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Informal Care in the Light of Well-Being – the Case of Finland

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Vasa 12.4.2023

Sarah Åkerman

Abstract

The societal triumph in terms of increased life expectancy has, in combination with other development, contributed to an increased need for socially and financially sustainable care forms for older adults in Finland, as in many other parts of the Western world. An example of such a solution is informal care, that is, a formalisation of informal care where a close one with the help of public support services cares for care dependents who cannot manage on their own. The promotion of well-being of older adults is an important part of Finnish social policy. Macro-level decisions and local implementations affect well-being. Support services and benefits shape the prerequisites for coping in everyday life and subsequently experiencing well-being of older adults concerned with informal care. Simultaneously, well-being is a more complex and holistic phenomenon than only the outcome of welfare. Care is a relational and dynamic process, where norms and personal life stories are examples of factors that shape the experiences of how care services—and subsequently well-being—ought to be given or received.

This dissertation aims to study the informal care of older adults in light of well-being theories in a Finnish setting. In the first study, informal care recipients' care preferences and thoughts on the future were explored from a life course perspective. In the second study, well-being was investigated by applying the capability approach to dismantle an informal care dyad's care arrangements and consequences on well-being across time. In the third study, the caregiver stress process model was used to investigate associations between individual economic, social, and political resources and subjective caregiver burden among older spousal caregivers in the Bothnia region. The fourth study explored the feasibility of a co-designed intervention developed in line with the World Health Organization's Healthy Ageing paradigm with the aim of training former caregivers to become expert caregivers.

In studies 1 and 2, informal care recipients' experiences were explored based on data collected from semi-structured interviews with seven informal care recipients (Study 1) and follow-up interviews with the same respondents and their informal caregivers in Study 2. The results illustrated that the development of social care for older adults contributed to the care recipients' well-being in both direct and indirect ways. The informal care recipients appreciated living at home despite a declined functional capacity, and the offered support services promoted this ability to some extent. Simultaneously, the social care system sometimes acted as a barrier towards experiencing well-being. As an indirect effect, negative experiences and/or perceptions of formal care alternatives contributed to feelings of insecurity and uncertainty regarding future care arrangements.

In Study 3, multivariate logistic regression was used on data derived from the Gerontological Regional Database (GERDA) survey 2016 to study the associations between individual social, economic, and political resources and subjective caregiver burden among older spousal caregivers in Österbotten/Pohjanmaa (Finland) and Västerbotten (Sweden). About half of the spousal caregivers reported experiencing subjective caregiver burden, and this was slightly more common among Finnish-speaking caregivers. Frequent contact with family members indicated subjective caregiver burden, potentially meaning that frequent contact with family members is an indicator for intensive informal care. High levels of financial stress indicated subjective caregiver burden, while personal income did not. Out of the control variables, being Finnish speaking, reporting low perceived self-rated health and receiving formal support for informal care indicated subjective caregiver burden.

In Study 4, quantitative and qualitative methods were used to explore the feasibility of a co-designed intervention for former informal caregivers—a group that is largely overlooked in both research and policy. The participants took part in a training programme to become 'expert caregivers' for current caregivers. Partly due to the already existing infrastructure for social activities for informal caregivers and/or older adults in the region of Österbotten, the intervention was successfully implemented. The results showed that there was a demand for the intervention among former caregivers and a demand among current caregivers to take part in the support offered by the trained expert caregivers. The intervention created a social context for the expert caregivers, most of whom were bereaved widows/widowers.

The main conclusion of the thesis is that well-being of older adults concerned with informal care is highly complex and prone to change in terms of needs and resources. Both facilitators and barriers to well-being are interwoven in the Finnish welfare context. The results in this thesis imply that an extended view of informal care and the meaning of social relationships can lead to until now unutilized resources. To ensure that resources as well as needs are considered across different phases of informal care and among different target groups, the co-operation between different welfare actors is crucial. Well-functioning co-operation and development involving multiple welfare actors and citizens themselves form a solid foundation for successful interventions that promote well-being.

Keywords: *informal care, well-being, Finland, Sweden, life course, capability, caregiver stress process, caregiver burden, ageing, healthy ageing, intervention, feasibility*

Abstrakt

Den samhälleliga triumfen i form av en ökad förväntad livslängd har i kombination med annan utveckling bidragit till ett ökat behov av socialt och ekonomiskt hållbara omsorgslösningar för äldre i Finland såsom i många andra delar av västvärlden. Ett exempel på en sådan lösning är närståendevård, d.v.s. en formalisering av informell omsorg där en anhörig med hjälp av offentliga stödtjänster ger vård och omsorg åt vårdbehövande som inte klarar sig självständigt. Främjandet av välbefinnande bland äldre utgör en viktig del av Finlands socialpolitiska verksamhet. Politiska beslut på makronivå och lokala implementeringar i kommunerna påverkar välbefinnande. Stödtjänster och förmåner formar förutsättningar för att klara vardagen och därmed uppleva välbefinnande bland äldre som berörs av närståendevård. Samtidigt är välbefinnande ett mer komplext och holistiskt fenomen än enbart resultatet av välfärd. Omsorg är en relationell och dynamisk process, där normer och den personliga livshistorien är exempel på faktorer som kan forma upplevelserna av hur omsorg bör ges eller tas emot – och därmed välbefinnandet.

Syftet med denna avhandling är att studera närståendevård bland äldre i ljuset av välbefinnandeteorier i en finländsk kontext. I den första delstudien undersöktes närståendevårdtagares vårdpreferenser och tankar om framtiden med hjälp av livsloppsperspektivet. I den andra delstudien användes kapabilitetsteorin för att demontera en närståendevårddyads vårdarrangemang och dess konsekvenser för välbefinnande över tid. I den tredje delstudien användes närståendevårdares stressprocessmodell för att studera sambanden mellan individuella ekonomiska, sociala och politiska resurser och subjektiv närståendevårdarbörda bland äldre makar som ger närståendevård i Botniaregionen. I den fjärde delstudien studerades genomförbarheten och effekterna av en samskapad intervention som utvecklats i enlighet med Världshälsoorganisationens Hälsosamt Åldrande-paradigm med syfte att utbilda före detta närståendevårdare till att bli erfarenhetsmentorer.

I studie 1 och 2 undersöktes närståendevårdmottagares erfarenheter med fokus på vårdpreferenser och vårdarrangemang baserat på data insamlat från semistrukturerade intervjuer med sju närståendevårdmottagare (delstudie 1) samt uppföljningsintervjuer med samma respondenter och deras närståendevårdare i delstudie 2. Resultaten från studie 1 och 2 illustrerade hur utvecklingen inom äldreomsorgen bidrog till närståendevårdtagares välbefinnande på både direkta och indirekta sätt. Närståendevårdtagarna värdesatte att få bo hemma trots en nedsatt funktionsförmåga och de erbjudna stödtjänsterna främjade denna möjlighet till viss del. Samtidigt fungerade social- och hälsovårdssystemet ibland som ett hinder för att

uppleva välbefinnande. Som en indirekt effekt bidrog negativa erfarenheter och/eller föreställningar om formella vårdalternativ till känslor av otrygghet och osäkerhet gällande framtida vårdarrangemang.

I studie 3 användes multivariat logistisk regression på data från GERDA-enkätundersökningen 2016 för att studera sambanden mellan individuella sociala, ekonomiska och politiska resurser och subjektiv närståendevårdbörda bland äldre närståendevårdmakar i Österbotten och Västerbotten. Ungefär hälften av närståendevårdarna rapporterade att de upplevde subjektiv närståendevårdbörda och detta var något mer förekommande bland finskspråkiga närståendevårdare. Frekvent kontakt med familjemedlemmar indikerade subjektiv närståendevårdbörda, vilket potentiellt kan innebära att frekvent kontakt med familjemedlemmar är en indikator för intensiv närståendevård. En hög nivå av ekonomisk stress indikerade subjektiv närståendevårdbörda, medan personlig inkomst inte gjorde det. Av kontrollvariablerna indikerade finsk språkgruppstillhörighet, låg självskattad hälsa och formellt stöd för närståendevård subjektiv närståendevårdbörda.

I studie 4 användes både kvantitativa och kvalitativa metoder för att studera genomförbarheten i en samskapad intervention för före detta närståendevårdare – en grupp som till stor del är förbisedd inom både forskning och policy. Deltagarna tog del av ett utbildningsprogram för att bli ”erfarenhetsmentorer” för nuvarande närståendevårdare. Delvis på grund av den redan existerande infrastrukturen för sociala aktiviteter för närståendevårdare och/eller äldre individer i regionen Österbotten, kunde interventionen framgångsrikt implementeras. Resultaten visade att det fanns efterfrågan på interventionen bland de utbildade erfarenhetsmentorerna och en efterfrågan bland nuvarande närståendevårdare att ta del av erfarenhetsmentorernas stöd. Interventionen skapade en social kontext för erfarenhetsmentorerna varav de flesta var änkor/änklingar.

Avhandlingens huvudsakliga slutsats är att villkoren för att uppleva välbefinnande bland äldre berörda av närståendevård är mycket komplexa och föränderliga i termer av behov och resurser. Både möjliggörande och hindrande faktorer för välbefinnande är inbäddade i den finländska välfärdskontexten. Resultaten i avhandlingen tyder på att en vidgad syn på närståendevård och sociala relationers betydelse kan leda till hittills outnyttjade resurser. För att säkerställa att såväl resurser som behov tas i beaktande under närståendevårdens gång och bland olika målgrupper som berörs av närståendevård, bör samarbetet mellan olika aktörer inom välfärden fungera. Ett välfungerande samarbete och utvecklingsarbete som involverar olika välfärdsaktörer och medborgare själva skapar en god grund för framgångsrik verksamhet som stöder välbefinnande.

Nyckelord: *informell omsorg, närståendevård, välbefinnande, Finland, Sverige, livslopp, kapabilitet, stressprocessmodell, närståendevårdbörda, åldrande, hälsosamt åldrande, intervention, genomförbarhet*

List of articles

Study 1

Åkerman, S., Nyqvist, F. & Nygård, M. (2018). ”Man får hjälp då man behöver” - äldre närståendevårdtagares vårdval ur ett livsloppsperspektiv. *Gerontologia*, *32*(2), 102–114. https://doi.org/10.23989/gerontologia.66720

Study 2

Åkerman, S., Zechner, M., Nyqvist, F. & Nygård, M. (2021). Capabilities in care for older adults in Finnish familialistic policy transformations: a longitudinal one-case study. *International Journal of Care and Caring*, 5(2), 229–246. https://doi.org/10.1332/239788220X16065616064747

Study 3

Åkerman, S., Nyqvist, F. & Nygård, M. (2023). A cross-sectional study on the associations between economic, social, and political resources and subjective caregiver burden among older spousal caregivers in two Nordic regions. *Nursing Reports*, *13*(1), 365–377. http://dx.doi.org/10.3390/nursrep13010034

Study 4

Åkerman, S., Nyqvist, F., Coll-Planas, L. & Wentjärvi, A. (2021). The Expert Caregiver intervention targeting former caregivers in Finland: a co-design and feasibility study using mixed methods. *International Journal of Environmental Research and Public Health*, *18*(19), 10133. http://dx.doi.org/10.3390/ijerph181910133

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List of abbreviations

GDP	Gross Domestic Product
ICA	Informal Care Allowance
KELA	The Social Insurance Institution of Finland
NGO	Non-governmental Organization
NPM	New Public Management
SWLS	Satisfaction With Life Scale
SOC	Sense of Coherence
STEA	Funding Centre for Social Welfare and Health Organisations
STM	Ministry of Social Affairs and Health
THL	Institute of Health and Welfare
WHO	World Health Organization

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1. Introduction

1.1. Background

For the past some decades, informal care has been a hot topic in social and health care policy development throughout most of the Western world, partly because it has been seen as an inevitable solution to the increasing care demands of the rapidly ageing population (European Commission, 2021). Informal care, defined here as care provided by family members and friends (as opposed to employed [formal] professionals), is the core of any social and health care system in the world. However, the premises for and outcomes of informal caregiving may vary in different social policy systems. In Finland, there were about 350,000 informal caregivers in 2014 (Vilkko et al., 2014), and in 2021, about 50,000 informal caregivers received the national Informal Care Allowance (ICA) (Sotkanet, 2022). As for care coverage of Finns aged 65 and above, in 2018, 3% received informal care through the ICA, while 6% received regular[1] home care and 4% received institutional care (Sotkanet, 2022). In a recent comparison of European citizens aged 16–79, Finland was found to host the highest rate of informal caregivers (44%) but the lowest rate of intensive caregivers (5%), defined as those providing care for at least 11 hours a week (Verbakel, 2018).

Providing informal care is included as one of the dimensions of the Healthy or Active Ageing paradigm proposed by the World Health Organization (WHO) (2020; 2002). Informal caregiving may entail various positive experiences, such as personal growth and a deepened relationship with the care recipient (Pysklywec et al., 2020). However, providing intensive informal care is also related to various negative health outcomes such as for example depressive symptoms (Ekström et al., 2020; Adelman et al., 2014; Pinquart & Sörensen, 2003). Caregiving activities and their outcomes on well-being may be shaped by socio-demographic characteristics (WHO, 2020; Schulz et al., 2020; Adelman et al., 2014), but to what extent may vary within different welfare contexts. Finland, with its social policy legacy characterised by universal and gender-equalising social services, stands out as an interesting case in this respect (Szebehely & Meagher, 2018) as theoretically, informal caregiving activities and outcomes should not depend on sociodemographic factors in a welfare context characterized by universalism.

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[1] Receiving regular home care is at the time of writing this defined as receiving publicly organised home-help services, home nursing or day hospital care at least once a week (Institute of Health and Welfare [THL], 2023a).

This thesis emphasises the Finnish context of informal care. Additionally, Sweden was included in one of the studies for comparison. Finland and Sweden share many similarities in terms of welfare state characteristics and policy trends in care for older adults in a larger international comparison (e.g. Szebehely & Meagher, 2018), but there are also differences. One example is the development of marketisation mechanisms, where the rate of for-profit actors in the sector developed later in Finland (Meagher & Szebehely, 2013), but it has increased rapidly during the twenty-first century (Szebehely & Meagher, 2018). Lowered public coverage of services has been argued to weaken the principle of universalism and increase the reliance on family members in both countries (Szebehely & Meagher, 2018; Karsio & Anttonen, 2013). An increasing reliance on family members is not only an indirect consequence of the greying population but also an explicit policy objective, as the aim in Finland is to increase the proportion of older adults receiving informal care by a close one through the ICA (Ministry of Social Affairs and Health [STM], 2019). Most informal caregivers who receive support through the ICA provide intensive care equivalent to institutional care (ibid.).

Informal care research and policy tend to focus more on the active caregiving phase and less on the post-caregiving phase. Previous international research examples have suggested that former caregivers may experience a loss of important identities and connections when the caregiver role ends (Corey & McCurry, 2018; Larkin & Milne, 2017), but also that most former caregivers recover from negative health symptoms associated with caregiving within two years (Tsai et al., 2016; Kuo et al., 2019). More research is needed on both the needs and resources of former caregivers, as they constitute a significant proportion of the population due to the high number of informal caregivers.

1.2. Previous research and the contribution of this thesis

In this section, I summarize the current state of informal care research and then explain the contribution of this thesis. Since informal care has been studied quite extensively both in Finland and internationally, I will limit this subchapter to research that can be seen as relating to well-being among older adults concerned with informal care in Finland published from 2010 onwards.

In 2014, two national mixed-method reports investigating the situation of informal caregivers encompassed by the national ICA were published. The results of the first report, published by The Social Insurance Institution of Finland (Kela), showed, among other things, that there were local differences in care allowances and eligibility criteria for becoming an informal caregiver and that central government-funded grants for informal care were sometimes not allocated to informal care in practice. The results also revealed that without the ICA, informal caregivers had a lower annual income than the average population. Moreover, two-thirds of the informal care recipients had care needs equivalent to institutional care (Tillman, Kalliomaa-Puha & Mikkola, 2014). The other report, launched by THL (Linnosmaa et al., 2014), pointed out the need for nationally standardised eligibility criteria for the ICA while simultaneously highlighting the need for a diversification of informal caregiver support as each caregiving context is unique. The results of the report also showed that only about half of the caregivers used their right to statutory holidays despite providing intensive care. Linnosmaa et al. (2014) found that about 26–46% of informal care recipients had care needs equivalent to institutional care. The results also showed that more than one-fifth of ICA applications were rejected, some of them because of a lack of municipal financial resources.

In 2019, a national report (STM, 2019) concluded, among other things, that informal care was becoming more common in all age groups, particularly older people. The most typical informal caregiver encompassed by the ICA was an older woman. The findings also showed regional differences in the ICA coverage in Finland. Municipalities were increasingly offering a variety of support services, such as health examinations and training courses for informal caregivers. However, despite increasing support services and respite care alternatives for informal caregivers providing intensive care, about half of them continued not to use their rights to days off. The results also showed that cognitive decline as the main reason for needing care was becoming more common among informal care recipients encompassed by the ICA (ibid.). Providing informal care to someone with cognitive decline is generally considered the most burdensome care context (Adelman et al., 2014; Schulz et al., 2020).

Recent Finnish studies using register data found that informal caregivers encompassed by the ICA were more likely to use antidepressants than non-caregivers (Mikkola et al., 2021a); however, informal caregivers' all-cause mortality rates were lower than for non-caregivers (Mikkola et al., 2021b). The researchers interpreted these results as ICA-caregivers in Finland experiencing negative impact on their mental health, but that individuals who became ICA-caregivers were generally in good health.

In an international qualitative study including informants from Finland, Slovenia and Austria, Van Aerschot and colleagues (2022a) found that unmet needs among community-dwelling older adults and their informal caregivers were largely psychosocial to their nature. The lack of personal relationships with care workers and scarce opportunities for developing other social contacts created unmet psychosocial needs and led to excessive responsibilities for the community-dwelling adults and their informal caregivers.

In a recent study on Finnish spousal caregivers providing care to someone with memory disorders (Eskola et al, 2022), the results showed that the spouses were the ones who first noticed symptoms and behavioural changes caused by memory disorders. The researchers used the social exchange theory as a theoretical framework and the analysis showed that the opportunities for reciprocity were decreased due to the care recipient's behavioural symptoms. The emotional bonds and shared history made the caregiver stay in the relationship despite the lack of reciprocity.

In a qualitative study on Finnish older adults with memory disorders and their spousal caregivers, the analysis showed that the informal caregivers and their close one experienced inadequacy in the support received (Van Aerschot, Eskola & Aaltonen, 2021), The informal caregivers were more dissatisfied with the services than their next of kin. The informal caregivers were forced to compensate for the lack of inadequate support, with their own coping at stake.

Finland has also been included in comparative international quantitative studies on informal care. As mentioned in the introduction, Finland was found to host the highest rate of informal caregivers (44%) but the lowest rate (5%) of intensive caregivers in a European study of respondents aged 16–79 (Verbakel, 2018).[2] Similarly, other comparative studies have found that Finnish informal caregivers tend to provide less intensive care as Finnish care recipients enter alternative care forms at earlier stages than in the other studied countries (Bleijlevens et al., 2015; Verbeek et al., 2015; Konerding et al., 2018). A few studies have also examined cultural differences in subjective caregiver burden (Konerding et al., 2018; 2019). One study comparing informal caregivers in Finland, England and Greece found that Finnish caregivers were more likely to experience subjective caregiver burden related to conflicts regarding the reconciliation of care duties and social life, while Greek caregivers were more likely to express subjective caregiver burden in terms of impairments in their physical health (Konerding et al., 2019). English caregivers were more likely to report subjective caregiver burden related to their individual well-being (ibid.).

Several doctoral theses using mainly qualitative methods to explore the everyday lives of older adults concerned with informal care have been published in Finland since 2010. In Ulla Tikkanen's monography on political science (2016) where figurational sociology was applied as a theoretical

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[2] International studies suggesting that informal care in general is of low intensity in Finland is contradictory to national studies and doctoral theses exploring the situation of informal caregivers encompassed by the ICA. This can be explained by the variation in how informal care is defined. Depending on its definition, informal care can refer to everything from light, occasional help to 24/7 live-in care.

framework, various qualitative methods were used to explore human and material bonds. Tikkanen's (2016) research contributed to understanding informal care as an inter-relational experience consisting of human and material bonds both between the caregiver and care recipient, but also with other care workers and the home itself through for example assistive devices. The results showed that when care needs became overwhelming, the caregiver felt like a prisoner in the home. Gradually losing the spouse was depicted as the caregiver simultaneously losing central contents of life itself. Easing the burden of the caregiver was enabled by discretion, empathy and respect shown by other family members, care workers and service gatekeepers.

In Liina Sointu's (2016) monography on social policy, narrative methods were used to analyse relational agency among older spousal caregivers. The results showed that the spousal caregivers were constantly performing caregiving activities merely by being in the relationship. Caregiving involved thinking, feeling, sensing and remembering – and did not only constitute motivation for caregiving but were caregiving activities themselves. To endure the constant caregiving, it was important for spousal caregivers to have a break and enjoy space for themselves. Sointu (2016) concluded that in her research, caregiving as a relational activity was experienced as a personal responsibility in the context of an already established relationship and shared everyday life. Therefore, services should be sensitive to personal and relational needs, and a good life presumed mutual relationships, shared care and structures.

Marjo Ring (2021) investigated psychological contracts among Finnish spousal caregivers and their care recipients in her doctoral thesis in social sciences and business studies. The results showed that legislation and political discourse concerning informal care created expectations of reciprocity that were not met in the actual support received among informal caregivers. Ring (2021) pointed out how the current support system in Finland failed to incorporate both the care recipient and the caregiver as co-clients. Instead, the care recipient was given the main role in the service system. The informal caregivers perceived the support they received as inadequate but provided care regardless. Their motivation for doing so was based on psychological contracts between the caregiver and the spouse – rooted in emotions and moral perceptions. The caregiver and care recipient formed a single, shared reality in informal caregiving which was beyond political discourses and legislation. Nonetheless, adequate support could have made caregiving less emotionally and psychologically straining.

Minna Zechner (2010) used qualitative methods in the five original articles included in her doctoral thesis in social policy. Inspired by previous Nordic and British research on care, Zechner (2010) dealt with connections between care and social policy. She divided the connections between care and social policy into three main streams of thought: politicising informal care, formalising informal care and globalizing informal care. These three streams referred to how informal care was viewed as a personal, private activity with societal value (politicising informal care), how informal care was formalised through support services and benefits (formalising informal care) and finally, how informal care was interlinked to social policy by being globalized either through immigrant care workers, international care companies or informal caregivers providing transnational care (globalising informal care). The different connections between social policy and care affected the interviewees' trust, negotiations, and everyday lives in a (mainly) Finnish context.

This doctoral thesis builds on previous research that has visualised and explored the ways care and social policy are interlinked in informal care of older adults. In this thesis, informal care is studied in the light of well-being in and placed in a Finnish context, where macro, meso and micro mechanisms are included (this conceptualisation is further presented in chapters 2 and 3). The life course perspective (Elder, Johnson & Crosnoe, 2003), the capability approach (Sen, 1979), the caregiver stress process model (Pearlin et al., 1990) and the Healthy Ageing paradigm (WHO, 2020) are used to shed light on different aspects of well-being. The thesis adds knowledge both empirically and methodologically by exploring different angles of informal care in terms of caregivers', former caregivers', and care recipients' perspectives and by using both qualitative and quantitative methods. Most previous research on informal care in Finland and internationally has focused on caregivers, and therefore, the inclusion of care recipients and former caregivers widens the understanding of informal care. One of the studies includes data from two Nordic regions, which has rarely been done before in research on informal care.

The first two studies add important empirical findings from the perspective of care recipients. In the first study, the life course perspective was used to investigate care recipients' care choices and thoughts on future care arrangements. The second study contributed to the research on informal care not only empirically but also methodologically, as a qualitative longitudinal method was used with the capability approach as a theoretical framework to dismantle the care arrangements into micro, meso, and macro mechanisms across time. The study explored the care recipient's well-being by adapting a dyadic approach, where also the caregiver's well-being was seen as a mean to achieve a life with meaningfulness. The third study drew on previous research on informal caregiver well-being to investigate the role of individual economic, social, and political resources for subjective caregiver burden based on survey data collected in the Bothnia region in Finland and Sweden. While the resources assessed the caregiver's situation, one indicator could be seen as capturing the situation of the household which adds an important dyadic perspective on the relationship between individual resources and subjective caregiver burden. Further, a novel approach was used by juxtaposing the role of political resources with that of economic and social resources. The study also included an ethnolinguistic division of the respondents, which has rarely been done in Finnish research on informal care. The data included both informal caregivers covered by ICA and caregivers who were not covered by ICA, which is another contribution to quantitative research on informal care among older adults in Finland. In Study 4, mixed methods were used to assess the feasibility of a co-designed intervention targeting former caregivers in Finland—a target group whose experiences have been largely understudied so far.

1.3. Aim and research questions

The overarching aim of this thesis is to contribute to a nuanced understanding of informal care among older adults from a well-being perspective with a particular focus on the Finnish context.

To achieve this aim, we posed the following research questions:

1. a. How do older informal care recipients choose and manage their care arrangements? (Articles I and II)
   b. What kind of factors hinder or facilitate the care arrangements? (Article II)
   c. What are the consequences on informal care recipients' subjective well-being? (Articles I and II)

2. a. What is the extent of subjective caregiver burden of older spousal caregivers in the Bothnia region, and are there regional differences in the Bothnia region? (Article III)
   b. What are the associations between economic, social and political resources and subjective caregiver burden? (Article III)

3. a. How is an intervention focusing on peer support utilising previous experiences of informal caregiving experienced by the participants? (Article IV)
   b. What is the demand for such an intervention, and how can it be successfully co-designed in the region of Österbotten, Finland? (Article IV)

1.4. Structure of the thesis

Chapter 1 introduces the topic of informal care of older adults in a Finnish welfare context, presents previous research and the contribution of this thesis and outlines the aim and research questions.

In Chapter 2, I present the key concepts of this thesis—care and well-being. In Chapter 3, I contextualise the topic of informal care and well-being by outlining the demographic, social, economic, and political developments in Finland. In Chapter 4, I present the data and methods used in the four original studies. In Chapter 5, I present the main findings in relation to the thesis's research questions. In Chapter 6, I provide the main conclusions of the thesis, discuss methodological strengths and limitations and finally, present policy implications and future research ideas.

2. Key concepts

In the following subchapters, I provide examples of how care has been defined and conceptualised theoretically in research. In Subchapter 2.1.2, I move on to present how care is defined in Finnish social policy. These subchapters add an understanding of what care may entail as a lived phenomenon in everyday life for people concerned with care, in comparison to how the state defines its care responsibilities towards its citizens. Care as a lived phenomenon and care as a political construct are interlinked, but care as a political construct does not capture the entire essence of what care may entail. These connections and discrepancies offer an interesting lens for discussing informal care in the light of well-being. Well-being is the second key concept of the thesis and is presented divided into two subchapters covering a general overview (2.2.1) and a presentation of the four well-being theories used in the original studies (2.2.2). This chapter ends with a figure that visualises how informal care and well-being is placed in a societal context in this thesis.

2.1. Care

2.1.1 Theoretical conceptualisations

The English word 'care' is defined as *the process of protecting someone or something and providing what that person or thing needs* (Cambridge Dictionary, n.d.). The English phrase thus entails both the more encompassing social dimension of care that is part of everyday life (in Swedish called 'omsorg' and in Finnish 'hoiva') and the more medically sounding Swedish term 'vård' (in Finnish 'hoito'). In Swedish language, 'omsorg' can be defined as *(noggrann och kärleksfull) vård och skötsel av någon el. något* (Svensk Ordbok, 2021a), while 'vård' is defined as *tillsyn förenad med viss behandling särsk. av svaga el. sjuka personer i syfte att uppehålla livet el. bota* (Svensk Ordbok, 2021b). Thus, the former term is described as an activity, motivated by love and carefulness, that can be done to someone or something regardless of condition, while the latter refers to frail people with a more curing or treating purpose. This chapter concentrates on the former term 'omsorg', although the differences between 'omsorg' and 'vård' are sometimes vague in this context, as elements of the more medically oriented vård can also be included in informal care. Both forms of care are mentioned in the act on ICA (2005/937). Nonetheless, this thesis, especially this chapter, concentrates on care as 'omsorg'.

Care is an important research topic for welfare regime theorists looking into how care responsibilities are shared and allocated in different welfare mixes of public, private and voluntary sectors (Daly & Lewis, 2000; Saraceno & Keck, 2010; Saraceno, 2016; Bettio & Plantenga, 2004). Even in the Nordic welfare model, where universalism is a key principle (Szebehely & Meagher, 2018), care for older adults has always been shared between different sectors. The division of responsibilities, however, differs depending on the time point of study due to a range of factors, such as demographic, economic, social and political developments.

Sometimes the allocation of care is approached in research through dichotomizations of for example private vs public settings, or in informal vs formal settings (Daly & Lewis, 2000; Bettio & Plantenga, 2004). The different spheres are however often interlinked, as for example the state's responsibilities can be allocated to other actors by for example offering public grants or by offering citizens service vouchers for purchasing care from the market. In this way, the lines between the state and the market, the private and public, or informal and formal, are not always clear. This is also the case in informal care among older adults in Finland, where the ICA blurs the lines between informal and formal care, as informal care takes places (usually) in the home between close ones, but formal arrangements such as care allowances, agreements and respite care are included. In this way, the ICA can be seen as introducing social rights for caregiving family members (Pfau-Effinger, 2005), as the state acknowledges not only an obligation to support its citizens in need of care but also those who provide care. This development of the ICA is further detailed in Subchapter 3.4.

Bernice Fisher and Joan Tronto (1990 through, Tronto, 1993; 2017) define care as broadly an *activity that includes everything that we do to maintain, continue and repair our 'world' so that we can live in it as well as possible*. Their conceptualisation of care is rooted in moral philosophy, where virtues associated with care, such as solidarity, responsiveness, and trust, are seen as the foundation of human life. With such a wide definition of care, care is viewed as a process that is meant not only for those who are frail and dependent but also as a constant process and as something we are constantly in need of from each other and from ourselves (Tronto, 2017). While Fisher and Tronto (1990, through Tronto, 1993; 2017) view care as an interactive process, other strands of care research rooted in feminist studies have aimed to scrutinise care into specific activities and distinguish the caregiver and the care receiver. Care research developed in the 1980s mainly as an effort to shed light on women's position in society by highlighting the amount of (unpaid) work women do for their homes and families (and for society) (e.g. see overviews in Ulmanen & Szebehely, 2015; Zechner, 2010; Anttonen & Zechner, 2009; Waerness, 1984). Norwegian sociologist Waerness (1984) distinguishes between different types of care depending on the care recipient. When care is given by women to adult children and husbands who can perform these activities themselves, the activities should be called personal services rather than care, but when care is given to someone dependent and frail, it is actual care work that requires care rationality. Care rationality involves both emotional and practical work (ibid.). Care work can also be divided into dimensions other than practical and emotional, such as intellectual care work (James, 1992). Practical care work is the most visible type of care, including household work and bodywork, while emotional and intellectual work is less visible. Emotional work is about dealing with emotions, listening, and supporting but also reminding and motivating the care recipient. The intellectual part of care work involves activities, such as taking care of bills but also organising and administrating care. This part of care often involves many contacts and negotiations with other care providers, both formal and informal, to create encompassing care coverage of all the different needs of the care recipient (ibid.).

While feminist researchers contributed to putting care and women's position in society on the research agenda, they were also criticised for neglecting the care recipients' point of view (e.g. Morris, 1997). By portraying care as (demanding) work and by focusing on the experiences of those giving care, care-dependents risk being viewed as passive and invisible objects rather than as active subjects. Research including the perspective of care recipients (e.g. Twigg, 2000) has illustrated care recipients' active agency in terms of managing complex power dynamics and emotions in encounters with formal care workers.

The conceptualisations of care and the examples of research orientations presented above reflect only a fragment of care as a research field. While care theories were not explicitly used in any of the original studies of this thesis, an understanding of what care may entail in the everyday lives among those concerned with informal care, and its relational and emotional dimensions can serve as a useful lens when interpreting the findings in this thesis as well. This will be further discussed at the end of this thesis, where the main conclusions are discussed (Chapter 6). Next, we will look at how care is conceptualised in social policy in Finland.

2.1.2. Care in Finnish social policy

The welfare system in Finland is usually categorised as a Nordic welfare model (Nygård, 2013), meaning, among other things, that citizens are entitled to publicly organised care according to need rather than the ability to pay. At the time of the data collection for this thesis, local municipalities[3] were responsible for organising social and health care services regulated by national legislation in Finland. According to the Social Welfare Act 710/1982, the aim of social services is to promote and sustain the individual's, family's

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[3] The responsibility for organising these services were transferred from municipalities to well-being service counties in 2023 in Finland.

and community's functional capacity, social well-being, safety and participation and to decrease inequality. Since 2012, Finland has had a specific act regulating services for older adults (Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons [Eldercare Act], 980/2012). It is stated in the act, among other things, that services for older adults should be of good quality and provided at the right time and that services should support independence and functional abilities (ibid.).

