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Vård i Norden

Family caregivers' daily life caring for a spouse and utilizing respite care in the community

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ABSTRACT

Although the workload of family caregivers has been a core topic in society, these problems are still underestimated when planning support for them. The objectives of this study were to show how family caregivers experience daily life when they care for a spouse at home, and to elucidate their daily life when utilizing residential respite care. Eighteen caregivers > 65 years old who cared for spouses with neurological disorders were interviewed. Content analysis was used. Two main themes emerged: 'Developing a role as family caregiver' and 'Satisfaction with daily life depends on the quality of care their spouse received'. Family caregivers' experiences of daily life at home involved helping their spouses with basic needs and meaningful activities. When they handed over responsibility to residential respite care institution they sometimes felt guilty to leave their spouse there. Continuous information and communication regarding their spouse's health and confirmation of good quality of care was of great importance for their own well-being. Otherwise they could not make use of the relief period to recover from their caring role. The role of the family caregiver was complex. They need continuous education and support to feel satisfied with their daily life.

KEY WORDS: Family caregiver, spouse, residential respite care, interviews, content analysis.

Introduction

The role and function of family caregiving to a person with neurological disorders at home has become increasingly important both for individuals and for society in general (1, 2). Family caregivers can be relatives, friends or neighbours who take care of someone without being paid for their services (3). In fact, elderly persons are themselves often responsible for spouses in daily care. This could be a source of enormous social, psychological and physical strain which often influences their health as well as put restrictions on their work life and in leisure activities (4, 5). The role as caregiver can also contribute towards isolation from their social network and relationships, which affects their well-being (4). Financial difficulties could drain away the family caregiver's energy and health (6). Lack of support and daily anxiety for their spouses' well-being affected their own psychological health (7). Women are the most common family caregivers in home care (8, 9) but for ages 75-84 years old, both genders are represented (10). In a European perspective, the attitudes and norms for family caregiving varied and e.g. in catholic countries it is common to care for frail, older people within the family (11).

The communities in Sweden have an extensive responsibility for facilitating the heavy workload that family caregivers take on when caring for their spouse at home (2). The residential respite care services can offer relief for the family caregivers, so they can regain their strength and stay healthy. This service makes it possible for them to care for their spouses at home for longer periods of time (2, 12). How the caregivers use this relief service is dependent on what social support they receive from their families and network (13). Other studies showed that utilization of this relief service was also dependent on the quality of the care that the spouse received (12,14,15).

There are a variety of studies on family caregiver's physical and emotional situation as well as their social life and how they handle their new role as caregivers. Studies argued that further work is needed to increase the support services offered. Family caregivers of persons with neurological disorders take great responsibility for their spouse. However, studies about how family caregivers experience their work, especially when they utilize periods of residential respite care, are sparse. Against this background the objectives of this study were two-fold: to shed light on how family caregivers experience their

daily life when they care for a spouse at home, and to elucidate their daily life when utilizing residential respite care.

Methodology

A qualitative descriptive design was chosen to collect data through individual interviews with family caregivers.

Participants

The *inclusion criteria* for the study were family caregivers over 65 years of age cohabiting with a spouse who had neurological disorders and had cared for at home at least 6 months. The *exclusion criteria* were family caregivers who cared for a spouse with cognitive dysfunction. The study was performed in collaboration with responsible administrators of the respite care and home help services in the community, who suggested names of local contact persons. The authors contacted these individuals and were given names of the family caregivers after they had obtained informed consent from them to be contacted. Eighteen family caregivers (thirteen women and five men) were interested. All caregivers lived in their own homes with their spouses in rural or urban environments. Fifteen of the spouses had the diagnosis stroke, one person had Parkinson's disease and two had neurological symptoms with aphasia and disturbance of balance. The spouses had also different degrees of physical dysfunctions and abilities to communicate.

