CARERS' EXPERIENCES WITH OVERNIGHT RESPITE CARE. A QUALITATIVE STUDY.

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ABSTRACT

Aim

The aim of this study was to explore experiences with overnight respite care (ORC) of Norwegian carers who provided care to frail elderly awaiting nursing home placement.

Background

In many Western countries respite care has become part of health care service provision, and various types of respite care are available. The intent with respite care can be twofold; caring for the care receiver and supporting the carer.

Methods

This was a descriptive qualitative study. Interviews were conducted with 15 carers, transcribed and analysed by qualitative content analysis.

Findings

The carers described various experiences with ORC. If ORC supported the family unit, it was welcomed by carers and experienced as supportive. If ORC did not support the family unit, many carers rejected ORC, and it was experienced as non-supportive. Two categories were constructed: 'experiencing ORC as supportive for the family as a unit' and 'not experiencing ORC as supportive for the family as a unit'.

Conclusion

To support more carers, nurses have to listen to carers' experiences about ORC. Nurses need to take responsibility for the family as a unit and provide more flexible ORC services based on both carers' and elderly's needs.

Key words

Nurse, family caregiver, carer, elderly, respite care

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INTRODUCTION

In Norway, the number of frail elderly is increasing (1) which poses great demands on elderly care such as nursing home (NH) placement (2). Due to a lack of NH beds (3), many elderly have long waiting periods after NH has been assessed as their needed level of care. The workload of the carers in home care of elderly has been well documented (4). Many carers need support to be able to continue their caregiving. In response to this need, respite care (RC) has been widely developed (5) to support carers by offering them temporary relief and assisting them in maintaining their relative at home (6). This study focuses on the experiences of the carers with overnight respite care (ORC), lasting up to three weeks. Norwegian municipalities have a juridical duty to offer RC to families providing particularly burdensome care (7). Despite a recommendation by the Norwegian Board of Health (8) to use 15 % of NH beds for ORC to provide adequate RC to carers, a 2007 study showed that one-third of 37 Norwegian municipalities lacked ORC beds (9).

Research about outcomes of RC has been reviewed: Mason *et al.* (10) found small positive benefits of ORC as part of a respite package; ORC reduced carers' burden and improved their mental or physical health. Lee and Cameron (11) found no statistically significant effects of any RC and concluded this could reflect a lack of high quality research in the area. Stoltz *et al.* (12) indicated respite services did not sufficiently meet carers' needs. Pinquart and Sorensen (13) reported small but significant effects of RC on carers of persons with dementia disease, by reducing the carers' burden and depressive symptoms and increasing their well-being. Mason *et al.* (10) found no evidence that RC delayed entry to residential care. Zarit *et al.* (14) suggested ORC could be a transitional service before or an accelerating factor to permanent NH placement by helping carers break their emotional bonds or overcome their negative apprehension about NH care. Two Australian studies reported ORC enabled some carers to continue giving care and the carers were overwhelmingly satisfied with RC (15-16).

A review of the literature showed 22-50% of carers rejected RC, even when they needed it and when financial barriers were removed (17). The most frequently mentioned reason for refusal of American carers was the elderly's resistance (18). Other carers felt guilty about

accepting RC because the elderly might think the carers were unable to cope with the situation (19). Some Finnish carers welcomed RC as a relief, but did not benefit from it because of guilt, troubled conscience and loneliness (20). Some Canadian carers experienced guilt following ORC, especially if the elderly's condition deteriorated (21). Mason *et al.* (10) found no adverse effects on the elderly. Many American carers worried about the quality of RC (18). It was important to some Australian carers that the elderly were well cared for, happy and had opportunities to socialise with others at ORC (14).

In this study, we explored how Norwegian carers of elderly awaiting NH placement experienced ORC. Because these elderly were particularly frail and actually needed NH care, ORC might be important to their carers during the waiting period. These carers differed from other carers because they had already requested NH placement, which meant they actually wanted to end their caregiving. Still, because of a lack of NH beds, they had to continue giving care, perhaps beyond their boundaries. Illuminating the experiences of these carers with ORC may contribute to a broader understanding of how to support them.