While older Finns are entitled to social and health care services promoting social well-being (Eldercare Act 980/2012), the social dimension of care has decreased (Kröger & Leinonen, 2012) creating unmet social needs among older adults and their informal caregivers (Van Aerschot et al, 2022a). Since 2013, institutional care can no longer be granted for social reasons but only on medical grounds (Eldercare Act 980/2012). Time for social interaction in publicly organized home care has decreased, as the number of clients per day in home care has increased between 2005 and 2015 in Finland (Kröger, Van Aerschot & Mathew Puthenparambil, 2018). With the help of public support, non-governmental organizations (NGOs), churches and municipalities organize social support and peer support groups for different target groups of older adults in Finland (STM 2019; 2020). Such initiatives can be interpreted as the state acknowledging needs for social support but choosing to provide such support in a less standardized manner than in the case of physical or medical needs. Similarly, services such as cleaning and other household work have been almost completely excluded from public home care (Kröger & Leinonen, 2012) and must be met by informal sources of care or by private service providers instead. Referring to the care conceptualisations mentioned in Subchapter 2.1.1, we can thus conclude that there is variation in which parts of care that are acknowledged as the Finnish state's responsibility and to what extent. Care activities aiming to support autonomy and functional capacity are currently prioritised (Eldercare Act, 980/2012), while for example administrative care is rather invisible in Finnish policy, despite a development in care that requires increasing amounts of administrative caregiving activities (Zechner, 2017; Kröger, 2019). The pathway from experiencing care needs to having needs met may require individual resources, for example cognitive, social, and financial (Anttonen & Häikiö, 2011). This development and its possible consequences for care recipients' and informal caregivers' well-being will be further discussed in chapter 3. Next, we move on to present the concept of well-being.

2.2. Well-being

2.2.1. Well-being as a general concept

One of the main goals of social policy is to provide citizens with the necessary means to experience well-being (Nygård, 2013). Well-being is, however, a complex phenomenon that can cover many underlying concepts (Searle, Pykett & Alfaro-Simmonds, 2021). Previously, along with economic development in the nineteenth century, well-being largely focused on macro-level economic metrics (Nygård, 2013). During the second half of the twentieth century, citizens' levels of standard of living were increasingly assessed on the micro-level, and the scope of well-being began to include not only economic metrics but also other indicators such as health and social resources. During the 1970s and onwards, the research field on well-being became increasingly influenced by sociological and psychological traditions, which resulted in an interest in more subjective dimensions of well-being (ibid.).

A key distinction between different theories of subjective well-being is that of hedonic and eudaimonic philosophical traditions, where the former views well-being as pleasure and the absence of pain, while the eudaimonic philosophy underlines the role of meaningfulness and purpose as crucial for well-being (Forgeard et al., 2011). The eudaimonic tradition generally views well-being as a process rather than an outcome or end state (Deci & Ryan, 2008). Closely related to the hedonic and eudaimonic distinctions are the emotional and cognitive dimensions of subjective well-being (Pavot & Diener, 1993). Emotional well-being refers to positive emotions and/or the absence of negative emotions, while the cognitive dimension measures an individual's judgement of her or his life conditions in relation to her or his own specific criteria of what is important (Pavot & Diener, 1993). Cognitive subjective well-being is assessed in for example Diener's life satisfaction scale (ibid). While there are individual, cultural, and perhaps age-cohort differences in life satisfaction, Diener (2006) concludes that for most people, a high level of life satisfaction generally presumes at least close social relationships, paid or unpaid work that feels meaningful and important, and personal sources of satisfaction deriving from religious life, learning and growth and leisure.

While Diener (2006) seems to depart from the notion that certain domains in life need to be fulfilled to experience high levels of life satisfaction, sociologist Aaron Antonovsky (2012) theorised that an individual's sense of coherence (SOC), is about how meaningful, comprehensible, and manageable an individual's life circumstances are experienced. An individual's SOC is affected by the amount of available generalised resistance resources (intrinsic and extrinsic) available (ibid). Examples of generalised resistance resources include spirituality, social networks, and financial resources. In this way, individuals in similar life circumstances may experience different levels of

SOC, and individuals in harsh life circumstances may still experience SOC (ibid.).

The psychological tradition of subjective well-being has developed scales and conceptualisations of well-being based on earlier psychological theories, such as life span development, personal growth, and positive mental health (see overview in Forgeard et al., 2011). In the psychological tradition, well-being can include domains such as self-acceptance, autonomy and purpose in life, or human flourishing entailing positive emotions, engagement, and achievement (ibid). Attempts have also been made to specifically explain well-being, or burden, among informal caregivers. An example of such a psychological theory is the caregiver stress process model theory (Pearlin et al., 1990), where informal caregiving is seen as a multidimensional stress process consisting of, amongst other things, subjective and objective stressors related to the caregiving context. This theory is further presented in the following subchapter.

Partly due to the ageing populations, policy frameworks have been developed to promote the well-being of older adults, and this has led to different conceptualisations of what well-being in specifically old age may entail. Old age itself entails both challenges and resources in comparison to other stages in life (Näsman, 2021). A leading paradigm in the context of well-being in old age is that of successful, active and/or healthy ageing (Bowling, 2007; Foster & Walker, 2015). The United Nations has recently declared the Decade of Healthy Ageing (2021–2030) and the Global Action Plan (WHO, 2020). At the core of active and/or healthy ageing frameworks is the discourse that old age is more than losses and disabilities (Foster & Walker, 2015; WHO, 2020; 2002) and that older adults should strive to stay active and integrated in society. Different models of successful, active and/or healthy ageing have been developed, with some conceptualisations and/or assessment tools being more psychological, social, or biological. Well-being is usually included in psychosocial models, for example, by measuring life satisfaction (Bowling, 2007).

In the context of informal care, we can assume that there are both barriers and facilitators to experiencing well-being and that there is variation in these factors depending on the target group and the dimension of well-being assessed. Objective indicators typically measure the health status and/or functional capacity of the care recipient and/or the hours spent caregiving (Pearlin et al., 1990). Such indicators are commonly used to track inequalities by for example analysing whether care needs and/or use differ according to educational level, gender and/or country (Schulz et al., 2020; Verbakel, 2018; 2014). Subjective well-being in informal care is perhaps more complex to grasp than objective well-being. For example, the caregiver may experience caregiving as a meaningful activity (Pysklywec et al., 2020) but simultaneously be deprived of the capability to enjoy other activities (Tikkanen, 2016). Thus, informal caregiving may contribute to eudaimonic well-being, but hinder hedamonic well-being. Some aspects of subjective well-being may be more shaped by the objective health status of the care recipient, the caregiving context and available support, while others may be more related to intrinsic factors such as personality traits. By combining both subjective and objective dimensions of well-being, and various methods, accumulated evidence can not only contribute to knowledge gaps in research but also guide policymakers to better support well-being among those concerned by informal care.

This thesis aimed to shed light on subjective and objective aspects of well-being by using four different well-being theories in the original studies of this thesis. The theories used were the life course perspective, capability approach, caregiver stress process model and the WHO's Healthy Ageing paradigm. In the following subchapter, I present the theories used in the original studies as well as an illustrative figure that visualises the contribution of this thesis to research on well-being in informal care.

2.2.2. Well-being theories used in the original studies of this thesis

The well-being theories used in this thesis were chosen to highlight specific aspects of well-being that were deemed especially relevant considering the target group (informal care recipients, informal caregivers, and former informal caregivers) and the chosen data method. Instead of using the same theory to compare the same well-being aspects in different target groups, or by using different methods, I chose to use different theories to highlight various aspects and nuances of well-being. All theories were applied in such a manner that the results could be related to the societal context, although some theories allowed for this contextualisation to a greater extent than others. Next, I will present the chosen theories.

In Study 1, the life course perspective (Elder, Johnson & Crosnoe, 2003) was used in the analysis of older informal care recipients' care preferences and thoughts on future care arrangements. According to Elder, Johnson and Crosnoe (2003), there are five important principles to acknowledge when using the life course perspective: ageing and/or development should be seen as a part of *life span development*, where an individual acts and makes choices within a particular historical and social context of opportunities and restrictions (*agency*). An individual is affected by *time* and *place* and the *timing* of important life events. A fifth and final remark is the notion of an individual's life as interlinked with other lives (*linked lives*) (ibid.). While the life course perspective is not a well-being theory per se, it enabled visualising how the personal life story and the shared life story, together with the caregiver, contributed to subjective aspects of well-being interwoven in the care arrangements and preferences. The life course perspective also allowed for analysing the role of the formal care system for the care recipient's agency and, thus, ultimately, subjective well-being.

In Study 2, the capability approach (Sen, 1979; Nussbaum, 2000; Robeyns, 2016) was used to track the care arrangements and well-being of one informal care recipient across time. According to this influential, holistic well-being framework focusing on subjective perceptions of a meaningful life (Nygård, 2013), attention is placed on the actual opportunities that individuals have to live the kind of life that they value. Central in the capability approach are the mechanisms (called conversion factors) mediating the processes from resources to actual capabilities, and the interlinks between achieved functionings and available opportunities (capabilities). According to Sen (1979), the meaning of a good life is individual, while Nussbaum (2000) listed ten central capabilities needed for any life of human dignity. In Study 2, we adapted Sen's (1979) capability approach and explored the care recipient's valued capabilities and the pathways towards these goals. The capability approach can be seen as relevant to studying care arrangements among older adults as it moves beyond formal rights to care to actual realised (or unrealised) functionings. The conversion factors mediating the processes can be divided into macro, meso and micro levels to achieve a nuanced understanding of the pathways from resources to functioning (Hvinden & Halvorsen, 2018). In Study 2, the conditions for experiencing well-being were investigated by scrutinizing the care arrangements into macro-, meso- and micro-level mechanisms.

In Study 3, the caregiver stress process model (Pearlin et al., 1990) was used as a theoretical framework to explore the associations between individual resources and subjective caregiver burden[4] among older spousal caregivers in two Nordic regions. The caregiver stress process model (ibid) is a psychological theory that combines subjective and objective dimensions of a caregiving situation and its potential outcomes. According to this theory, caregiving can be seen as a stress process consisting of primary and secondary stressors, or objective and subjective stressors. The former consists of stress infused by the characteristics of the caregiving situation, such as the condition of the care recipient, care intensity and available resources. These primary or objective stressors lead to secondary stressors of subjective experiences of the situation that can cause more stress, such as worry about not managing as a caregiver or not having enough time for oneself, to name a few potential secondary stressors. This process, affected by mediators throughout the process, leads to certain outcomes, such as effects

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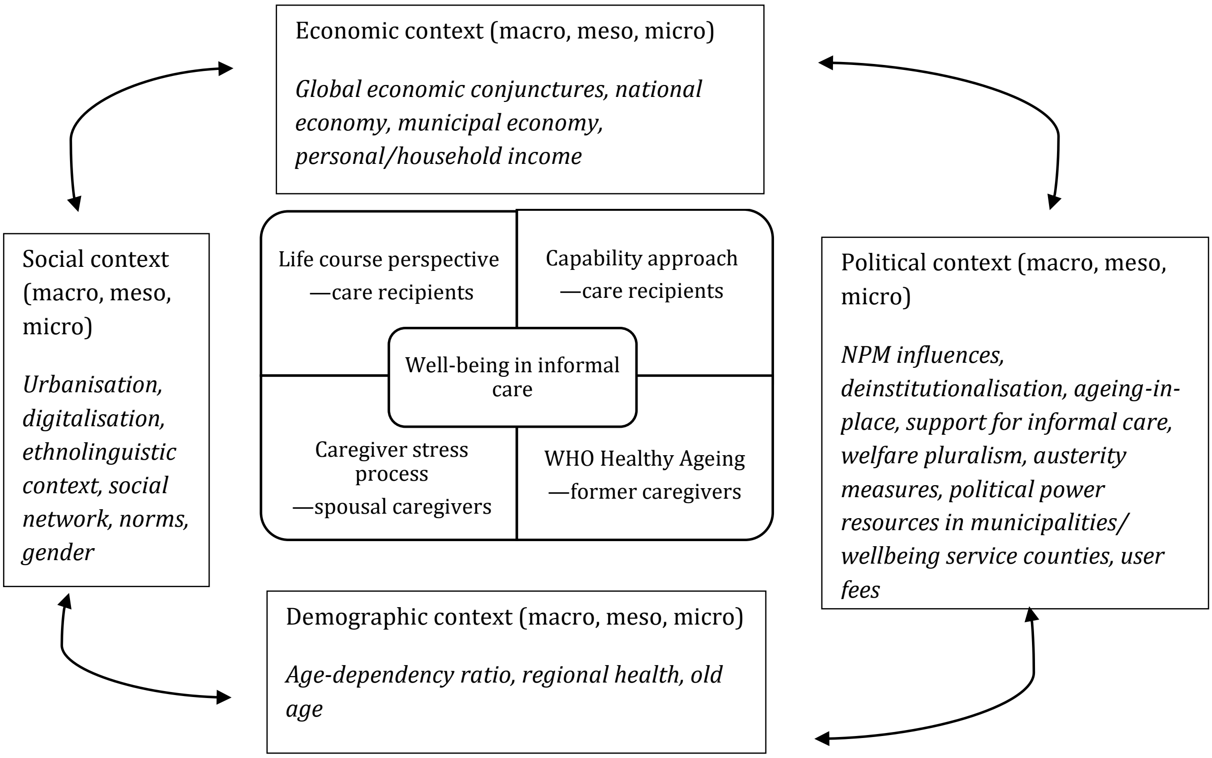
[4] Subjective caregiver burden is a state characterized by stress, fatigue, and altered self-esteem caused by the negative effects of caregiving (Elmståhl, Malmberg & Annerstedt, 1996; Zarit, Reever & Bach-Peterson, 1980).

on health or dropping out of the caregiver role (ibid.). As already mentioned, the theory combines subjective and objective dimensions, which is a fruitful way of encompassing well-being (Forgeard et al., 2011). While it has been argued that an informal caregiver's well-being is beyond the impact of caregiving (Verbakel, 2014), caring for a dependent spouse can also be seen as a specific life situation where aspects of well-being are most feasibly captured in a theory explicitly developed to explain that experience. Therefore, using a theory developed for informal caregivers was deemed feasible in Study 3.

In Study 4, an intervention targeting former caregivers was developed in line with the WHO's Healthy Ageing paradigm (2020). The WHO's Healthy Ageing policy framework, previously called Active Ageing (WHO, 2002), is a strategy aiming to support the well-being of explicitly older adults by strengthening the opportunities to remain active and participate in society for as long as possible. Through supported functional abilities, older people are enabled to be and do what they value, which is a clear reference to the capability approach. The WHO (2020) defines 'Healthy Ageing' as *having the functional abilities to meet (their) basic needs; learn, grow and make decisions; be mobile; build and maintain relationships; and contribute to society*. This rather normative paradigm guided the content of the intervention targeting former caregivers, mainly bereaved spouses. Given that informal caregivers providing intensive care may risk social isolation (Van Aerschot et al, 2022a; Sointu, 2016; Tikkanen, 2016), it is important to consider the situation of former caregivers when the caregiving situation ends. This will be further discussed in chapter 3. The WHO Healthy Ageing paradigm has been considered better suited for older adults who have not yet reached very high old age or physical decline (Fritzell, Lennartsson & Zaidi, 2021), and consequently this framework could be seen as applicable to an intervention aiming to train and recruit volunteers. Older volunteers generally represent a pool of healthy individuals in comparison to non-volunteering peers (e.g. Musick, Herzog & House, 1999).

In this thesis, informal care and well-being are contextualised in a Finnish setting. In a similar manner as the multi-dimensional model proposed by Broese van Groenou and De Boer (2016), where they conceptualise how macro-, meso- and micro-level mechanisms affect the choice to become an informal caregiver, informal care and well-being are placed in a multi-dimensional societal context in this thesis. The societal context, divided here into four subdimensions (demographic, social, economic, and political), will be further elaborated on in the following chapter. In Figure 1, I have visualised how the applied well-being theories contribute to an understanding of informal care in a societal context.

Figure 1. *Informal care in the light of well-being in a societal context.*



3. Contextualising informal care in the light of well-being

In the following subchapters, I outline demographic, social, economic, and political development that form a context for studying informal care in the light of well-being. Almost all respondents in studies 1, 2 and 4 were born in the 1930s and 1940s (Study 4 also included two younger respondents), while the respondents in Study 3 were born in 1930, 1935, 1940, 1945 and 1950. When appropriate, the development is outlined on macro (national or international), meso (municipal or regional) and micro (individual or social network) levels, although the distinctions between the levels are sometimes blurred. Similarly, demographic, social, economic, and political developments are often interlinked as well. Nonetheless, the chapter presents a brief overview of societal development that can be seen as affecting the conditions for experiencing well-being among older individuals concerned with informal care.

3.1. The demographic context

The financing of the Nordic welfare model presumes high rates of labour force participation (Nygård, 2013). Finland is, however, one of the countries with the most rapidly ageing populations in the world (THL, 2023b). The Finnish age dependency ratio[5] of 62 years (World Bank, 2020) in combination with decades of low birth rates (World Bank, 2022) makes care of older adults a question of both social and financial sustainability, as pension costs, care needs and costs are expected to increase while the numbers of working-aged taxpayers and caregivers (both informal and formal) decrease. This unfavourable demographic development is often used as a political argument to make cuts in social care for older adults (Kröger, 2019). The evidence is however not consistent on whether increased life expectancy brings increased years of illness and disability, or if the prolonged life expectancy rather postpones, or even decreases, the number of years of illness and dependency. Some longitudinal studies have not found any clear improvements in good self-reported health in Finland during the last few decades (Koponen et al., 2018; Vaarama et al., 2014), while others have found improvements in both functional and cognitive performance among 75- and 80-year-old Finns (Koivunen et al., 2021; Munukka et al., 2021). Nonetheless, the demographic forecast has led to policy development in Finland that emphasises ageing-in-place, informal care and downsizing of institutional care and other more costly forms of public care (THL, 2023b). This development has direct effects on the micro level among care recipients and

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[5] The age dependency number refers to the number of people in non-active ages, such as children and older people, compared to every 100 people in working age.

their close ones in terms of developed support services for informal care and living at home, but possibly also scarcer availability of other care alternatives.

Most of the data collected for this thesis originated from the region of Österbotten. Despite its universal social and health care system, there are significant health differences in Finland depending on region and municipality (THL, 2019). Österbotten is one of the healthiest regions in Finland in terms of expected life expectancy (Statistics Finland, 2022a) and overall low morbidity (THL, 2019), but the region's dependency ratio of 68 is higher than the national average of 62 (Statistical Information on Welfare and Health in Finland, 2021). Regional demography thus entails information about micro level opportunities for informal care. Regional demography is also connected to economy, as regional health indicators are used in calculations of central funding for the newly established wellbeing service counties (Act on Financing Wellbeing Service Counties 617/2021) where a healthy region like Österbotten risks less funding than other unhealthier regions. This too has consequences for micro level opportunities among those with poor health and their informal caregivers.

3.2. The social context

Previous studies have found that most older Finns support the public provision of care as opposed to relying on family members or the market (Vilkko et al., 2014; Van Aerschot, 2014). Despite the wide support for public care, informal care is commonly provided in Finland. According to a study conducted by Vilkko et al. (2014), about 40% of Finns aged 55–64, 26% of Finns aged 65–74 and 21% of Finns aged 75–79 provided informal care. As mentioned in the introduction, in a European comparison of people aged 16–79 (Verbakel, 2018), Finland was found to host the highest number of informal caregivers but the lowest rate of intensive caregivers (providing care for more than 11 hours a week). The high numbers of caregivers and the low numbers of intensive caregivers were interpreted as the result of shared care responsibilities, thus protecting the main caregiver from an overwhelming caregiving situation. This might be less true for older informal caregivers, as it is common for older ICA caregivers to provide intensive care equivalent to institutional care (STM, 2014; 2019). Older caregiving adults in Nordic countries tend to not share care tasks as much as family members in younger generations (Swedish National Board of Health and Welfare, 2020; Lamura et al., 2008), thus risking extensive, objective care burden. Furthermore, older informal caregivers often provide spousal caregiving to a co-residing recipient which is another indicator of experiencing subjective and objective caregiver burden (Schulz et al., 2020; Adelman et al., 2014).

Age-related differences in caregiving patterns might, to some degree, be explained by norms. In Finland in the 1970s, the judicial obligation to look after one's spouse in old age was abolished from legislation years later than adult children's obligation to look after their old parents (Tikkanen, 2016), which could be seen as reflecting differences in care expectations depending on the direction of the relationship between the caregiver and the care recipient. The familialism norm (referring to the norm of family members' caring obligations) in Finland when it comes to adult children's obligation to look after their older parents is among the lowest in Europe (Verbakel, 2018). Urbanisation and mobility are also social trends that affect informal caregiving patterns, and these trends are stronger among younger age cohorts in Finland (Mikkola & Hänninen, 2021), potentially contributing to a lack of adult children nearby to share practical care and household work with (although some parts of informal care can be done from a distance, even transnationally [Zechner, 2010]).

Traditionally, caregiving and household work are seen as female activities, and this could affect the scope of informal caregiving (Zygouri et al., 2021) in both objective (e.g. in terms of care intensity) and subjective terms (e.g. worrying and experiencing negative emotional impact). Female gender is generally considered an indicator of experiencing both subjective and objective caregiver burdens (Adelman et al., 2014; Schulz et al., 2020). The role of gender in informal care well-being could, however, be seen as less important in the Nordic welfare model, with its class and gender inequality reducing goals (Szebehely & Meagher, 2018). The gender division of Finns who receive ICA among older age groups is small (STM, 2019); nonetheless, gender differences may still prevail in terms of the caregiving activities being undertaken (Ulmanen & Szebehely, 2015) and professionals' and citizens' perceptions about care responsibilities (Valokivi & Zechner, 2009).

In today's individualistic society, norms of efficacy and independence are highly valued (Hoppania et al., 2016). Older adults with care needs may also internalise such norms and struggle to experience themselves as dependent. Feelings of shame and taboo may contribute to other known issues in informal care, namely loneliness and social isolation (Hajek, Kretzler & König, 2021). In Finland, social and peer support activities are organised for informal caregivers and recipients, especially by NGOs, but these activities tend to focus on the active phase of care. Given that women's life expectancy is higher than men's, and women are often younger than their spouses, bereaved female caregivers born in the 1930s and 1940s can be considered at risk for experiencing loneliness, as they may have lost important social contacts while providing intensive care for years. According to a previous national study of informal caregivers, the average length of the informal care relationship had lasted eight years, and usually women provided informal care for more years than men (Tillman, Kalliomaa-Puha & Mikkola, 2014). Furthermore, Finns born in the 1930s and 1940s tend to be more conservative than younger age cohorts in their relationship patterns, as the former groups, to a greater extent, have stayed in their first marriage and remained single as bereaved (Hägglund & Rothkirch, 2021). This could mean that former caregivers belonging to older age cohorts are more likely to live alone post-caregiving.

Digitalisation is another development that might affect well-being among older adults concerned with informal care. In the case of loneliness, digitalisation might increase opportunities for social interaction either with other family members or with peers through activities organized by NGOs. Digitalisation can also make everyday life easier through home deliveries of food and medicine for example. Virtual meetings with home care staff and doctors are also increasingly developed to support informal caregivers and their next of kin (STM, 2019; 2020). In 2019, about 51% of Finns aged 75–89 had used the internet during the past three months, and 30% had used the internet several times a day during the past three months (Official Statistics of Finland, 2019). Thus, digitalisation can make everyday life easier and increase opportunities for social contact for older adults concerned with informal care; however, internet literacy is not yet that widespread among older age groups in Finland. This creates risks of social exclusion for those who lack internet literacy in an already quite digitalised society.

Differences in the social context of well-being are visible in a regional, or rather ethnolinguistic, context. In a comparison of Swedish- and Finnish-speaking older adults in Österbotten, the Swedish-speaking were found to possess more social resources and be more frequently engaged in voluntary organisations (Nyqvist, Nygård & Snellman, 2019; 2021). Given the important role of voluntary organisations in health-promoting work among informal caregivers in Finland (STM, 2019) and the potential relationship between social support and informal caregiver well-being (Carter et al., 2020; Verbakel, 2014; Verbakel, Metzelthin & Kempen, 2018; Del-Pino-Casado et al., 2018), it is possible that Swedish-speaking informal caregivers possess more health-promoting resources than their Finnish-speaking peers. In contrast, Swedish-speaking informal caregivers belonging to a lingual minority can be seen as vulnerable compared to Finnish-speaking caregivers due to potential local variations in the availability of services in their mother tongue. This relationship is, however, less clear in Österbotten, as Finnish speakers are in minority in some municipalities in this region (Statistics Finland, 2022b). Nonetheless, potential ethnolinguistic differences, whether cultural or linguistic, are important to consider in studies on well-being among informal caregivers, especially in an increasingly diverse ageing society.

3.3. The economic context

Some of the informants in this thesis experienced the shift from an agrarian to a service-led economy that took place in Finland after World War II. This development was exceptionally fast and accompanied by rapid annual growth of the gross domestic product (GDP) that lasted for decades (Hjerppe, 1989). The expansion of the Finnish national economy (and the welfare state) continued all the way until the 1990s when Finland entered a tough recession. This recession, together with other simultaneous political reforms of the time, had a major impact on the social care system for older adults in Finland. The economy slowly recovered, but it entered a new recession sparked by the global financial crisis in 2008–2009. It was during the aftermath of the global financial crisis in 2008–2009 that most of the data were collected for this thesis (data for studies 1–3 were collected in 2015, 2016 and 2017, while the data for Study 4 were collected in 2019 and 2020). The public economy is deeply connected with political decisions regarding social and health care services, and therefore the macro-level economy in Finland affects many aspects of well-being of those concerned by informal care on the micro level.

In a European comparison in 2019, Finland ranked third in terms of highest social expenditure, with 29.5% of GDP (Eurostat, 2021). In an overview of public spending on social security in Finland between 1980 and 2019, the overall public spending in terms of real expenditure has increased every year except for 2017 and 2018 (Virtanen, 2021a). In 2019, the largest post (30.9 billion euros) in social security spending was connected to older adults, comprising 43% of all social security spending (ibid.). In contrast, a report by the Nordic Social Statistical Committee (2017, p. 254) noted that Finland spent only 1.6% of the GDP on social services for older adults in 2015, while a much larger post was cash benefits, such as public pensions comprising 10.8% of the GDP. The same pattern in terms of pensions comprising a much larger post than care is visible in the report by THL (Virtanen, 2021a, p. 2), where the development of spending on services and cash benefits (including public pensions) for older Finns between 1995 and 2019 is outlined. There are different ways of calculating GDP, and consequently, the costs of social care can also be assessed in different ways (e.g. older adults' care user fees are sometimes calculated as costs in the public economy). In any calculation, it can be concluded that pensions, rather than care, constitute the largest costs related to ageing.

The municipal economy is also relevant to informal care, as it was the municipalities that were legally responsible for organising social and health care services[6] in Finland at the time of the data collection. Social and health

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[6] This, however, changed with the social and health care reform in 2023 when the responsibility for social and health care services were shifted to wellbeing service counties.

care services have been organised on the municipal level since the 1990s when a decentralisation reform ended an era of strict central regulation (Kröger, 2019). The decentralisation reform was accompanied by a major economic downturn and resulted in cuts in public expenditure, and long-term care for older adults was especially hit (ibid.). The central grant system has been debated since the beginning of the 2000s because of the regional variation and inequality in support and services that have emerged, also among those concerned with informal care (STM, 2014; 2019). The ICA depends on local budgets, and, therefore, it is sometimes not granted despite the informal caregiver meeting the criteria (Linnosmaa et al., 2014). This is also the case despite that the ICA saves the municipality at least 20,000 euros per person a year in comparison if the care needs had instead been met through formal care (Kehusmaa, Autti-Rämö & Rissanen, 2013; STM, 2014).

The economic context is also important for informal care well-being on an individual level, as, once again, socio-demographic variables are related to health. For example, older adults from lower socioeconomic social groups may experience greater needs for social and health care services (Hannikainen, 2018) and pay more user fees in relation to their disposable income in comparison to older adults with higher disposable income (Vaalavuo, 2020). Social and health care needs can also be financially challenging for informal care dyads, despite the Finnish social policy system aiming for equal access to services in terms of, for example, income-related user fees and care allowances to cover care-related fees. User fees for social care for older adults are higher in Finland than in other Nordic countries (Szebehely & Meagher, 2018). Financial stress is commonly included as one of the dimensions of subjective caregiver burden (Zarit, Reever & Bach-Peterson, 1980; Elmståhl, Malmberg & Annerstedt, 1996) and can thus be seen as both an outcome of and a contributing factor to poor well-being. Previous national studies have shown mixed results on whether older informal caregivers encompassed by ICA have a lower average annual income than non-caregivers (Tillman, Kalliomaa-Puha & Mikkola, 2014; STM, 2019).

3.4. The political context

In this chapter, the political context of informal care in light of well-being will be outlined. The chapter is divided into two subchapters. The first subchapter outlines general trends in social care for older adults in Finland, while the other subchapter presents the development of support for informal care.

3.4.1. Development of social care for older adults

A modern welfare system was developed in Finland after World War II (Kröger, 2019; Nygård, 2013). At the turn of the 1960s and 1970s, the principle of universalism grew increasingly stronger as public services were developed to be used by all citizens rather than only by certain groups of people (ibid.). The services were originally developed for children due to rising female employment but were later developed for older adults as well. In the early 1980s, public care homes and long-term wards were the two main solutions for older adults with extensive care needs in Finland (Kröger, 2019). At this time, public home care was also well-developed for older adults with light care needs.

In the 1990s, criticism started to increase towards all types of public institutional care, as institutional care was perceived as too costly for the state and as not providing individual and human care (Kröger, 2019; Anttonen & Karsio, 2016). Simultaneously, the New Public Management (NPM) paradigm (Nygård, 2020) was introduced in Finland, which is a set of ideas about how cost efficacy and quality in the public sphere can be increased through market mechanisms, competition, freedom of choice and citizen influence. Consequently, marketisation mechanisms[7], such as the introduction of public procurement and later service vouchers, were introduced (Anttonen & Häikiö, 2011). This paved the way for for-profit actors that had been almost non-existent in Finland thus far. The rate of care workers (in all social sectors) employed by private for-profit companies increased from 0.5% to 14.5% between 1990 and 2009 in Finland (Karsio & Anttonen, 2013, p. 107). In 2018, 29% of caregivers working in social care for older adults were employed by private, for-profit companies (Virtanen, 2021b).

In line the NPM paradigm, institutional care was reformed into service housing options, where the user rents an apartment and purchases the services separately (Kröger, 2019). The idea was that older adults could move in rather early and gradually buy more services as their needs developed. However, in practice, older adults with quite extensive care need moved into service houses since one-third of the former coverage rate of residential care disappeared in Finland (ibid.). An alternative with effective service housing with 24-hour assistance was developed to replace institutional care for those needing round-the-clock care and assistance. In 2012, Finland got its first act specifically regulating services for older adults (Eldercare Act 980/2012) and this act was accompanied with a stronger emphasis on ageing-in-place, meaning that older adults should live in their home for as long as possible, as it was the stipulated in the act that institutional care can no longer be granted for other than medical reasons. The rate of older Finns aged 85 years and over living in their homes increased from 77% to 82% between 1997 and 2020

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[7] For a comprehensive review of the development in marketisation of eldercare in Nordic countries until 2013, see the research report *Marketisation in Nordic eldercare: a research report on legislation, oversight, extent and consequences* by Meagher & Szebehely (2013).

(Sotkanet, 2022), while the rate of Finns aged 80 and above living in their homes increased from 85% to 88% (ibid.).

The policy principle and outcome of deinstitutionalisation resulted in an extensive reduction of traditional institutional care and an emphasis on ageing-in-place (Anttonen & Karsio, 2013), meaning that older adults should live in their own home for as long as possible. The deinstitutionalisation process was not accompanied by strengthened home care; rather it was the opposite (Kröger, 2019; Szebehely & Meagher, 2018). In 2018, 6% received publicly organised regular home care (Sotkanet, 2022), while in 1990[8], about 20% of Finns aged 65 and above received home help (Kröger & Leinonen, 2012). Home care was developed to target those with the highest needs and to cover more basic and medicalised needs, while other tasks, such as household tasks, became practically excluded from municipal home care (Kröger & Leinonen, 2012). As already mentioned in chapter 2, the social dimension of public home care has also been decreasing since 1990s (Kröger, Van Aerschot & Mathew Puthenparambil, 2018) which has created risks of unmet social needs affecting the well-being of both formal care workers, care recipients and informal caregivers (Van Aerschot et al, 2022a; Van Aerschot, et al, 2022b).

Marketisation mechanisms have further been claimed to blur the lines between public and private eldercare and decrease public responsibility of care for older adults and instead increase the responsibilities of older adults themselves and their close ones (e.g. Anttonen & Häikiö, 2011). This shift can be seen in line with an overall development in social policy towards an emphasis on active citizenship, where choice, responsibility and participation are keywords (Newman & Tonkens, 2011). The consequences of such a development among frail older adults and their close ones is important to track, not least from an inequality perspective.