Data collection

The interviews were conducted by both authors separately during the spring of 2007 after the interview guide had been pilot-tested twice. Participants were asked to *describe their everyday life and living conditions when their spouse was cared for at home and when their spouse was cared for at residential respite care institution*. Follow-up questions for broadening the answers were: Can you elaborate? What does that mean to you? The interviews were carried out in the home of the family caregivers, tape-recorded and lasted for about 45 to 60 minutes.

Data analysis

The interviews were transcribed verbatim and analyzed using qualitative content analysis by Graneheim & Lundman (16). All interviews

Table I. Analysis process from text to code, category and theme

Meaning unit	Code	Category	Theme
... I make all the food myself ... – because he cannot eat anything with eggs in ... he is very allergic, I have to check everything I buy ...	Meals and nutrition intake	Basic needs of help for spouse	Developing a role as family caregiver
... he is a big diapers... I have to lift him out of bed ... and roll him with the toilet seat to the toilet... cannot put on his pants...	Personal hygiene and elimination		

were read through repeatedly in order to create a sense of the whole. What the text literally "says" was linked to the manifest content, while what the text "talks about", which captures the deep structure meaning conveyed by the text, comprised the latent content analysis. Meaning units were identified and condensed. Codes were formulated and marked according to identified words and phrases. The codes were assessed with respect to similarity and difference and sorted into sub-categories. Coherent sub-categories were sorted under categories (manifest content). Discussions in the analysis process were held between the authors until consensus was reached. From the categories, two themes aroused (latent content).

Ethical considerations

The study was approved by the Ethical Research Committee at a University in Sweden. The family caregivers were informed verbally and received an information sheet about the study. Participation was voluntary and they could withdraw at any time. Informed consent was obtained from the family caregivers before the interviews were carried out. Presentation of the results would be treated confidentially.

Findings

The experiences of family caregivers, when they cared for a spouse at home were expressed in the first theme as: *Developing a role as family caregiver* (including three categories and eight sub-categories) (Table II).

Table II. The family caregiver's life situation when their spouse was at home

Theme I: Developing a role as family caregiver			
Category	Basic needs of help for spouse	Social needs	Need of security
Sub-category	Personal hygiene and elimination	Fellowship with friends and family	Professional support
	Meals and nutrition intake	Communication and cooperation with staff	Adequate and safe equipment
	Communication with spouse		
	Meaningful activities		

The experiences of family caregivers in their daily lives when their spouses were at residential respite care were expressed in the second theme as: *Satisfaction with daily life depends on the quality of care their spouse received* (including two categories and four sub-categories) (Table III).

Table III. The family caregiver's life situation when their spouse was at residential respite care

Theme II: Satisfaction with daily life depends on the quality of care their spouse received		
Category	Consultation and communications with caring staff	Expectations and demands
Sub-category	Open and permitting communication	Requirements of good quality care
	Hand over responsibility	Relief from the caring role

Quotations from the interviews are presented in the sub-categories in order to validate the results.

Theme I. Developing a role as family caregiver

The three categories: *Basics needs of help for spouse, social needs and need of security* emerged when analyses the interviews. The family caregivers expressed how their living condition changed, when their spouses were at home. They expressed how their lives had changed and they had to make something out of the situation. The change of role from spouse to family caregiver meant a development with increased self-knowledge and changed values in life.

Basic needs of help for spouse

This category included four sub-categories: personal hygiene and elimination, meals and nutrition intake, communication with spouse, meaningful activities.

In spousal care, personal hygiene and elimination included morning wash/shower, dressing/undressing and helping the spouse get out of bed in the morning and into bed at rest during the day and in the evening. Help with going to the toilet could be "very difficult" for caregivers. The burden for the caregivers varied depending on the degree of disability and physical state of the spouses, as well as on how much energy and patience they had themselves. When a spouse had a mobility dysfunction, the work became heavy for the caregiver and it demanded a lot of care: ... *he is paralyzed, he can't stand up, he can't walk...* Another quotation was... *it's an adventure every time she needs to take a shower.*

Helping their spouse at meals and nutrition intake could be a great part of their daily work and worrying. If a special diet was required (e.g. for diabetes or allergies), family caregivers expressed insecurity and worry ... *I have to ask how the food is cooked ... I make all the food myself...* about making mistakes. Temporary support from the caring staff could be obtained if needed.

