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# EXHAUSTION AMONG ELDERLY INFORMAL CAREGIVERS — A GENDER SENSITIVE APPROACH

In this study, we examine the factors that affect coping among elderly informal caregivers. Elderly informal caregivers have been defined as those who have reported providing help or taking care of a person who is long-term ill, disabled or aged. The analysis is based on gender-related findings of differences between elderly male and female caregivers and goes beyond observations from earlier research to analyse the reasons for gender differences in experiences of exhaustion by asking Why do elderly women more often experience caregiving as exhausting than elderly men? What explanatory factors can be found?

To answer the research question, we used the data of the longitudinal GOAL-study (Good Ageing in Lahti Region, a.k.a. Ikihyvä Päijät-Häme). In this article, we applied data from the third wave of GOAL-study (2008). The original GOAL-study sample consisted of 4,272 individuals, of whom 2,814 (66%) participated in the baseline. Among them 2,064 participated in the third wave (2008). For the data analysis, multivariate logistic regression analysis was used to examine how the variables related to caregivers' experience of exhaustion when the effects of other variables were standardised.

We discovered that among elderly people, informal caregiving is still clearly a gender- and culture-specific phenomenon. As our study shows, the experiences of female and male caregivers may be similar, but the basic elements of everyday life are likely to be more difficult for women because of cultural, health and economic inequalities. Women are more likely to live in situations consisting of a daily occurrence of intensive caregiving tasks. Those women from the youngest age group and who were still of working age had the highest risk of exhaustion. This may also reflect women's triple and intergenerational burden during the sixties' age period (here 58-62 years).

**Key words:** exhaustion, elderly, informal caregiver, informal care, care, caregiving, a gender sensitive approach, well-being, coping

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# УСТАЛОСТЬ ПОЖИЛЫХ, УХАЖИВАЮЩИХ ЗА СВОИМИ БЛИЗКИМИ — ГЕНДЕРНО-ЧУВСТВИТЕЛЬНЫЙ ПОДХОД

В данной статье мы рассматриваем факторы, влияющие на то, как справляются пожилые, которые неформально ухаживают за своими близкими — хронически больными, инвалидами или пожилыми людьми. Анализ основан на результатах, отражающих гендерные различия между ухаживающими мужчинами и женщинами. В данной статье явление рассматривается глубже, чем в предыдущих исследованиях, и причины различий в степени усталости анализируются с помощью следующих исследовательских вопросов: Почему пожилые женщины, ухаживающие за близкими, испытывают усталость чаще, чем пожилые мужчины, находящиеся в аналогичной ситуации? Какие факторы объясняют данное явление?

Для того чтобы ответить на этот вопрос, мы анализируем количественные данные из лонгитюдного исследования GOAL (Достойная жизнь пожилых на территории г. Лахти, Ікінуvä Päijät-Häme), собранные в Финляндии. В статье используются данные, которые были собраны на третьем этапе исследования в 2008 г. В оригинальном исследовании выборка состояла из 4 272 человек, из которых 2814 (66 %) участвовали на первом этапе. Из них 2064 приняли участие на третьем этапе исследования (2008). Для анализа данных был использован многовариантный логический регрессионный анализ, который позволил установить влияние факторов, связанных с усталостью ухаживающих, в то время как другие переменные были стандартизированы.

Результаты исследования показали, что уход, который осуществляют пожилые люди за своими близкими, представляет собой все еще явно гендернои культурно-специфический феномен. Несмотря на то, что опыт ухаживающих женщин и мужчин может быть похожим, основные элементы повседневной жизни оказываются более трудными для женщин из-за неравенства в культуре, здоровье и экономических ресурсах. Результат объясняется тем, что женщины чаще находятся в ситуациях, в которых от них требуется интенсивный повседневный уход. Кроме того, женщины, входящие в более молодую возрастную группу и продолжающие работать, подвергаются самому большому риску усталости. Это может быть отражением большой межпоколенной нагрузки, которая ложится на женщин примерно 60 лет (в данном исследовании 58—62 года).

**Ключевые слова:** усталость, пожилые, ухаживающий за своим близким, неформальный уход, уход, гендерно-чувствительный подход, благосостояние, преодоление

#### Introduction

In recent decades there have been remarkable changes in the service structures of elderly care in Finland. The coverage level of services has plummeted, and care is increasingly targeted at those in greatest need (Noro et al. 2014; Finne-Soveri et al. 2014), which means that sources of care other than public provision are of growing importance.

From the viewpoint of families, and especially women, these changes amount to a rupture in the ideals of the Nordic welfare model, which is characterised by significant public sector responsibility (Rissanen 1999; Greve 2007) and gender equality (Kiander and Lönnqvist 2002: 24–26).

The changes in welfare policy translate into decreasing public responsibility for the needs of many older people and, correspondingly, an increasing reliance on informal caregivers (Kröger and Leinonen 2012). These recent developments can be characterised as a weakening defamilisation as the welfare state facilitates even less female autonomy and economic independence from the family than in recent years (Bambra 2007). According to Jallinoja (2006), the period of familisation began in Finland in 2000. While it is clear that the responsibility of care has never relied entirely on the public sector, even in Nordic countries (see Törrönen 2012), the role of the family and informal networks has grown in the form of reductions in public welfare services and benefits and the promotion of homebased care and informal care (Leinonen 2011: 91).