According to Szebehely and Meagher (2018), marketisation has weakened the principle of universalism in Nordic social care for older adults, which, in turn, has increased the risks of class and gender inequalities. A declining universalism is believed to increase the risk of care poverty, a term

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[8] The numbers are not completely comparable, as the home care system has undergone transformation and home care clients are today more strictly defined in statistics than in 1990 (ibid.) For example, before 1995, there was no strict definition of a home help receiver in national statistics. In 1995, the concept of “regular home care” was introduced and users were defined as those who received home care (home nursing, home help or home hospital service) as part of a valid care plan and at least once a week (ibid). From 2016 onwards, home care users are defined as those who have received care for at least six days during the last 60 days (THL, 2023a).

established by Finnish researchers Kröger, Mathew Puthenparambil and Van Aerschot (2019) referring to *the deprivation of the adequate coverage of care needs resulting from an interplay between individual and societal factors*. Indeed, since the 1990s, service fees for formal care have become raised (Häikiö, Anttonen & Van Aerschot, 2011) and according to national statistics (Sotkanet, 2022), in 2021, only 64% of Finns aged 65 and above who used social services experienced the use of the services as smooth. According to survey data collected in two cities in Finland, of those aged 75 years living at home, 14% reported that they did not receive enough help and support (Van Aerschot, 2014). Two of the reasons for not receiving enough support were high service costs and an overly complicated service system (ibid.). In another study using the same data, it was found that older Finns with higher education, better finances and better health were more likely to use private home care, while those with fewer resources used public home care, and those with the poorest health used both private and public home care (Mathew Puthenparambil, Kröger & Van Aerschot, 2015). The results thus indicate that service use depends on individual resources and that extensive care needs require various care providers.

To conclude, macro-level political development in social care has major effects on the everyday lives of older adults concerned with informal care on the micro level. The development of formal care shapes well-being both directly in terms of available support and indirectly through perceptions of available support. As a mediator between macro and micro levels is the meso level, where municipalities, (and since 2023 wellbeing service counties) organise social and health care services regulated, and partly financed, by the state. On the meso level, local political power resources and their priorities and implementations too shape the lives and, thus, the well-being of older adults concerned with informal care. Finnish social care for older adults does offer services for its citizens, but the outlined development during the past decades suggests that managing extensive and complex care needs might demand individual resources and skills, and that there is regional diversity in care resources (and needs).

3.4.2. Development of support for informal care

Professionalisation and modern care politics can be argued to have started in 1950 when an act on municipal home care workers was introduced in Finland (although the service was originally aimed at families with children) (Tikkanen, 2016). In the 1960s and 1970s, some municipalities started to pay a type of home care allowance that was later included in the Social Welfare Act 710/1982 in the 1980s. The municipalities were not obliged to pay for the support, but in practice, all municipalities paid, although there were significant differences in the eligibility criteria and the benefits. The home care allowance was changed to informal care support in the 1990s, but the phrase 'informal caregiver' was not widely used even in the beginning of the 2000s (for a detailed and illustrative overview in Finnish, see Tikkanen, 2016, p. 18–29).

In 1993, support for informal care became a municipal statutory social service that consisted of care allowance and services to both the caregiver and the care recipient (Tikkanen, 2016, p. 26). Then, it included the right to pension and one-day off per month for the caregiver. In Finland, support for informal care has emphasised the right and position of the caregiver and less the perspective of the care recipient. Support for informal care was introduced simultaneously as the economic recession prevailed in the 1990s (previously mentioned in subchapters 3.3 and 3.4.1).

Apart from care allowance, additional support services were offered; however, since only a few used the right to one-day off per month, this right was changed in 1998 so that it was used by only those caregivers who provided intensive care. In 2002, caregivers' rights to respite care were changed to two days a month, and the target group was widened. Informal caregivers' legal position was also improved as their pension began to be regulated in the Municipal Pension Act 549/2003, and informal caregivers also started to be covered by the Employment Accident Insurance Act 459/2015. In 2004, a change in the Act on Client Charges in Healthcare and Social Welfare 734/1992 resulted in a maximum fee of nine euros per day for respite care. In 2006, the new Act on ICA 937/2005 substituted the previous regulations on informal care included in the Social Welfare Act 710/1982. In the new Act on ICA 937/2005, informal care was defined as *informal care arranged in homelike arrangements for an older, disabled or other sick person by next of kin or some other close individual who has the informal care agreement with the municipality*. The support for informal care included services for the care recipient, care allowance, respite care and support services for the caregiver. The act also regulated eligibility criteria, amount of respite care days, minimum and maximum care allowances, the informal care agreement and its accompanied care and service plan, agreement termination and withdrawal, as well as pension and accident insurance security (see amendments in Act on ICA 937/2005). In 2007, informal caregivers' right to two days off per month was changed to three days off a month, and a new regulation stipulated that support services for the caregiver also had to be defined in the care recipient's care and service plan. A final change was that a specific contact person in the municipality had to be named in the care plan.

In 2014, partly as a response to getting a remark from the European Committee of Social Rights for allowing older adults and informal caregivers into unequal positions, a national expert team in Finland presented a strategic programme for improving the support for informal care (STM, 2014). It concerned both caregivers encompassed by the then-new informal care agreement, ICA, with the municipality as well as other informal caregivers. The aim was to strengthen informal caregivers' position and promote equality and coping among informal caregivers. The report suggested several reforms, such as clearer eligibility criteria for the allowance, fixed care allowance levels and viewing publicly supported informal care as a subjective right of the care recipient (ibid.). These changes have, however, not been adapted, except for the introduction of a national minimum and a maximum level of economic benefit included in the ICA (Act on ICA 937/2005).

In 2016, there was again time for amendments to improve the situation of informal caregivers (STM, 2019). Legislated rights to two days of monthly respite care were enforced to encompass all informal caregivers receiving the ICA, while those informal caregivers bound to caring obligation 24/7 continued to be entitled to three days off every month. Opportunities to take advantage of respite care in shorter time intervals than entire 24-hour entities were also strengthened. In addition, it was established that from 2018, informal caregivers encompassed by the ICA were to receive training, education and health check-ups by the municipalities according to need (see amendments in Act on ICA 937/2005). It also became regulated in the Social Welfare Act 710/1982 that municipalities must strengthen the opportunities for informal caregivers without the ICA to take advantage of days off or shorter rests. In the Act on Client Charges in Healthcare and Social Welfare 734/1992, regulations were enforced so that client fees for respite care arranged during the informal caregiver's rest (both with and without the ICA) must not exceed 11.50 euros per day. Furthermore, a simultaneous key project launched tests with personal budgets for informal caregivers and multidisciplinary informal care centres (STM, 2019).

The support for informal care, as outlined above, concerns support that is mostly provided by public authorities. However, in Finland, NGOs also play an important role in supporting informal caregivers (STM, 2019; 2020). In Finland, NGOs and other non-profit organisations can apply for funding for health-promoting activities through the national Funding Centre for Social Welfare and Health Organisations (STEA) administered by the STM. Much of the STEA-funded activities for informal caregivers focus on education and health promotion (STM, 2019), while other smaller pilot projects have highlighted specific issues, such as alcohol, drugs, and medication misuse, among informal care dyads.

The developed support for informal care has a major impact on well-being at the micro-level among older adults concerned by informal care. It both facilitates and hinders different aspects of well-being, which will be further discussed in chapters 5 and 6. Next, we move on to the data and methods.

4. Data and methods

Table 1 provides an overview of the research questions, data and methods used in the original studies. Each study includes a more detailed methodological description and discussion. This chapter continues with a brief methodological presentation of each study and ends with ethical considerations of the four studies.

Table 1. *Research questions, data and methods*

	Research questions/aims	**Data and methods**
Study 1	How can the background of the care recipient's care choice be understood from a life course perspective? What are their thoughts on the future?	Semi-structured individual interviews were conducted with seven care recipients. The interviews were recorded and transcribed. Qualitative content analysis with a mainly inductive approach was used for the analysis.
Study 2	What facilitates or hinders the care arrangements across time? What are the implications of receiving care for older adults' functioning?	Semi-structured individual interviews with seven care recipients were conducted in 2015, and follow-up interviews were conducted with them in 2017. In 2017, six informal caregivers were interviewed. One informal care dyad was chosen for the analysis. A longitudinal qualitative analysis with a directed approach was used for the analysis.
Study 3	What is the extent of subjective caregiver burden among older spousal caregivers in the northern parts of Sweden and the western parts of Finland? What are the associations between economic, social and political resources and subjective caregiver burden?	Cross-sectional survey data collected in 2016 in the Bothnia region of Finland (Österbotten/Pohjanmaa) and Sweden (Västerbotten) were used. Out of 9,386 participants, 674 older spousal caregivers were identified and included in the analyses. Contingency tables with Pearson's Chi-square tests and multivariate logistic regression were performed.
Study 4	The aims were to assess the feasibility of Finnish expert caregiver intervention by co-designing and implementing the intervention and by assessing demand and practicality with special attention to the impact of COVID-19.	Non-controlled exploratory intervention was conducted. Qualitative focus group interviews were conducted with 13 informants. The interviews were recorded and transcribed. The analysis was interpretative-phenomenological. The distribution of all the participants' (T1: 25, T2: 24, T3: 23) SOC and satisfaction with life scale (SWLS) variables was calculated. Variables with a normal distribution (Kolmogorov–Smirnov test with $p \leq 0.05$) were analysed with a one-way repeated ANOVA to compare the differences in average scores between the time points. Variables without a normal distribution were analysed using the Friedman test.

4.1. Study 1

Study 1 is based on data collection from semi-structured qualitative interviews (Kvale & Brinkmann, 2009) with seven older informal care recipients. They were interviewed about informal care and ageing in their homes. Criteria for participating in the interviews included being an older adult, Swedish speaking, being cared for by an informal caregiver either through an official agreement with the municipality or not, and not having memory disorders. The selection was made by contact with NGO Folkhälsan, the largest social and health care organisation in Swedish-speaking Finland. The informants were aged 71–80 years; five were women, and two were men. Five were cared for by their spouse, one was cared for by both the spouse and an adult child, and the seventh informant was cared for by a sibling. All care recipients lived with their main informal caregivers. Four of the informants lived in the countryside, and three lived in an urban environment. The reasons for needing care varied and included, for example, stroke and visual impairment. All interviews were carried out in their homes. The interviews lasted 35–88 minutes. An informal caregiver was present in four cases. The informal caregivers' comments were not used in the analysis.

The interviews were recorded and transcribed verbatim. They were analysed in the software programme NVivo10. For the analysis, mainly an inductive approach was mainly chosen where the material guided the categorisation, but there were also deductive influences, for some of the interviews revolved around care, life course and reciprocity (Kvale & Brinkmann, 2009).

4.2. Study 2

In Study 2, the same respondents as in Study 1 were interviewed again two years later. This time, their informal caregivers were also interviewed separately by another researcher. The interviews were again recorded, transcribed verbatim and analysed in NVivo. The follow-up interviews with the care recipients were semi-structured theme interviews concerning changes in health status, care policies, services and care preferences. We used a directed content analysis (Hsieh & Shannon, 2005). Inspired by Saldana's (2003) guide developed for analysing longitudinal qualitative data, we used a three-step set of questions (framing, descriptive and interpretive/analytic) to reach a rich analysis of change across time. Instead of providing an account of the entire data, we chose to focus on presenting the dynamics behind care arrangements in detail by analysing the interviews of one care dyad, where a great variety of commodities and conversion factors was expressed. We then constructed a narrative including the commodities, the transformation of commodities into capabilities and the transformation of capabilities into achieved functioning, which will be further presented in the results.

4.3. Study 3

In Study 3, analyses were based on a cross-sectional survey carried out in 2016 as part of an interregional research project (GERDA). The overall aim of the project was to map the living and health conditions of older adults in the Bothnia region in Sweden (Västerbotten) and Finland (Österbotten/Pohjanmaa and Etelä–Pohjanmaa). The questionnaire was sent out to every 66-, 71-, 76-, 81- and 86-year-old living in the rural areas and in the city of Seinäjoki (Finland), while to every second living in the city of Vaasa (Finland) and every third in the city of Umeå and in the city of Skellefteå (Sweden). The Bothnia region in Finland is bilingual, with about 52% Swedish speakers and 48% Finnish speakers. The Finnish region, despite belonging to the same geographical region, is treated in the study as two separate regions based on language group affiliations. Swedish-speaking participants were coded as belonging to Österbotten, and those with Finnish as their mother tongue in Pohjanmaa and in Seinäjoki in Etelä-Pohjanmaa were coded as belonging to Pohjanmaa. Questionnaires were sent to 14,805 older adults, of whom 9,386 participated, resulting in a total response rate of 63%. The questionnaire was answered by 4,375 participants in Västerbotten, Sweden, and by 2,296 in Österbotten and 2,715 in Pohjanmaa, Finland, resulting in a response rate of 70.8%, 61.7% and 54.9%, respectively.

The distribution of the studied variables were presented in the selected regions respectively and in the total sample. Contingency tables with Pearson's chi-square tests were used to analyse the bivariate association between subjective caregiver burden and social, economic and political resources in the regions respectively and in the total sample. To assess the multivariate associations, logistic regression analyses were conducted by calculating odds ratios with 95% confidence intervals for the likelihood of subjective caregiver burden by economic, social and political variables and control variables. Four models were analysed. All analyses were conducted using the SPSS 24 software programme.

4.4. Study 4

Study 4 was a non-controlled exploratory intervention study with a pre-post design. Qualitative and quantitative methods were used. We conducted a baseline assessment, an assessment at the end of the four-month training course, and assessment 13 months after baseline. The only eligibility criterion for participating in the training course had experience providing informal care to an older person with care needs. Participants were recruited by marketing on social media, radio, newspapers and through information events organised in three different municipalities across the Österbotten region.

We assessed demand (Bowen et al., 2009) by studying actual use and perceived demand. This was done by counting the number (and, when applicable, percentage) of participants enrolling in the training course, completing the training course, volunteering one time, volunteering multiple times, as well as the number of organisations, congregations or municipalities involved in the intervention (apart from the intervention providers) and finally the caregivers reached through peer support activities.

To assess practicality (Bowen et al., 2009), we studied the participants' ability to conduct activities and their effects on participants from the perspective of expert caregivers. We analysed data collected from qualitative semi-structured focus group interviews with 13 participants 13 months after the baseline. The participants were divided into four natural groups of three or four persons and were asked to discuss the process from caregiver to becoming an expert caregiver, the experiences of and perceived positive and negative effects on their well-being by volunteering, as well as their experience of volunteering during the COVID-19 pandemic. The qualitative focus group interviews were recorded and transcribed verbatim by one of the researchers. The same researcher divided each transcript into inductively chosen categories. Initially, the data were scrutinised into multiple categories by one researcher. Step-by-step, the categories were reread and reorganised into broader themes that shared common patterns. To ensure the trustworthiness of the findings, two other researchers then independently read through the transcribed interviews and compared the data with the coding schemes. Finally, the three researchers discussed the coding scheme until an agreement was reached.

The analysis of the focus group interviews was interpretative–phenomenological (Smith & Osborn, 2003), meaning that the researchers are active in the dynamic research process, aiming to help the participants make sense of their personal and social world. Interpretative, phenomenological analysis usually involves small sample sizes from heterogeneous populations, as the aim is to investigate the meaning of a certain group's experiences of a specific phenomenon or event. For the analysis, the Nvivo 12 software programme was used.

To further explore the intervention outcomes on the participants, we used repeated questionnaires collected at baseline, at the end of the four-month training course, and 13 months after baseline. The perceived effects on the participants' well-being were explored by assessing the participants' SOC (Antonovsky, 2012) and SWLS (Diener, 2006). The scales showed good internal consistency at all time points of the study, with scores from Cronbach's alpha tests ranging from 0.74 to 0.89. The quantitative data were collected on-site at all three time points of study and sent out by post to those not present. For the analysis of the quantitative data, the distribution of all the participants' variables was calculated. Statistical analyses were conducted to assess the mean, range, standard deviation, and median for the participants' SOC and SLWS scores at all three time points. The participants' average scores on SOC and SLWS were compared to report differences between the three time points of study (baseline, four months after baseline, and 13 months after baseline). Variables with a normal distribution (Kolmogorov–Smirnov test with $p \leq 0.05$) were analysed with a one-way repeated ANOVA to compare the differences in average scores between the time points. Variables without a normal distribution were analysed using the Friedman test. All statistical analyses were performed in the IBM SPSS Statistics 27 statistical programme.

4.5. Ethical considerations

In all four studies, standard ethical guidelines developed by the Finnish Advisory Board On Research Integrity (2012) are followed.

In Study 1, the informants voluntarily participated in the interviews after first being informed about the purpose of the study and then asked to participate by a contact person on NGO Folkhälsan. If they wished to participate, they gave their contact information to the contact person, who then passed on the information to the researcher. The interviews took place in the participants' homes, where they were again informed about the study's purpose and their right to cancel their participation at any point. Oral consent was thus obtained. In the analysis and the presentation of the results, the informants' anonymity was secured by excluding dialectal words or detailed information about the locations or persons mentioned. In Study 2, the same informants as in Study 1 were asked to participate again. All informants agreed, and this time, the informal caregivers (if available) were also asked to participate. Written informed consent was obtained. Only one case was chosen for Study 2, and as longitudinal data in combination with rich detail can jeopardise the anonymity of the respondents, extra attention was paid to not revealing the identity of the respondents. A few personal details were therefore omitted.
Study 3 is based on anonymised cross-sectional survey data, where the data collection was approved by the Regional Ethical Review Board of Umeå, Sweden (05/084 & 2016/367–32). In Finland, ethical approval is not needed for anonymous population-based postal surveys (Medical Research Act 488/1999).

Ethical committee approval was not deemed by the researchers to be needed for Study 4, where the feasibility of an intervention focused on education and knowledge transfer was assessed. The risks of unforeseen mental or physical harmful consequences were assessed as non-existent by the researcher team.

Written informed consent was, however, gathered from those participating in the focus group interviews to ensure that they understood the purpose and conditions of the research activities.

5. Results

In this chapter, the main findings derived from the studies are presented and discussed in relation to the research questions of the thesis.

5.1. Research questions 1a–c

How do older informal care recipients choose and manage their care arrangements? (Articles I and II)

By applying the life course perspective (Elder, Johnson & Crosnoe, 2003) in study 1, the results showed that the declining functional capacity of the care recipient served as a mutual turning point in life for the care dyads. Receiving informal care at home, in combination with different support services, enabled continuing the previous lifestyle to some extent, despite the illnesses and/or declining functional capacity.

The care recipients, born in the 1930s and 1940s, had witnessed the development of social care in Finland, both in terms of a less developed welfare system, but also a more generous home care system than at the time of the interviews. It has however the current social care system that mainly affected their care preferences. The care recipients had partly negative experiences and/or conceptions of formal care in terms of a lack of continuity and resources in home care. These issues can be seen as corroborated by previous research on the worsening working conditions of home care workers in Finland (Kröger, Van Aerschot & Mathew Puthenparambil, 2018) and the increasing number of them considering quitting their jobs (Olakivi et al., 2021). International studies have also confirmed the relationship between generous formal long-term care system and informal caregivers' well-being (Wagner & Brandt, 2018; Verbakel, 2018).

The results further showed that it was mainly the caregivers, as opposed to the care recipients, who navigated the care system in practice. Some care recipients used strategies to ease the burden of the caregiver by, for example, agreeing to use respite care in health care ward settings, despite not being comfortable in that environment, while other dyads chose to not take advantage of the right to respite care. The issue of informal caregivers providing intensive care but not using their right to respite care has been recognised for years in Finland (STM, 2014; 2019). Previous international studies have shown that various factors can contribute to a non-uptake of support services, such as bureaucracy, costs and the care recipients' wishes (Lamura et al., 2008). Thus, (not) using services can be seen as related to both resources and skills, but also emotional aspects. Qualitative research investigating the everyday lives of spousal caregivers in Finland has shown that the social policy system sometimes fails to grasp the emotional reasoning (Sointu, 2016) and/or psychological contracts between spouses (Ring, 2021) which can result in informal caregivers exceeding their power in the efforts to provide good care for their next of kin. Efforts have however been made in Finland to offer more flexible respite care options, such as respite care in the dyads' homes and/or respite care being split up into shifts instead of several days and nights in a row (STM, 2019). Still, in 2018, about half of ICA caregivers continued to not use their right to days off (ibid.).

The results in study 2 also showed that informal caregivers and recipients seemed to lack influence over their public services in negotiations with service gatekeepers. The use of services was often prone to changes due to macro-level decisions and meso-level implementations that were outside the informal care dyads' control. The power dynamics between informal caregivers (and recipients) and service gatekeepers are uneven (Häikiö & Anttonen, 2011), despite national and international strategic documents stressing the need for professionals and informal caregivers to form co-partnership (STM, 2019; European Commission, 2021). The capacity and willingness to negotiate with service gatekeepers can also be seen as depending on individual resources and skills (Häikiö & Anttonen, 2011) possibly related to the individual life course.

What kind of factors hinder or facilitate the care arrangements? (Article II)

By scrutinising the care arrangements using the capability approach (Sen, 1979) in Study 2, it became evident how the informal care dyad used various sources and strategies to manage their everyday lives. They found ways to earn extra income, bought devices on the private market, (sometimes) negotiated with local service gatekeepers and asked for help from individuals in their surroundings. Some care dyads received help from adult children living nearby, while others lacked such support. It seemed that for many informal care dyads, the contacts with their adult children (and grandchildren) merely served as social contacts rather than as additional sources of care. Nonetheless, in several cases, the adult children offered administrative and/or occasional practical support. Few informal care dyads seemed to expect and/or receive extensive help and support from adult children, as these family members were busy living their own lives with work and children. In addition, familialism norms in Finland regarding expectations of help from children to older adults are low in a European comparison (Verbakel, 2014).

The findings also illustrated at least two instances in which the care dyads should have sought more assistance and/or medication but chose not to do so. It is possible that previous negative experiences influenced their decisions not to seek help, but the dyads could also be lacking information and experiencing difficulties in assessing their needs. Health literacy is becoming more important with the strong emphasis on ageing-in-place (Chesser et al., 2016). The findings also illustrated how a local service gatekeeper convinced the dyad to accept support services they initially did not want but later came to appreciate, which further supports the need for professional evaluation apart from the care dyads' own assessment.

A previous Finnish study (Mathew Puthenparambil, Kröger & Van Aerschot, 2015) identified that use of private services was more common among older adults with higher educational levels and more financial resources, while older adults with lower educational levels and financial resources were more likely to use public services. Those who were very ill used a combination of private and public services (ibid.). Our results in Study 2 are in line with those results, as the older informal care dyads used a mix of informal, private, and public care forms to cover all needs. Even though they mentioned financial difficulties, they still paid for additional private physiotherapy services and bought assistive devices. The Finnish social policy system offers care allowances not only to caregivers but also to older care recipients with care needs to cover medical expenses. There are also tax deduction possibilities for using private services. Furthermore, publicly organised care is subsided. Despite these various financial support forms, it is still common in Finland to experience costs hampering social services (Sotkanet, 2022), and as previously noted, it is common for informal caregivers to use the allowance to cover basic daily needs, such as food and medicine (Tillman, Kalliomaa-Puha & Mikkola, 2014).

The data for Study 2 were collected in 2015 and 2017, meaning that the interviews took place during political turmoil. At that time, the Sipilä government ran a strategic programme aiming to cut billions in public spending (Finnish Government, 2015) while simultaneously aiming to incentivise informal caregiving by improving and introducing new rights for informal caregivers. Central government funding was allocated for these initiatives but was not earmarked (STM, 2019), and this, in combination with overall austerity measures, contributed to less than half of municipalities noticing any effect of the investments (ibid.). An interesting finding in Study 2 was that, despite the national aim to improve the caregivers' situation, the municipal implementation led to the respite care being worsened in the case of the informal care dyad interviewed, and this challenged the sustainability of informal care and ageing-in-place, which were contradictory to the goals of the policy changes. Naturally, this also had consequences for the informal care dyad's well-being, which will be further discussed under research question 1c.

Another main goal of Finnish social care for older adults is to promote self-determination and the ability to manage on one's own (Eldercare Act, 980/2012). Most older adults in Finland can live lives characterised by self-determination and autonomy, as partly reflected in the service uptake in Finland, where, in 2018, only 11% of those aged 65 and above received home care and/or lived in effective service housing (Sotkanet, 2022). However, in the case of ICA recipients, few can be seen as capable of living lives characterised by autonomy and self-determination, given the fact that 57% have needs equivalent to intensive home care (more than 60 visits per month) or institutional care and 34% suffer from cognitive decline (STM, 2019). Thus, in many cases, it is in practice the informal caregivers whom autonomy and self-determination concern. This was also shown in the results of study 2, where the informal caregiver was largely responsible for the coordination and acquiring of services. At times, assessing the needs was difficult but then she chose to consult her adult child. Another example in study 2 illustrated how services were sometimes gained by chance, such as when local service gatekeepers happened to witness the care dyad struggle on a parking lot. In this case, the service gatekeepers deemed that additional services were needed even though the care dyad had not sought such assistance.

In the case of informal care in old age, the caregiving context does not always promise progress and improvement in terms of the care recipient's health. Therefore, acknowledging when the caregiving situation at home has become too overwhelming may be difficult for both the caregiver and the care recipient. Nonetheless, the roles, relationships and/or identities in an informal care context may still be subject to change in everyday life at home as well (Andréasson, 2021; Ringo, 2021; Sointu, 2016; Tikkanen, 2016). The care situation may involve, for example, washing one's spouse's genitals, being exposed to disturbing behaviour due to the recipient's cognitive decline and/or being trained to perform physiotherapy sessions. These elements of care may introduce new roles and activities, possibly in sharp contrast to one's norms and preferences regarding what behaviour and activities are acceptable in a relationship between two spouses (Twigg, 2000). These examples illustrate how extensive informal care is not entirely a continuum of a previous lifestyle, even though it may involve certain aspects of it in comparison to if the care recipient was placed in a nursing home.

Norms may also shape the recipients' agency in their care arrangements, just as norms have been theorised as one of the factors contributing to taking on the caregiving role (Broese van Groenou & De Boer, 2016). In Study 1, it seemed that most care recipients accepted needing help in old age from their long-term spouse, which could reflect norms about obligations in a marriage internalised by the respondents, mainly born in the 1930s and 1940s. Norms related to informal care can be seen as interlinked with the availability of public services (Miettinen, 2012) in the sense that a lack of formal options enforce norms about informal responsibilities. Van Aerschot (2014) found that older Finns preferred care from the public sector rather than from informal sources but that publicly supported informal care blurred these lines to some extent. Receiving informal care may be experienced as easier for the care recipient when the caregiver receives financial support and other support services (Wolff & Agree, 2004). This could be experienced as a form of reciprocity, although the informal care recipient is not the main part balancing the caregiver's efforts.

What are the consequences for the informal care recipients' well-being? (Articles I and II)

In Study 1, the life course perspective (Elder, Johnson & Crosnoe, 2003) illustrated both personal and practical reasons for choosing informal care. As previously mentioned, living at home with one's spouse is to some degree a continuum of the previous lifestyle despite a declining functional capacity. However, as care needs become overwhelming for the informal caregiver to cope with, extrinsic factors become more important in terms of both support and perceptions of other care alternatives. The former enables the opportunity to continue to live at home, while the latter shapes the sense of security and control. The support system for informal care both promoted and hindered subjective well-being, as the support system on one hand was crucial for the current living arrangements in several instances, but on the other hand, quality issues especially in terms of a lack of continuity also hindered well-being. A lack of support can cause tension in the relationship among the spouses, as the caregiver risked overwhelming care strain if the care recipient's needs were not adequately met by the formal care workers. The care recipient's needs being met by the formal care workers was enabled by continuity and communication with the care workers.

According to the capability approach (Sen, 1979), the exact definition of a meaningful life is individual. In Study 2, the care recipient's valued capability was to continue living at home with his wife, despite experiencing several health issues. The capability approach also enabled studying issues with adaptive preferences (Gandjour, 2008); for example, the care recipient chose not to seek help for his depressive symptoms. This had consequences for his (and the caregiver's) well-being and could be seen as counterproductive to his capability to continue to age at home. On one occasion, the local service gatekeeper did not accept the informal care dyad's initial reluctance to use shower help. When the dyad was convinced to accept the support, the dyad realised that they did appreciate the help and that it supported the care recipient's capability to live at home. These findings can be seen as a contribution to the debate about the complexities of self-determination and autonomy as guiding principles in care (Häikiö, Anttonen & Van Aerschot, 2011).

The findings in Study 2 also showed that the care recipient's well-being was interlinked with the informal caregiver's well-being in numerous ways. Even though the care recipient was unsatisfied with his monthly stay at respite care, he agreed to go there for the sake of his wife. If he stayed at home for too long, she would become tired. In this way, respite care promoted the care recipient's subjective well-being by easing the caregiver's burden. Both parts of the informal care dyad were affected when the caregiver's days off were suddenly cut, and the caregiver consequently struggled to cope.

A previous study on care preferences in a Nordic context showed that older adults do not wish to be dependent on someone who does not know them (Harrefors, Sävenstedt & Axelsson, 2009). In a Nordic comparison of elder care workers' work satisfaction and conditions conducted in 2015 (Kröger, Van Aerschot & Mathew Puthenparambil, 2018, p. 25), the results showed that public home care workers in Finland reported an average of 10–27 clients per working shift. Naturally, a high number of clients leave little time for bonding with the client. In the case of informal care, typically between two older spouses, the risk of not knowing the caregiver is naturally erased. It is, however, important to note that not all informal care relationships are well-functioning irrespective of the previous relationship history. For example, in an American study, abusive behaviour was more likely to occur among spousal care dyads in comparison to other informal care dyads (Beach et al., 2005). Especially cognitive disorders and related behavioural changes may change the relationship and communication patterns severely (Eskola et al, 2022).

In Study 2, the caregiver felt proud of her ability to help her husband rehabilitate. Her subjective well-being, and objective health, suffered however when her efforts replaced rather than complemented professional support. Being denied services did not harm the caregiver's well-being only objectively but was experienced as hurtful. This simultaneously points out the importance of the support services provided. Services such as respite care and financial support, when used, were perceived as supporting the ability to cope in everyday life at home and promoted the dyad's well-being both objectively and subjectively.

5.2. Research questions 2a–b

What is the extent of subjective caregiver burden among older spousal caregivers in the Bothnia region, and are there regional differences in the Bothnia region? (Article III)

The descriptive analysis in Study 3 showed that in Pohjanmaa[9] (Finland), 53% of spousal caregivers reported subjective caregiver burden, 44% of spousal caregivers in Österbotten (Finland) reported subjective caregiver burden, and 43% reported it in Västerbotten (Sweden). These findings can be seen as corroborating previous qualitative research that explores the experiences of informal caregiving in Finland (Tikkanen, 2016; Sointu, 2016) and as previous corroborating research suggests that informal care of older spouses tends to be a burdensome experience, especially in terms of care intensity (STM, 2014; 2019; Lamura et al., 2008).

In Västerbotten (Sweden) and Österbotten (Finland), 8% of the participants were identified as spousal caregivers, while 6% were spousal caregivers in Pohjanmaa (Finland). In Pohjanmaa, where it was the most common to report subjective caregiver burden, it was also more common to receive formal support (35%) than in Österbotten, where 27% received formal support. In Västerbotten, only 13% received formal support. In line with the results of a previous study in Sweden, where 13% of older caregivers received formal support (Ekström et al., 2020), only 13% of spousal caregivers in our study reported receiving formal support in Västerbotten. This is an important finding, as formal support has been found to have alleviating effects on caregiver burden (Tillman, Kalliomaa-Puha & Mikkola, 2014; Verbakel, Metzelthin & Kempen, 2018) and 43% reported caregiver burden in our study. However, formal support may indicate intensive caregiving (Swedish National Board of Health and Welfare, 2012; Tillman, Kalliomaa-Puha & Mikkola, 2014) and not all caregivers who receive public services experience that their needs are being adequately or sufficiently met (ibid.; ibid.). Nonetheless, the support system for informal caregivers in Finland could be seen as more developed than in Sweden, as the services for informal caregivers in Sweden have been less standardised thus far (although Sweden's first national strategy for supporting informal caregivers was launched in 2022 [Swedish Government, 2022]). Simultaneously, the overall social care system for older adults in Sweden is more generous (Verbakel, 2014; Szebehely & Meagher, 2018) with lower user fees (Szebehely & Meagher, 2018) than in Finland where user fees can be especially challenging for home care users with low levels of income (Ilmarinen, Van Aerschot & Kröger, 2022; Vaalavuo, 2020).