Caregivers expressed that communication with spouse about everyday life was important in order to maintain an intellectual fellowship. Mutual experiences and interests enriched the relationship between spouses and could lead to a deepened relationship for either of them – there was more time to talk and reflect – *the basic warmth of our relationship has become more evident ... we haven't had time to talk to each other like this before ...* . In spite of communication difficulties, the caregivers felt that it was important to talk to one another ... *he participates, although he might not enrich the conversation very much ...* .

Meaningful activities included physical training to improve mobility for the spouse. The responsibility for continued rehabilitation in connection to discharge from the hospital was experienced as laborious ... *after rehabilitation at the hospital, I was told he wasn't allowed to lose*

the abilities he had gained from the physical therapy ... my goodness, do I – as a caregiver – have to be able to do that as well? Other meaningful activities could be cultural needs, such as listening to music or going to concerts or to the theatre. The caregivers also tried to involve spouses in current events in society by reading newspapers together ... but I'm not sure how much my spouse is present and understands...?

Social needs

This category included two sub-categories: fellowship with friends and family, and communication and cooperation with staff.

The fellowship with friends and family, such as previous friends and acquaintances of family caregivers, had been impaired by difficulties to understand the spouses: *They don't have the same respect for him anymore, because of his difficulties with communication ... Thoughts like that just make it hard.* Caregivers also described this change as ... *Social relations are almost gone – they are afraid – they don't come here.* The caregivers felt guilty if they contacted friends and acquaintances outside the home, stayed away for too long or stopped to chat with someone. They felt they had to hurry home: *He is waiting for me ...* Support from children and grandchildren were an important part of their social needs in order to live a normal life as possible. No matter how, but it was not always easy to ask the children for help: *They come and help sometimes, but it mustn't be a burden for them ...*

There was lack of time for communication and cooperation with staff about their own caring role. They needed to be educated in the caring tasks for their spouse and they wished to receive acknowledgement about their efforts, as well as about how they felt themselves: *They could just call and ask, how are you? ... but there are so many rules... .* They did not know the rules for respite services in the community. Sometimes financial limitations caused an unwillingness to ask for more support or help. Their worries about the future were expressed ... *if I become ill or fall and hurt myself, what will happen to my spouse then ...?* The cooperation with the caring staff concerning their spouses' need of help – “the logistic approach” – was insufficient e. g during the night when spouses needed help from home-care services: *I can't sleep when the night caring staff arrives, because they turn the lights on... and then I wake up and it's impossible to go back to sleep... .*

Needs of security

This category included two sub-categories: professional support and adequate and safe equipment.

There was a great need for encouragement and to receive professional support from nurses and doctors after the spouse's discharge from hospital. Both positive and negative aspects expressed. Entering the caring role was connected to strong experiences of heavy work and emotions, which influenced their sense of security in caring. They were not prepared for the extent of the changes that arose in everyday life. ... *I don't know how much energy I'll have from day to day... .* One caregiver cited her father's opinion: *You don't have to walk up the hill until you arrive at it ... and I don't know how many times I have said it right now.* They need knowledge and advice on how the spouse could best be cared for with satisfactory quality of care and to feel secure, e. g in situations when spouse had cramps or fits of dizziness: *The staff has been amazing at being present ...* Encouragement from professionals mostly worked well, but problems with accessibility during holiday periods were stressed. One caregiver said: *I think it's a bit odd that they haven't passed it on to someone ... so I don't know who to call ...* Security for family caregivers meant being able to call the home-help services and be met by warm, careful and qualified staff.