Recent empirical research has shown that older people most often receive care from family members (Haavio-Mannila et al. 2009; see also Varjonen 2011: 30), not only because of problems relating to accessibility of services but also because of reluctance to use public services (Leinonen 2011: 91). However, as care needs increase, care receivers themselves seek to rely more on increased public sector involvement (Van Aerschot 2014).

In Finland, unlike many other European countries, adult children are not legally obligated to provide care to their parents. That duty of care remained in Finnish law until 1956; in marriage, the care obligation between spouses was removed in 1977. Thus, the municipality's duty is to take care of inhabitants in need; but Finland, like other Nordic countries, has a strong collective tradition of non-public intergenerational care (e.g. Van Aerschot and Valokivi 2012).

It can be argued (see Lewis 2007) that beyond the question of the care needs of elderly people, families' care needs and commitments may be overlooked. Current policy relating to the elderly emphasises the increasing role of informal caregiving by older persons (Vasara 2014: 16; see also Kröger and Leinonen 2012). At the same time, there are expectations that the labour force should include all people of working age. These policies create contradictory situations, especially for the children of older adults, when trying to combine paid employment and family care as closest relatives are also expected to provide extensive informal help (Lewis 2007; Leinonen 2011: 92). In many cases, the informal caregiver is the spouse of an older person, and in the contemporary societal situation characterised by a rapidly ageing population, coping among elderly informal caregivers has become a crucial question. This issue will become even more pertinent in the near future because the number of informal carers is increasing along with the number of ageing people. In Finland, the proportion of persons older than 65 years is projected to be 26.1 per cent by 2030 (Population by Age 1900–2060).

Gender has been found to play an important role in well-being and in the quality of care. Seventy-five per cent of informal caregivers are women, most commonly retired (Kalliomaa-Puha and Mattila 2010: 19, 21; see also Sointu 2011: 159). Women are more often caregivers while men help with other practical matters; women also help their parents more than men, but both genders help their children equally often (see Hämäläinen and Tanskanen 2014: 367). For instance, Collins and Jones (1997) have found that elderly women in particular, experience caring as exhausting (see also Zarit et al. 1986). In their study, Yee and Schulz (2000) highlighted the greater levels of psychological symptoms that female, as opposed to male, caregivers experience. In a meta-analysis of studies of gender

differences, Pinquart and Sorensen (2006) observed that women experienced higher levels of burden and depression and that their subjective well-being was lower than that of male caregivers. Davidson et al. (2000, 536) also found that gendered roles and expectations are crucial in understanding the mainly negative experience of older women as carers, which contrasts the more positive experience of older men.

In this study, we examine the factors that affect coping among elderly informal caregivers. We use a gender sensitive approach, which has to do with the gendered nature and impact that gender has on the relationship between the caregiver and the care recipient in informal care and how it shapes the experiences of both sexes (see also Davidson et al. 2000, 536). We do not follow the traditional understanding of gender roles as care for parents by daughters (see also Arber and Ginn 1990: 430; Ungerson 1995: 31; Davidson et al. 2000: 536); instead, our investigation looks at differences according to sex.

Elderly informal caregivers have been defined as those who have reported providing help or taking care of a person who is long-term ill, disabled or aged. The analysis is based on gender-related findings of differences between elderly male and female caregivers and goes beyond observations from earlier research to analyse the reasons for gender differences in experiences of exhaustion. Despite the fact that our focus is on exhaustion as a usually negative experience, we do not understand caregiving only in negative terms — as a social burden — or that the level of dependency of elderly people simply increases equivalently towards disability (see Arber and Ginn 1990: 429-431; Davidson et al. 2000: 539). We understand care as a mixture of both positive and negative feelings and actions, which include love, caring, attachment as well as anxiety, displeasure and perhaps one may even be overcome by a sense of despair. If caregiving consists of reciprocal actions, it renders joy, pleasure, company and meaning to one's existence. The research asks: Why do elderly women more often experience caregiving as exhausting than elderly men? What explanatory factors can be found? By elaborating the connection between gender and experiences of exhaustion among caregivers, we hope to contribute to knowledge of how to empower caregivers in their daily tasks in society.

#### Informal care

Care is embedded in different social relations, and as a central part of life, it binds together families and communities. Caring by family members has been referred to as *informal care*, which is understood as unpaid care carried out at home, whereas the concept of formal care refers to paid and organised care work (Phillips 2007; 2010); for example, a nurse is a formal caregiver, and a family member is an informal caregiver (Lai 2013).