THE STUDY

Aim

The aim of this study was to explore the experiences with ORC of Norwegian carers who provided care to frail elderly awaiting NH placement.

Design/Methodology

This was a descriptive study. Semi-structured interviews were performed and analysed by qualitative content analysis (22).

Sample/Participants

This study was conducted in a small municipality in northern Norway. A convenient sample of 15 carers of the elderly awaiting NH placement (seven men, eight women; 71-99 years; Median = 85; 10 with ADD; eight living alone) were invited to participate by the head nurse in their home services area. Inclusion criteria were providing care to the elderly on a municipal NH waiting list (n=63) for NH care and Norwegian speaking. Breadth and diversity in data were desired. Thus, participants were selected with different kinship to the elderly and varying degrees of workload. There were six wives aged 70-83 years, three sons aged 60-62

years, and six daughters aged 44-72 years. The caregiving period varied from one to more than 10 years. Ten carers provided care several times a day; six provided care more than eight hours daily. Eight carers were employed and worked outside the family.

Data collection

September-November 2005, carers were asked to narrate their experiences with elderly care, daily routines and health services, including ORC. Most interviews were conducted in the carers' home. All interviews (n=15) lasted 50-60 minutes each, were audio-recorded and transcribed verbatim, including emotional reactions. Saturation was reached during data analysis.

Reliability and validity issues

Morse *et al.* (23) proposed five verification strategies to ensure rigor in qualitative research: methodological coherence, sampling sufficiency, data collection and analysis, thinking theoretically and theory development. Methodological coherence ensures congruence between the research question and components of the method. Semi-structured interviews were suitable for exploring the research question. To obtain an appropriate sample, participants were chosen from diverse contexts with different kinship to the elderly and varying degrees of workload. During data collection, the carers were encouraged to freely narrate their experiences for giving care to the elderly, which provided rich textual data. The co-authors, who knew the field well, checked and discussed analysis and interpretations until they reached a consensus. Quotations from the interviews support the categories that were linked to relevant literature (23). While the context for this study was a community in Norway, these findings may be transferable to similar settings. Information about the research process and the Norwegian society allows readers to appraise the study's transferability.

Data analysis

The interviews (about 110 000 words) were analyzed by qualitative content analysis (22). The co-authors audited the textual analysis by reading and re-reading sections of the interviews and discussing the process of analysis. All interviews were divided into meaning units that were coded, condensed and abstracted. Nine sub-categories were constructed and grouped into two categories: 'experiencing ORC as supportive for the family as a unit' and 'not experiencing ORC as supportive for the family as a unit'. Table I contains an example of the analysis process. An overview of sub-categories and categories is given in Table II.

Please, insert Tables I and II

Ethical considerations

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

Participants were promised confidentiality and anonymous presentations of findings, guaranteed 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 from each participant.

FINDINGS

There was great variation in carers' experiences with ORC. The following sections present the categories with sub-categories and quotations.

'Experiencing ORC as supportive for the family as a unit'

Some carers experienced ORC as supportive for the family as a unit. It was crucial that the ORC was advantageous for both the carers and the elderly in the long run.

'Being able to continue caregiving because of ORC'

One wife described how ORC provided the relief necessary for her coping. She was very exhausted and in poor health. She narrated *'He does not want to go to the NH…. I have told him if I shall survive the caregiving, and we shall continue living together, he just has to.'*

'Engaging in refreshing activities and relaxation'

Some carers were able to do refreshing activities while the elderly received ORC, but because most carers regularly visited the elderly during ORC, it was difficult to travel a great distance. One wife narrated how she initially was reluctant to travel, but when she did, it was a great experience: *'I did not want to go, but it was a great journey. I slept a lot, but I woke up when the bus stopped. I experienced a lot of things.'* Another wife went to the couple's cottage with her mobile phone, so she could be contacted if something happened to her husband.