The sense of security of caregivers was also dependent on having adequate and safe equipment when caring at home. The physical environment was primarily related to the bathroom and stairs or other obstacles in the immediate environment. Early information and instructions about suitable aids and how they are used were important... *At first there was a lot of unnecessary trouble, but now everything works fine There were so many things I had to do that I was forced to find my own way of doing.*

Theme II. Satisfaction with daily life depends on the quality of care their spouse received

The two categories: *Consultation and communications with caring staff and expectations and demands* emerged when analyses the interviews. The family caregivers expressed relief when they handed over the responsibility of care for their spouse to caregivers at the residential respite care institution, but also anxiety about the quality of care their spouse was provided. The period the spouse spent in respite care varied, both concerning time and number of days, and was dependent on economic conditions (both for the family caregiver and the community) and assessment of needs.

Consultation and communications with caring staff

This category contained two sub-categories: open and permitting communication and hand over responsibility. The experiences of family caregivers in daily life were dependent on how open and permitting communication was between the caring staff and themselves. They wanted to make visits to see how it worked: *The staff accepts my questions, but they don't always provide an answer ... Maybe it is my fault?* There was a lack of occasions for contact when they could receive information about the condition of their spouse. It was a matter of being able to hand over responsibility for the care of the spouse. Caregivers' feelings included both relief and worrying. They felt guilt and shame when the spouse did not like the respite care period, and when it was time for a new stay it was ... *psychologically hard.* They struggled with feelings of handing over responsibility versus remained responsibility for their spouse. The staff encouraged the family caregiver to stay home and not visit the spouse every day. Recovery from the role as family caregiver was dependent on the staff's capability to provide satisfactory care for their spouse. For some, the respite care period of the spouse was a welcome break in the everyday lonely life as family caregiver as they could meet others with similar experiences. It was seen by them as ... *a struggle through a loss of the relationship with the spouse and their own loneliness.*

Expectations and demands

This category included the two sub-categories: Requirements of good quality care and relief from the caring role. The requirements of good quality care to the spouse was intimately related to how they perceived their period of self-care and rest: *I am happy when she is happy.* Furthermore, their demands for follow-ups and check-ups of health status and medication for their spouses were not respected, and neither was increased rehabilitation during respite care periods. They fought for the best possible care from the community for their spouse ... *because he still thinks he will improve.* If the respite periods were a passive upkeep, and the spouse had to sit alone in the room, they felt guilty to hand over responsibility and could not find relief from the caring role. They still felt they had responsibility for the spouse: *He doesn't like to be there, because he says it gets too boring ... spouse asks for me if I don't make daily visit.* This could make them unwilling to go anywhere and do something else during respite care periods.

The residential respite care periods could also meet the expectations of family caregivers and be a positive experience, as the period gave them an opportunity for relief, relaxation and rest. Time for oneself meant physical and mental rest and recovery: *I really can relax.* They could run errands and perform activities that they might not be able to do while their spouse was at home. Meeting friends and acquaintances with similar experiences to talk about the caring role and exchange thoughts about the future was felt to be of great value. However, the negative way, sometimes it could be difficult to rest because of the workload that had been building up during the care period at home, such as cleaning up the home. Therefore, the rest could be neglected in order to have time for these chores before the spouse returned home again.

Discussion

The study describes narratives from thirteen women and five men about their experiences of daily life when they care for a spouse at home and when utilizing residential respite care in the community.

Informal health-care is usually performed by someone in the family and mostly by women (8, 17). Since the caring role can be experienced differently by men and women when it comes to workload, it is important to consider this when planning needs of support from the community (14, 18).