Taking care of loved ones is often understood as a matter of honour or responsibility; if one cannot fulfil this obligation, the result is often guilt. Reciprocity is also embedded in relationships of informal caregiving (Lewinter 2003) when people want to provide care because of love, mutual friendship or because of feelings of guilt or duty. Love, a long-shared life or even pity can be strong motives for informal caregiving. Adult children do not want to send their parents to institutions; spouses do not want to give up even if their partner is in poor health (see Salanko-Vuorela 2010: 7, 11–12). The matrimonial promise is also seen as an obligation in the ups and downs of life in which informal caregiving can be seen as the uphill of that promise (e.g. Henderson 2001). Caregivers are occasionally unwilling to use supplementary services, or care recipients are reluctant to accept other services in their homes (Leinonen 2011: 94). Sometimes, there is no option other than to take on the role of a caregiver; sometimes, it is a question of negotiating the caregiver's role in a context where various spatial and organisational factors shape the preconditions for such decisions.

Negotiation and decision-making ensue within a complex network of social relationships and conflicting interests (Mikkola 2009; Edgell 2013). Moreover, prevailing cultural assumptions and normative kin obligations are important factors in becoming an informal caregiver, especially for women (Aronson 1990; Rissanen 1999).

In Finland, the Support for Informal Care Act (2005, 2§) defines informal caregivers as those who are closely related to an elderly person or those who are close to the elderly person who have entered into an informal caregiving agreement. The law must guarantee the best interest of care receivers. An informal caregiving agreement is usually made when the elderly person has a long-term physical illness or injury, suffers deteriorating performance because of ageing or dementia or is disabled (see Support for Informal Care Act 2005: 3§; Kalliomaa-Puha and Mattila 2010: 21). Here, we use the concepts of informal care and informal caregiving to refer to caregiving by family members or by others who are close to the elderly person, regardless of their formal status as caregivers.

The concept of *caregivers* rise to many different components and distinctions. In the United Kingdom, for instance, the term 'carer' is used to refer to informal caregivers, meaning family members or significant others (Lai 2013). In the Finnish research literature, care has been defined as comprehensive caring, which a person needs because of their weakened functional capability (Sipilä 2003; Van Aerschot 2014). This definition differentiates care from many other forms of help given by family members to each other or other forms embedded in other social relations. Elderly people play a significant role in informal care, which often means care between spouses (Mikkola 2009).

Most often, informal care is given to older adults by close relatives (spouse or children), although the law does not require informal caregivers to be relatives; the prerequisite is that caregivers are close to the elderly person (Kalliomaa-Puha and Mattila 2010: 19, 21). This definition distinguishes caregivers from voluntary workers. Informal caregiving most often occurs in families where an elderly person requires continuous or around-the-clock care (pp. 19, 21). While care is provided by a spouse at the couple's common home, new forms are emerging in the care provided by adult children. Many younger caregivers are also in employment; consequently, distant informal caregiving has become increasingly common. Distant informal caregivers are thus those who care for their relatives from a different household or town (Salanko-Vuorela 2010: 7–11).

In Finland, there is an on-going process of deinstitutionalisation in the sphere of elderly care, and there is also strong political support for home-based care, which means that the elderly stay at home for as long as possible with the help of informal caregivers and home care services as needed. One Finnish study (Kattainen et al. 2008; see also Leinonen 2011, 92; Vilkko et al. 2010: 62) indicates that one in every five Finns provides informal help to a relative, friend or acquaintance in need. The number of elderly Finnish (over 63 years) reached almost one million in 2013, of whom about 140,000 regularly utilise various services, and about 90,000 receive home services on a regular basis in the form of home care services or informal care. About 50,000 elderly people are in institutional care; the aim is that in the near future, only two to three per cent of people over 75 years of age will be in institutional care (Laatusuositus...2013: 13; see also Supporting the Functional Capacity of the Older Population and the Social and Health Care Services for Older Persons Act 980/2012). This is seen as a means of guaranteeing people's quality of life in old age. Clearly, however, a problem arises when the elderly population increases dramatically against the backdrop of insufficient availability in home-based services (Salanko-Vuorela 2010: 7, 11–12).

Unlike many other Western countries, Finland has introduced a support system for informal care. The Support for Informal Care Act (2005) defines the forms of assistance

that are available to relieve the burden on the informal caregiver. The motivation behind this policy is partly economic; for instance, the financial aid given to informal caregivers in 2013 has brought municipalities saving of approximately 1.1 billion euros in social service provision (Salanko-Vuorela 2013: 7; see also Kehusmaa et al. 2013). In addition to direct payments, the support system for informal care includes services for informal carers. The level of financial aid and service provision depends on the needs and functional capability of the person requiring care (see Leinonen 2011: 93). These services and forms of aid require an agreement between the caregiver and the municipality. Currently, most of those receiving support are elderly persons caring for a spouse (Vaarama et al. 1999: 79).