'Being satisfied with ORC's quality and regularity'

One daughter was very satisfied with the quality of ORC. Her mother with ADD was living alone, and the daughter often worried about her quality of life. However, with ORC, she knew her mother's basic needs were met. She said: *'They gave her attention, followed her to the toilet and regularly gave her food and medicines. She ate a lot. I think she really flourished.'* When community services provided flexible respite arrangements, carers expressed satisfaction. Two elderly alternated between two weeks in NH and two weeks at home. In this way, carers received enough ORC to manage a burdensome situation. One wife narrated how scheduled ORC helped her cope: *'Getting this ORC each 14th day has made us live again.'*

'Experiencing the elderly's satisfaction and benefits from ORC'

Some carers narrated that it was easier for them to enjoy ORC when the elderly felt satisfied. Some elderly could flourish during ORC. One daughter said: *'The greatest effect of her ORC is that she can be together with other people for two or three weeks. It brings her out of her depression.'* Another daughter narrated that her mother with ADD was very pleased thinking the NH was a hotel.

'Not experiencing ORC as supportive for the family as a unit'

Some carers did not experience ORC as supportive for the family as a unit. When the carer or the elderly had disadvantages from the ORC, carers were likely to reject further offers.

'Being dissatisfied with quality, security and unpredictability'

Some carers expressed dissatisfaction with the quality of ORC. One wife described: *'The staff changes all the time. The few personnel are too busy. It is really terrible…He can be sitting wet in urine the whole day.'* Some elderly were not thriving at ORC because many residents had ADD. One daughter narrated how her mother with ADD complained: *'She said: 'I will not stay at this place because everybody here is old and senile.' She cannot see that she is in the same category.'* Cognitively well functioning elderly had similar experiences, and their carers found this was particularly difficult. One wife was dissatisfied with the security at the NH. The doors were unlocked so that various kinds of people entered. Some carers said the organization of ORC lacked predictability and flexibility. They could not be informed in advance about ORC availability, which made planning meaningful activities difficult.

'Being unable to relax'

Some carers narrated difficulties relaxing while the elderly received ORC. One wife said *'I had planned to do so many things when I finally got some time off, but I just sat there….'* Some carers missed the elderly's company during ORC and visited them daily.

'Experiencing the elderly deteriorating physically or mentally at ORC'

Most carers reported deterioration in the elderly's ADL-functions during ORC, especially when ORC was in a NH. After ORC they had to work diligently to restore the elderly's earlier level of function. One daughter described *'He comes home a little reduced, and we have to give him some extra training. We have to speak directly into his ear: 'You have to stand, and you have to walk'. Perhaps they automatically nurse him in bed.'* One wife did not like the use of a lift when her husband regularly received ORC every two weeks because it decreased his ability to stand up. Even in specialized rehabilitation units, some carers experienced a lack of time for training in mobility during ORC. Returning home again after ORC could be difficult, as one daughter narrated, whose mother had ADD with high anxiety: *'She was at a respite stay for four weeks, and she felt safe and flourished with all the people surrounding her. The worst thing I have ever done was to take her back home… I cannot stand her being a shuttlecock.'* After ORC, her mother became more confused and anxious, and she would telephone her daughter several times during the night.

'Rejecting offers of ORC'

One daughter, living with her mother, rejected ORC because she experienced it as too stressful. She narrated *'I find ORC too stressful, to get from home to NH and back again, and clothes constantly disappear. I just can't take it.'* Some carers stretched themselves to spare the elderly from unpleasant episodes and to conserve his/her dignity. One wife described how she was doing intimate washing as long as she could to spare her husband from being degraded by the nurses' care: *'I needed nurses' help much earlier, but I am a bit stubborn, and I would spare my husband. He needed intimate washing, and he is quite shy….'* This wife refused ORC for a long time, but finally she had to admit she needed a break to avoid burnout. Many carers hesitated to use ORC when the elderly rejected it. One wife described how she, although very exhausted herself, would not force her husband: *'I have promised to care for him as long as I can manage. I would feel like a traitor transferring him by force.'* One son described how it seemed like his mother maintained a crystal clear opinion in spite of her ADD. Throughout her adult life, she stated clearly she would never move to a NH. He

narrated what happened when he told her about an ORC offer: *'It is the most obvious "no" I have heard in years. She shouted it over and over with increasing volume, and a look in her face expressing ´over my dead body', totally terrified. If we had accepted the offer, we would have had to move her by force.'* Although he experienced the situation as hopeless, he rejected the offer because he could not move his mother against her will.