The results showed a complex picture based on the burden when providing care to a spouse. Physical and mental strains and questions of how to handle the new role as family caregiver were found. A great deal of the work consisted of supporting a spouse's basic and social needs. These tasks led to alteration in the relationship between the caregiver and the spouse. This affected their integrity and autonomy, which demanded acclimatization and support for the family caregiver (9, 19, 20). They had two roles in their new life; both as caregiver and spouse. The life situation had radically been changed and they had to adjust. This has also been described in earlier studies by Stoltz et al. (1) and Franzén-Dahlin (7). The changing relationship between the spouses was expressed either as positive or negative. For some it led to personal growth with increased self-awareness and changing values in life (19, 21). Their everyday life and well-being was to a high degree dependent on support from friends and family, according to what Grant et al. (22) have reported. Another study by Grant et al. (23) has evaluated a telephone support programme to caregivers, with satisfactory results. This is an excellent example of how caring staff can support caregivers by phone. Another form of support is through networks of people in the same situation, which has been described by Stoltz et al. (1) and Salin et al. (12, 24).

A notable find in our study was the caregivers' worries for the future if they became ill and could not care for their spouse. These worries have been expressed by Cheung and Hocking (19) as "the care through worries." Schultz and Beach (25) have described how this concern for someone can cause continual stress for an individual and run the risk of premature death.

The caregivers' expectations on the residential respite care periods for spouses put forward the importance of safe care of good quality. If these demands were fulfilled, it would help the caregivers to relax and gain new energy and time for self-care. Poor quality of care for the spouse meant that the family caregiver could not make full use of the time for recovery. This is in line with Stoltz et al. (1) which put forward that good quality of respite care periods for the spouse was a prerequisite for the family caregiver to provide opportunities for relief. The periods of the spouse's residential respite care were both described as positive and with conflicting feelings, such as guilt and concern, particularly, when spouses did not wish to leave their home for this period (26).

In line with Salin et al. (12), our results showed that family caregivers' desires were to be seen and treated as a partner and share the goals about the care of spouses even during the respite care period. To make use of the residential respite care periods, financial factors had certain significance. Huang et al. (20) has discussed critical aspects of costs, meaning that if good quality could not be offered, the caregivers declined the opportunity for relief. According to Jegermalm (26) it must be an advantage for the community to invest in good quality respite care services, so that caregivers can feel safe and confident when handing over responsibility for their spouse. Although the situation of caregivers is acknowledged in different studies, few studies have described "good examples" of interventions with strength for evidence and problem-solving (27). A framework for possible intervention could be McCormack et al. and the advanced model called person-centred nursing. This structure is four-pronged and focused on prerequisites, care environment, person-centred process and expected outcomes (28). If referred to person-centred nursing, the quality of respite care periods for a spouse could have been evaluated better.

Methodological considerations

In qualitative studies, the trustworthiness refers to quality control through all stages in the research process where the strengths of the study is referring to the depth of data and is representative to the narratives of the informants. When interviewing, we strived to be sensitive to the responses of informants and asked for clarification when something was unclear. During the analysis process, categories and

sub-categories were continuously discussed between the authors and comparisons with interview texts were made until consensus was reached. Notwithstanding the reality, one must bear in mind that the study reflected the life situations of some family caregivers in only five communities out of 290 in Sweden.

Conclusion and implications for practice

The family caregiver has to balance two different worlds, i.e. the world of the caregiver and the world as a spouse. They need early education from professionals and support from family and friends. As a key factor, individually adapted support and follow-up from caring staff of the work-load and needs of family caregivers contributes to a satisfactory daily life for them. The knowledge and individual experiences of family caregivers should be more extensively followed up via the community's organization of the service to family caregivers. In the caregiving world, the importance of good quality of care and of alternating respite care was stressed. Family caregivers need opportunities for self-care, which was highly dependent on the quality of care their spouse received during respite care periods. They had to feel safe about handing over their spouses to respite care in order to gain energy for further caring at home.

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Ethical Approval

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Author contribution

Anna-Lena Berglund, contributed to the study conception and design, data collection, data analysis and drafting the manuscript.

Inger Johansson, contributed to the study conception and design, data collection, data analysis and drafting the manuscript.

The authors have contributed equally to the different phases in the study

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