## Elderly care at the cost of the carer's well-being and coping?

Informal caregiving between a caregiver and an elderly person should always be voluntary, but this is not always the case. Informal caregivers and elderly care recipients often have a relationship that predates the informal caregiving relationship. The situation may gradually become more challenging over time, and it can be difficult for informal caregivers to distinguish normal everyday help from informal caregiving (Salanko-Vuorela 2010: 7–11). Elderly people themselves often help their adult children by taking care of grandchildren, picking them up from day care, driving them to activities or providing care if they are unwell. The elderly often welcome this role as it offers satisfaction and joy in being with their grandchildren (Varjonen 2011: 30). In cases of elderly care, older adults also help those closest to them and may find this fulfilling (p. 31). For example, for relatives who have a long relationship or whose spouse is suffering from mental difficulties, it can be difficult to see when a normal family relationship gradually turns into an informal caregiving relationship. It has been estimated that most informal caregivers do not receive any financial or other formal support for caregiving. During the critical periods of everyday life, when the energy of the caregiver starts to weaken, the informal caregiver's coping ability is at risk.

In some cases, the caregiving situation may escalate, perhaps because of the poor health of the caregivers themselves. However, terminating the receiver-provider relationship is not without difficulty (Salanko-Vuorela 2010: 7, 11–12); supplementary home help services might not be available, there might not be adequate resources to implement or pay for the more the caregiver simply may not be aware of his/her own exhaustion. Other reasons for not using other available services might include a lack of knowledge about services and costs, or caregivers might receive supplementary support from other family members (Leinonen 2011: 94). Sometimes, the motivation to provide help may involve the misuse of benefits. Such a relationship may not serve the best interests of the elderly person, in some cases, constituting abuse or mistreatment. In Japan, for instance, elderly care has traditionally been based on informal caregiving. After several cases of maltreatment, the Japanese state began work on laws to protect elderly people and considered new ways of organising work with the aged in order to create options for other forms of caretaking beyond the informal care provided by women or adult children within families (Hanaoka and Norton 2008).

Informal caregivers' own well-being and coping are crucial. Research has shown that informal caregiving is a risk factor for the well-being of caregivers; for instance, family caregivers have a mortality rate of 63 per cent higher than other elderly people. This is attributed to the experience of loss, prolonged stress and the physical demands of caregiving on caregivers (Schulz and Beach 1999). Informal caregivers are more susceptible to depression than other people of the same age (Schulz et al. 1995). Their age and income level have been identified as factors influencing their experience of caregiving as exhausting

(Montgomery et al. 1985). In general, women earn less than men, and poverty among elderly women has increased (Schaffner Goldberg 2010: 292; see also Törrönen 2014: 24). In their research, Vilkko et al. (2010: 68) noted that elderly women are overrepresented in the sample group that has difficulty taking care of their finances whereas there are no differences by sex when the financial situation is stable. Female caregivers have been found to suffer more mental symptoms than men (Yee and Schulz 2000), and wives more often experience caregiving as exhausting than husbands when informal caregiving takes place between spouses (Collins and Jones 1997; see also Zarit et al. 1986).

The negative relationship between informal caregiving and well-being has been demonstrated in several studies. Verbakel (2014: 426) has proposed two possible explanations: i) caregiving has a direct impact on well-being because of the various difficult tasks, problematic behaviour and changes in the relationship between the care receiver and caregiver; ii) the indirect consequences of caregiving, such as overload due to multiple roles and reduction of time spent on activities that bring pleasure and joy, may also impact on well-being.

The dimension of exhaustion in informal caregiving has also been highlighted in the Finnish context. Representatives of local municipalities who answered the Social and Health Ministry survey discovered that the most common problems in informal caregiving are strenuousness and the fatigue and mental exhaustion of the caregiver. Informal caregivers who answered the survey as part of the 'Well Sick' project (Sairaanhyvä-projekti 2003; Malmi 2004) reported that mental stress, illness/ageing and the binding nature of the care were stressful for them. Informal caregiving is most often on-going throughout the day and night. Surveys by the Central Association of Carers in Finland indicate that mutual understanding, sharing the experiences of informal caregivers and supporting their coping are major challenges for those who work with informal caregivers. Professionals also note that emotions like anger, bitterness, guilt and exhaustion are commonplace. Imminent death and thoughts of renouncement are among the most demanding experiences resulting from informal caregiving. (Salanko-Vuorela et al. 2006.)

In cases of exhaustion, a lack of services is not always the only problem. Sometimes, it may be difficult for informal caregivers or receivers to accept care from other persons or from the community. A Ministry of Social Affairs and Health project (2003) discovered that the most widespread problem was the unwillingness of informal caregivers, despite exhaustion, to take time off and leave the elderly person in someone else's care. On the one hand, this illustrates that there is an insufficient number of appropriate alternatives for substitute care; on the other hand, informal caregivers ignore their own well-being and caretaking. The barriers to taking their own free time include guilt when leaving the elderly person in substitute care or a fear of poor quality substitute care. According to the 'Well Sick' project (Malmi 2004), the elderly person is constantly on the mind of the informal caregiver, and the latter has difficulty organizing time for him/herself. Informal caregivers find it arduous to bear sole responsibility for the difficulties of the future. Illness in the elderly person, especially mental problems, increases the caregiver's concerns; because they are not professionals, informal caregivers are not familiar with methods for maintaining distance in caregiving relationships.