We used an ethnolinguistic rather than a geographical distinction between caregivers in Finland, and previous research on older adults in this region has shown that, in general, Swedish speakers possess more social resources and are more frequently engaged in voluntary organisations than their Finnish-

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[9] Pohjanmaa/Österbotten belongs to the same region geographically but was divided ethnolinguistically in study 3. Those who were Finnish-speaking were coded as belonging to Pohjanmaa, and Sweidsh-speakers were coded as belonging to Österbotten.

speaking peers (Nyqvist, Nygård & Snellman, 2019; 2021). As also discussed in Chapter 3, voluntary organisations play an important role in Finland in terms of creating health-promoting training for informal caregivers (STM, 2019) and the higher rates of membership in voluntary organisations of Swedish speakers might bring some kind of advantage among Swedish-speaking caregivers. Then again, Swedish-speaking informal caregivers can be seen as vulnerable in comparison to Finnish-speaking caregivers due to potential local variations in the availability of services in their mother tongue, but this relationship is not straightforward in Österbotten, as Finnish speakers are in minority in some municipalities in Österbotten. A higher rate of Finnish speakers also reported receiving public support, which could mean that it is more common among Finnish-speakers to provide intensive care. Nevertheless, the observed differences warrant future research on ethnolinguistic differences in the caregiver experience.

What are the associations between individual economic, social and political resources and subjective caregiver burden? (Article III)

The results from the multivariate logistic regression analysis showed that low perceived ability to make ends meet and frequent contact with family members were statistically significantly associated with caregiver burden, while personal income, contact frequency with friends and neighbours, internal political efficacy and political participation were not statistically significantly associated with subjective caregiver burden.

According to the caregiver stress process model (Pearlin et al, 1990), well-being outcomes of informal caregiving can be seen as the result of a process from objective to subjective burden, that is affected by mediators of support throughout. The mediators can include for example additional resources of informal care, financial resources, and formal support for informal care. Trends in social care for older adults, such as increasing marketisation trends and lowered coverage of public services (Szebehely & Meagher, 2018; Kröger & Leinonen, 2012), have been claimed to weaken the principle of universalism and increase the risks of inequality in care use and/or care provision. A less studied area is whether inequality exists in terms of individual resources shaping subjective caregiver burden. The findings in study 3 indicate that the comparatively generous welfare model in Finland seemed to manage to reduce previously elsewhere identified inequalities in subjective caregiver burden associated to gender and educational level (Adelman et al., 2014; Schulz et al., 2020). However, research on inequality often assesses only the caregiver, while a more household-representative analysis may be more feasible (Tough et al., 2020). In Study 3, experiencing financial strain was statistically significantly associated with subjective caregiver burden, while the caregiver's personal income was not. Financial strain can be seen as better reflecting the household situation and thus a dyadic perspective (Tough et al., 2020). The relationship between contact frequency with family members and subjective caregiver burden was the opposite of what could be anticipated, as frequent contact indicated subjective caregiver burden. This relationship could be interpreted as turning to other family members serving as a last resort for the spousal caregiver in a context with low familialism norms regarding children's caring responsibilities for their parents (Verbakel, 2014). The role of adult children in the informal care dyads' everyday lives was present but rather limited in the interviews collected for studies 1 and 2.

The analysis in study 3 also included individual political resources which has rarely been done before on research on informal caregiver well-being. Previous studies conducted elsewhere have identified associations between subjective social status (which can be seen as sharing similarities with internal political efficacy) and subjective wellbeing among professional care workers in Israel (Ayalon, 2008) and informal caregivers in UK (Victor et al, 2021). The bivariate analysis in study 3 showed a correlation between political internal efficacy and subjective caregiver burden, but the relationship disappeared in the multivariate analysis.

5.3. Research questions 3a–b

How is an intervention focusing on peer support utilising previous experiences of informal caregiving experienced by the participants? (Article IV)

The analysis of the focus group interviews revealed mostly positive effects on the expert caregivers' well-being, such as meaningfulness and a sense of belonging with the other participants, most of whom were older bereaved spouses. The expert caregivers not only used their personal past as informal caregivers as an asset in the volunteering activities but also took advantage of other personal skills. The participants reported high levels of SOC and SLWS throughout the intervention, although no statistically significant differences were found across the three time points of the study. Risks of (but not experienced) adverse effects were noted in terms of, for example, demanding peer support clients and/or malfunctioning peer support relationships, and therefore the need for continuing support from intervention facilitators was stressed. The results, in terms of the main positive impact but also the risks of adverse effects, are in line with previous findings on similar interventions targeting former caregivers. In a Norwegian study (Halvorsrud et al., 2020), the trained peer supporters appreciated using their past as a resource but also experienced the need to safeguard their free time and set limits. Emotional gains and new social contacts were reported as positive effects of a peer support programme in England, while the participants also highlighted the role of timing of transitioning into the peer supporter role (Brooks et al., 2014).

As outlined in subchapter 3.2, former caregivers may have lost important social contacts while providing informal care for years, as social isolation is a common issue among informal caregivers (Hajek, Kretzler & König, 2021). Most of the informal care dyads interviewed for studies 1 and 2 seemed to spend their days rather alone, partly due to their adult children being busy working and taking care of their own children and/or living far away. In addition, care expectations from adult children to old parents are low among Finns (Verbakel, 2018), and perhaps, therefore, the NGOs' role in organising social and peer support activities in Finland can be seen as important. Such relationships, however, often end when informal care ends, as current caregivers are prioritised target groups. Given the emotional and burdensome experience that informal care can be (Van Aerschot et al, 2021; Van Aerschot et al, 2022a; Tikkanen, 2016; Sointu, 2016), former caregivers may face barriers to engage in 'normal' social life after informal caregiving has ended, even though the practical opportunities suddenly re-emerge. The participants in the intervention mentioned that they appreciated the intervention because it offered them, as mainly bereaved caregivers, an appropriate social context.

What is the demand for such an intervention, and how can it be successfully co-designed in the region of Österbotten/Pohjanmaa, Finland? (Article IV)

The findings implied that the intervention was feasible as it resulted in a co-designed (Bjögvinsson, Ehn & Hillgren, 2012) training course consisting of 30 hours with 25 participants enrolling and 19 of them trying volunteering activities. The trained "expert caregivers" reached 69 unique informal caregivers.

Much of the success of the intervention is to be explained by the co-design method (Bjögvinsson, Ehn & Hillgren, 2012), where local stakeholders were engaged throughout the entire process to enable local needs to be matched with local resources. The NGO involved in the intervention was a main contributor to the success of the intervention, as already established contacts to former caregivers were established and thus easily recruited. By further utilising the existing regional infrastructure and co-operation between actors for informal caregivers, the intervention was relatively easily implemented.

The intervention had to be adapted to COVID-19, leading to most of the volunteering activities being rearranged and provided via telephone or video calls. The intervention was therefore prolonged by six months from the initial plan. Teaching the participants how to use digital devices required extra resources, but at the end of the intervention, almost all participants used digital devices and experienced that they worked well. A few participants estimated that face-to-face peer support would have been even more effective. Research (e.g. Bergmann & Wagner, 2021) has shown that informal caregivers (and recipients) were especially affected and vulnerable during the COVID-19 crisis, which could be seen as contributing to the expert caregivers being especially useful for supporting informal caregivers during this time.

6. Conclusions, strengths, limitations, and implications

In this chapter, the main conclusions, strengths, and limitations of the thesis are outlined and finally, policy implications and future research directions are presented.

6.1. Conclusions

The overarching aim of this thesis was to contribute to a nuanced understanding of informal care from a well-being perspective by focusing on the Finnish context. This was done by including the perspectives of former caregivers, current caregivers, and care recipients and by using mixed methods to investigate different aspects of well-being.

The different theoretical perspectives on well-being were placed in multi-dimensional demographic, social, economic, and political contexts (Figure 1). These contexts are interlinked with each other and shape the well-being of those concerned with informal care in both direct and indirect ways. The demographic, economic and political developments can be seen as more related to external factors shaping well-being. The social context is partly related to intrinsic factors in terms of norms and values, although such factors are also connected to other societal development. Well-being is a complex phenomenon, and depending on its definition and study population, the role of the social, political, demographic, and economic context might differ. As seen in the results of this thesis, the Finnish social policy system entails both barriers and facilitators to experiencing well-being of older adults who provide or receive informal care, or among those who are former caregivers. The pathways from macro-level decisions to meso-level implementations and individual uptake are complex as visualised, especially in Study 2. These findings corroborate previous research on the complex connections and differences between social policy and lived realities among those concerned by informal care (Ringo, 2021; Sointu, 2016). For example, the Finnish social policy system offers important support services and benefits that are important for the informal care dyads' well-being, but the care system, in many cases, presumes health literacy and neutral assessment that are not necessarily reflected in the realities of an informal care dyad, typically two spouses.

Furthermore, the social policy system and its local service gatekeepers are regulated by priorities and scarce resources, which leads to informal care dyads' needs and wishes not always being met when they seek help. Experiences of poor-quality support or being denied services may also affect the care dyad's future care-seeking behaviour, as seen in Study 2. This ultimately challenges the capability to age at home. The results of care-seeking and accessing have a rather direct impact on the care recipient's ability to have their needs met, which affects the subjective and objective burden of the caregiver (Pearlin et al., 1990; Van Aerschot, Eskola & Aaltonen, 2021: Van Aerschot et al, 2022a). It can be claimed that the relational dimension of the dyads' care-seeking behaviour and agency constitutes a barrier to the care dyad's well-being in some respects while simultaneously promoting other dimensions of well-being. For example, informal care was experienced as meaningful and the preferred alternative for a wide range of reasons relating to the shared life history and to the experienced lack of other good options, as shown in study 1 and 2. Simultaneously, relational aspects also hindered care-seeking and led to the caregiver sometimes exceeding his or her powers. These findings are corroborated by previous research (Van Aerschot, Eskola & Aaltonen, 2021; Sointu, 2016; Tikkanen, 2016).

It is not only the support services directed to informal care dyads that shape their well-being. The overall development in social care for older adults also has an indirect impact on the well-being of informal care dyads, as it affects feelings of security regarding future care arrangements when informal care will no longer be a possible care alternative. Recent international studies have indeed found associations between caregivers' well-being and the generosity of formal long-term care systems (e.g. Wagner & Brandt, 2018). The Finnish welfare system offers quite generous formal social care and support for informal care in comparison to other care regimes (Verbakel, 2018; Zigante, 2018; Saraceno, 2016), but it has become more fragmented since the 1990s, partly due to austerity measures and increasing marketisation mechanisms such as split purchaser/provider models (Kröger, 2019). Inequalities have been found in terms of care needs (Hannikainen, 2018) and service use (Van Aerschot, 2014; Mathew Puthenparambil, Kröger & Van Aerschot, 2015). This motivates the study of potential inequalities in subjective well-being in informal care as well. In Study 3, inequalities were not identified in terms of spousal caregivers' personal income, although experiencing financial strain did indicate subjective caregiver burden. Financial strain can be seen as better assessing the situation of the household, and such a dyadic perspective would be feasible to use in future studies.

The findings of this thesis can be placed in the ongoing 'care crisis' in Finland and elsewhere (Tronto, 2017), where difficulties in recruiting and maintaining workers in social and health care are increasing (Kangas, 2022) simultaneously as Finland is facing an economic recession (Bank of Finland, 2022). The issue of care workers having many clients and little time to actually provide care (Kröger et al., 2018; Olakivi et al., 2021) thus seems to affect not only the well-being of informal care dyads (Van Aerschot et al, 2022a; Van Aerschot, Eskola & Altonen, 2021); but also, the care workers (Van Aerschot et al, 2022b). Joan Tronto (2017) is one of the scholars who believe that piecemeal adjustments are not going to solve a care crisis; rather, she proposes a caring democracy where care and human bonds are seen as the core of society. What could this mean in the Finnish case, and what would it mean for informal care and well-being? A more caring society would allow for more time for social interactions and a deeper recognition for care needs among all citizens and across all sectors. With an ageing population and a pressed national economy, allowing more resources for bonding between care workers, informal caregivers and care recipients seem utopian. A re-evaluation of the meaning of 'care' and thus relationships could, however, pave the way for until now unrecognised resources (e.g. former caregivers, as seen in Study 4) and potentially result in enhanced well-being of those concerned by informal care either in personal or professional life. More time for care and building relationships in the care sector would also make it more likely that a 'co-partnership' between service gatekeepers/care workers and informal caregivers would at all be possible. In Finland, it would be relatively easy to implement a more caring society due to already existing infrastructure in social and health care.

6.2. Strengths and limitations

Next, I will discuss the strengths and limitations of the four studies and the thesis as a whole. A more detailed description of each study can be found in the appended articles.

During the data collection for Study 1, the informal caregiver was present in some interviews with the care recipient. It cannot be ruled out that information was left out or altered as a result.

All contacts for Study 1 (and thus Study 2) were recruited through an NGO, meaning that the informal care dyads engaged in social activities. This indicates that the interviewed informants live a somewhat socially integrated and active lifestyle that does not represent the everyday lives of all informal care dyads. Similarly, the interviewed care dyads were encompassed by public support, which is not the case for all informal care dyads (Ministry of Social Affairs and Health, 2019).

Studies 1 and 2 are based on subjective experiences of informal care, and the results cannot be claimed to represent all informal care dyads. This is especially so as people with memory disorders were excluded, despite cognitive decline being a common health condition of informal care recipients encompassed by the ICA (STM, 2019) and generally seen as the most burdensome caregiving context (Adelman et al., 2014; Schulz et al., 2020). Furthermore, the informal care dyads included in this thesis seemed to have a history of a close and warm relationship, which is not always the case (Barnes, 2006). Informal care dyads with healthy relationships can be seen as more likely to participate in research. It is important to note, however, that such informal care dyads only represent parts of a wider picture.

In Study 3, quantitative methods were used to explore the role of individual resources in subjective caregiver burden in two Nordic regions. One limitation includes missing details on the objective caregiver burden (Pearlin et al., 1990), such as caregiving hours. The caregiver receiving formal support was used as a rough estimation of care intensity; still, many caregivers provide intensive care without seeking or receiving formal support. Another limitation includes assessing subjective caregiver burden using only one item, although multi-item scales are often used (Elmståhl, Malmberg & Annerstedt, 1996; Zarit, Reever & Bach-Peterson, 1980). This makes the results less comparable to those of other studies. Finally, the cross-sectional design of the study does not allow for determining a cause-effect relationship between subjective caregiver burden and resources.

In Study 4, the feasibility of the expert caregiver intervention in Österbotten was assessed by using mixed methods. Limitations include a small sample size and the absence of results from a control group. Questionnaires and focus group interviews were collected and held on-site, which could affect the validity of the data, as the respondents may have been influenced by other present participants. The implementation of the intervention was affected by the COVID-19 pandemic, as some of the volunteering opportunities were offered digitally instead of face-to-face. The COVID-19 pandemic also resulted in a relatively low number of focus group interview participants. Only participants who had tried volunteering participated in the focus group interviews, contributing to a lack of qualitative data collected from participants who chose not to try volunteering. Finally, the dual role of the focus group interviewers in terms of both researchers and intervention facilitators can also have affected the informants' answers in the focus group interviews.

In this thesis, well-being was placed in demographic, social, economic and political contexts. These contexts largely focused on the prerequisites and conditions for managing care arrangements with regard to both social care and support for informal care in a Finnish context and how this might affect well-being among those concerned by informal care. The interview guides in used for study 1 and 2 included questions about care. It is possible that the impact of care arrangements for the participants' well-being was overly emphasised because of the chosen focus in the interview guides. However, it can be deemed likely that everyday life (and well-being) revolves around care arrangements in this study population because of the documented frail health of Finnish ICA-care recipients (STM, 2014; 2019).

A strength of this thesis is the inclusion of different target groups concerned with informal care, as well as the use of different well-being theories to shed light on different aspects of informal care and well-being. A major methodological strength is the use of both quantitative and qualitative methods, thus contributing evidence on both associations and in-depth experiences. The longitudinal analysis of macro-, meso- and micro-level changes for the understanding of well-being in Study 2 contributes methodologically to the research field on older adults with care needs. Further strengths of the studies include close cooperation and discussion with established researchers throughout every step of the research process.

6.3. Implications for policy and future research

The findings of this thesis have shown that older informal care recipients appreciate living at home with their informal caregiver not only due to their personal shared life history but also due to partly negative experiences and/or conceptions of other formal care options. The latter affects the care recipients' (and caregivers') well-being not only objectively but also in terms of their sense of security. Therefore, when investigating how to support the well-being of informal care dyads, the focus should be not only on the support directed to them but also on the overall care system. Further, while informal caregiving may contribute to several aspects of subjective well-being, extensive care needs require shared responsibilities to ensure well-being (both for the caregiver and the care recipient). Indeed, older informal care recipients often have a multimorbid complex health status, and the dyads are forced to use multiple resources and coping mechanisms to manage their everyday lives that are prone to change. The current care system emphasising autonomy and self-determination is, in practice, applied to informal caregivers who have emotional ties with the care recipient and therefor may face difficulties in making objective decisions regarding care. Informal care dyads often lack influence in their care negotiations with service gatekeepers and consequently struggle to cope if their needs are not met. Simultaneously, informal care dyads may not always seek help when needs arise and/or increase. Unmet needs challenge the ability to continue to live at home and continue with informal care, and it is therefore important to acknowledge the consequences of any unmet need for the both the caregiver's and care recipient's subjective and objective well-being. Altogether, these findings support policy development that embraces a holistic and dyadic evaluation of informal care dyads and regular evaluations of the current life situation. Furthermore, it would be important to establish 'co-partnership' between informal care dyads and service gatekeepers, but this is unlikely to occur unless resources are invested in establishing trust and bonds between the dyad and the formal sector.

Given the multiple actors and service providers needed in a complex care situation, innovative models for enhancing co-operation between the public sector, private market, third sector, informal care dyads and other informal resources should also be further investigated and tested. The possible substitutionary or complementary mechanisms among users of care in the welfare mix should also be investigated to make sure that older adults are not increasingly being divided into those who succeed in managing the fragmented care system and those who do not, possibly depending on the availability of individual resources (either informal care resources, financial resources, or cognitive resources).

This thesis explored the feasibility of a co-designed intervention targeting former caregivers, which is an overlooked target group in both research and practice. The intervention, which resulted in a new support form for current caregivers utilising former caregivers, was easily co-designed and implemented due to the pre-existing infrastructure for support for informal caregivers. This infrastructure includes both public authorities, NGOs, and congregations in Finland. The inclusion of several welfare actors as well as the concerned target group created a solid foundation for an intervention where resources and needs were met. This is a promising finding for future interventions.

More qualitative longitudinal research should be done to explore how care is managed and chosen in the light of well-being for both older adults with care needs and their next of kin and to investigate how the two perspectives are interlinked but potentially also conflicting. Longitudinal quantitative studies can assist in both identifying risk factors and promoting factors for different aspects of well-being. Such studies could further investigate potential ethnolinguistic differences both among the official national language groups in Finland but also among informal care dyads with immigrant background.

Lastly, interventions influenced by care ethics and thus a greater recognition of social aspects of care, and well-being, could be tested to see what effects they have on a range of factors—public expenditure, health, work satisfaction and sick leave—among both care recipients, informal caregivers and formal care workers and service gatekeepers. While market-based rationality and care rationality differ in their logic, it should not be ruled out that a more caring society could also bring results in terms of, for example, cost efficacy in the long run.

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Appendix: Declaration of author contributions

Each article is the result of a collaboration between Åkerman and different authors. Åkerman has been the first and corresponding author in all four studies.

In Study 1, Åkerman collected the interviews, analysed the data and drafted the article, while Nyqvist and Nygård contributed to the manuscript by providing critical reflections and suggesting revisions and references.

In Study 2, Åkerman and Nyqvist collected the data. Åkerman conducted the analysis of the data and drafted the article, while Zechner, Nyqvist and Nygård provided critical reflections and added comments and references. Åkerman and Zechner drafted the discussion.

In Study 3, Åkerman drafted the article, while Nyqvist and Nygård contributed to the process with comments and reflections in all sections of the manuscript. Åkerman conducted the statistical analyses with close guidance from Nyqvist and Nygård.

In Study 4, Åkerman drafted the article, while Nyqvist, Coll-Planas and Wentjärvi contributed to the process with comments and reflections in all sections of the manuscript. Åkerman and Nyqvist conducted the statistical analyses, while Åkerman conducted the analysis of the qualitative data.

Articles

Åkerman, S., Nyqvist, F. & Nygård, M. (2018). ”Man får hjälp då man behöver” - äldre närståendevårdtagares vårdval ur ett livsloppsperspektiv. *Gerontologia*, *32*(2), 102–114. https://doi.org/10.23989/gerontologia.66720

”Man får hjälp då man behöver” – äldre närståendevårdtagares vårdval ur ett livsloppsperspektiv

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Privatiseringens, marknadiseringens och närståendevårdens betydelse ökar i den finländska äldreomsorgen. Det finns ett behov av att studera hur förändringarna påverkar vårdtagare och anhöriga. Temat för den här artikeln är närståendevårdtagares vårdval. Enligt livsloppsperspektivet ses åldrande som en livslång process. Ett livslopp påverkas av de begränsningar och möjligheter som styr individens val och handlingar i en specifik historisk och social kontext. I studien har sju vårdtagare intervjuats med kvalitativa semistrukturerade intervjuer. Syftet var att studera äldre närståendevårdtagares vårdval ur ett livsloppsperspektiv. Studiens frågeställningar var: hur kan bakgrunden till närståendevårdtagarnas vårdval förstås ur ett livsloppsperspektiv? Vad har vårdtagarna för tankar om framtiden? Resultaten visade att valet av närståendevård upplevdes som naturligt, dels som en följd av den nära relationen till vårdaren och dels på grund av delvis negativa attityder till formell äldreomsorg. Vårdtagarna oroade sig för närståendevårdarens hälsa och framtida vårdarrangemang. Studien bidrar med kunskap om äldreomsorgen ur vårdtagares perspektiv.

Inledning

Den demografiska utvecklingen i kombination med politiska och ekonomiska förändringar leder till att äldreomsorgen genomgår en omorganisering i Finland. Den utökade privatiseringen, marknadiseringen och betoningen på närståendevård innebär förändringar i vem som erbjuder vården och vem som finansierar den (Anttonen & Meagher 2013; Van Aerschot 2014). Dessa förändringar kan ses som ett steg bort från den klassiska nordiska välfärdsmodellen mot en mer nyliberal och konservativ modell (Anttonen & Häikiö 2011; Karsio & Anttonen 2017). Denna utveckling kommer till uttryck bland annat i form av större satsningar på närståendevård. Den ökade betoningen på närståendevård kallas ibland för refamilisering, vilket avser förskjutningen av vårdansvaret för äldre från offentlig äldreomsorg tillbaka till familjerna. Refamiliseringen sker efter en längre tids omfattande, universell och offentligt producerad äldreomsorg som byggts upp från 1950-talet fram till 1990-talet, då nedskärningar började i Finland (Anttonen 2009). Den offentliga sektorn är fortfarande omfattande, men de närståendes roll antas växa allt mer då service skärs ner trots att andelen äldre ökar (Van Aerschot 2014). Majoriteten av äldre föredrar dock offentliga tjänster framom anhörigas hjälp (Van Aerschot 2014; Vilkko m.fl. 2014).

Inom den nordiska äldreomsorgen tycks det tidigare sociala medborgarskapet med universella sociala rättigheter ha fått ge plats för ett aktivt medborgarskap, där ledord såsom ansvar, valfrihet och självbestämmanderätt dominerar diskussionen (Anttonen & Häikiö 2011). Man utgår från att äldre vill och kan planera sin vård själva efter sina behov. Den kritik som har förts fram mot ett sådant synsätt är bland annat att denna sorts äldreomsorgspolitik lämpar sig för äldre som är friska och ekonomiskt välbärgade, men att den däremot inte är lika anpassad för andra grupper av äldre. Häikiö, Van Aerschot och Anttonen (2011) konstaterar att det faktum att många äldre befinner sig i en fysiskt, socialt och ekonomiskt mer utsatt position än andra samhällsgrupper förbises i den nya diskursen om det aktiva medborgarskapet. Det finns äldre som saknar förmågan att planera sin egen vård och service. Valfriheten har också ifrågasatts eftersom valet många gånger enbart står mellan privata aktörer och anhöriga som en följd av nedskärningar i den offentliga omsorgen. Forskning från Sverige (Ulmanen & Szebehely 2015) visar att informell vård ökar speciellt i lägre samhällsklasser. Det skapar i sin tur en dubbel ojämlikhet, eftersom vårdbehovet drabbar både vårdtagaren och dennes anhöriga. Forskarna poängterar ändå att anhörigas insatser har ökat i alla samhällsgrupper som en följd av nedskärningar.

Enligt en enkätundersökning i Finland utförd bland 75 år fyllda och äldre hemmaboende ansåg 14 procent av de äldre att de inte fick tillräckligt med hjälp och service. Av dessa 14 procent ansåg 38 procent att orsaken till att de inte fick tillräckligt med hjälp var höga servicekostnader, medan knappt en tredjedel upplevde att själva anskaffningen av hjälp var komplicerad (Van Aerschot 2014, s. 128). Enligt en annan studie utförd i Finland baserad på samma enkätundersökning visade resultaten att det främst var äldre med högre utbildning, ekonomi och bättre hälsa som använde sig av privata hemvårdtjänster, medan äldre med svagare ekonomi, lägre utbildningsgrad och sämre hälsa använde offentlig hemvård. De äldre som var mest sjuka använde en kombination av privata och offentliga tjänster, vilket väcker frågan huruvida offentlig service inte längre räcker till för omfattande vårdbehov (Puthenparambil, Kröger & Van Aerschot 2015).

I forskning om närståendevård har uppmärksamheten hittills varit riktad främst på vårdarnas situation, medan vårdtagarnas upplevelser är ett mindre utforskat område (Zechner & Valokivi 2009). Vårdtagare ses ofta som passiva objekt trots att även vårdmottagande är en aktiv handling (Twigg 2000; Dunér 2007). Att behöva vård innebär att en individ inte klarar sig själv utan hjälp. Behovet leder till att den vårdbehövande måste förhandla och påvisa sitt beroende av hjälp, vilket kan upplevas som motstridigt i dagens samhälle där självständighet är en rådande norm. En studie om äldres vårdpreferenser i en svensk välfärdskontext visade att deltagarna inte ville vara en börda för varken samhället eller anhöriga (Gunnarsson 2009). En annan studie om äldres vårdpreferenser i Sverige visade att deltagarna var rädda för att förlora sin identitet och värdighet genom att bli beroende av hjälp från vårdare som inte känner dem (Harrefors, Sävenstedt & Axelsson 2009).

Syftet med denna artikel är att lyfta fram en viktig aspekt i utvecklingen av den finländska äldreomsorgen genom att studera äldre närståendevårdtagares upplevelser av sina vårdval. Frågeställningarna är: hur kan bakgrunden till närståendevårdtagarnas vårdval förstås ur ett livsloppsperspektiv? Vad har vårdtagarna för tankar om framtiden? Vi använder livsloppsperspektivet som en teoretisk referensram för att analysera hur vårdtagarnas vårdpreferenser kan kontextualiseras i deras livslopp. Vi utgår från att närståendevård är en unik vårdform dels för att vårdformen ofta baserar sig på ett nära förhållande vårdtagaren och vårdaren emellan som sträcker sig över tid, och dels för att närståendevård är en form av vård där en icke-vårdutbildad anhörig ingår ett vårdavtal med kommunen.

Oss veterligen har fokus inte varit på vårdpreferenser i tidigare kvalitativ forskning om närståendevårdtagare i Finland. Vi känner inte heller till att livsloppsperspektivet skulle ha tillämpats i forskning om närståendevård i Finland. Närståendevård finns i alla åldersgrupper, men vår studie är avgränsad till äldre vårdtagare som vårdas av i huvudsak äldre närståendevårdare.

Teoretisk referensram och centrala begrepp

Vi vill med vår studie tillföra kunskap om närståendevård genom att inkludera en hittills relativt outforskad målgrupps perspektiv, nämligen vårdtagarnas. Livsloppsperspektivet möjliggör att vi kan förankra deras erfarenheter i ett dels subjektivt livslopp, en dels gemensam historia vårdtagaren och vårdaren emellan och slutligen i en samhällelig kontext där de jämnåriga deltagarna i studien representerar en generation som upplever liknande historiska skeenden under samma livsperiod. Vi vill särskilt studera hur äldreomsorgens utveckling och utformning idag influerar vårdtagarnas vårdval.

Inom den socialgerontologiska forskningen har livsloppsperspektivet fått ett allt större genomslag (Alley, Putney, Rice & Bengtson 2010). Teorin möjliggör studier av en individ eller en kohort i en kontext som sträcker sig över tid. Livsloppsperspektivet har tillämpats speciellt i kvantitativ longitudinell forskning, men även i till exempel kvalitativa livsberättelser (Mayer 2009). Enligt Elder Jr., Kirkpatrick Johnson och Crosnoe (2003) finns det fem viktiga principer att utgå från i livsloppsperspektivet. Åldrande och utveckling ses som en livslång process (*life-span development*), där individer agerar och gör val inom ramen för de möjligheter och begränsningar som den historiska och sociala kontexten omfattar (*agency*). En individ påverkas av tid och plats (*time and place*) och i vilket skede viktiga vändpunkter inträffar (*timing*). En individs livslopp påverkar och påverkas av andras livslopp (*linked lives*). I vår studie utgår vi inte från principerna i detalj, utan väljer att betrakta livsloppsperspektivet som en övergripande förståelseram för att studera vårdtagarnas vårdval.

Närståendevård

Enligt finländsk lagstiftning definieras *närståendevårdare* som ”en närstående till den vårdbehövande eller någon annan som står den vårdbehövande nära och som ingått ett avtal om vård” (Lag om stöd för vård 937/2005). I artikeln inkluderar vi även vårdare utan avtal i begreppet närståendevårdare. Avtalsbaserad närståendevård omfattar tjänster såsom vårdarvode, ledighet, pensions- och olycksfallservice samt socialservice för vårdaren. Vårdarvodets storlek varierar mellan kommuner och beroende på vårdbördan som delas in i olika klasser. År 2017 varierade minimivårdarvodet mellan 392,00–926,80 euro (SHM 2016a). Närståendevårdare med avtal har rätt till minst två dagars ledighet i månaden.

Enligt en undersökning om avtalsbaserad närståendevård i Finland år 2012 var ungefär 70 procent av vårdarna kvinnor. Ungefär hälften av vårdarna vårdade sin make/maka. Över hälften av vårdarna hade fyllt 65 år, medan en fjärdedel hade fyllt 75 år. Av vårdtagarna hade 67 procent fyllt 65 år. Både äldre vårdare och äldre vårdtagare var med andra ord i majoritet. I Finland uppskattas 350 000 vara närståendevårdare, medan enbart cirka 40 500 av dessa har ett vårdavtal (SHM 2014, s. 21–23).

Avtalsbaserad närståendevård besparar de finländska kommunerna cirka 1,3 miljarder euro i året i jämförelse med om samma vårdbehov skulle ha tillgodosetts på annat sätt i offentlig regi. Social- och hälsovårdsministeriet [SHM] har som målsättning att utöka närståendevården från nuvarande ca 40 500 till 60 000 fram till år 2020 (SHM 2014, s. 11). Närståendevård är ett område som statsminister Juha Sipiläs regering vill satsa på i de rådande åtstramningstiderna. Regeringen har beviljat ett nationellt spetsprojekt (2016–2018) 30 miljoner euro för att utveckla närståendevården och äldres hemmaboende. Projektets målsättningar är bland annat att starta upp så kallade närståendevårdcenter, främja närståendevårdares möjligheter att ta ut ledigheter och erbjuda hälsoundersökningar för närståendevårdare (SHM 2016b).

I Finland visar en undersökning om avtalsbaserad närståendevård att uppskattningsvis 26–46 procent av vårdtagarna skulle få institutionsvård om de inte hade en närståendevårdare (Linnosmaa, Jokinen, Vilkko, Noro & Siljander 2014, s. 15). Den stora vårdbördan och det faktum att enbart hälften av närståendevårdarna tar ut sin lagstadgade ledighet innebär en risk för utmattning. Många närståendevårdare önskar hemlik avlösarservice, men ofta erbjuds enbart kortvarig institutionsvård för vårdtagaren under närståendevårdarens ledighet. Det ekonomiska stödets storlek, tillgång till stödet samt andra stödtjänster för närståendevård varierar beroende på kommun (SHM 2014). Samtidigt finns det förhoppningar om att den planerade social- och hälsovårdsreformen ska utjämna ojämlikheterna mellan kommunerna (Vård- och landskapsreformen u.å.).

Metod och material

Studien är en avgränsad, omarbetad version av en magisteravhandling vars syfte var att studera äldre vårdtagares upplevelser av närståendevård och åldrande genom att tillämpa livsloppsperspektivet och den sociala utbytesteorin. Den här artikeln, vars data härstammar ur ovan nämnda avhandling, är en fallstudie som baserar sig på kvalitativa intervjuer (Esaiasson, Gilljam, Oscarsson & Wägnerud 2007). Kriterierna för deltagande i studien var svenskspråkiga äldre över 63 år, som inte led av minnessjukdomar och som vårdades av en närstående antingen med eller utan vårdavtal. Urvalet gjordes av en kontakt vid Folkhälsan, som är en allmännyttig social- och hälsovårdsorganisation verksam i hela Svenskfinland (Folkhälsan u.å.).

