	Condensation	Sub-categories	Categories
As long as I can manage, I want to have Roald at home. After all he is my husband. We have been married for almost 50 years. We have had a very good life.	Wanting to have her husband at home because of a long and good life together.	Expressing love	Feeling responsible
It has nothing to do with love. It is more that I am a kind of person easy getting troubled conscience.	It is not love, only because of troubled conscience.	Expressing duty	
I spend a lot of hours helping her. It feels like having double work. I should have double wages (laughing).	Helping her mother so much, it feels like double work.	Experiencing overwhelming responsibility	
My siblings could have done more, but I suppose they have enough in their own families.	Her siblings are not doing enough.	Feeling alone with the responsibility	
I have not been there as much as she needs, but I am too exhausted. I have not been able to spend enough time with her.	Not helping her mother enough	Experiencing troubled conscience	
This is my mother, and I have to live with the fact that I cannot take care of her. I am not able to help her as much as I want.	Not being able to take care of her mother.	Feeling guilty	

Table 4 Sub-categories and categories in the qualitative content analysis

Sub-categories	Categories
Expressing love Expressing duty Experiencing overwhelming responsibility Feeling alone with the responsibility	Feeling responsible
Feeling exhausted Feeling worried Feeling helpless Feeling depressed Feeling isolated Feeling bitter Feeling troubled conscience	Feeling burdened
Feeling ambivalent about institutionalization Feeling ambivalent about use of coercion	Feeling ambivalent

Figure 1. Rating of physical and psychological workload by different groups of elderly.



(1 = minimal, 2 = low, 3 = medium, 4 = high, 5 = maximal)

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