#### Data and methods

On the basis of earlier elderly care research (see for instance Collins and Jones 1997), we sought to understand why elderly female caregivers more often than elderly men experience caregiving as exhausting and what factors increase the risk of exhaustion. To

answer the research question, we used the data of the longitudinal GOAL-study (Good Ageing in Lahti Region, a.k.a. Ikihyvä Päijät-Häme) in which the ageing of people from three five-year cohorts (born in 1926–30, 1936–40 and 1946–50) were followed up from 2002 to 2012 at four measurement points: 2002, 2005, 2008 and 2012. The region of Päijät-Häme— the geographical target of the GOAL-study — lies in southern Finland, 100–150 km north of Helsinki, and its population is typical of the Finnish population living outside the most advanced urban centres.

In this article, we applied data from the third wave of GOAL-study (2008). The age ranges of the respondents were 58-62, 68-72 and 78-82 years. The original GOAL-study sample consisted of 4,272 individuals, of whom 2,814 (66 %) participated in the baseline. Among them 2,064 participated in the third wave (2008). The attrition until 2008 (27 %) was quite large in the oldest cohort (45%), but in the two younger cohorts, it was moderate (21–22%). The data in 2008 is thus quite representative (Fogelholm et al. 2006; Haapola et al. 2009; Haapola et al. 2013).

For the data analysis, multivariate logistic regression analysis was used to examine how the variables related to caregivers' experience of exhaustion when the effects of other variables were standardised. Caregiving as exhausting was transformed into a dichotomous variable (exhausting or not exhausting). Binary logistic regression (see e.g. Nummenmaa 2004: 319) was then used to explain the experience of exhaustion.

In our analysis, we used the concept of care in a very broad sense, including both intensive care and the provision of more occasional help. We distinguished those elderly people who can be described as informal caregivers by their response to the following survey question (see also Arber and Ginn 1990: 433): 'Do you help or provide care to a person who is long-term ill, disabled or aged?' The response options were: 'No', 'Yes, 'occasionally' and 'Yes, daily'.

Exhaustion relating to caregiving was measured with the question: 'If you are caring or helping someone, how exhausting is the experience?' The answer options were 'not at all exhausting', 'quite exhausting' and 'very exhausting'.

Previous research has alluded to some of the factors that explain the gender differences between experiencing caregiving as exhausting: length of education, amount of caregiving, factors connected to physical functioning and factors showing attitudes towards care services as influencing coping. In addition to these factors, caregivers' concerns regarding their own ageing were examined; this is different from coping, which is connected to well-being in the economic, social, cultural and health senses.

In this study, caregivers' exhaustion and the differences between men and women are explained according to age, marital status, living arrangements, education, economic situation, physical functioning, trust in public care services and concerns about the future and their own aging.

The economic situation was measured by the question: 'How sufficient is your income to cover your daily expenses after financial obligations (such as housing costs and debt repayments) have been covered?' The response options were: 'very sufficient', 'fairly sufficient', 'barely sufficient', 'fairly insufficient', and 'very insufficient'. These were combined into three categories; easily (fairly and very sufficient), barely (barely sufficient) and poorly (fairly and very insufficient).

The measure of physical functioning is the average of 10 items drawn from the Rand Corporation's 36-Item Health Survey (Aalto et al. 1999). For the analysis, it was graded on three levels: 'not limited' (scores 90-100), 'a bit limited' (scores 70.1-89.9) and 'very limited' (scores 0-70).

The variable 'confidence or trust in public care services' was based on three items describing the potential causes of anxiety or insecurity: difficulties in getting help and care if needed, the high price of care services and the low quality of care services. Respondents were rendered 'concerned' if at least one of these caused anxiety or insecurity in them.

The variable 'concern about own ageing' was also based on three items that might cause anxiety: ending up in institutional care, dementia and being forgotten or abandoned. Respondent were rendered 'concerned' if at least one of these caused anxiety or insecurity in them.

## **Providing care**

About one-fourth of all respondents reported that they were providing care at least sometimes (Table 1).

Proportion of respondents who help or provide care to a person who is long-term ill, disabled or aged (in percentages)

Table 1

Table 2

	men		women		in all age groups				
		68-72 y (n=382)						women (n=1112)	both sexes (n=2064)
Yes, daily	5	3	8	5	7	6	5	6	5
Yes, now and then	19	15	14	29	21	12	17	23	20
No	76	82	78	66	72	82	77	71	75
All	100	100	100	100	100	100	100	100	100
Percentage of all caregivers (daily or occasional)	24 %	18 %	22 %	34 %	27 %	18 %	22 %	29 %	25 %

Differences between age groups: men p=.064; women p=.000; both genders p=.000.

We can report substantial differences among men and women. Women rendered informal care more frequently than men. In particular, occasionally help was more common among women than men. Age was associated with helping, but the pattern was complicated. For women and men, occasional informal care was most common in the youngest age group, decreasing with advanced age among women, while intensive caregiving in the oldest age group was more common among men than women

In the following table (Table 2), we present the basic characteristics of caregivers by gender before further analysing their exhaustion.