Informanterna var i åldern 71–80 år och alla utom en informant vårdades av närståendevårdare med vårdavtal. Fem av informanterna var kvinnor och två var män. Fem av sju vårdades av sin make/maka. En informant blev vårdad av sitt syskon, medan en annan vårdades av både sin partner och sin dotter. En informant bodde på servicehus och de övriga i egna hem. En informant vistades regelbundet på en bäddavdelning för att avlasta närståendevårdaren, medan en annan informant vistades på en bäddavdelning någon gång i året. Tre informanter fick hemvårdtjänster i varierande utsträckning. Fyra av informanterna bodde på landsbygden och tre i stadsmiljö.

Vårdperiodens längd varierade mellan 3 och 51 år. Makarna hade varit gifta mellan 50 och 60 år. Samtliga informanter bodde tillsammans med sin vårdare, förutom i det fall där informanten blev vårdad av både sin partner och dotter, där enbart partnern bodde tillsammans med informanten. Orsaken till informanternas vårdbehov varierade, men inkluderade till exempel stroke, förlamning, synskador och nedsatt balanssinne. Intervjuernas längd varierade mellan 35 och 88 minuter. På grund av informanternas nedsatta funktionsförmåga utfördes samtliga intervjuer i deras hem. Det visade sig vara svårt att intervjua informanterna utan närståendevårdarens närvaro vilket kan tänkas påverka resultaten i viss mån. Informanten verkade i en del fall känna sig tryggare ifall närståendevårdaren närvarade, och en del informanter oroade sig för att inte kunna svara ”rätt” på frågorna. Fyra av intervjuerna skedde därför i närståendevårdarens närvaro i varierande utsträckning. Närståendevårdarens kommentarer har inte använts i analysen.

I studien utfördes sju kvalitativa semistrukturerade intervjuer, vilket innebär att forskaren följer en intervjuguide samtidigt som följdfrågorna och ordningsföljden på frågorna anpassas efter informantens svar (Bryman 2011). Intervjuerna bandades in och transkriberades kort efter intervjutillfället, vilket är i enlighet med Kvale och Brinkmanns (2009) rekommendationer. Materialet analyserades med hjälp av kvalitativ innehållsanalys i dataprogrammet NVivo10. I analysen tillämpades främst en induktiv ansats där materialet styrde kategoriseringen (Kvale & Brinkmann 2009), men vissa deduktiva inslag ingick eftersom intervjuerna kretsade kring tre huvudkategorier: *vård, livslopp* och *reciprocitet.* Frågorna kretsade kring till exempel informanternas bakgrund, deras relation till närståendevårdaren, för- och nackdelar med att få närståendevård samt vårdtagarens förmåga till reciprocitet med närståendevårdaren. Underkategorierna skapades utgående från informanternas berättelser. I den här omarbetade studien är syftet och frågeställningarna inte de samma som i magisteravhandlingen och utgör därmed en sekundär analys. Kategoriseringen skedde efter flera genomläsningar av intervjuerna och efter diskussion mellan intervjuaren och en annan forskare.

Informanterna deltog i intervjun frivilligt. De blev tillfrågade av kontaktpersonen på Folkhälsan och gav därefter tillåtelse att överlämna sina kontaktuppgifter till intervjuaren. Vi har säkrat informanternas anonymitet genom att exkludera kännspaka uttryck eller ord och genom att exkludera namn på orter eller personer[1]. För studien behövdes inget etiskt tillstånd sökas. Makar och kvinnliga vårdtagare är överrepresenterade i den här studien, medan vårdtagare med minnessjukdomar är exkluderade trots att det är en vanlig grupp vårdtagare i närståendevård (SHM 2014). Denna skevhet i representationen av äldre närståendevårdtagare samt det ringa antalet informanter innebär att resultaten inte bör generaliseras. Istället bidrar denna fallstudie med subjektiva upplevelser av en hittills relativt outforskad målgrupp, det vill säga närståendevårdtagare.

Livsloppsperspektivet används i analysen som ett redskap för att förstå materialet, men teorin användes också i intervjuguiden genom att till exempel be respondenterna berätta om sitt liv. Intervjuguiden inkluderade den direkta frågan om varför vårdtagarna valt närståendevård istället för någon annan vårdform, men det är främst från svaren på övriga frågor som analysen härstammar. Genom att dels studera vårdtagarnas bakgrund, dels den samhällsutveckling som vårdtagarna som generation upplevt samt speciellt genom att inkludera dagens äldreomsorg som en kontext, har vi analyserat vårdtagarnas resonemang kring sina vårdval utgående från livsloppsperspektivet. Vi utgår från att det levda livsloppet påverkar äldre individers vårdval genom normer, värderingar och resurser i form av ekonomi, den anhörigas ork och boendemiljö, samtidigt som livsloppet utspelar sig i ett visst samhälle med specifika möjligheter och begränsningar. Alla dessa faktorer bildar tillsammans en kontext för vårdtagarnas val och handlingar gällande sina vårdarrangemang. Livsloppsperspektivet möjliggör att vi kan förstå subjektiva upplevelser om hur äldre vill bli vårdade och vilka valmöjligheter de upplever sig ha.

Resultat

Underkategorier som tas upp i den här omarbetade analysen är: *ohälsa som en gemensam vändpunkt, närståendevård som ett självklart val* och *framtidens ovisshet.* I den första underrub-

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[1] Förkortningen ”N” används istället för närståendevårdarens namn i citaten.

riken analyseras uppkomsten av vårdbehovet och vårdsituationen som en bakgrund till vårdvalet. I den efterföljande delen analyseras valet av närståendevård med vårdtagarnas personliga motiv och speciellt den övriga äldreomsorgen som kontext. Slutligen behandlas informanternas syn på det fortsatta livsloppets vårdarrangemang.

Ohälsa som en gemensam vändpunkt

Enligt livsloppsperspektivet är det viktigt att studera viktiga vändpunkter i en individs livslopp och även att ta i beaktande *när* vändpunkten inträffat (Elder Jr., Kirkpatrick Johnson & Crosnoe 2003). Att bli vårdtagare kan klassificeras som en viktig vändpunkt i livet, även om ohälsa i hög ålder inte alltid innebär en enskild sjukdom eller plötslig händelse. Vårdbehovet kan också vara en följd av en allmänt försämrad funktionsförmåga som uppstått under en längre tid. Att bli vårdtagare som äldre är en speciell fas i jämförelse med när ett vårdbehov uppstår i andra åldrar, eftersom en äldres vårdbehov sällan förutspås försvinna (Zechner 2008). För informanterna i vår studie kan närståendevård ses som ett sätt att förlänga det ”normala” tidigare livsloppet trots en försämrad hälsa. Genom att fortsätta bo hemma och vara tillsammans med vårdaren förlängs den tidigare livsstilen i viss mån, för både vårdtagaren och vårdaren.

> Det var ju helt naturligt det att jag ville vara hemma. Inte ville jag börja ligga på någon anstalt. Det ville inte hon heller. (Informant 4)

Samtliga vårdtagare i studien behövde mångsidig hjälp i vardagen, vilket ofta är ett kriterium för att vårdtagarens anhöriga ska få ingå ett närståendevårdavtal. Hur och när vårdtagarnas vårdbehov hade uppstått varierade. För de flesta informanterna hade den allmänna funktionsförmågan försämrats gradvis, även om det ofta var något speciellt som hade utlöst vårdbehovet till exempel en stroke eller en fraktur. En respondent som slutligen blivit blind efter flera decennier av långsam försämring av synen ansåg att hon accepterade sin situation bättre än många andra synskadade eftersom försämringen skett gradvis.

För en kvinnlig respondent hade vändpunkten inträffat redan i ungdomen. Hon blev förlamad i tjugoårsåldern. Kvinnan berättade att hon i början trodde att förlamningen var temporär men att den sedan visade sig vara bestående. Denna kvinnas livslopp skiljer sig därmed markant från de andra vårdtagarna eftersom hon varit vårdtagare i merparten av sitt liv.

> N jobbade men han hade ju mig sedan, nätter och… Och han har inte skilt sig (skratt). Konstigt. Fast de skiljer sig allihop. (Informant 1)

Kvinnans tacksamhet över att närståendevårdaren inte velat skilja sig trots alla år som vårdare framgår i citatet ovan. Vårdtagarens ohälsa innebär nämligen stora förändringar också för den anhöriga som bland annat får en ny roll som närståendevårdare. Rollen kan komma stegvis eller plötsligt men oavsett påverkas parternas tidigare rutiner och gemensamma livsstil av vårdbehovet. En informant beskriver den förändrade vardagen som något varken hon eller närståendevårdaren kunnat förvänta sig.

> Och sen när N hör att jag smäller, så då vet han ju att jaha, nu ligger jag på golvet. Så då kommer han och lyfter upp mig. Men att de här sista åren skulle vara så här eländiga så det har nog varken han eller jag fantiserat. (paus). För att vi har ju varit väldigt aktiva. (Informant 5)

Närståendevård som ett självklart val

Närståendevård som vårdform upplevdes av vårdtagarna som ett självklart val: ett val som inträffat så gott som automatiskt. Att vårdtagarna upplevde valet som naturligt uttrycktes bland annat i form av att en del respondenter upplevde att det knappt behövdes någon förklaring till varför man valt vårdformen. Liknande resultat återfinns i Miettinens (2012) studie om vårdstrategier bland föräldrar som är närståendevårdare till vuxna barn med intellektuella funktionsnedsättningar. Miettinen (2012) konstaterar att bakom upplevelsen av det ”naturliga” med närståendevård återfinns ofta normer såsom till exempel det finländska samhällets förväntningar på att föräldrar tar hand om sina barn. Normen förstärks ytterligare i och med bristande offentlig servicestruktur.

Att vårdtagarna i vår studie hyser normer om att det hör till att ställa upp för varandra syns i en kvinnlig vårdtagares berättelse om hur hennes make initialt inte ville bli kallad för ”vårdare” trots att han inte hade något emot att utföra själva vården. Han ville hellre utföra omsorgen utan hjälp utifrån. Till sist gick mannen med på att ingå ett närståendeavtal med kommunen efter vårdtagarens påtryckningar i kombination med ekonomiska skäl.

> Det var kanske för det där med hjälp utifrån, men också p.g.a. ordet, vårdare. (skratt). Men jag sa att han måste ju iallafall hjälpa hela tiden, han måste handla och ska någonting ut, det är ju han som gör det, ja, jag vet inte. Så det var mest det där namnet. Men nu inser han att det är bra att få pengarna. För vi har ju inte så höga pensioner, utan det är ju mest det där vanliga. Man har ju inte det då man har varit själv, egenföretagare. Så nog är det bra. (Informant 3)

Informanterna är födda på 1930- och 1940-talet vilket innebär att de har växt upp i en efterkrigstid då den finländska välfärdsstaten ännu inte var uppbyggd (Anttonen 2009). En vårdtagare beskrev uppväxtåren som en tid ”då det inte fanns någonting”. En annan informant berättade att framtiden var väldigt oviss och att socialarbetet var outvecklat. Det var därför vanligt att man hjälptes åt och tog hand om till exempel äldre grannar, vilket flera respondenter hade bevittnat eller själva varit med om. Vårdtagarna i vår studie kan hysa normer om att det hör till att ställa upp för varandra, dels som en följd av den långa relationen med vårdaren men också som en följd av generationstillhörigheten och den samhällsutveckling de upplevt, inte minst gällande äldreomsorgen. Samtidigt som närståendevård sågs som något naturligt hos informanterna, var det inte något som alla tog för givet. Flera uttryckte stor tacksamhet mot vårdaren. Förut var vård- och hushållsarbete traditionella kvinnosysslor (Anttonen & Zechner 2009), men samtliga informanter var medvetna om att situationen idag är annorlunda. Både de manliga och kvinnliga vårdtagarna ville utföra hushållsarbete efter förmåga vilket vittnar om att deras attityder ändrat med åren och med situationen.

På samma sätt som vårdtagarna upplevt en tid då den finländska välfärdsstaten ännu inte var utvecklad, har vårdtagarna även sett äldreomsorgen när den varit som mest generös. De visste att hemvården tidigare var mer omfattande än den är idag. Den offentliga hemvården i Finland riktade sig på 1970- och -80-talen till en stor del av finländare över 65 år och personalen utförde både hushållsarbete och personlig omvårdnad, men sen 1990-talet har hemvården skurits ner och omorganiserats (Kröger & Leinonen 2012). Idag riktas hemvården enbart till äldre med störst vårdbehov och fokus är på personlig omvårdnad istället för hushållstjänster. Hemvården har därför blivit mer fragmenterad och det medför att äldre och deras anhöriga får koordinera sina tjänster i ett allt mer komplext system för att alla behov ska bli tillgodosedda (Anttonen & Häikiö 2011). Majoriteten av informanterna hade personliga erfarenheter av dagens hemvård och ansåg att personalen byts ut för ofta och att de har tidsbrist. En informant var missnöjd med att hemvårdspersonalen inte städar längre, eftersom det var just den biten hon mest önskade hjälp med. Hon konstaterade att besöken var väldigt korta då hennes medicinering sköttes av hemvården under en tillfällig period.

Kvinnan jämförde sin erfarenhet av hemvården med hur det fungerade då hennes förälder fick vård då servicesystemet ännu var mer omfattande.

> Ja, de var bara in och gav mig (medicinen), och pratade några ord och sen iväg. Det är ju synd, annat var det när mamma hade, de gjorde allt. (Informant 6)

En informant upplevde frustration över bristande kontinuitet i hemvården. Hon konstaterade att så fort en patrull har lärt sig rutinerna så byts patrullen ut mot en ny. På så sätt avbryts klientens invanda rutin och vardagen ändrar igen.

> Men nog förstår man ju de här närvårdarna, vad skulle de kunna och de byts så ofta. Då man har kommit in i det, då de har lärt sig och vet, så då har de ställt om någonting, de hade någon patrull kallas det som var här då i början, och när de var inne i ”rulten” så då skulle det upphöra. Så då kom jag till en annan grupp som skulle lära sig. Det tar ju tid innan de vet hur de ska göra. Somliga har inte sett liften förr och hur de ska göra med den. (Informant 1)

Informanterna jämförde ofta närståendevård med hemvård och ansåg att det fanns många praktiska fördelar med närståendevård, såsom att vårdaren visste var saker och ting fanns i hemmet och att vårdaren visste vad vårdtagaren klarade och inte klarade av. Dessutom innebar närståendevård att närståendevårdaren fanns tillhands hela tiden till skillnad från hemvårdspersonalen.

> Man får hjälp då man behöver. (Informant 2)

Förutom den ständiga tillgängligheten uppskattades också närståendevårdarens kännedom om vårdtagarens behov. En informant konstaterade att hon till sin närståendevårdare bara behövde säga ett ord så förstod vårdaren hur han skulle göra, medan hemvårdspersonalen behövde mer direktiv. De praktiska fördelarna med närståendevård kompletterades även av andra trygghetsaspekter. En informant konstaterade att hon inte skulle kunna lita på någon utomstående på samma sätt som hon litade på sin närståendevårdare, medan en annan kvinnlig informant ansåg att hon inte kunde vara sig själv i främmande vårdares sällskap.

> Så klart det är bättre om det är N hela tiden. Men han kan ju inte med såren åtminstone. Så ibland sitter man nog så vint och snett, men han får ju fixa till det han då de har gått. Så får jag vara arg på honom (skratt). (Informant 1)

I citatet ovan framgår det att informanten inte vågade säga åt den utomstående vårdpersonalen att de hade placerat henne dåligt. Istället tog hon ut sin frustration på närståendevårdaren. Samtidigt konstaterade vårdtagaren i samma citat att närståendevårdaren inte kunde hantera hennes sår, eftersom han saknade de rätta yrkeskunskaperna om hur han skulle sköta dem. Närståendevård erbjuder en annan kontinuitet i vården än vad hemvården gör eftersom vårdaren alltid är densamma, men samtidigt uttryckte flera informanter uppskattning över att vårdas av någon som var utbildad inom hälso- och sjukvård.

Framtidens ovisshet

Det fortsatta livsloppet oroade informanterna i varierande utsträckning, eftersom de visste att det var oundvikligt att vårdarrangemangen skulle behöva ändras förr eller senare som en följd av antingen vårdarens eller vårdtagarens ohälsa. En del vårdtagare försökte underlätta den anhörigas vårdbörda för att göra den nuvarande vårdsituationen mer hållbar. En informant konstaterade att hon inte ville vara till besvär mer än nödvändigt. Det innebar till exempel att hon som tyckte om levande ljus valde att inte be vårdaren tända dessa, eftersom det innebar extra arbete för honom. En annan informant uppgav att han tänkte på närståendevårdarens arbetsbörda då han åkte in på intervallvård regelbundet för att avlasta frun. När han hade varit hemma en längre tid tog nämligen hennes ork slut. Utmattning är som tidigare nämnt ett välkänt problem inom närståendevård (SHM 2014). Genom att hitta strategier för att klara sig i vardagen kan parets gemensamma livslopp förlängas.

> Det fungerar bra det här. Inte... Men... Det är ju som jag brukar säga åt N att vi ska vara snälla med varandra så orkar vi nog. Ja. Men nog är det, nog fungerar det så här. Det är ju nog turvis så att rösten är hög här. Så då kan jag ropa till och säga ”hur fan ska vi få slut på det här nu”. (Informant 4)

Flera informanter funderade på att flytta i framtiden men det upplevdes som besvärligt och något som de helst drog ut på. Samtidigt var det i flera fall redan för tungt för vårdaren att ta hand om vårdtagaren, gården och huset. Ett par hade valt att flytta tillsammans till ett servicehus för att inte behöva ta hand om egnahemshuset. På servicehuset fanns dessutom personal på plats och de använde sig av ett trygghetslarm. Det kan ses som ett exempel på en strategi som dyaderna använder sig av för att kunna fortsätta bo tillsammans. Vårdarens ork oroade informanterna, eftersom flera närståendevårdare hade egna hälsoproblem. Närståendevårdarna var dessutom jämngamla eller äldre än vårdtagarna. De flesta informanter upplevde därför att vårdarens ork redan hade blivit sämre och det väckte oro inför framtiden.

> Och N orkar inte så mycket som han orkade förut. Så tänker man ju nog att vart kommer man sedan. (paus) Inte skulle man ju vilja ligga på någon åldersanstalt. Men dit kommer jag ju då inte han orkar sköta något mer. För inte tycks jag dö, brukar jag säga (skratt). (Informant 1)

I citatet ovan där informanten å ena sidan var humoristisk och å andra sidan allvarlig, kan man tolka det som att informanten hellre skulle dö än att åka in på en institution. Rädslan för att bo på institution framgår i flera citat. Det är möjligt att äldres tankar om boendemiljö påverkas av den starka rådande kvarboendeprincipen på nationell nivå där målsättningen är att alltfler ska åldras hemma (SHM 2017). Vårdpreferenserna kan också påverkas av media och andras berättelser om dålig vårdkvalitet i äldreomsorgen (Gunnarsson 2009). Att få vård i hemmet istället för på en institution kan ses som ett sätt att behålla kontrollen och vara på sitt eget ”revir” trots att man är beroende av hjälp från andra (Twigg 2000). Pirhonen (2017) har studerat ett gott liv bland äldre vårdtagare på serviceboenden. Klienternas värdighet och identitet tryggades med hjälp av bland annat upprätthållande av livslånga vanor och beaktande av personliga önskemål, medan standardiserad behandling och resursbrist påverkade klienterna negativt. Det är troligt att deltagarna i vår studie upplever att deras identitet och värdighet är bättre tryggad i närståendevård i jämförelse med andra vårdformer, eftersom deras unika livslopp syns mera i den personcentrerade vårdformen som närståendevård är. Pirhonens (2017) studier om identitet på serviceboenden kan även kopplas till de tidigare nämnda svenska studierna om äldres vårdpreferenser där deltagarna upplevde en rädsla för att känna sig identitetslösa (Harrefors, Sävenstedt & Axelsson 2009). Beroende på boendetyp finns det även en risk för att vårdtagarna i vår studie i framtiden inte skulle kunna bo med sin vårdare längre. På det sättet skulle parets gemensamma livslopp genomgå en potentiellt ännu större vändpunkt än hittills.

Diskussion

I den här studien har äldre närståendevårdtagares tankar om sina vårdarrangemang studerats ur ett livsloppsperspektiv. Resultaten i vår studie visade att vårdtagarnas val av närståendevård påverkas av flera olika faktorer. Närståendevård innebär en förlängning av den tidigare livsstilen i viss mån då vårdtagaren får fortsätta bo hemma tillsammans med sin partner eller anhöriga trots en försämrad funktionsförmåga. Närståendevård innebär också att vårdtagaren kan lita på att få vård när hon eller han behöver det, vilket har ett samband med både den nära relationen och de praktiska arrangemangen. Vårdtagarna upplever delvis att det är naturligt att ställa upp för varandra, samtidigt som de känner en stor tacksamhet gentemot närståendevårdaren och oroar sig för dennes hälsa. Vårdtagarna är uppväxta i ett Finland där välfärdsstaten ännu inte var uppbyggd och det var vanligt att man istället fick hjälpas åt, samtidigt som de också bevittnat den finländska välfärdsstatens och äldreomsorgens glansdagar.

Den viktigaste faktorn för vårdtagarnas vårdval tycks ändå vara deras erfarenheter och/eller föreställningar av den nutida äldreomsorgen. Den formella hemvården upplevs som otrygg eftersom personalen hela tiden byts ut och har för bråttom. Institutionsvård upplevs av vårdtagarna i studien som ett ännu sämre alternativ. Det leder till en oro för framtida vårdarrangemang, eftersom vårdtagarna vårdas av jämnåriga anhöriga med begränsad ork.

Den finländska äldreomsorgen omorganiseras som en följd av demografiska och politiska krav på nationalekonomiska vårdlösningar. Närståendevård utmålas som en möjlig lösning och regeringen har som målsättning att utöka vårdformen. Äldre vårdtagare och speciellt närståendevårdtagare förbises ofta i forskning och det finns ett behov av att närmare studera omorganiseringarnas konsekvenser för dem som de främst berör. Studiens viktigaste bidrag är att lyfta fram äldre närståendevårdtagares röst, eftersom de är en relativt understuderad målgrupp. Kunskap om äldre vårdtagares situation behövs för att kunna utveckla närståendevården och annan äldreomsorg. Vård är en komplex och emotionell process för både vårdtagaren och vårdaren. Vem som utför vården och under vilka omständigheter har stor betydelse för vårdtagarens välbefinnande.

I vår studie har vi valt att tillämpa livsloppsperspektivet för att fånga och analysera äldre närståendevårdtagares resonemang kring sina vårdval. Livsloppsperspektivet har möjliggjort en förståelse av vårdtagarens bakgrund som en kontext till valet av närståendevård. Erfarenheter av äldreomsorgens utveckling har diskuterats i intervjuerna och vårdtagarna har utmålat brister i dagens formella äldreomsorg som en viktig bidragande orsak till deras val av närståendevård. Närståendevård uppfyller emellertid många andra funktioner förutom att fungera som ett alternativ till mindre lockande möjligheter. Närståendevården möjliggör i bästa fall en känsla av trygghet och kontroll, det vill säga ett sätt att förlänga det vanliga, önskvärda livet i så stor omfattning som möjligt trots att funktionsförmågan försämrats. Samtidigt är det en tidsfråga innan vårdsituationen ändras eftersom både vårdtagaren och vårdaren blir äldre och risken för ohälsa ökar. Närståendevårdtagarnas oro för framtida vårdarrangemang vittnar om problem i den finländska äldreomsorgen. Vårdtagarna som hade erfarenhet av hemvård upplevde stora brister i kontinuitet och resursomfattning. Närståendevård borde både för vårdtagares och anhörigas skull vara ett frivilligt val och inte basera sig på att den formella vården fungerar bristfälligt. Närståendevård är inte heller ett alternativ för alla äldre eftersom vårdformen förutsätter att det finns en potentiell närståendevårdare i den äldres sociala nätverk.

Subjektiva upplevelser av närståendevårdtagare kan berätta något viktigt om hur välfärden och äldreomsorgen fungerar i dagens Finland. Samtidigt går det inte att generalisera äldre finländares vårdpreferenser baserat på sju röster. Vårdtagarna i den här studien var nöjda med närståendevård och det är troligt att sådana respondenter är lättare att nå än närståendevårdtagare som är missnöjda med sin vård. Närståendevårdarens närvaro vid flera intervjuer kan ha påverkat resultaten i viss mån. I fortsatt forskning kunde närståendevårdaren och vårdtagaren intervjuas samtidigt men separat för att undvika att båda parterna oavsiktligt deltar i samma intervjutillfälle. I framtiden borde äldres vårdpreferenser och erfarenheter studeras i större utsträckning för att trygga välfärden och utveckla tjänster som motsvarar målgruppens önskemål och behov. Uppföljningsstudier kunde göras med närståendevårdtagare och/eller närståendevårdare för att studera hur livssituationen utvecklas vartefter vårdtagarens vårdbehov ändras eller närståendevårdarens hälsa försämras.

Sammanfattningsvis visade vår studie att vårdtagarna upplevde många fördelar med närståendevård, samtidigt som de hade delvis negativa erfarenheter och föreställningar av annan äldreomsorg. Vårdtagarna oroade sig för på vilket sätt de framtida vårdbehoven skulle tryggas då närståendevård inte längre är möjligt. Att studera äldres vårdval utgående från livsloppsperspektivet möjliggör en nyansrik analys och kopplar ihop individens personliga resonemang kring hur hon vill bli vårdad med äldreomsorgens praktiska möjligheter respektive begränsningar.

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NOT

Vi vill tacka redaktören och granskarna för deras kommentarer under granskningsprocessen. Vi tackar även Svenska Kulturfonden och Waldemar von Frenckells stiftelse för finansiering av arbetet med studien.

Litteratur

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article

Capabilities in care for older adults in Finnish familialistic policy transformations: a longitudinal, one-case study

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As public provision of health and social care to older adults remains fixed or is scaled back, informal care is increasingly emphasised in policy and in practice. This is also the case in the Nordic welfare state of Finland. Little is known about how individual care arrangements are made. In this study, the capability approach is used to investigate the processes from resources to the actual functionings of receiving care of one older informal care recipient across time. The results reveal difficulties, discontinuity and unpredictability that challenge the capabilities to achieve valued beings and doings.

Key words older adults • care • capability approach • familialism

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Introduction

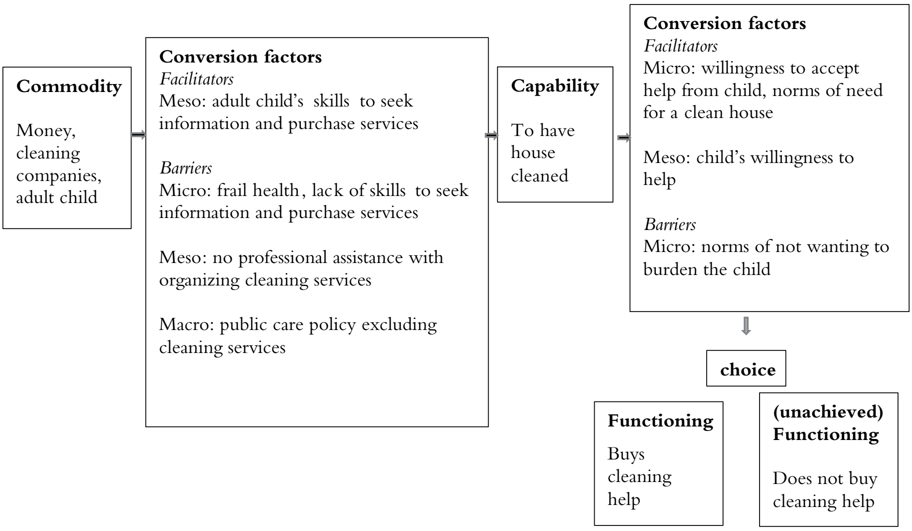
Despite universal rights to formal services, and older Finns' preferences for this source of care (Van Aerschot, 2014), informal care is the most common type of care among older adults in the Nordic welfare state of Finland (Huber et al, 2009; Pickard, 2011). Here, formal care is defined as predominantly publicly funded health and social care services carried out by professionals, while informal care is provided by family members. In Finland, the informal care allowance (ICA) (see Act on Informal Care Allowance 2005[1]) is an example of a development where care provided by family members has been, to some extent, formalised (for a discussion, see Leinonen, 2018). The ICA is a service that includes an allowance for the care recipient paid to the carer. The allowance accumulates pension entitlements and includes insurance contributions. In addition, social services can be offered and the carer has the right to two or three days off every month (see Act on Informal Care Allowance). In this way, the formalisation of informal care can be understood as a development of new social rights for carers (Pfau-Effinger, 2005).

In Finland, there are an estimated 350,000 informal carers (Ministry of Social Affairs and Health, 2019); about 47,000 of them are encompassed by the ICA. In 2018, 4.9 per cent of care recipients aged 75 and above received the ICA (Sotkanet Indicator Bank, 2019), while 11 per cent received regular homecare and 8.7 per cent received institutional care. The majority of ICA care recipients have extensive care needs equivalent to institutional care and are cared for by an older spouse (Ministry of Social Affairs and Health, 2019). The national aim is to increase the share of older adults receiving ICA to avoid other care forms that are seen as more costly. As a part of a strategic programme aiming to save up to €4 billion in public finances (Finnish Government, 2015), the previous Finnish government (2015–19) attempted to incentivise informal caring by improving opportunities for respite care and introducing rights to education and health examinations (Ministry of Social Affairs and Health, 2019). In Finland, health and social care services are regulated by national legislation that is implemented locally in the municipalities (Social Welfare Act 710/1982[2]).

The emphasis on informal care is also a result of stricter eligibility criteria and increasing user fees for formal services (Hoppania et al, 2016; Hannikainen, 2018). This development has been argued to challenge universalism in social care and instead refamilialise it (Kröger, 2019), as well as increasing the degree of *familialism by default* (Saraceno and Keck, 2010; Saraceno, 2016), which occurs in the absence of publicly provided care alternatives and support for family care. *Supported familialism*, on the other hand, occurs when the state supports family members in their caring responsibilities. In the case of the Finnish ICA, the state supports family members' caring responsibilities through both cash and in-kind benefits, though the extent of, and eligibility criteria for, services varies between municipalities (Ministry of Social Affairs and Health, 2014). The lack of standardised eligibility criteria in support services for informal care, and in social care for older adults in general (Szebehely and Meagher, 2018; Kröger et al, 2019), nourishes a system where accessing services depends on individual features, resulting in different opportunities for older adults with care needs (Zechner, 2007; Häikiö and Anttonen, 2011). This suggests a need for further study of how care arrangements are made and managed.

The main objective of this study is to investigate the processes behind one informal care recipient's functionings of receiving care encompassed by ICA in a two-year period. Research on informal care tends to focus on the carer, rather than the care recipient (Martire et al, 2003). Here, we focus on the person needing care in everyday life due to old age, deteriorating health and/or disabilities. By using a longitudinal, one-case perspective and applying the capability approach (Sen, 1993) for the analysis, we can study and instantiate the pathways through which resources become transformed into achieved functionings of receiving care over time. We identify the facilitating and hindering micro-, meso- and macro-level mechanisms behind the care arrangements as the informal care recipient encounters changes in, for example, health condition (micro), national care policies (macro) and implementations in the municipality (meso) over a two-year period. Lastly, we discuss identified forms of familialism (Saraceno and Keck, 2010) and the implications for those in need of care.

Figure 1: A capability approach to an older adult coordinating cleaning services



Source: Figure adapted from Robeyns (2005) and Bonfanti (2015).

In the following section, we explain our theoretical framework and introduce the research questions before moving on to present the data and method of the study. After, we present the findings and end with a discussion.

The capability approach

Originally developed by Amartya Sen (1979), the capability approach was created as an alternative way of studying human conditions and well-being by looking into actual freedoms rather than goods. The focus of Sen's theory was on the possibilities one has to be able to live a meaningful life and on the conditions that prevent or hinder these possibilities (see Sen, 1993). Subsequently, however, there has been a proliferation of theoretical stands on capabilities. According to Sen, the implication of a meaningful life is individual and varies between time and space, whereas Martha Nussbaum (2011) has developed a capability theory of justice with a list of central capabilities needed for any life with human dignity. Thus, the capability approach has developed into something of an open paradigm, which has led to both praise and criticism (for a discussion, see Robeyns, 2016). Robeyns (2016) distinguishes between *the capability approach* as a general normative framework, where the focus is on what a person is able to be and do and/or the capabilities realised (functionings), and the various *capability theories* based on the capability approach, which share common core principles but differ in their focus and operationalisation.

Despite the specific capability theory used, *commodities*, *capabilities*, *functionings*, *agency/choice* and *conversion factors* are key concepts (Robeyns, 2016; Yerkes et al, 2019). Commodities are defined as available resources, such as money and family members. Capabilities are the functionings one could achieve, and available opportunities are those that one chooses or chooses not to pursue. If one lacks the opportunity to choose a functioning, that capability is also missing. Agency and choice refer to individuals choosing their functionings from available opportunities according to values and preferences. A functioning is what one actually ends up being or doing, such as riding a bike or being educated. The transformation of commodities into capabilities, and of capabilities into functionings, is affected by conversion factors that work as either facilitators for or barriers to the process (Hvinden and Halvorsen, 2017). Conversion factors exist on various levels and can be divided into, for example, personal, social or environmental ones (Robeyns, 2005), or micro-, meso- and macro-level ones (Bonfanti, 2015).