'Lacking sufficient ORC services'

One son, living next to his mother, told us he and his mother wanted to manage on their own. However, he now felt exhausted, and his mother wanted ORC in a rehabilitation unit to train for mobility with the intention to improve her physical function, but they just had to wait. Some carers said that the elderly with a tendency to fall were prioritized too late for ORC. According to these carers, the elderly had to fall several times before nurses understood the seriousness. Perhaps some falls could have been prevented with earlier ORC. One daughter narrated: *'One month he was at the emergency ward three times. At last the doctors said he was too frail to stay at home alone, and he finally got the ORC we had asked for.'* Some carers thought they had a restricted quota of ORC, so they tried to economize with the number of weeks available. One daughter had not got any ORC. She said she called and repeatedly requested ORC without any response. She did not know what more she could do, so she was about to give up. She narrated: *'I asked again a while ago, and she is on their list. I just have to wait. They promise I will get ORC. What more can I do?'*

DISCUSSION

This study found great variation in Norwegian carers' experiences with ORC while caring for frail elderly awaiting NH placement. The same carers could have some positive and some negative experiences with ORC.

Family focused nursing

The last 25 years, there has been an increasing interest in family focused nursing (24). The World Health Organization has pointed out the nurses' responsibility for the health of the whole family when one family member gets a disease (25). In this study, it was evident that the whole family was woven together and that the other family members were affected by the frailty of the elderly awaiting NH placement. Therefore, it was crucial to the carers that ORC was flexible and adjusted, meeting both the carers' and the elderly's needs. Then, ORC could be experienced as supportive for the family as a unit. In a Canadian study, a clear relationship

was found between the carers' ability to experience relief and the carers' perception that their relative was comfortable and safe (26). Carers in this study had to be assured of the elderly's safety and well-being, too. Then, they could get the intermittent and necessary relief to be able to continue with their caregiving. Other studies (10,13) have shown similar carer experiences . If ORC was not adjusted to meet the elderly's needs, some carers felt ORC even worsened their situation.

Deterioration of the elderly during ORC

Many carers narrated that the elderly's ADL functions deteriorated during ORC. This is contradictory to a literature review which found no evidence of deterioration of the elderly during RC (10). One reason for our findings can be that the elderly were more frail than the care receivers in other studies as they were assessed to need NH care. As a result, the elderly's levels of functioning could be marginal for carers to handle. In addition, by requesting NH placement, their carers had clearly signalled they wanted to end caregiving. Still, due to lack of NH beds, carers had to continue providing care during the waiting time. Therefore, the resources of the carers could be marginal, and a slight decline in the elderly's ADL functions could make caregiving unbearable for them. An example of this was the wife who complained about the NH staff's use of a mechanical lift for her husband during ORC, resulting in his reduced ability to stand. The use of the lift was a reasonable device to physically protect the staff and perhaps the wife should have a lift at home to protect her as well. In a study for New Zealand, deterioration of the elderly during RC was an important reason why many carers did not take advantage of the respite time (27). In this study, many carers accepted ORC, even when elderly deteriorated in ADL functions because they could not continue giving care without respite. Some researchers have concluded if outcomes for the elderly were negative, many carers did neither benefit from RC nor accept it (21, 28).