Characteristics of caregivers (daily or occasionally) by gender

	men %	women %	all %
Age group			
58–62 years	60	58	59
68–72 years	25	30	28
78–82 years	15	12	13

End of table 2

	men	women	all
	%	%	%
Family situation			
Living alone	10	36	26
Living with spouse/partner	78	53	63
Living with spouse/partner and others (e.g. children)	10	7	8
Living with children or other persons	3	4	4
Education			
Less than 10 years of schooling	52	50	51
At least 10 years of schooling	48	50	49
Economic situation: how is the respondent able to make ends meet			
Easily	64	60	61
Barely	25	32	29
Poorly	11	8	10
Physical functioning			
Not limited	56	43	48
A bit limited	22	24	23
Very limited	22	33	29
Confidence (trust) in public care services			
Confident/trustful	65	57	60
Concerned	35	43	40
Concerns about own ageing			
Not concerned at all	56	50	52
Concerned a little or a lot	44	50	48

There were some clear gender differences. Male caregivers mostly lived with their spouses whereas one-third of female caregivers lived alone. Moreover, physical functioning was less favourable among women who provided informal help. Women were also more concerned about public services.

#### **Exhaustion among caregivers**

In this section, we discuss the experience of exhaustion among caregivers. We first describe how prevalent and grave these kind of experiences are. Then we explore the bivariate associations between exhaustion and the basic characteristics of caregivers. In the next section, we move to the multivariate regression analysis in order to find out the effect of each variable while controlling the influence of all other variables.

Altogether, 18 per cent of men and 29 per cent of women experienced caregiving as at least somehow exhausting, which means that among all those who provided care, one out of four experienced caregiving as exhausting (Table 3).

 $Table\ 3$  Experience of exhaustion among men and women who provide care occasionally or daily

Experience of caregiving duties	men %	women %	all
Not at all exhausting	82	71	75
Quite exhausting	15	27	22
Very exhausting	3	2	3
All	100	100	100

In the subsequent analysis, the categories 'quite exhausting' and 'very exhausting' were combined into one category. This way, a dichotomous variable was formed: 'experiences helping as exhausting' (1) and 'does not experience helping as exhausting' (0).

In our sample (N=2,064), every fourth respondent (25%) rendered support or was helping someone. As mentioned earlier, every fourth respondent experienced caregiving as exhausting (Table 4).

Table 4
Exhaustion among informal caregivers according to gender and the intensity of caregiving (percentage of those feeling exhausted)

Intensity of caregiving /helping	men	women	all
Helps occasionally	15	23	20
Helps daily	29	55	44
All	18	29	25

Eighteen per cent of males and 29 per cent of females experienced caregiving as exhausting. The gender differences increased when only the caregivers who provided daily care were considered. Of these, 44 per cent experienced caring as exhausting: 29 per cent of men and 55 per cent of women.

In Table 5, we examine the association between exhaustion and other background variables among women and men. In the comparisons between the age groups, we can see that exhaustion does not grow linearly according to age: the middle group consisted of the least exhausted caregivers.

 $Table\ 5$  Exhaustion among caregivers by gender (percentages of those experiencing exhaustion)

	men	women	all
	%	%	%
Age group			
58–62 years	19	32	27
68–72 years	14	24	20
78–82 years	26	30	28
Family situation			
Lives alone	13	22	21
Lives with a spouse/partner and/or others	19	33	26

End of table 5

	men	women	all
	%	%	%
Education			
Less than 10 years of schooling	15	25	21
At least 10 years of schooling	17	33	27
Economic situation: ability to make ends meet			
Easily	14	28	22
Barely	22	24	23
Poorly	30	59	46
Physical functioning			
Not limited	15	21	19
A bit limited	16	26	22
Very limited	30	42	39
Confidence (trust) in public care services			
Confident/trustful	18	24	21
Concerned	19	36	30
Concerns about own ageing			
Not concerned at all	15	25	21
Concerned a little or a lot	22	34	29

Exhaustion was most commonly experienced among those caregivers who did not have sufficient income levels to cover daily expenses. The connection between one's economic situation and the experience of caregiving as exhausting was stronger among women than men; the majority of the women belonging to that group experienced exhaustion. Of those informal caregivers whose economic situation was favourable, 22 per cent experienced caregiving as exhausting whereas, of those caregivers whose economic situation was unfavourable, 46 per cent experienced caregiving as exhausting.

Physical functioning clearly affects the experience of exhaustion in caregiving. Of those whose physical functioning was *good*, 19 per cent experienced caregiving as exhausting; of those categorised as *limited*, 39 per cent experienced caregiving as exhausting. Nevertheless, most of those whose physical functioning was weakened did not experience caregiving as exhausting. Still, in terms of severe difficulties, exhaustion is a common feature, especially among women. For female caregivers, physical functioning was weaker than for men (weakened for over half of caregiving women and for about one-quarter of men). However, when physical functioning is controlled, the experiences of exhaustion are more common among women.

Confidence in care services correlated with the experience of caregiving as exhausting, especially among women. One-fourth of women who did have trust in care services and 36 per cent of those who did not have confidence in care service experienced caregiving as

exhausting. Caregivers' concerns about their own future and ageing were also clearly connected to their experience of caregiving as exhausting. Twenty per cent of those who were not concerned about their future and ageing and 32 per cent of those who were concerned experienced caregiving as exhausting.