In Figure 1, we illustrate how the capability approach is applied in this study, based on the example of an older adult coordinating cleaning help. The case is derived from data collected for this study from interviews with seven informal care recipients and six carers (further presented in the section on data and methods).

Figure 1 highlights the process from commodities to functionings or unachieved functionings by dismantling conversion factors on different levels. For example, the commodity of money is useless without the conversion factors of skills to purchase services or, as in the example above, the combination of the commodity of an adult child and the conversion factors of the child's skills and willingness to help.

In a manner akin to that of Tanner et al (2018), who studied the experiences of self-funding care among older adults in the UK by applying a relational-political capability approach (Deneulin, 2011), we apply a similar lens as we study informal care encompassed by the ICA in Finland. A relational-political lens explores the social, economic and political conditions, as well as relational reasoning, affecting individuals' capabilities and functionings (Deneulin, 2011). We argue that care mainly provided by a family member through a care agreement with the municipality in times of austerity makes an interesting case for analysing the relational-political mechanisms behind the achieved care arrangements. We track the paths from commodities to capabilities, and from capabilities to functionings, by dismantling micro-, meso- and macro-level mechanisms: the micro level represents individual circumstances; the meso level refers mainly to the social network and municipal level, where care policies are implemented; and the macro level includes national care policies and legislation. We include the aspect of time not only to investigate effects of policy transformations, but also to track other changes as the care arrangements of a care dyad consisting of two older adults are both vulnerable and prone to changes in health. Lastly, based on our findings, we discuss how care responsibilities are divided between the state, family members and other actors, as well as the possible implications of this for those needing care. We attempt to answer the following research questions:

- What facilitates or hinders the care arrangements across time?
- What are the implications of receiving care for older adults' functionings?

Data and methods

Seven older adults with care needs (five women and two men aged 71–80) were interviewed in their homes in the baseline study in 2015 and then again in 2017, using semi-structured thematic interview schemes. The interviews were recorded and transcribed for the analysis.

The respondents were recruited through maximum variation sampling (Moser and Korstjens, 2018) via staff working in a non-governmental organisation (NGO) that supports informal carers. Despite being the most common health status among informal care recipients (Ministry of Social Affairs and Health, 2019), individuals with memory disorders were excluded for ethical reasons. All care recipients in the baseline study lived with their carers. Spouses cared for five of the care recipients; a co-resident spouse and a non-resident daughter cared for one older adult; and a sibling cared for one care recipient. All care recipients received, or had previously received, ICA. In the baseline study, six of the care recipients received ICA. In 2017, five recipients were still receiving ICA. Reasons for ending ICA were, in one case, the carer's deteriorating health and, in the other, the carer's dissatisfaction with support services.

The baseline interviews with the care recipients were carried out in 2015 and revolved around the recipients' background, everyday life and care, the relationship with the carer, and features of Finnish care policies. The follow-up interviews with the care recipients were semi-structured themed interviews concerning changes in health status, care policies, services and care preferences. In 2017, six of the carers were also interviewed. The baseline study showed that some care recipients lacked information on how the care arrangements were made and managed. Consequently, interviews with the carers were included here as a source of additional information on the care arrangements. The interviews were conducted separately.

The interviews were analysed in the software programme NVivo 11. We used a directed content analysis (Hsieh and Shannon, 2005). We first identified one central capability (to continue living at home with the informal carer) concerning the informal care recipient's valued states of being through care. This overarching capability was divided into three subcategories: to receive support for informal care; to rehabilitate; and to preserve mental health. We subsequently identified related functionings, commodities and conversion factors for each subcategory. Here, functionings are understood as achieved states of receiving care. Having identified the functionings, commodities and conversion factors, the analysis continued by looking into the narratives of each care dyad, with a special focus on changes. Here, we were inspired by Saldana's (2003) guide developed for analysing longitudinal qualitative data by using a three-step set of questions (framing, descriptive and interpretive/analytic) in order to reach a rich analysis of change across time.

Instead of providing an account of the entire data, we chose to focus on presenting the dynamics behind care arrangements in detail by analysing the interviews of one care dyad where a great variety of commodities and conversion factors was expressed. We then constructed a narrative including the commodities, the transformation of commodities into capabilities and the transformation of capabilities into achieved functionings, as presented in the following section. As longitudinal data in combination with the rich detail of one case could jeopardise the anonymity of the respondents, personal details are omitted from the results.

Findings

Mr Korhonen (a pseudonym) lived in the countryside with his wife. Mr Korhonen suffered a stroke in 2013 when in his early 70s. The stroke reduced his physical functioning on one side of his body and left him with an inability to walk. Mr Korhonen's valued beings and doings revolved around one overarching capability: to continue to live at home with Mrs Korhonen. This overarching capability was divided into three subcategories: to receive support for informal care; to rehabilitate; and to preserve mental health. The results are presented in the following three subsections in a narrative manner. The processes from commodities to achieved functionings are presented (see Tables 1–3) at the end of each subsection and are referred to throughout the narratives.

To receive support for informal care

Mrs Korhonen had been Mr Korhonen's informal carer since the stroke. Mr Korhonen described informal care as a natural preference, as opposed to institutional care, for both him and for Mrs Korhonen (cell 1C in Table 1). Mrs Korhonen was a crucial commodity (1A) for Mr Korhonen's capability to live at home, and her health and willingness to provide care were essential conversion factors (1B, 1C). These micro-level mechanisms, together with meso-level commodities and conversion factors, such as information (1B), the municipal budget (1A) and the local care manager's assessment (1B), facilitated an ICA agreement with the municipality in 2014. As already noted, health and social care services in Finland are regulated by national legislation that is implemented locally in the municipalities (see Act on Informal Care Allowance).

As a part of Mr Korhonen's care plan after the stroke, he started receiving bathing assistance twice a week from the municipality (2D). At first, Mr Korhonen hesitated to accept the help and thought that he and Mrs Korhonen would manage on their own; however, a local care manager convinced the couple to try the service (2C) and they decided to keep it. The shower help was the only home-care service they received. Mr and Mrs Korhonen concluded that any additional service would add costs, which suggests that concerns of money affected their use of services. In contradiction to the principles of universalism, income has proved a determining factor in the use of services in Finland (Van Aerschot, 2014; Hannikainen, 2018). Furthermore, Mr Korhonen believed that local home-care employees would not have time for him (2C). Media reporting on employees' high care burden can affect care preferences (Gunnarsson, 2009). Preferences and attitudes about care provision are also shaped by welfare structures (Miettinen, 2012). For example, Mr Korhonen's experience may have been that he did not want more home-care services as he believed he was not entitled to them – a form of adaptive preferences where deprived individuals lower their expectations (Nussbaum, 2000).

The right (3A) to have one's dwelling made accessible is crucial for enabling informal care in the home. After the stroke, the municipality granted Mr Korhonen a ramp in the house and a few other assistive devices (3A, 3B). However, Mr and Mrs Korhonen also had to buy additional devices on the private market (4D). This was enabled by the commodity of money (4A) and Mrs Korhonen having the skills to assess the needs and purchase the devices, here classified as micro-level conversion factors (4B).

In Finland, national reports have pointed out that only about half of informal carers use their right to days off, despite many being responsible for care 24/7 (Ministry of Social Affairs and Health, 2014; 2019). One reason for not taking days off is the experienced lack of good respite care options (Tillman et al, 2014). In Mr and Mrs Korhonen's case, Mrs Korhonen experienced that she needed to take days off in order to cope as a carer. Taking days off was further enabled by Mr Korhonen accepting to go into respite care in the local health centre ward (5C). He agreed to go for the sake of Mrs Korhonen as he noticed that she became exhausted over time:

Table 1: Commodities and conversion processes applying to functionings of receiving support for informal care

Commodities	Factors affecting the conversion of commodities into capabilities	Factors affecting the conversion of capabilities into achieved functioning	Achieved functioning
1A.	1B.	1C.	1D.
Mrs Korhonen, municipality budget, Act on ICA	*Facilitators Micro:* coronary intervention, Mrs Korhonen's health	*Facilitators Micro:* norms of taking care of each other, negative attitude to other care forms	Receives ICA
	Meso: information about ICA, care manager's assessment	*Meso:* Mrs Korhonen's willingness to provide care	
2A.	2B.	2C.	2D.
ICA legislation	*Facilitators Meso:* care plan, care manager's assessment	*Facilitators Meso:* care manager's encouragement	Receives public home-care services
	Barriers Macro: high user fees	*Barriers Micro:* adaptive preferences	
		Macro: media reports on scarce resources in home care	
3A.	3B.	3C.	3D.
Care policy, Social Welfare Act, ramp	*Facilitators Meso:* local care manager's needs assessment		Gets home made accessible through the public sector
	Barriers Meso: municipality not providing all necessary devices		
4A.	4B.	4C.	4D.
Money, Mrs Korhonen, local supply of private assistive device companies	*Facilitators Micro:* Mrs Korhonen's skills to select and buy assistive devices from the private market		Gets home made accessible through the private market
5A.	5B.	5C.	5D.
Act on ICA	*Facilitators Micro:* Mrs Korhonen's negotiation skills about quality of the respite care and reduced days of respite care	*Facilitators Micro:* Mr Korhonen's willingness to go to respite care	Goes to respite care
	Barriers Micro: Mr Korhonen's lack of skills to negotiate about reduced respite care *Meso:* local implementation of government's strategic programme *Macro:* government's strategic programme	*Barriers Micro:* experienced bad quality of respite care	
6A.	6B.	6C.	6D.
Neighbours, adult children, Internet, NGOs, public funding for NGOs, Kela courses	*Facilitators Micro:* Mrs Korhonen's Internet skills	*Facilitators Micro:* norms of accepting help from adult children and neighbours	Receives social and practical support
	Meso: children's willingness to help, neighbours' willingness to help, peer group activities for caregivers, doctor's referral and assessment for Kela rehabilitation for informal carers		
	Barriers Meso: geographical distance between children and couple		

> ‘I don’t mind going to the hospital for respite for one week. But I have to say, I do prefer, I like it best at home. But I have to think about her too. You notice as time goes by here, when I’m at home, that the voices get louder.’ (Mr Korhonen, 2015)

The respite care service had been one week per month, but by the time of the follow-up study, the local care manager had cut it down to five days. New national regulations were reinforced in 2016 establishing two days off per month as a national minimum for informal carers encompassed by the ICA (see Act on Informal care Allowance). The new regulations, in combination with overall lowered subsidies to municipalities, seemed to have led to this municipality reconsidering its previous more generous standards (5B). This resulted in Mrs Korhonen not coping as well at the time of the follow-up study. She feared that the lack of sufficient rest would result in both herself and Mr Korhonen ending up in institutional care. Mrs Korhonen had discussed this matter with the local care manager, without result. It is nevertheless a facilitating conversion factor (5B) that Mrs Korhonen possessed negotiation skills. Mr Korhonen seemed to lack these skills although he too was unsatisfied with the situation.

> ‘She, Mrs Korhonen, was very offended; she even rolled around at night crying.… The [staff’s] explanations [for reducing the days off] are quite ridiculous. They say there is not enough space at the hospital. There is no room and no time either; there is no … I guess it’s a saving measure. It’s ridiculous, there are empty beds in the rooms and they [staff] are always sitting down when I’m on respite. One does not even want to think about it. They can have it their way, the way they have organised it.’ (Mr Korhonen, 2017)

The previous quote illustrates Mr Korhonen’s inability or reluctance to negotiate about the service (5B). This too may be an example of adaptive preferences (5C).

Mr and Mrs Korhonen also relied on types of support other than services and devices from the municipality or private market. They had neighbours (6A) who helped with gardening and occasionally came to their aid if Mr Korhonen fell. They also had adult children (6A), but because of geographical distance, they mostly kept in contact through the telephone or Skype. The children had taught Mrs Korhonen how to use a computer and the Internet. These skills (6B) supported ageing in place as Mr and Mrs Korhonen could manage, for example, bank errands without leaving the house. Increasingly, services for informal carers, such as contact with care managers, are being digitalised to save costs (Ministry of Social Affairs and Health, 2019). However, Mr and Mrs Korhonen were not yet using any digitalised services.

Although Mr and Mrs Korhonen’s adult children seemed not to offer much practical help due to distance, they offered other types of support. Close family members can play an important role in seeking information about services and negotiating about them (Hoppania et al, 2016). Members of the social network can also provide support in making decisions as it may be difficult for older adults to assess the need for services (Chesser et al, 2016). Mrs Korhonen described one scenario when Mr Korhonen was having respiratory problems and she hesitated to call the ambulance: “He [Mr Korhonen] said, ‘I’m having trouble breathing.’ I got so worried and said, ‘What should I do?’ But then my son said on the phone, ‘Call an ambulance and they will tell you if they take him in or not.'" (Mrs Korhonen, 2017). It is possible that older adults have experiences of calling the ambulance without ending up in hospital, depending on need assessments (Yle, 2019). In the described scenario, Mrs Korhonen preferred to call her son instead of directly calling the ambulance. After being encouraged, she then called the ambulance and Mr Korhonen was immediately hospitalised and given a coronary intervention. This resulted in better health and supported his capability to continue to live at home.

Apart from support from friends and family members, Mrs Korhonen emphasised the role of peer support activities. Informal carers are known to be at risk of becoming socially isolated, with negative health consequences (Vasileiou et al, 2017; Greenwood et al, 2018). The activities were mostly organised by NGOs (6A) but Mrs Korhonen also gained important peer support from other informal carers she met at a rehabilitation course held by the national social insurance institution in Finland (Kela). Courses are organised for informal carers at risk of not coping in their caring role due to health problems or exhaustion. Mrs Korhonen gained access to the course through a doctor's referral and needs assessment (6B). Not all carers with doctor's referrals are selected to join the course (Zechner, 2007; Miettinen, 2012).

To rehabilitate

> 'This situation is, of course, not nice. We would like me to get somewhat well. Then it would be easier for her and for me. Life is a bit like hell the way it is now. My wish is to become as healthy as possible.' (Mr Korhonen, 2015)

Already in the baseline study in 2015, Mr Korhonen was frustrated about not rehabilitating quickly enough. He wanted to be able to walk again. Shortly after the stroke, Mr and Mrs Korhonen were sent to a rehabilitation centre, where Mrs Korhonen spent four days learning how to help Mr Korhonen recover physically, while Mr Korhonen was given intensive rehabilitation services for weeks. The commodity of a rehabilitation policy (see cell 7A in Table 2) and meso-level conversion factors (7B) enabled informal care as they gave the couple tools for restoring Mr Korhonen's physical functioning. Mr Korhonen has requested to visit the rehabilitation centre again but he has not managed to get a doctor's referral (7B). To qualify for any rehabilitation service or allowance in Finland, one needs a doctor's referral, though it does not necessarily grant the service (Metteri, 2012). According to Mr Korhonen, the local doctor thought Mr Korhonen received the best rehabilitation at home from Mrs Korhonen. Her efforts were thus paralleled with professional rehabilitation services (7B).

Mr Korhonen experienced the monthly respite care as unsatisfactory, to the extent that he returned home in a worse condition than when entering the respite care service. His physical functioning changed in only a few days. Mr and Mrs Korhonen unsuccessfully negotiated with the staff for more rehabilitation exercises during his stays. The poor respite care was perhaps a result of scarce resources, or a matter of individual staff members' attitudes and skills (7B). Mr Korhonen explained that some staff members did rehabilitation exercises with him and others did not, and that their professional skills differed.

Table 2: Commodities and conversion processes applying to functionings of rehabilitating

Commodities	**Factors affecting the conversion of commodities into capabilities**	**Factors affecting the conversion of capabilities into achieved functioning**	**Achieved functioning**
7A.	7B.	7C.	7D.
Rehabilitation policy	*Facilitators Micro:* Mr and Mrs Korhonen's negotiation skills	*Facilitators Micro:* Mr and Mrs Korhonen's motivation	Receives public rehabilitation
	Meso: care plan, care manager's assessment, individual staff members' professional skills, small size of the municipality	*Barriers Micro:* Mr Korhonen's experiences of poor quality of respite care	
	Barriers Meso: municipality budget, local supply of rehabilitation services, local doctor's assessment, municipality employment situation, scarce resources for respite care, Mrs Korhonen's efforts substituting professional care, individual staff members' negative attitude or poor skills		
	Macro: restricted rehabilitation policy		
8A.	8B.	8C.	8D.
Mrs Korhonen, money, local supply of private companies	*Facilitators Micro:* Mrs Korhonen's skills to buy private physiotherapy	*Facilitators Micro:* Mr Korhonen's motivation	Receives private rehabilitation
	Meso: local supply of private services		
9A.	9B.	9C.	9D.
Mrs Korhonen, care policy	*Facilitators Meso:* Mrs Korhonen receiving education in how to rehabilitate Mr Korhonen, Mr Korhonen's rehabilitation programme	*Facilitators Micro:* Mr and Mrs Korhonen's motivation	Exercises with Mrs Korhonen
	Barriers Micro: Mrs Korhonen's limited health		

Mr Korhonen usually received public physiotherapy once or twice a month but this service depended on the municipality having adequate staff (7B). When a physiotherapist went on maternity leave, Mr Korhonen received no physiotherapy for months. The service was reinstated by chance as local care managers happened to witness Mr and Mrs Korhonen struggling on a parking lot trying to get Mr Korhonen out of the car:

> 'We got to the health centre and when I was about to get him out of the car, he couldn't use his legs. They happened to come, those who are from the eldercare and offer gymnastics, when his legs were stuck on the threshold of the car. I had to have them help us get home; it was so late that day, 4pm, so everyone else had already gone home. But then those two happened to come and, afterwards, they wanted to help and give him exercises.' (Mrs Korhonen, 2017)

This example illustrates how care managers may be unaware of developments among informal care dyads. Informal care agreements are updated annually and it is up to the care dyad to be in contact with health and social care services should the situation change between these annual assessments. When Mr and Mrs Korhonen ended up regaining the service by chance, they had not been in contact about the need for physiotherapy. Perhaps the small size of the municipality (7B) enabled the staff members to recognise Mr Korhonen and reinstate the service.

Although money was a concern, Mr Korhonen was affluent enough to go to private water gymnastics with a physiotherapist once a week (8A). This capability was enabled by money, Mrs Korhonen and the local supply of private service providers, as well as the skills (8B) to buy services – that is, he (or Mrs Korhonen) was able to search for, select and pay for them. Mr Korhonen would also have liked Mrs Korhonen to assist him in going to a local gym. However, Mrs Korhonen felt she was unable to do more for him than she was already doing; thus, Mr Korhonen's capability was restricted by Mrs Korhonen's limited capability (9B).

To preserve mental health

> 'Well I hope to become better and better with this [physical capacity] and that my head stays in shape.' (Mr Korhonen, 2015)
> 'I think it takes a damn long time before I recover somewhat.… So, the will to live is not that big.' (Mr Korhonen, 2017)

In the baseline study in 2015, Mr Korhonen hoped that his head "stays in shape", referring mainly to memory disorders running in the family; he also struggled to accept his reduced physical functioning. Mr Korhonen received therapy for a while after the stroke but did not know who provided it or why it ended. Unpredictability and discontinuity of services are negative conversion factors caused by national policies and local implementations (see cell 10B in Table 3). Another barrier affecting the capability to preserve mental health is the lack of information on eligibility for therapy (10B). Missing information makes it more difficult to regain a service. The discontinued therapy may have been the result of poor communication in the municipality or of individual difficulties in obtaining information about services and their allocation (10B).

In the follow-up interview in 2017, Mr Korhonen's depressive symptoms seemed to have worsened as he then described his situation as hopeless. Even so, he was reluctant to seek professional help. Mr Korhonen had previously tried anti-depressants but they made him feel worse. Since he possessed the required skills to receive a prescription in the past, it is possible Mr Korhonen also had the capability to receive anti-depressant treatment in 2017 but chose not to access it at that time. Alternatively, his ability may have reduced over time due to his health. Depressive symptoms are a negative individual conversion factor (10C) as they can lead not only to an actual reduction of capabilities, but also to a perceived lack of capabilities (Gandjour, 2008). The previously experienced discontinuity of therapy may also have worked as a barrier to seeking help.

According to Mr Korhonen, the lack of rehabilitation during respite care contributed to his depressive symptoms. For him, it was important that someone assisted him

Table 3: Commodities and conversion processes applying to functionings of preserving mental health

Commodities	Factors affecting the conversion of commodities into capabilities	Factors affecting the conversion of capabilities into achieved functionings	Achieved functioning
10A.	10B.	10C.	10D.
Healthcare policy	*Facilitators Meso:* staff noticing his need and providing medication and talk therapy	*Barriers Micro:* Mr Korhonen's depressive symptoms and negative attitude towards medication	Being treated for depression
	Barriers Micro: lack of information		
	Meso: service disrupted due to employment situation or professional assessment *Macro:* scarce resources affecting municipality's service provision		
11A.	11B.	11C.	11D.
NGOs, municipality, children, Mrs Korhonen, money, car	*Facilitators Micro:* Mrs Korhonen's driver's licence	*Facilitators Micro:* Mr Korhonen's motivation, Mrs Korhonen's willingness to help	Participating in peer support and physical activities
	Meso: children helping to buy car		
	Barriers Micro: geographical distance to activities		
	Meso: long breaks in peer group activities, few people attending, poor quality of respite care		
12A.	12B.	12C.	12D.
Mrs Korhonen, ramp	*Facilitators Meso:* ramp provided by the municipality (see Table 1)	*Facilitators Micro*: Mrs Korhonen's willingness to help	Spending time outside

in walking every day but this request was seldom granted at the health centre ward (11B): "Anyone understands that it gets depressing if one wants to walk 8–10 metres and they say they don't have time, and they don't have time" (Mr Korhonen, 2017). Social and physical activities are ways of maintaining mental health as they prevent depressive symptoms, as well as cognitive decline (Fratiglioni et al, 2004; Teychenne et al, 2008). As previously mentioned, both Mr and Mrs Korhonen enjoyed peer group activities. Mr Korhonen attended a peer support group organised by the municipality. Unfortunately, there were sometimes long summer breaks or few people attending. Mrs Korhonen's willingness to help was once again a crucial conversion factor (11C) for Mr Korhonen's capability to attend activities:

> 'There are a lot of people who don't go anywhere.… But I think if they organise something, one should go. And he has always been one of those who likes to be around people, so I have reasoned that I cannot take that away from him. That he would just sit at home and I would say, "No, we are not going there and we are not going there."' (Mrs Korhonen, 2017)

As Mr and Mrs Korhonen lived in the countryside, a car was needed to be mobile (11B). The couple's children had helped them find and buy an accessible car to transport Mr Korhonen more easily. Being mobile was further enabled by Mrs Korhonen's driver's licence and money to buy a car and fuel (11A). Mr Korhonen going to activities enabled Mrs Korhonen to rest as she drove home and spent time alone while he was there. In Finland, older adults may be entitled to a limited number of taxi vouchers each month (see the Social Welfare Act) but these would not have covered the extra travel needed for Mrs Korhonen to go home during Mr Korhonen's activities.

Another activity that promoted Mr Korhonen's mental health was spending time outside. The previously mentioned ramp (see Table 1) and Mrs Korhonen's help enabled this activity (12A).

Discussion

In this study, we have investigated the pathways from resources to actual functionings of one ICA care recipient across time by applying a political-relational capability approach. We identified facilitating and hindering micro-, meso- and macro-level mechanisms interlinked with the care arrangements, with the micro level including the individual circumstances of Mr Korhonen and his wife, the meso level representing their social network and the municipal level, and the macro level representing national policies.

For Mr Korhonen, as an older stroke patient, valued beings and doings revolve around one central theme: the capability to continue living at home with Mrs Korhonen. This overarching aim was divided into three subcategories: to receive support for informal care; to rehabilitate; and to preserve mental health.

On the micro level, our findings show Mrs Korhonen's health and skills to be a cornerstone for Mr Korhonen's care arrangements. Not only does Mrs Korhonen provide care, but she is also the main coordinator of the services. Coordinating services is enabled by conversion factors of skills to do so, some of which are personal (micro) and others are gained through courses organised for informal carers due to national policies and local implementation (macro- and meso-level conversion factors).

Our findings highlighted how Mr and Mrs Korhonen sometimes struggled to assess their needs and turn their resources into functionings of receiving care. Here, the role of professionals and the couple's social network became evident. Members of the social network are commodities that not all informal carers and recipients have, and their helpfulness and skills are categorised here as conversion factors on the meso level. Similarly, the personal traits of care managers are conversion factors on the meso level. Depending on the care manager's assessment and persuasion skills, services were gained, despite the initial reluctance of Mr and Mrs Korhonen. In the same manner, carers' professional and communication skills led to Mr Korhonen experiencing the quality of respite care as either good or poor. This represents the relational aspect of the capability approach.

Moving on to the more political dimension of the care arrangements, the study took place during the first two years of a government strategic programme (Finnish Government, 2015), where social spending was cut at the same time as selective measures were directed to informal care. In this way, the policy changes made during the strategic programme 2015–19 can be seen as a shift towards both supported familialism and familialism by default (see Saraceno and Keck, 2010). They thus represent conversion factors on the macro level that simultaneously hinder and facilitate informal care. In Mr and Mrs Korhonen's case, the selective measures aimed to strengthen carers' rights to days off resulted in fewer days of respite care as the municipality had to revise its standards due to lower overall central funding for health and social care services. Mr Korhonen experienced the quality of respite care as so poor that it affected both his mental and physical health, though he still agreed to go there for Mrs Korhonen's sake. Resting is crucial for Mrs Korhonen, and the findings illustrate how the cut in her days off challenged her ability to continue informal care.

The macro-political dimension is interlinked with the municipal (meso) level as that is where policies are implemented in Finland. At the municipal level, budgets for ICA are unpredictable, eligibility criteria vary and the availability of support services is prone to change (Tillman et al, 2014). In Mr Korhonen's case, this became evident as few changes in services were made as a result of his or Mrs Korhonen's wishes, being rather due to policy shifts, local implementation or even chance.

The couple also emphasised the role of peer activities for informal carers organised by NGOs. On the one hand, the state transferring some of its support services to NGOs represents familialism by default; however, on the other, as NGOs can apply for public funding, their role in informal care also indicates supported familialism (see Saraceno and Keck, 2010). This arrangement implies a form of diverted familialism as public support for family members is provided in an indirect way, instead of being transferred directly to carers or care recipients. Our findings also revealed that when the physiotherapy services and assistive devices granted by the municipality are insufficient, the couple turn to the private market. Informal carers in Finland have been encouraged to buy services on the private market and to take advantage of tax deductions (Zechner, 2017). However, not all carers can do so as tax deductions assume that there is taxable income, which many older adults do not have. This again implies a diverted form of familialism, where some may benefit and others do not, depending on their initial resources, as well as conversion processes along the way from resources to actually ending up buying private services and taking advantage of tax deductions.

A weakening supported familialism challenges the universal principles of the Nordic welfare model, and raises concern about the capabilities of older adults who are not as resourceful as Mr and Mrs Korhonen. The majority of informal carers do not receive ICA (Tillman et al, 2014) and thus receive even less support. In a larger perspective, the policy shift from the Nordic welfare model towards a more individualistic and family-oriented model poses questions for increasing inequality, where better-off older adults have the possibility to rely on services whereas those in lower-income groups must rely on informal care (Ulmanen and Szebehely, 2014). The lack of sufficient support for informal care also poses a risk for the implementation of policies of ageing in place, and thus care poverty for some older adults (Kröger et al, 2019).

Generalisations cannot be drawn from the data of one single case; rather, our findings have contributed to evidence on the dynamic processes from resources to actual functionings of receiving care over time. Future research should continue to investigate these processes in different policy settings, especially among those who are 'resource poor' in terms of money, negotiation skills and family members. More longitudinal studies are needed on older adults as both care recipients and carers as this group may be deemed the most likely to face changes in their needs and capabilities.

Notes

[1] Act on Informal Care Allowance 2.12.937/2005, available at: www.finlex.fi/fi/laki/ajantasa/2012/20120980

[2] Social Welfare Act 710/1982, available at: http://finlex.fi/en/laki/kaannokset/1982/en19820710_20140491.pdf

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Conflict of interest

The authors declare that there is no conflict of interest.

[1] Act on Informal Care Allowance 2.12.937/2005, available at: www.finlex.fi/fi/laki/ajantasa/2012/20120980

[2] Social Welfare Act 710/1982, available at: http://finlex.fi/en/laki/kaannokset/1982/en19820710_20140491.pdf

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III

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Article

A Cross-Sectional Study on the Associations between Economic, Social, and Political Resources and Subjective Caregiver Burden among Older Spousal Caregivers in Two Nordic Regions

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Abstract: Inspired by the caregiver stress process model emphasising the role of resources for caregiving outcomes, the aim of this study was to investigate the prevalence of subjective caregiver burden (SCB) and its associations with individual social, economic, and political resources among older spousal caregivers in a Nordic regional setting. Cross-sectional survey data collected in 2016 in the Bothnia region of Finland and Sweden were used, where 674 spousal caregivers were identified and included in the analyses. The descriptive results showed that about half of the respondents experienced SCB. SCB was more common among Finnish-speaking caregivers. Results from the multivariate logistic regression analysis showed that none of the assessed political resources were significantly associated with SCB when controlling for other variables. Experiencing financial strain was associated with SCB, while personal income was not. Frequent contact with family members was statistically significantly associated with SCB. Future research could use longitudinal data to determine causal relationships, and when data allow, test the full caregiver stress process model to investigate the role of mediating factors in different comparative settings. Accumulated evidence on risk factors for negative outcomes of informal caregiving can contribute to effective screening tools for identifying and supporting vulnerable caregivers, which is becoming increasingly important with the ageing population.

Keywords: informal care; community dwelling; ageing; spousal caregivers; subjective caregiver burden; caregiver stress process model; ethnolinguistic; resources

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1. Introduction

Informal caregivers are the backbone of any social and health care system [1,2] and this is also the case in the Nordic countries of Finland and Sweden where care for older adults is formally a public responsibility as opposed to a family obligation. Informal caregivers are generally defined as persons who provide unpaid care to older and dependent persons with whom they have a social relationship [3]. Although informal caregiving may entail positive experiences [4] with positive or no effects regarding some health aspects [5,6], there is still vast evidence on the negative outcomes on wellbeing and/or health associated with providing intensive informal care. Such negative outcomes may include depression and poorer subjective wellbeing [7–10]. Among informal caregivers providing intensive care in Nordic countries, older co-residing spouses are overrepresented [11,12]. Given the expected increased care needs due to the ageing population in many parts of the world, the life situation of informal caregivers warrants further investigation with attention to individual risk factors that can assist in screening for informal caregivers especially at risk of negative outcomes of caregiving.

According to the caregiver stress process model [13], caregiving can be seen as a stress process departing from a specific context where the caregiver's and care recipient's socioeconomic status and health are examples of important influential factors. The caregiving stress process depends on objective stressors, such as the condition of the care recipient and the type and amount of care provided. These objective (or primary) stressors are transferred into secondary stressors of subjective strains that may include, for example, family conflicts, constriction of social life, and loss of self and/or sense of mastery. The objective and subjective stressors end in outcomes for the caregiver, such as negative health effects or giving up the caregiving role, but available resources and support mechanisms mediate the pathway between stressors and outcomes. Mediating resources exist on both micro, meso, and macro levels [13,14].

Recent international studies have identified the importance of formal service availability for informal caregiver wellbeing [2,15–17], with Finland and especially Sweden representing some of the most generous public welfare systems. Further, due to the class and gender class difference reducing goals of the Nordic welfare model [18], the role of individual resources can be seen as less important in Finland and Sweden. However, some studies in Finland and Sweden have found that accessing services for older adults may still depend on individual resources [12,19–22]. For example, negotiating with service gatekeepers may be easier for those with more resources than for informal caregivers who possess less resources and experience themselves as less influential [23]. Further, informal caregiving activities and the outcomes on wellbeing have been found to affect Swedish informal caregivers differently depending on educational level [24,25]. These inconsistencies present a need to further explore the role of sociodemographic resources for the wellbeing of informal caregivers in Nordic countries as well.

In a European comparison of people aged 16–79 [15], Finland and Sweden hosted the highest numbers of informal caregivers but the lowest share of intensive caregivers (providing care for more than 11 h). The high numbers of caregivers and low numbers of intensive caregivers are believed to be the result of shared care responsibilities. Indeed, friends and other family members are important mediators of support for informal caregivers as members of the social network may not only provide emotional support to the main caregiver, but also decrease the care intensity by sharing care tasks and assisting in accessing services [2,13,15]. Most Finnish informal caregivers receiving formal support perceive themselves as well supported by family members and relatives [26], and according to a report assessing informal care in the general adult population, 57% of Swedish caregivers receive support from friends and family members [27]. However, older Nordic caregivers have been found to not share care tasks as much as informal caregivers in younger generations [12,27]. This means that older Nordic caregivers could be at higher risk of subjective and objective caregiver burden than caregivers in other age cohorts.