Refusal of ORC

Many elderly refused to move to a NH, even for ORC, and few carers would forcefully move their loved ones. Research has shown that the elderly's refusal was a common reason for carers not to use RC (18). According to Norwegian laws, it is illegal to move the elderly to RC by coercion. During the course of ADD, many elderly become incompetent to give informed consent, and their next of kin may consent on their behalf (29). Although this was possible for many carers, it was difficult to accept ORC on behalf of the elderly when they previously refused ORC and could not be persuaded to accept it. Instead, these carers tried to

manage without ORC and became more and more exhausted. In the Netherlands, some respite care programs have been designed to help the carers and the elderly to overcome their initial resistance to RC (30). Moving to a NH has been reported as stressful, even for the elderly who accepted RC (31). Relocation of the elderly has resulted in conditions, such as confusion and changes in mortality rates and morbidity (32). More flexible home health services, like home-based ORC, might be a way to offer the carers temporary relief without having to move the elderly.

Lacking sufficient ORC

Although Norwegian families with particularly burdensome care have a right to RC (7) some carers had difficulty obtaining sufficient ORC. The lack of RC is not only a Norwegian phenomenon; it was also a problem in Canada (33), Finland (34) and Sweden (35). Harrison and Neufeld (36) reported some carers had several barriers requesting support for themselves. It was somewhat easier to accept support if it was offered to them. This finding is important for community nurses to consider. It is important to avoid offering ORC only to carers who repeatedly request it.

Study limitations

This study included only the experiences of the carers with ORC. The elderly who received ORC were not interviewed. Recommendations for further research are to appraise the elderly's level of functioning before and after ORC, implement an observational study to deepen understanding of ORC and interview the elderly receiving ORC to illuminate their experiences. In addition, research that clearly investigates the type of RC is needed. Also, a comparison of the effects of home-based ORC and NH ORC is necessary.

CONCLUSIONS

This study explored the experiences of Norwegian carers with ORC while caring for frail elderly awaiting NH placement. The findings showed that to support the carers, ORC had to be adjusted both to the carers' and the elderly's needs. The whole family must be viewed and treated as a unit. Since there was a great complexity in the carers' situations, ORC could be organized with more flexible services based on the individual carers' and the individual elderly's needs. Some carers and elderly who refused ORC would have benefited if home-based ORC could have been provided.

In spite of insufficient resources in home health care, providing appropriate support for the elderly and their carers means that nurses have to consider the individual concerns in each situation. Nurses need to acknowledge an ethical responsibility for the family as a unit. They have to co-operate with the carers and listen to their experiences about ORC. Instead of providing a standard solution, the individual carers' and the individual elderly's needs should be considered. In addition, nurses need to contribute to policy revisions by advocating for funding, pointing out invidious consequences for both the elderly and their carers.

Table I Meaning units, condensations, sub-categories and category in the qualitative content analysis

Meaning units	Condensations	Sub-categories	Category
'It has been wonderful to get outside and away from him for a while….. I needed some time alone. Everybody does, I think'.	The carer had time alone as she needed.	Being able to continue caregiving because of ORC.	Experiencing ORC as supportive for the family as a unit.
'I went to the cottage because there I can relax, but I have a mobile phone'.	The carer was able to relax.	Engaging in refreshing activities and relaxation.	
'We are not complaining. After we had ORC regularly, I was able to continue the caregiving'.	Regular ORC helped the carer to continue the caregiving.	Being satisfied with ORC's quality and regularity.	
'She is seldom content, but this time she was really thriving and she appreciated the good service she received'.	The elderly was thriving at ORC.	Experiencing the elderly's satisfaction and benefits from ORC.	

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

Sub-categories	Categories
Being able to continue caregiving because of ORC. Engaging in refreshing activities and relaxation. Being satisfied with ORC's quality and regularity. Experiencing the elderly's satisfaction and benefits from ORC.	Experiencing ORC as supportive for the family as a unit.
Being dissatisfied with quality, security and unpredictability. Being unable to relax. Experiencing the elderly deteriorating physically or mentally at ORC. Rejecting offers of ORC. Lacking sufficient ORC services.	Not experiencing ORC as supportive for the family as a unit.

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