## Multivariate analysis of exhaustion

Exhaustion was explained by constructing a logistic regression model for both genders separately and together as dependent variables, using the above-discussed variables as independent variables (Table 6). Analyses were conducted separately for each gender because, as noted in the preliminary analysis, there was a clear gender difference in the risk of exhaustion. The results of the logistic regression will now be discussed in order to examine the connection between gender and the experience of caregiving as exhausting.

 $Table\ 6$  Logistic regression on factors affecting exhaustion among caregivers (odds ratios)

	Women (n=273)	Men (n=158)	Both genders (n=431)
Age group (ref. = 58–62 years)	-/-		( - /
68–72 years	0.4*	0.7	0.5*
78–82 years	0.5	1.4	0.7
Physical functioning (ref. = no limitations)			
A bit limited	1.6	0.5	1.2
Very limited	3.2**	1.2	2.6**
Family situation(ref. = lives alone)			
lives with a spouse/partner and/or others	2.1*	1.9	2.0*
Education, length of (ref. = less than 10 years)			
at least 10 years	1.6	1.3	1.4
Economic situation: ability to make ends meet			
(ref. = easily)			
barely	0.7	1.3	0.9
poorly/not at all	1.7	1.8	1.7
Confidence in public care services(ref. = confident)			
not confident (concerned)	2.5**	1.2	1.9*
Concerned about own ageing(ref. = not)			
yes(concerned a least a little)	1.4	2.1	1.6
Intensity of caregiving (or helping others)			
(ref. = helps occasionally)			
helps or cares daily	6.0***	2.8*	4.5***
Gender (ref = male)			
female			2.3**
Constant	0.06***	0.04***	0.04***
Nagelkerke R <sup>2</sup>	.268	.113	.221

*Notes*: ref. = reference category (OR = 1)

*Significance levels*: \* p<0.05, \*\* p<0.01, \*\*\* p<0.001

In a logistic regression, we examine the odds ratio, which describes the relation between explanatory variables and the experience of caregiving as exhausting. When the odds ratio achieves a value above one, this indicates a higher risk of experiencing caregiving as exhausting in the particular variable's class compared to the reference group (OR = 1). Values under one, in turn, indicate a lower risk of experiencing caregiving as exhausting compared to the control group.

When analysing both genders together, we discovered that the intensity of caregiving was the most powerful predictor of exhaustion. If the care or help is provided on a daily basis, it includes the risk of being tired. If the person providing the help also has problems with his/her functional capacity, the risk becomes more evident, especially for women. An interesting and partly surprising finding was connected to age: the youngest age group (that in working life) was more likely to be exhausted even when other factors (intensity of care, physical performance and gender) were controlled. In the 'middle group' (comprising people in early retirement), the risk of exhaustion was lowest.

The regression model showed interesting gender differences. The variables in the model were able to predict exhaustion among the female caregivers, but for the male caregivers, the variables in the model could not statistically significantly predict exhaustion. This could be explained by the smaller number of exhausted male caregivers, which affected the statistical analysis. An alternative explanation is that there are many different factors that explain exhaustion in men.

As the model shows, women were more likely to be exhausted if they were within the younger age groups and had difficulties regarding functional capacity. Education or caregivers' economic situation did not have an effect on exhaustion, but confidence in public services was a significant predictor of exhaustion. However, the strongest individual predictor of exhaustion was the intensity of caregiving. Those who help daily are more likely to become exhausted, regardless of the presence of other factors.

## Discussion

Taking care or helping someone in need was quite common; about one in four of our respondents belonged to the group of caregivers who we examined more closely in our study. We discovered that a substantial number of older adults who help or provide care to persons in need feel exhausted at least sometimes. Women are more likely to get tired or exhausted than men. The majority of the women who provide intensive help experience exhaustion. Women are also more likely to live in situations consisting of a daily occurrence of intensive caregiving tasks. This might be linked to the fact that women's life expectancy is about seven years longer than that of men, which is why women more often end up caring for their husbands in the later phases of their lives.

A combination of factors affect female caregivers' experience of exhaustion. It is quite evident that exhaustion occurs when caring is most intensive, regardless of the circumstances regarding caregivers' functional capacity and other aspects. Physical functioning also matters as an independent variable. If the caregiver has problems with it, the risk of exhaustion becomes more real. Possible attitudes of distrust towards care services were connected to experiencing caregiving as exhausting; those who experienced caregiving as exhausting have more negative expectations or experiences of care services than those who do not experience caregiving as exhausting.