As outlined above, individual levels of economic and social resources are commonly included in research on caregiver wellbeing, although the relationships are not entirely clear when it comes to the Nordic countries officially characterized by universalism. Thus far, political resources have received less attention in the literature on care. To our knowledge, the role of political resources has not been studied in previous research on caregiver wellbeing in Nordic countries. A previous study conducted in Israel found that subjective social status, an indicator that can be seen as sharing similarities with internal political efficacy, was associated with more positive caregiving experiences and lower risk of caregiver burn-out among professional care workers [28]. Another study found that high levels of internal political efficacy was statistically significantly associated to higher levels of wellbeing, life satisfaction, and quality of life among informal caregivers providing care to older adults with dementia in UK [29]. We anticipate that political resources, measured as internal political efficacy and political participation, can play a role in the caregiving experience in a similar manner as social and economic resources.

Our study takes place in two Nordic regions—the northern region of Sweden (Västerbotten) and the western parts of Finland (Swedish-speaking Österbotten and Finnish-speaking Pohjanmaa). In a comparison among Swedish- and Finnish-speaking older adults in this region in Finland, the Swedish-speaking have been found to possess more social resources and to be more frequently engaged in voluntary organizations than their Finnish-speaking peers [30]. Given the important role of voluntary organizations for health promoting work among informal caregivers in Finland [11] and the role of social support for informal caregiver wellbeing [31,32], it is possible that Swedish-speaking caregivers possess health-promoting resources in comparison to Finnish-speaking caregivers. By using a linguistic rather than a geographical division of Österbotten/Pohjanmaa (further described in Materials and Methods), our study contributes to research on cultural differences in informal care [33,34].

In this study, we explore a particular dimension of caregiver wellbeing, namely subjective caregiver burden. Subjective caregiver burden [35,36] is a state characterized by stress, fatigue, and altered self-esteem caused by the negative effects of caregiving. Subjective caregiver burden may "threaten the physical, psychological, emotional, and functional health of caregivers" [32]. By using the caregiver stress process model [13] as a theoretical framework, this study aimed to explore the associations between individual resources (*mediators of support/individual resources*) and subjective caregiver burden (*subjective strain*), while controlling for care intensity (*objective strain*) and background variables (*mediators of support/individual resources*). The research questions were as follows:

- What is the extent of subjective caregiver burden among older spousal caregivers in the northern parts of Sweden and the western parts of Finland? Are there regional differences?
- What are the associations between individual levels of economic, social, and political resources and subjective caregiver burden?

2. Materials and Methods

The study reporting was complied with the "Strengthening the Reporting of Observational studies in Epidemiology" (STROBE) guidelines [37].

The analyses were based on a cross-sectional survey carried out in 2016 as part of a larger inter-regional research project called the Gerontological Regional Database (GERDA [38]. The overall aim of the research project is to map living and health conditions of older adults in the Bothnia region in Sweden (Västerbotten) and Finland (Österbotten/Pohjanmaa and Etelä-Pohjanmaa). In 2016, the questionnaire was sent out to every 66-, 71-, 76-, 81-, and 86-year-old living in the rural areas and in the city of Seinäjoki, Finland, whilst to every second one living in the city of Vaasa, Finland and every third in the city of Umeå and in the city of Skellefteå, Sweden. The Bothnia region in Finland is bilingual with about 52% Swedish-speakers and 48% Finnish-speakers. The Finnish region is, despite belonging to the same geographical region, treated here as two separate regions based on language group affiliations. Swedish-speaking participants were coded as belonging to Österbotten, and those with Finnish as their mother tongue in Pohjanmaa and in Seinäjoki in Etelä-Pohjanmaa were coded as belonging to Pohjanmaa. Questionnaires were sent to 14,805 older adults and 9386 participated, resulting in a total response rate of 63%. The questionnaire was answered by 4375 participants in Västerbotten, Sweden, and by 2296 in Österbotten and 2715 in Pohjanmaa, Finland, resulting in a response rate of 70.8%, 61.7%, and 54.9%, respectively.

In the questionnaire, an informal caregiver was defined as 'a person looking after a family member/ ... /that due to illness, lowered functional capacity, or another reason needs help and support and therefore does not manage independently in everyday life'. Participants were categorised as caregivers if they chose at least one of the two first answering options (loved one in my household, loved one in another household, I do not give informal care to anyone) in response to the question 'Who do you give informal care to?'. Similar self-reported questions have been used to identify informal caregivers in the European Social Survey [15] and the Swedish "Good Aging in Skåne" survey [9].

Among the caregivers identified for this study in the GERDA survey, 674 spousal caregivers were identified by answering 'spouse' to the question 'Who do you help?'.

2.1. Outcome Variable: Subjective Caregiver Burden

The question 'As an informal caregiver, have you been worrying about not going to be able to care for your loved one in a proper way? (yes, no)' was used to measure subjective caregiver burden. A similar item as the one used in this study was categorised as an environmental question in the Caregiver Burden Scale [36].

2.2. Measures of Economic, Social and Political Resources

The variables used for testing economic resources were personal income and perceived ability to make ends meet. Personal income measured monthly income after taxes with five answering options (0–500 euros, 501–1000 euros, 1001–1500 euros, 1501–2000 euros, more than 2000 euros). The variable was dichotomised into '0–1000 euros' and '>1000 euros'. The other economic variable was measured by the question 'Is it possible for you to make ends meet?', with four answering options. This question was dichotomised into 'without difficulty' and 'with difficulty' (with some difficulty, with difficulty, with much difficulty).

Social resources were assessed by measuring contact frequency with other social network members than the spouse. One variable measured contact frequency with family members and relatives, while the other variable measured contact frequency with neighbours and friends. The original question 'How often are you in contact with one/several of the following persons?' had five answering options. Both variables were dichotomised into 'frequent contact' (several times a week) if the respondent had contact with at least one person in the category several times a week. 'Infrequent contact' (several times a month, a few times a year, never, the person does not exist) indicated that the respondent was in contact with someone in the category less often than several times a week.

Political resources were measured by internal political efficacy and political participation. Internal political efficacy was assessed with the statement 'I feel strong and influential in society'. This variable was dichotomised into 'high' (fully agree, partly agree) and 'low' (do not agree). Political activity was assessed by the question 'Have you during the last five years engaged in the following activities: contacted a civil servant or trustee, appealed against a decision launched by authorities, written a letter to the editor/an article in a newspaper/journal, signed a petition, participated in a demonstration, boycotted a product?'. A sum variable was created on the basis of these six items and dichotomised into 'high' (yes, many times; yes, occasionally) and 'low' (no, do not remember).

2.3. Control Variables

Socio-demographic variables included age, gender, educational level (less than 10 years, 10 years or more), and rural or urban residence. The caregiver's self-rated health was tested with the following question: 'In general, how would you say your health is?'. The variable was dichotomised into 'good' (excellent, very good, good) and 'poor' (fair, poor). As a rough estimation of the intensity of the care provided, a question on formal support was used as a control variable. The caregiver receiving formal support for her/his caregiving tasks indicates that the care recipient needs help with basic routines on a daily basis. The question targeted to the caregiver was 'Do you receive support from the municipality or another organisation for providing care? (for example respite care, economic compensation, service vouchers, etc.)', with the answering options of 'yes, what kind?' and 'no'. Region was also included as one control variable (Västerbotten, Österbotten, and Pohjanmaa).

2.4. Analyses

The distribution (%) of all variables was calculated according to region (Table 1). Contingency tables with Pearson's Chi-square tests were used to analyse the bivariate association between subjective caregiver burden and social, economic, and political resources (Table 2). Logistic regressions were conducted by calculating odds ratios (OR) with 95% confidence intervals (CI) for the likelihood of reporting subjective caregiver burden by economic, social, and political variables and control variables (Table 3). Four models were analysed, and the variables were entered stepwise in the following sequence: (1) economic, social, and political resources; (2) region; (3) sociodemographic variables; (4) self-rated health and formal support. To test robustness of the model, multicollinearity statistics were run. Variance influence factors ranged between 1–1.5.

All statistical analyses were performed in the statistical program IBM SPSS Statistics 27 [39].

2.5. Ethical Considerations

The study follows the Guidelines of the Finnish Advisory Board on Research Integrity [40]. The data collection was approved by the Regional Ethical Review Board in Umeå, Sweden 13 October 2016 (2016/367-32, 05-084Ö).

3. Results

As shown in Table 1, less than half of the spousal caregivers reported subjective caregiver burden in Västerbotten, Sweden (42.8%) and Swedish-speaking Österbotten, Finland (43.7%), while the number was higher in Finnish-speaking Pohjanmaa, Finland (53%).

Table 1. Distribution of variables among older spousal caregivers in Västerbotten (Sweden), Swedish-speaking Österbotten (Finland), and Finnish-speaking Pohjanmaa (Finland).

Variable	**Total (n = 674)**	**Västerbotten (n = 343)**	**Österbotten (n = 178)**	**Pohjanmaa (n = 153)**
Age (n = 673)				
66	117 (17.4%)	56 (16.4%)	29 (16.3%)	32 (20.9%)
71	179 (26.6%)	94 (27.5%)	49 (27.5%)	36 (23.5%)
76	149 (22.1%)	80 (23.4%)	40 (22.5%)	29 (19.0%)
81	151 (22.4%)	72 (21.1%)	35 (19.7%)	44 (28.8%)
86	77 (11.4%)	40 (11.7%)	25 (14.0%)	12 (7.8%)
Gender (n = 674)				
Female	353 (52.4%)	172 (50.1%)	92 (51.7%)	89 (58.2%)
Male	321 (47.6%)	171 (49.9%)	86 (48.3%)	64 (41.8%)
Education (n = 668)				
Lower secondary	311 (46.6%)	181 (53.4%)	78 (43.8%)	52 (34.4%)
Upper secondary	357 (53.4%)	158 (46.6%)	100 (56.2%)	99 (65.6%)
Residence (n = 656)				
Rural	259 (39.5%)	123 (37.0%)	98 (56.0%)	38 (25.5%)
Urban	397 (60.5%)	209 (63.0%)	77 (44.0%)	111 (74.5%)
Personal income (n = 653)				
0–1000 euros	228 (34.9%)	131 (39.3%)	55 (31.8%)	42 (28.6%)
>1000 euros	425 (65.1%)	202 (60.7%)	118 (68.2%)	105 (71.4%)
Ability to make ends meet (n = 655)				
Low	245 (37.4%)	125 (37.2%)	66 (38.6%)	54 (36.5%)
High	410 (62.6%)	211 (62.8%)	105 (61.4%)	94 (63.5%)
Contact with family members (n = 663)				
Infrequent	271 (40.9%)	130 (38.5%)	69 (39.2%)	72 (48.3%)
Frequent	392 (59.1%)	208 (61.5%)	107 (60.8%)	77 (51.7%)
Contact with friends and neighbours (n = 649)				
Infrequent	377 (58.1%)	178 (53.3%)	100 (59.2%)	99 (67.8%)
Frequent	272 (41.9%)	156 (46.7%)	69 (40.8%)	47 (32.2%)
Political participation (n = 653)				
Low	288 (44.1%)	139 (41.5%)	65 (38.5%)	84 (56.4%)
High	365 (55.9%)	196 (58.5%)	104 (61.5%)	65 (43.6%)
Internal political efficacy (n = 627)				
Low	246 (39.2%)	137 (42.3%)	61 (38.6%)	48 (33.1%)
High	381 (60.8%)	187 (57.7%)	97 (61.4%)	97 (66.9%)
Self-rated health (n = 665)				
Poor	295 (44.4%)	149 (44.2%)	69 (39.2%)	77 (50.7%)
Good	370 (55.6%)	188 (55.8%)	107 (60.8%)	75 (49.3%)
Formal support for informal care (n = 661)				
No	516 (78.1%)	290 (86.6%)	126 (72.8%)	100 (65.4%)
Yes	145 (21.9%)	45 (13.4%)	47 (27.2%)	53 (34.6%)
Subjective caregiver burden (n = 580)				
No	317 (54.7%)	174 (57.2%)	80 (56.3%)	63 (47.0%)
Yes	263 (45.3%)	130 (42.8%)	62 (43.7%)	71 (53.0%)

Table 2 shows the bivariate associations between subjective caregiver burden and economic, social, and political resources in the three regions and the total sample. Subjective caregiver burden was statistically significantly associated ($p < 0.05$) with ability to make ends meet in Västerbotten, Sweden and Swedish-speaking Österbotten, Finland, but not in Finnish-speaking Pohjanmaa, Finland. Statistically significant associations between subjective caregiver burden and contact with family members was found in the total sample and in Finnish-speaking Pohjanmaa. Internal political efficacy was statistically significantly associated with subjective caregiver burden in the total sample and in Västerbotten, Sweden.

Table 2. Bivariate association between subjective caregiver burden and economic, social, and political resources among older spousal caregivers in Västerbotten (Sweden), Swedish-speaking Österbotten (Finland), and Finnish-speaking Pohjanmaa (Finland), respectively.

	Total, (n = 263) %	***p***	**Västerbotten, Sweden (n = 130) %**	***p***	**Österbotten, Finland (n = 62) %**	***p***	**Pohjanmaa, Finland (n = 71) %**	***p***
Personal income		ns		ns		ns		ns
0–1000 euros	46.9		46.5		48.9		45.5	
>1000 euros	44.9		40.2		42.6		56.3	
Ability to make ends meet		***		**		*		ns
Low	56.0		53.2		55.8		63.0	
High	39.8		37.4		36.8		48.2	
Contact with family members		**		ns		ns		**
Infrequent	38.8		37.6		37.5		42.2	
Frequent	50.1		45.9		47.7		65.2	
Contact with friends/neighbours		ns		ns		ns		ns
Infrequent	47.9		45.9		45.5		54.0	
Frequent	40.4		37.9		40.0		50.0	
Political participation								
Low	45.7	ns	43.0	ns	39.6	ns	54.1	ns
High	44.8		42.5		43.7		53.4	
Internal political efficacy								
Low	50.5	*	49.6	*	40.7	ns	65.1	ns
High	41.1		35.8		44.0		48.8	

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. Ns indicates non-significant result.

In Model 1 (Table 3), poor perceived ability to make ends meet and frequent contact with family members were statistically significantly associated with subjective caregiver burden. In Model 2 (Table 3), where regions were added as control variables, poor perceived ability to make ends meet, frequent contact with family members, living in Pohjanmaa, and low internal political efficacy were statistically significantly associated with subjective caregiver burden. When sociodemographic variables were controlled for in Model 3 (Table 3), poor perceived ability to make ends meet, frequent contact with family members, and living in Finnish-speaking Pohjanmaa, Finland were still statistically significantly associated with subjective caregiver burden. Low internal political efficacy was no longer statistically significantly associated with subjective caregiver burden. In the last Model 4, (Table 3), when we controlled for self-rated health and formal support, poor perceived ability to make ends meet, frequent contact with family members, and living in Finnish-speaking Pohjanmaa, Finland remained statistically significantly associated with subjective caregiver burden. In addition, poor self-rated health and receiving formal support were statistically significantly associated with subjective caregiver burden.

Table 3. Odds Ratios (OR) and 95% confidence intervals (CI) for subjective caregiver burden among older spousal caregivers (n = 673) in Västerbotten (Sweden), Swedish-speaking Österbotten (Finland), and Finnish-speaking Pohjanmaa (Finland).

	Model 1 OR (95% CI)	**Model 2 OR (95% CI)**	**Model 3 OR (95% CI)**	**Model 4 OR (95% CI)**
Personal income				
>1000 euros	1.00	1.00	1.00	1.00
0–1000 euros	0.81 (0.54–1.21)	0.86 (0.57–1.29)	0.80 (0.50–1.27)	0.77 (0.47–1.25)
Ability to make ends meet				
High	1.00	1.00	1.00	1.00
Poor	2.13 (1.45–3.13) ***	2.12 (1.44–3.13) ***	2.25 (1.50–3.38) ***	2.16 (1.43–3.26) ***
Contact with family members				
Frequent	1.00	1.00	1.00	1.00
Infrequent	0.59 (1.41–3.13) **	0.55 (0.38–0.81) **	0.59 (0.38–0.82) **	0.55 (0.37–0.81) **
Contact with friends/neighbours				
Frequent	1.00	1.00	1.00	1.00
Infrequent	1.39 (0.96–2.01)	1.33 (0.92–1.93)	1.37 (0.93–2.01)	1.43 (0.97–2.12)
Internal political efficacy				
High	1.00	1.00	1.00	1.00
Low	1.44 (1.00–2.07)	1.50 (1.03–2.16) *	1.46 (1.00–2.14)	1.35 (0.91–2.01)
Political participation				
High	1.00	1.00	1.00	1.00
Low	1.03 (0.72–1.48)	0.94 (0.65–1.37)	0.96 (0.65–1.42)	0.97 (0.65–1.43)
Region				
Västerbotten		1.00	1.00	1.00
Österbotten		1.01 (0.65–1.59)	0.94 (0.59–1.51)	0.89 (0.55–1.45)
Pohjanmaa		1.91 (1.20–3.03) **	2.00 (1.23–3.25) **	1.77 (1.08–2.92) *
Gender				
Male			1.00	1.00
Female			1.34 (0.90–2.00)	1.21 (0.80–1.82)
Age				
66			1.00	1.00
71			1.05 (0.60–1.83)	0.98 (0.56–1.74)
76			1.33 (0.74–2.42)	1.30 (0.71–2.38)
81			0.71 (0.39–1.31)	0.67 (0.36–1.24)
86			1.22 (0.54–2.74)	0.95 (0.41–2.21)
Education				
Higher			1.00	1.00
Lower			0.94 (0.62–1.40)	0.97 (0.64–1.46)
Residence				
Urban			1.00	1.00
Rural			1.26 (0.84–1.88)	1.24 (0.82–1.88)
Self-rated health				
Good				1.00
Poor				1.51 (1.01–2.24) *
Formal support for informal care				
No				1.00
Yes				1.70 (1.06–2.74) *
−2 Log Likelihood	676.415	668.178	645.047	627.029
Cox & Snell R Square	0.059	0.074	0.092	0.106
Nagelkerke R Square	0.079	0.099	0.123	0.142

Model 1 is adjusted for economic, social, and political variables. Model 2 is adjusted for economic, social, political, and regional variables. Model 3 is adjusted for economic, social, political, regional, and sociodemographic variables. Model 4 is adjusted for economic, social, political, regional, sociodemographic, caregiver's self-rated health, and formal support for informal care. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

4. Discussion

This study aimed to study the prevalence of subjective caregiver burden among older spousal caregivers and explore the associations between subjective caregiver burden and individual social, economic, and political resources in a Nordic regional setting. This was done by using cross-sectional survey data collected among five different older age cohorts in the Bothnia region in Finland and Sweden.

In Västerbotten, Sweden and Swedish-speaking Österbotten, Finland, 8% of the participants were identified as spousal caregivers, while 6% were spousal caregivers in Finnish-speaking Pohjanmaa, Finland (Table 1). Previous research has identified that about one out of six among the Swedish population aged 65 and above are informal caregivers providing care to a close one of any age [27], with the corresponding share in Finland being 12–26% depending on age cohort [41]. Given that most older caregivers in Finland and Sweden provide care for a spouse [24,26,41], the observed prevalence of spousal caregivers in our study (6–8%) could be seen as in line with previous studies.

About half of the spousal caregivers in our study reported experiencing subjective caregiver burden. In Finnish-speaking Pohjanmaa, Finland, it was more common to report subjective caregiver burden (53%) and to receive formal support (35%) than in Swedish-speaking Österbotten, Finland, where 44% reported subjective caregiver burden and 27% received formal support. Formal support for informal care may on one hand indicate alleviating support services offered in-kind and in-cash, but it may also indicate intensive caregiving [11,26]. Previous research has identified lower membership rates in organizations among Finnish-speaking older adults in the Bothnia region [30]. This could tentatively explain the high prevalence of subjective caregiver burden among caregivers in Finnish-speaking Pohjanmaa, Finland, as third sector organizations play a crucial role in supporting informal caregivers in Finland [11] and Sweden [27]. Nonetheless, the observed regional differences in subjective caregiver burden and formal support are issues that warrant further research. In line with the results of a previous study in Sweden where 13% of older caregivers received formal support [9], only 13% of spousal caregivers in our study reported receiving formal support in Västerbotten, Sweden. Formal support has been found to have alleviating effects on subjective caregiver burden [2,16,26], but as mentioned, receiving formal support may also indicate intensive caregiving [24,26] and not all caregivers who receive public services experience that their needs are being adequately or sufficiently met.

Out of the two economic resource indicators, poor perceived ability to make ends meet was highly associated with subjective caregiver burden in all four models while personal income was not. Perceived ability to make ends meet captures the situation of the household and thus is more representative of a dyadic approach [42], which may be deemed especially relevant when investigating a sample of spouses. Still, our finding that personal income was not associated with subjective caregiver burden is contradictory to a previous finding among Swedish caregivers [43]. To validate our findings further, another scaling of income was tested in a re-run of our analysis, but the results remained the same.

According to the caregiver stress process model [13], social resources may serve as important mediators of support for informal caregivers by not only providing emotional support to the main caregiver, but also by decreasing the objective caregiver burden through sharing care tasks and assisting in accessing services [13,16]. Several previous studies investigating the role of social support for subjective caregiver burden have found alleviating effects [2,16,32]. Out of the two social resource indicators assessed in our study, however, only contact with family members was statistically significantly associated with subjective caregiver burden. Frequent contact indicated subjective caregiver burden which could be deemed as frequent contact being a sign of hardship. Both Finland and Sweden represent low levels of familialism norms [15,41], potentially meaning that older caregivers do not ask for help from other family members unless the care intensity is very high. Indeed, older caregivers in Nordic countries have been found to not share care tasks as much as family members in younger generations [12,27]. Nonetheless, our findings warrant further investigation on the causal relationship between subjective caregiver burden and social resources in a Nordic context.

To the best of our knowledge, our study is the first to investigate the role of political resources among caregivers in a Nordic setting. Previous studies conducted elsewhere have identified associations between a similar indicator, subjective social status, and different aspects of wellbeing among professional care workers in Israel [28] and informal caregivers in UK [29]. The bivariate analysis (Table 2) in our study showed statistically significant associations between internal political efficacy and subjective caregiver burden among spousal caregivers in Västerbotten, Sweden, but this relationship disappeared in the multivariate analyses (model 1–4, Table 3) where no statistically significant associations between subjective caregiver burden and internal political efficacy nor political participation were found.

Guided by previous international research on informal caregiving [8,14,44], our analysis included some common control variables such as gender. In our study, gender was not statistically significantly associated with subjective caregiver burden, which could be interpreted as the Nordic welfare model succeeding in its gender inequality-reducing goals [18]. The gender gap in terms of who becomes an informal caregiver is quite small in the oldest age groups in Finland and Sweden [11,27]. Similarly, other commonly used [8,14] background variables such as educational level, age, and rural or urban residence were not associated with subjective caregiver burden in our study. This could again potentially be attributed to the Nordic welfare model. However, the relationship between subjective caregiver burden and age and educational level could have been better assessed with a dyadic approach including both the caregiver and care recipient.

In our study, the results from the multivariate analysis (model 4, Table 3) showed that poor self-rated health increased the likelihood of reporting subjective caregiver burden. Self-rated health could be seen as an appropriate factor to include when investigating a sample of older caregivers as their own health may be facing greater risks than caregivers in other age groups. Our results thus stress the need for health promoting initiatives for informal caregivers. Nonetheless, it is also possible that subjective caregiver burden causes poorer self-rated health, and future longitudinal studies should explore the causal relationships between the two factors.

Methodological Limitations and Strengths

Limitation of the study includes missing details on the objective caregiver burden, such as for example caregiving hours and type of caregiving tasks. According to the stress process model [13], such objective stressors are closely interlinked to subjective stressors, and this relationship has gained support in several studies [8,14]. Therefore, the model used in this study would have been more robust if it had included details on the care recipient's health status and the type and amount of care provided to him or her. Unfortunately, such variables were unavailable in the data. Instead, the caregiver receiving formal support was used as a rough estimation of care intensity. A similar assessment in terms of receiving formal support being equivalent to providing intensive care has been made by other researchers [6,10]. The caregiver stress process model [13] also includes other indicators than the ones included in our analysis, but the entire model was not possible to test due to the data available from the survey aimed for the general adult population.

Subjective caregiver burden is often assessed through multi-item scales [35,36], but due to the data available, we used a single-item question similar to one categorised as an environmental question in the Caregiver Burden Scale by Elmståhl and colleagues [36]. Using a single question limits the ability to investigate different aspects of strain and the validity of the scale, but also has practical advantages as the response rate was high. Single-item questions to determine subjective caregiver burden have also been used in previous studies [9,45].

Financial stress is commonly included as one of the dimensions of subjective caregiver burden [35,36] and can thus be seen as both a dimension of and as an explaining factor for poor wellbeing among informal caregivers. We interpreted individual levels of economic factors as explaining factors for subjective caregiver burden in our study. However, it is also possible that subjective caregiver burden contributes to financial stress, as subjective caregiver burden is likely to be interlinked with a demanding care situation [13], and care needs usually bring costs [18,19,46]. Future studies investigating the relationship between economic resources and subjective caregiver burden could preferably use longitudinal data to determine causality.

We assessed social resources by measuring contact frequency, while perceived social support has been suggested to be a better measurement tool [32]. Future studies investigating the role of social resources for informal caregivers could use other indicators to more accurately capture the relationship between subjective caregiver burden and social support. In future studies on social support among informal caregivers, other sources of support could be feasible to include, such as, for example, support from social and health care staff, or social and/or peer support received through activities organized by churches, NGOs, and/or municipalities. By including various sources of support, the social context of informal caregivers and its potential effect could be more accurately captured.

One of the strengths of the study includes a comparatively large regional sample of older spousal caregivers (674 respondents), which is not limited to caregivers who receive formal support. The subsample is obtained from survey data collected from a representative sample of older adults. The response rates were high, ranging from 55–71% in the different regions. Still, there is a risk of bias as informants who are healthier may be more willing and able to participate in surveys. Further, not everyone who cares for close ones may identify themselves as caregivers and, therefore, it is possible that not all caregivers were identified in the survey.

Our study contributed to research on subjective caregiver burden by investigating geographical (Sweden) and ethnolinguistic (Finland) regions, but as social and health care services in Finland and Sweden are organized on a municipal (or county) level, future research could include such a perspective.

5. Conclusions

Inspired by the caregiver stress process model by Pearlin et al. (1990) emphasising the role of resources for caregiving outcomes, the aim of this study was to investigate the prevalence of subjective caregiver burden and its associations with individual social, economic, and political resources among older spousal caregivers in a Nordic regional setting. Despite comparatively generous public social and health care systems in Finland and Sweden, it was common for spousal caregivers in the Bothnia region to report subjective caregiver burden, especially among Finnish-speaking caregivers in Finland. There was a statistically significant relationship between financial strain and subjective caregiver burden, although no such associations were found with personal income or other sociodemographic variables. Financial strain can be seen as better reflecting the situation of the household than other sociodemographic factors assessing only the caregiver's resources. The bivariate analysis showed a significant relationship between internal political efficacy and subjective caregiver burden, but none of the investigated political resources remained statistically significantly associated with subjective caregiver burden in the multivariate analysis. Results from the multivariate regression analysis further showed that frequent contact with family members was statistically significantly associated with subjective caregiver burden, which could be interpreted as frequent contact being a sign of hardship. This relationship warrants future research, especially with regard to caregivers who lack such resources. The observed ethnolinguistic differences in the prevalence of subjective caregiver burden in Finland also warrant further investigation. Future research on subjective caregiver burden could preferably use longitudinal data to determine causal relationships. Future studies with more data available could also use multilevel analyses to test the full caregiver stress process model and investigate the role of mediating factors in the relationship between objective and subjective caregiver burden and/or other health outcomes in different comparative settings. Accumulated evidence on risk factors for negative outcomes of informal caregiving can assist in developing effective screening tools and support, which is becoming increasingly important with the ageing population.

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Institutional Review Board Statement: The study follows the Guidelines of the Finnish Advisory Board on Research Integrity TENK (https://tenk.fi/sites/tenk.fi/files/HTK_ohje_2012.pdf, accessed on 12 December 2022). The data collection was approved by the Regional Ethical Review Board in Umeå, Sweden 13 October 2016 (2016/367-32, 05-084Ö).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study, by agreeing to participate in the questionnaire after receiving information about the survey.

Data Availability Statement: More information about the Gerontological Regional Database (GERDA) is available on the following webpages: http://urn.fi/urn:nbn:fi:att:e917092f-e9c5-4a7b-91b5-bb704e3daeb9 (accessed on 5 December 2022) and https://www.gerdacenter.com/home?setlang=l3 (accessed on 5 December 2022).

Conflicts of Interest: The authors declare no conflict of interest.

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Article

The Expert Caregiver Intervention Targeting Former Caregivers in Finland: A Co-Design and Feasibility Study Using Mixed Methods

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Abstract: Informal caregivers face risks of social isolation. Given the high prevalence of informal caregivers in Europe, a considerable proportion of the population are also former caregivers. The Finnish Expert Caregiver intervention sought to train former caregivers to become volunteers aiming to support current caregivers through mainly peer support. The aims of this mixed method non-controlled exploratory intervention study were to assess the feasibility of the Finnish Expert Caregiver intervention by co-designing and implementing the intervention, and by assessing demand and practicality with special attention to the impact of COVID-19. The findings imply that the intervention was feasible as it resulted in a co-designed training course consisting of 30 h with 25 participants enrolling and 19 of them trying volunteering activities. The participants reported high scores on well-being at all timepoints of study, however, without statistically significant differences. The analysis of the focus group interviews revealed that the Expert Caregivers experienced the intervention as meaningful and offered them a sense of belonging with the other participants. Apart from using their caregiving past as an asset, the participants also took advantage of other personal skills and resources. Risks of adverse effects were related to the participants' expectations on their own contribution, demanding peer support recipients, poorly functioning peer support groups, and insufficient distance to one's caregiving past. The participants stressed the need for continuing support from intervention facilitators. Future studies with larger samples should investigate whether the effects differ between subgroups of participants and explore the perspective of the peer support recipients.

Keywords: caregiver; health promotion; co-design; intervention; feasibility; mixed method; volunteering; sense of coherence; life satisfaction

1. Introduction

Informal caregivers, referring to family and friends who provide usually unpaid care, are the backbone of any long-term care system in Europe [1,2]. While providing informal care may entail positive aspects [3], intensive informal caregiving is associated to various adverse effects such as depressive symptoms and social isolation [4]—effects that have been frequently reported among caregivers in Europe during the COVID-19 pandemic [5]. This study focuses on informal care targeted to older adults, here defined as aged 65 and over, with care needs. Given the high prevalence of informal caregivers throughout Europe [2,6], a considerable proportion of the population are also former caregivers, that is, caregivers who have ceased caring as the care recipient has died or been admitted to a nursing home. Negative health effects such as insomnia and depressive symptoms may prevail post-caregiving [7], but most former caregivers seem to recover from such effects within one to two years [8,9]. In fact, it is not uncommon for former caregivers to take up the caregiving role again or at least report being ready to do so if needed [10,11]. This may be partly explained by the concept of generativity [12], referring to the motivation and action to contribute to the welfare of others. Generative actions may have a positive impact on the contributor as well, as volunteering is associated to several health benefits [13–16]. Indeed, a clear focus within the World Health Organization (WHO) paradigm of healthy aging [17] is volunteering, given its positive impact on the one volunteering and the one receiving the support.

Peer support differs from other types of social support, as it involves shared experiences instead of any type of befriending activity where mutual experience is not a requirement. A recent scoping review on peer support for informal caregivers of people with dementia concluded that peer support seems to have a positive impact on the support recipients [18], although evidence on best practice is limited as intervention delivery and measured outcomes vary between studies. As for the impact on the ones offering the support, one previous study [19] in England found that the volunteers reported higher personal growth and mood in comparison to the support recipients, and that the volunteers' levels of well-being were maintained throughout volunteering, especially for those who volunteered for a longer period. Another study [20] in England identified positive effects on well-being in terms of shared experiences and a sense of connection with others within the social and organizational network as well as emotional and practical gains. However, a risk of evoking negative emotions was also noted in the results. Similarly, a recent Norwegian study [21] exploring the experiences of trained peer supporters for caregivers of people with dementia found that the peer supporters valued the activities but also stressed the need for safeguarding their privacy and setting limits.

Finland is one of the countries with the most rapid ageing populations [22]. In Finland, typically categorized as a Nordic welfare model, municipalities as opposed to family members are responsible for providing care for adults aged 65 and over who do not manage independently in everyday life [23]. In a comparison on populations aged 16–80, Finland was found to host more caregivers but fewer intensive caregivers (who provided care 11 or more hours per week) than the European average [6]. Nonetheless, intensive informal care is provided in Finland as well, especially by caregivers who are encompassed by the public Informal Care Allowance (ICA): a care agreement with the municipality including amongst other things an economic allowance and the right to respite care [24]. Most ICA caregivers are spouses aged 65 and over who provide intensive care equivalent to institutional care [25].