Those women from the youngest age group and who were still of working age had the highest risk of exhaustion. One explanation might be that caregivers receive more support as they get older. Arber and Ginn (1990: 437–440) have presented similar figures in relation

to the age of the adults in their sample; however, the average number of weekly hours of informal care by age and sex amongst all carers in their sample increases linearly and similarly by age and sex, although women around retirement age also have the heaviest burden of care. This may also reflect women's triple and intergenerational burden during the sixties' age period (here 58–62 years). They care for their own elderly parents, spouse, adult children and grandchildren and may still be employed at the same time. This issue is usually discussed in relation to women's double burden (Raijas and Pakoma 2010: 86) in the case of employed women with small children. For older women who are approaching the age of retirement, cultural expectations and the willingness to help a number of loved ones in need of support may span three generations. There are cultural expectations that women should be more intergenerationally active than men (see for instance Anttonen 2003: 184), although men's role as caregivers has been increasing (e.g. Törrönen 2012: 2014). There are also differences among women as some may still be employed with a heavy workload and without any relief from their paid work (concerning regional inequality in Finland, see for instance Kaikkonen 2014; Rissanen 2014, A17). However, the circumstance of ageing and the weakening condition of care recipients may attract care and help from others, thus easing their burden.

#### Conclusion

Families and significant others usually play the most important caregiving role during critical periods of everyday life in Finland. Caregiving usually involves the closest family members (Vilkko et al. 2010: 61, 72, 74; see also Arber and Ginn 1990: 444), and although the role of informal caregiving has increased in all Nordic countries, research on informal care has not risen proportionately (Vilkko et al. 2010: 61).

At least among elderly people, informal caregiving is still clearly a gender- and culturespecific phenomenon. In general, elderly women are more often seen to provide informal care, either daily or occasionally. Elderly men providing informal care most often do so to help their wives with their day-to-day tasks (see for instance Vilkko et al. 2010: 66). For men, caregiving usually coincides with a spouse becoming weaker and thus requiring assistance with day-to-day tasks, usually involving on-going and binding help or support for another person. Davidson et al. (2000: 548-549) observed an important gender difference relating to whether the cared-for spouse suffers from a mental or physical illness: a husband with dementia was reported to experience the greatest negative effects of caring compared with a physically impaired husband; a closer relationship was also reported towards the end of their life together (p. 548). Daily informal caregiving usually results in a lack of personal and physical time and a sense of continuous concern (Leinonen 2011: 91), a decrease in caregivers' own financial status, social relationships and health (Arber and Ginn 1990: 451; Ungerson 1995: 48; Davidson et al. 2000: 539), the continuous need to be ready and available, caring and staying awake as well as the increasing longingness for relaxation without any such concerns (Sointu 2011: 159, 170).

Conversely, elderly women's caregiving spans a continuum from lighter care to more strenuous caregiving, a role that has changed with time as the needs of care recipients grow. It seems likely that gendered and cultural expectations and attitudes inform the idea that women require less support in caregiving than men. As our study shows, the experiences of female and male caregivers may be similar, but the basic elements of everyday life are likely to be more difficult for women because of cultural, health and economic inequalities. As a cultural phenomenon, it has been noted that the care undertaken by men for women does strengthen men's self-esteem because of their pride in their own achievements, the

admiration of professionals and kin as well as the gratitude of the spouse (Davidson et al. 2000: 540, 546). However, care by women is perceived as what women 'do', which is considered a normal part of marriage (p. 545). As noted by Davidson et al. (2000: 551), another cultural phenomenon might be that women as care recipients are praised as 'good patients', and they feel guilty when they are not performing their tasks. However, the frustration of older men at their loss of good health may be manifested as 'very demanding behaviour', as described by their widows later on (p. 551).

Nordic citizens, including Finns, often remain in their own homes for as long as possible without necessarily being taken care of by their relatives or significant others (Vilkko et al. 2010: 62). According to Hämäläinen and Tanskanen (2014: 371), care is directed to helping families with children rather than those with ageing parents, and elderly persons who receive formal care usually also receive help from their relatives (see Fokkema et al. 2008; ref. Hämäläinen and Tanskanen 2014: 372). Hämäläinen and Tanskanen have maintained that this is why universal care services are still a necessity for elderly people (p. 371). In particular, there is a need to take account of elderly persons who do not have family around them to provide care or support or to apply for formal care on their behalf. Our study also showed that trust in care services is important; if a person feels confident about getting formal services when needed, the risk for exhaustion decreases. Thus, a functioning service system with reliable access to information can awaken trust, prevent the experience of exhaustion and support the well-being of caregivers. In worst scenarios, an urgent and demanding situation can occur when an older person, giving intensive care to, e.g., a spouse, experiences serious exhaustion. Social workers and other professionals often face situations in which both spouses suddenly require institutional care or intensive services from the public sector because of an escalated situation.

The results of our study have highlighted the need to ease the care burden of women who are approaching retirement. Women in Nordic countries continue to participate in working life, but there are no complementary provisions for taking care of their loved ones in a loving and caring way. In Finland, educated women may feel caught in a trap during old age even while trusting in the equality of citizens. If women become exhausted, this clearly weakens the support of care recipients. In building the future Finnish welfare state and national well-being, it should be noted that informal or voluntary care alone is not enough. It is virtuous and of utmost importance to take care of loved ones, but this cannot happen at the cost of the caregiver's health and ability to cope. Working life must be organised to take account of people's different life situations. Formal and practical support is needed on a universal basis but also with particular sensitivity to the gender and age of caregivers.

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