Finnish municipalities, Non-Governmental Organizations (NGO), and congregations organize information, social support, and education for caregivers partly through central government funding. These activities tend to be organized by professionals. Coordinated activities for former caregivers are rather scarce in Finland, although there are some exceptions such as examples of local peer support activities organized by the nationwide association Omaisena edelleen [26] and a training program for former caregivers to become experts by experience organized by "Polli", which is an association for caregivers in the capital region [27]. Nevertheless, there is a need for further developing activities involving relevant stakeholders to coordinate action for adults with the experience of providing informal care to support current caregivers through peer support. Such action would potentially not only benefit current caregivers but holds the potential to promote health among former caregivers as well.

Originally inspired by the Expert Caregiver program in Catalonia, Spain [28], the Finnish Expert Caregiver program sought to create a health-promoting intervention for individuals with experience of providing informal care to older adults. A co-design approach [29] was applied in the development and implementation of the intervention, thus bringing together relevant stakeholders to design local solutions to local problems.

More specifically, the Finnish Expert Caregiver program sought to co-design, implement, and evaluate an intervention by training the participants to become Expert Caregivers and take part in coordinated volunteering opportunities to support current informal caregivers through peer support activities and spokesman assignments contributing to increased awareness of informal care in society.

The main aim of this exploratory mixed-method study was to co-design, implement, and assess the feasibility [30] of the Finnish Expert Caregiver intervention for individuals with experience of providing informal care to older adults with care needs. This main aim was divided into the following specific aims:

- To co-design and implement the Finnish Expert Caregiver intervention with special attention to the impact of the COVID-19 pandemic;
- To assess demand in terms of actual use and perceived demand;
- To assess practicality in terms of the participants' ability to carry out volunteering activities and the effects on the participants.

2. Materials and Methods

2.1. Research Design

This was a non-controlled exploratory intervention study with a pre-post design. Qualitative and quantitative methods were used. We conducted baseline assessment, assessment at the end of the 4-month long training course, and assessment 13 months after baseline.

When reporting the development of the intervention in this study, we follow the recommendations in the validated Guidance for reporting intervention development studies in health research (GUIDED) [31]. We also adhere to the items recommended in the Template for intervention description and replication (TIDieR) [32] when describing the final intervention.

2.2. Setting of the Intervention

The Expert Caregiver intervention was held predominantly in the mixed rural/urban area of Ostrobothnia with 177,649 inhabitants [33] living on about 7621 square kilometers of land. Ostrobothnia is one of the healthiest regions in Finland in terms of expected life expectancy [34], but the region's dependency ratio of 68 is higher than the national average of 62.

The intervention was held in a Swedish-speaking ethnolinguistic context. Swedish is one of the two official languages in Finland. Approximately 5% of the Finnish population is Swedish-speaking, while in the region of Ostrobothnia, the Swedish speakers constitute about 51% of the population. Swedish speakers live longer than their Finnish-speaking peers [35], and Swedish-speaking older adults in Ostrobothnia have been found to possess more social resources and to be more frequently engaged in voluntary organizations than their Finnish-speaking peers [36]. Thus, the setting of the intervention involved demographic challenges but also health and cultural advantages.

2.3. Intervention

The primary goals of the health-promoting intervention were to train individuals with experience of providing informal care to an older adult to become Expert Caregivers to support current informal caregivers of older adults mainly by offering peer support.

More specifically, the initial goals of the co-design phase were to create a regional reference group consisting of five persons representing NGOs, municipalities, and current or former caregivers, to create a steering group consisting of five people in leading positions, and to co-develop a training course focusing on peer support for former caregivers. We initially planned to recruit 10–15 participants in the training course and anticipated that 10 of them would try volunteering.

2.4. Study Population

The only eligibility criteria for participating in the training course was having experience of providing informal care to an older person with care needs. Participants were recruited by marketing on social media, radio, newspapers, and through information events organized in three different municipalities across the Ostrobothnia region. The events and recruitment process were organized and marketed by the project partners and further advertised by reference and steer group members working with informal caregivers.

2.5. Measures

To assess the demand [30] of the intervention in terms of actual use and perceived demand, we counted the number (and when applicable percentage) of participants enrolling in the training course, completing the training course, volunteering one time, volunteering multiple times, as well as the number of organizations, congregations, or municipalities involved in the intervention (apart from the intervention providers) and finally the caregivers reached through peer support activities.

To assess practicality [30], we focused on two key concepts: ability of participants to carry out activities and effects on participants. We explored practicality from the perspective of the Expert Caregivers. We used data gathered from qualitative semi-structured focus group interviews with 13 participants collected 13 months after baseline. The participants were divided into four natural groups of three or four persons and were asked to discuss the process from caregiver to becoming an Expert Caregiver, the experiences of and perceived positive and negative effects on their well-being by volunteering as well as their experience of volunteering during the COVID-19 pandemic. A descriptive analysis (not presented here) showed that proportionally, participants of male gender, living in singe households, and holding an upper secondary education degree were slightly more represented in the focus group interviews than in the total sample. The focus group interviews were held by four project staff members: three researchers and one educational planner. The qualitative data are reported according to the standards for reporting qualitative research [37].

To further explore the effects on the participants, we used repeated questionnaires collected at baseline, at the end of the 4-month-long training course, and 13 months after baseline. The perceived effects on the participants' well-being were explored by assessing the participants' sense of coherence (SOC) [38] and Diener's Satisfaction With Life Scale Index (SWLS) [39]. The scales showed a good internal consistency at all timepoints of the study with scores from Cronbach's alpha tests ranging from 0.74 to 0.89.

The SOC results were assessed both as a whole and divided into the three dimensions of comprehensibility, manageability, and meaningfulness. Comprehensibility is the cognitive dimension and refers to the extent to which an individual perceives his or her circumstances as understandable [38]. Manageability is the behavioural dimension and refers to the experience of possessing the resources needed to cope with current circumstances, leading on to the motivational dimension, meaningfulness, that refers to whether the individual finds motivation and meaning in facing his or her challenges. The 13-item SOC-index was to be answered on a 1–7 Likert scale. The whole SOC-index score ranges between 13 and 91 points. The subscale for meaningfulness has a range of 4–28 points, that for comprehensibility has a range of 5–35 points, and that for manageability has a range of 4–28 points. Higher scores indicate higher SOC.

The SLWS assesses life satisfaction and is a 5-item questionnaire to be answered on a 1–7 Likert scale [39]. Higher scores indicate higher satisfaction, so that 30–35 indicates very high score, 25–29 indicates a high score, 20–24 is average, 15–19 is slightly below average, 10–14 is dissatisfied, and 5–9 is extremely dissatisfied. The quantitative data were collected on site at all three timepoints of study and sent out by post to those not present.

2.6. Analysis

The qualitative focus group interviews were recorded and transcribed verbatim by one of the researchers (Sarah Åkerman). The same researcher (Sarah Åkerman) divided each transcript into inductively chosen categories. The analysis of the focus group interviews was interpretative–phenomenological [40], meaning that the researchers are active in the dynamic research process, aiming to help the participants make sense of their personal and social world. Interpretative phenomenological analysis usually involves small sample sizes from heterogeneous populations, as the aim is to investigate the meaning of a certain group's experiences of a specific phenomenon or event.

Initially, the data were scrutinized into multiple categories by Sarah Åkerman Step by step, the categories were reread and reorganized into broader themes sharing common patterns. For the analysis, the software program of NVivo 12 (QSR International, Doncaster, Australia) was used. To ensure trustworthiness of the findings [41], two other researchers (Fredrica Nyqvist and Annika Wentjärvi) then independently read through the transcribed interviews and compared the data with the coding schemes. Finally, the three researchers discussed the coding scheme until agreement was reached.

For the analysis of the quantitative data, the distribution of all the participants' variables was calculated. Statistical analyses were conducted to assess the mean, range, standard deviation, and median for the participants' SOC and SLWS scores at all three timepoints.

To report differences between the three timepoints of study (baseline, 4 months after baseline, and 13 months after baseline), the participants' average scores on SOC and SLWS were compared. Variables with a normal distribution (Kolmogorov–Smirnov test with $p \leq 0.05$) were analyzed with a one-way repeated ANOVA to compare the differences in average scores between the timepoints. Variables without a normal distribution were analyzed with the Friedman test. All statistical analyses were performed in the statistical program IBM SPSS Statistics 27 (IBM Corp, Armonk, NY, USA).

2.7. Ethical Considerations

The study follows the Guidelines of the Finnish Advisory Board on Research Integrity TENK [42]. Ethical committee approval was not deemed by members of the experienced researcher team to be needed for this non-medical study where we evaluated an intervention focusing on education and knowledge transfer. The study subjects were all adults and participated in the research elements voluntarily after being informed about the aim of the research, data management, and use. The intervention required active participation from the study subjects, and therefore, they were deemed capable of making informed decisions about taking part in the intervention and research activities. Furthermore, the participants enrolled voluntarily in the intervention, comprising of a training course and coordinated volunteering opportunities, and the risks of unforeseen mental or physical harmful consequences were deemed non-existent. Written informed consent was gathered from those participating in the focus group interviews.

3. Results

3.1. Co-Design and Implementation

The Finnish Expert Caregiver Intervention in Ostrobothnia (the Finnish context is presented in the Introduction, while the Ostrobothnia region is described in Materials and Methods) was organized by two educational units (Åbo Akademi University and Novia University of Applied Sciences) and Folkhälsan, the largest NGO in the field of social and health services in Swedish-speaking Finland. The staff members from Åbo Akademi University consisted of three people: one associate professor (Fredrica Nyqvist) in Social Policy working as the project leader, evaluation planner, and researcher in the intervention, one Social Policy doctoral student (Sarah Åkerman) working as a project coordinator, researcher, and facilitator, and one educational planner with the main responsibility of the development of the training content and materials. The staff members from Novia University of Applied Sciences consisted of three people: one research leader (Annika Wentjärvi) who worked mainly as an evaluation planner and researcher, one research and development assistant who worked with administration, and finally one educational planner whose main responsibility was the training course content and materials. At

NGO Folkhälsan, one staff member was involved in the intervention. She, as an expert on informal caregiving and aging at Folkhälsan, worked as a facilitator and education planner in the intervention. All staff members were involved in planning the content of the training course and the materials.

The intervention was informed by previous research on the needs of caregivers, the potential resources of former caregivers, and the potential benefits from volunteering for both the support providers and receivers (discussed in the Introduction). Furthermore, the intervention was guided by a salutogenetic theoretical framework [38,43], as it sought to promote health by creating opportunities for the participants to bond with others in a similar situation, to reflect on the individual process from caregiver to volunteer, to reflect on personal skills, and be equipped with the appropriate tools and adequate support to be able to volunteer by offering mainly peer support. Thus, the intervention was also in line with the WHO paradigm of Healthy Aging including, amongst other things, the principles of continuing to learn, to maintain and build relationships, and to contribute [17].

A co-designing approach means the inclusion of users and producers of services at different stages throughout an intervention development to not only develop but infrastructure the new product [29]. A reference group and steering group were successfully established. Apart from staff members of the intervention, the reference group consisted of six former/current informal caregivers of older adults with care needs (of whom three participated in the intervention also as Expert Caregivers), two public social care workers from two different municipalities, one deacon, and one NGO worker. The steering members represented two NGOs and three municipalities. The co-design procedure before and during the intervention is further presented in Figure 1. Involving both Expert Caregivers and professional stakeholders in feedback discussions throughout the intervention enabled adjusting the intervention to match the local needs.

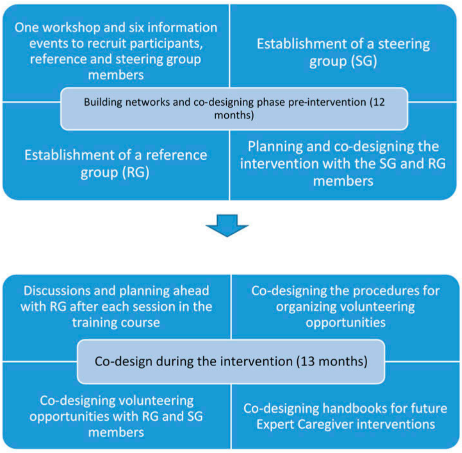

Figure 1. The co-design process.

The co-designing phase resulted in a group-based training course consisting of 30 h and 11 months of coordinated volunteering opportunities for the participants. The content of the intervention is presented in Table 1.

Table 1. The intervention content and timeline.

Session	Components
Training course session 1/3 August 2019 Theme: Me as an informal caregiver then and now (4 h)	• Presentation of participants and intervention • From caregiver to Expert Caregiver • Written promise of silence
	• Optional self-studies at home in terms of literature about how to cope as an informal caregiver written by a former caregiver (4 h)
Training course session 2/3 October 2019 Theme: The everyday puzzle of an informal caregiver (camp, 5 h + 8 h)	• Service, support, legislation, and rights for informal caregivers in Finland • The role of the Expert Caregiver: to listen • The role of the Expert Caregiver in peer group discussions • Visit from a person trained in performing spokesman assignments out of personal experience
October 2019–September 2020 11 months long period of optional volunteering opportunities coordinated by the intervention providers	• Agreement made between Expert Caregiver, intervention facilitator, and peer support recipient or organizer outside of the intervention to determine the timeline, content, and extent of the activity • Intervention facilitator attending first meeting between Expert Caregiver and peer support recipient(s) • Regular contact (about every 3 months) between intervention facilitator and Expert Caregiver (both those involved and those not involved in volunteering activities) to reflect on experiences of volunteering and to plan further activities according to the Expert Caregiver's wishes
Training course session 3/3 December 2019 Theme: Me as an Expert Caregiver—the journey so far and what next? (5 h)	• Discussions about what happens after the course • Self-reflection led by a trained supervisor
Follow-up session September 2020 Theme: Coping as an Expert Caregiver (3 h)	• How to take care of one's well-being as an Expert Caregiver • Self-reflection

In total, 25 participants answered questionnaires at baseline assessment with questions on health and background information. Of the 25 participants, 24 answered the questionnaires in the second assessment 4 months after baseline, and 23 participants filled in the questionnaires in the assessment 13 months after baseline. One participant withdrew from the program because of personal health problems, and one participant was unavailable for contact.

Out of the 23 final participants, 13 participated in the focus group interviews held on-site 13 months after baseline. The relatively low number of participants is explained by barriers to meeting on-site in September 2020 due to COVID-19.

One participant withdrew from the program after the first session of the training course because of personal health problems. One participant was unavailable for contact right after the third training course session.

As further presented in Section 3.2, 19 participants tried volunteering after the training course. The four participants who completed the training course but chose to not try volunteering were all female. The main reasons for not trying volunteering were providing informal care (n = 1), personal health concerns (n = 2), and family concerns (n = 1).

Five months into the intervention, the outbreak of COVID-19 reached Finland in March 2020. National recommendations were introduced advising Finns aged 70 years and older not to meet anyone outside of the household face to face. As these recommendations applied to almost all Expert Caregivers and their peer support recipients, all physical meetings were reorganized into telephone and virtual meetings. This required extra resources from the NGO involved in the intervention as both Expert Caregivers and peer support recipients needed technological guidance. For the intervention to be adequately tested and implemented in the region despite COVID-19, the intervention was extended from the planned 9 months to 13 months.

3.2. Demand

Twenty-five participants enrolled in the training course, and 23 (92%) participants completed it. The characteristics of the final 23 participants are available in Table 2.

Table 2. Characteristics of final 23 participants at baseline.

Variable	***n***	**%**	**Mean**	**Range**	**SD**
Age			72.52	57–82	6.93
Gender					
Female	18	78.3			
Male	5	21.7			
Education					
Lower secondary	7	30.4			
Upper secondary	16	69.6			
Household					
Alone	19	82.6			
With someone	4	17.3			
Relationship to main CR					
Spouse	18	78.3			
Parent	5	21.7			
Years since main caregiving ended	21		2.48	0–16	4.06
Years of caregiving to main CR			8.13	0–37	7.43
Age of former CR at death	21		78.29	62–101	10.15
Diagnosis of main CR					
Cognitive disorder	9	39.1			
Other	14	60.9			

CR = care recipient, SD = standard deviation.

Out of the final 23 participants, 19 participants (82%) volunteered during the intervention, and 17 (74%) volunteered at multiple occasions. All types of volunteering are included in these numbers: individual or group-based peer support activities or spokesman assignments.

In total, 15 organizations, municipalities, eldercare units, or congregations were involved with either marketing or co-organizing the volunteering activities with the intervention providers.

The Expert Caregivers reached 60 informal caregivers through group-based peer activities and nine informal caregivers through individual peer activities. Nine Expert Caregivers performed spokesman assignments in newspapers, radio interviews, and activities organized for informal caregivers and/or professional stakeholders.

3.3. Practicality: Ability to Carry Out Intervention Activities

Below, we present the analysis concerning the ability of participants to carry out intervention activities based on the focus group interviews. A summary of the results from the focus group interviews is available in Table 3.

Table 3. Summary of results from the analysis of the focus group interviews.

Research Focus	Main Theme	Subthemes
3.3. Practicality: Ability of participants to carry out activities	3.3.1. Individual barriers and facilitators to becoming an Expert Caregiver	*Enough distance to one's own caregiving experienceCurrent life circumstances*
	3.3.2. Competency as an Expert Caregiver	*Using new and old skills* *Relationship between Expert Caregiver and peer support recipient* *The role of the intervention organizers for feeling safe*
	3.3.3. Volunteering during COVID-19	
3.4. Practicality: Perceived effects on well-being	3.4.1. Perceived effects on the participants' well-being and related Mediators	*Expectations influencing the experience* *The needs of caregivers as a stressor* *Volunteering as a therapeutic, meaningful or joyful activity* *A sense of belonging with the other participants*

3.3.1. Individual Barriers and Facilitators to Becoming an Expert Caregiver

Enough Distance to One's Own Caregiving Experience

> *"It (the care recipient passing away) was about 2–3 years ago for me so I think I have the distance that is needed. As a recent widower I would not have been able to take on this assignment." Male participant*
>
> *"It's the same for me, it was about 2 years ago that, that I experienced . . . I would not have been ready before that. Then I was so tired and . . . I think I needed to work through the grief and move on and find myself, who am I in this? Because one has lived, my husband was ill for 10 years, I lived through him for 10 years. / . . . / When you are by yourself and it all runs off you, what do you do? Building, getting a new structure on everyday life . . . It takes time." Female participant*

Being able to volunteer as an Expert Caregiver was affected by the participants' distance to their own caregiving experience. While distance for some participants meant that enough time had passed since their caregiving situation ended, distance was also about the characteristics of the past caregiving situation. In general, the participants seemed to agree that providing care for a spouse with cognitive disorders was the most troublesome care context possible, which demanded more time to cope after the caregiving situation had ended. However, there were individual differences. One participant was a spousal dementia caregiver at the start of the intervention and still had the capacity to become an Expert Caregiver.

One participant experienced that the way the caregiving situation ended had helped her cope and be at peace with the past. For her, that meant being together at home until the very end when the care recipient, her husband, passed away. Not having him admitted to a nursing home made her feel content with her caregiving experience.

Current Life Circumstances

Personal health issues, family tragedies, being busy visiting one's spouse in a nursing home, or providing informal care to someone new were reported as personal obstacles for not volunteering actively.

> *"Well I had thirteen years of experience of providing care to my husband, but then I had to have surgery . . . I informed them (intervention facilitators) that I maybe could volunteer in the future but not at that time." Female participant*

> *"Somehow I ended up in a situation where I was an informal caregiver again, unpaid, and she . . . It was quite hard because she got very ill for a while and was in a hospital ward here in the X (municipality) and then I was in contact with the care staff daily, so I just went into that role completely. / . . . / so I was not an Expert Caregiver, I was an informal caregiver." Female participant*

3.3.2. Competency as an Expert Caregiver

Using New and Old Skills

Several participants deemed that their potential peer support recipients would appreciate that they had been trained for the assignment. The participants also highlighted the promise of silence they had signed during the training course. They honoured this promise and knew it was important for their peer support recipients.

The participants described using their past as an asset not only in terms of their caregiving experience but also because they got to take advantage of other skills. Several participants described using personal skills they had learned from their past working life, such as keeping emotional distance to clients or being used to talking in front of people. Participants also mentioned taking advantage of their personality traits such as being helpful and easily speaking about difficult topics or sociability.

> *"I haven't had any issues talking to people in the past either . . . So I'm not nervous when we get together." Male participant*

In the eagerness to help caregivers, some participants described potential difficulties with only listening to the caregiver instead of rather telling him or her what to do.

> *"The issue is that one wants to say: 'in my case, it was like this' but you shouldn't do that (laughs). So it's a little bit difficult to stay put in one's place." Male participant*

Relationship between Expert Caregiver and Peer Support Receiver

Personal chemistry was described as important in the relationship with the peer support receiver or group of peer support receivers. Well-functioning chemistry resulted in a more positive and boosting experience for the Expert Caregiver, while situations of poor chemistry made the Expert Caregivers self-doubt to some degree. This is illustrated in the quote below.

> *"It wasn't quite right / . . . / I don't know the reason why, if it was me or . . . / . . . / If it's a group in a small village, it can be difficult for the group participants to talk freely when there are others from the village around. I thought of that, that it was something . . . Something there that I couldn't see. In the air." Female participant*

The training course had limited focus on how to create well-functioning personal chemistry or manage poorly functioning relationships with peer support recipients. Instead, in case of malfunctioning personal chemistry, the participants were advised to reach out to intervention organizers to end such relationships.

The role of personal chemistry may be even more important in individual peer support relationships. One participant described her initial hesitant feelings toward becoming a peer supporter to someone known from the past but then concluded that this factor might have contributed to a relaxed peer support relationship.

> *"When I became a peer supporter to this person I'm supporting, I was a bit hesitant at first because it's an old acquaintance of mine. / . . . / But it works well. And now I don't know if it's because I already knew her, that we can have a natural relationship." Female participant*

One participant was used to providing informal peer support to friends but experienced that for her to be able to fully step into the Expert Caregiver role, she would need a stranger as a peer support recipient.

> *"I would like to have a stranger (as a peer support recipient) so that one could . . . Because trying to be an informal Expert Caregiver to old acquaintances is on another level." Female participant*

The Role of the Intervention Organizers for Feeling Safe

A few participants expressed feeling safe volunteering as an Expert Caregiver partly because of the available support from intervention professionals. One participant described how, as they are older themselves, potential peer support recipients already exist in their personal network. Having completed the course and the opportunity to dial an intervention organizer to ask for support increased the sense of safety and was experienced as a good thing also for the peer support recipient's sake.

> *"I dare to take on that role and they (the caregivers) also feel safe, those that I know. Because we get these peer support recipients automatically, we do not need to have them assigned to us, they are automatically around us. But I feel safer having you in the background, someone to talk to, I can dial X (intervention organizer) for example and discuss if there is something I'm thinking about. For the peer support recipient's sake as well." Female participant*

While none of the Expert Caregivers had experienced such a situation yet, a few participants expressed concern about potential demanding individual peer support situations where it would be difficult to set boundaries. While some participants had faith in the intervention organizers in case of a difficult situation, one participant was not sure it would help. This is illustrated below in the conversation between two participants:

> *"As long as you don't get a person who 'takes the whole hand'. Then you have to be quite good at setting boundaries, but it can be difficult." Female participant*
>
> *"It can be difficult, but we have X's (intervention organizer) support there." Male participant*
>
> *"But it's not certain that it helps." Female participant*

3.3.3. Volunteering during COVID-19

Volunteering during COVID-19 meant peer support through virtual contact either via face video technology or telephone. One participant thought that it would have been easier to convert to virtual support if she had known the peer support recipients for a longer time and had established solid relationships. One participant was more positive about the experience, but he had been trained to offer virtual peer support already before the pandemic.

> *"In the beginning it was difficult with the technique, but gradually it worked out and one became used to it. / . . . / So it's sort of fun, and enables connection with others." Male participant*

Two of the participants offering individual peer support via telephone experienced that it had worked well but was not the same as offering peer support face to face.

> *"It's been, what should I say, alright but . . . You haven't really been able to have the contact you meant to have, but we have been keeping in touch via telephone. It has worked well." Female participant*
>
> *"Well the telephone works of course, but it's not the same (as meeting face to face). Male participant*

Being an Expert Caregiver during the pandemic also enabled the participants the opportunity to stay connected to other people despite the social restrictions applying to most of them. One participant described how the virtual meetings were his only social contact during the pandemic. Another participant started providing informal care again during the pandemic, and while it was not an Expert Caregiver assignment, she explained the need to be useful and socially active during the pandemic:

> *"I lived in isolation but had daily social contact. For me it was a godsend that she (informal care recipient) came into my life and I got this role (as an informal caregiver)."*
>
> *Female participant*

3.4. Practicality: Perceived Effects on Well-Being

3.4.1. Perceived Effects on the Participants' Well-Being and Related Mediators

Expectations Influencing the Experience

An Expert Caregiver's main task in peer support situations was to listen. Still, the levels of expectations the Expert Caregivers had put on themselves varied. Those who had moderate expectations seemed to experience greater satisfaction. One participant described the issues with having too high demands on oneself in group-based peer support situations.

> *"If one starts to demand too much of oneself and think that now I don't live up to (the caregivers' expectations), it should be better, I should . . . If you put too high demands on yourself, then it becomes a torment. That I'm not enough, they must have been disappointed with the meeting, 'what was that, just sitting and drinking coffee and talking . . . '. You should have those demands on yourself on a reasonable level." Female participant*

Similarly, individual peer support may also bring certain expectations that may not be fulfilled. This is illustrated in the quote below:

"I have very little experience because I only have one adept and we have met mostly on the telephone, also physically a few times, but, but not . . . It has not been any counselling and that sort. / . . . / So there has not been any overwhelming experiences." Male participant

The Needs of Caregivers as a Stressor

In a similar manner as to how the distance to one's own caregiving history affected the ability to take on Expert Caregiver assignments, this distance also affected the well-being outcomes of volunteering. Not all participants experienced being at peace with the past yet. One participant described how being in contact with a current caregiver in her personal life awoke negative feelings.

> *"I met someone who was in the same situation that I was in, who had just left her husband (having him admitted to a nursing home), and I felt so bad the entire evening when she told me, because I went back to how it had been for me. I thought about her all night after she told me." Female participant*

Knowing the needs of caregivers contributed to some participants feeling stressed about all the things they wanted to improve, such as issues with caregivers who suffer but choose not to reach out for support.

> *"The only negative thing is that more people should take advantage of peer support, that you would really get it out there to those needing it, because the needs are actually extensive." Female participant*
>
> *"There are a lot of people in X (municipality) who should get in touch with us, but they don't." Male participant*

Volunteering as a Therapeutic, Meaningful, and Joyful Activity

One participant thought it was therapeutic to prepare himself for group-based peer support occasions, as it not only occupied his time but made him reminisce his own caregiving experience.

> *"I feel that these Expert Caregiver conversations have rewarded me in that I have had to prepare myself, I haven't dared to go unprepared to those conversations, but I have had to look through my life a bit in advance and try to formulate the questions that need to be ventilated. That has given me something to do ... and been like therapy for myself as well." Male participant*

The same participant described how offering peer support to current caregivers upset him to some degree, but that the rewarding effects still outweighed the negative.

> *"It does open old wounds somewhat, but on the other hand, I think that the positive dimension outweighs it. After the discussions that I have been part of, I have been left with a good taste." Male participant*

Another participant emphasized the rewarding effects of helping others.

> *"It's also rewarding. It gives to someone who has gone through it. It heals you." Female participant*

Knowing the needs of caregivers and the, for some participants, almost traumatic experiences of informal caregiving, contributed to several participants experiencing a sense of purpose in volunteering as an Expert Caregiver.

> *"I have many times thought that what if this existed when we started off as informal caregivers and one would have received this." Female participant*

One participant concluded that helping others always has a selfish side to it, as it feels nice to be needed. This was also illustrated in another participant's quote on the experiences of a group-based peer support event:

> *"And at times, I felt very important. And that was nice." Male participant*

Feeling needed also related to the participants' past as an informal caregiver where their everyday lives revolved around helping a loved one. Now when they were no longer caregivers, and in many of the cases no longer spouses due to the death of the care recipient, one of the participants described the positive experience of being needed once again as an Expert Caregiver:

> *"We have felt needed when they lived. You had to give 100% and more. You felt needed and now when they are gone you also want to be needed, so now I feel like we have a sense of purpose." Female participant*

While it was common for the participants to describe the experiences of volunteering as rewarding in terms of purposeful, a few of the participants described volunteering more as a joyful activity. This is illustrated in the quote below:

> *"I like these kinds of things, so I don't mind it. It's not work, it's pleasure. If you can say that, perhaps you should not say that. But I really don't mind it." Male participant*

A Sense of Belonging with the Other Participants

The participants seemed to experience a sense of belonging with the other participants, regardless of whether they had been active as volunteers or not. Most of the Expert Caregivers were bereaved spousal caregivers and several participants described how the intervention provided them a longed-for appropriate social context as a widow and former caregiver. This is illustrated in the quote below:

> *"And the thing is that when you become alone, there is so much where you feel like you don't fit in, but in this context, we fit in." Female participant*

3.5. Sense of Coherence and Satisfaction with Life Scale

Table 4 details the average scores and changes in the SOC and SLWS scales across the three timepoints.

Table 4. Average scores in SOC and SLWS among the participants at baseline (T1), 4 months after baseline (T2), and 13 months after baseline (T3).

Variable	T1 ($n = 25$)	T2 ($n = 24$)	T3 ($n = 23$)
SOC	67.60, 8.20, 51–82, 69	68.96, 7.79, 48–86, 69.5	68.52, 8.63, 50–81, 70
Comprehensability	24.64, 4.20, 14–32, 25	25.67, 3.63, 19–33, 26	25.43, 3.57, 17–31, 26
Manageability	20.24, 2.85, 14–25, 21	20.75, 2.97, 13–26, 21	20.52, 3.93, 9–25, 22
Meaningfulness	22.72, 3.08, 18–28, 23	22.54, 2.99, 16–27, 22.5	22.57, 3.30, 14–26, 23
SLWS	25.92, 5.24, 12–33, 26	26.38, 5.77, 15–34, 29	26.61, 4.92, 16–34, 28

The table shows mean, standard deviation, range, and median.

For all of the SOC dimensions, an increase in the score reflects an increase in SOC. Although the scores fluctuated somewhat, no statistically significant differences between the timepoints were found in the SOC total score and its subdimensions due to small sample sizes. As all the variables in the SOC subdimension of comprehensibility were normally distributed, a one-way repeated measures ANOVA was conducted to compare the scores between the three timepoints. There were no significant effects for time on comprehensibility, as the results from the ANOVA analysis showed Wilk's Lambda = 0.91, F = (2, 21) = 1.02, $p < 0.38$, multivariate partial eta squared = 0.09. For the rest of the SOC variables, which were non-normally distributed, the Friedman Test was used to compare the scores between the three timepoints. The result for the total SOC index showed X2 = (2, $n = 23$) = 0.64, $p < 0.73$. The result for manageability was X2 = (2, $n = 23$) = 2.85, $p < 0.24$. The result for meaningfulness was X2 = (2, $n = 23$) = 0.50, $p < 0.78$.

A high level of life satisfaction measured with SLWS [39] was observed at all timepoints, although the median scores fluctuated somewhat. No statistically significant difference between the timepoints was found in the Friedman Test: X2 = (2, $n = 23$) = 0.64, $p < 0.73$.

4. Discussion

4.1. Interpretation of Findings

The Expert Caregiver intervention in Ostrobothnia, Finland sought to co-design a training course for 10–15 individuals with experience of providing informal care to an older adult to become "Expert Caregivers" so that 10 of them would participate in coordinated volunteering opportunities for current caregivers with an emphasis on peer support.

The co-designing and building networks phase of the intervention resulted in the establishment of a reference group and steering group who supported the design and implementation on regular meetings throughout the process. A 30-h training course targeting individuals with experience of providing informal care was co-designed. The results showed that there was a demand of the intervention as 25 participants enrolled in the training course, despite a preliminary aim of only 10–15 participants. Furthermore, 19 participants volunteered during the intervention and 17 participants volunteered several times. Volunteering opportunities included both individual and group-based peer support meetings as well as spokesman assignments in newspapers, radio interviews, etc. Through peer support assignments, the Expert Caregivers reached 69 individual current caregivers with 15 organizations involved. The success of the intervention is to be explained by the participatory approach [29] used where the intervention departs from local needs and resources.

The intervention had to be adapted to the COVID-19 pandemic, leading to all peer support relationships being redirected to virtual or telephone contact. This required extra resources as many participants and their peer support recipients were aged 70 and over and varied in their digital skills. The Expert Caregivers experienced that offering virtual peer support worked well but estimated that this kind of support was less effective than if the support had been given face to face. However, technological solutions are increasingly emphasized for informal caregivers in Finnish national steering documents [25] as caregivers may be bound to their homes due to caregiving responsibilities. Therefore, preparing former caregivers to offer virtual peer support may be useful also in future peer support interventions. A review on the effects of virtual and face to face peer support to caregivers of people with dementia suggested that peer support may have a positive impact on caregiver well-being regardless of delivery mode [18].

The qualitative data gathered in the focus group interviews implied that former caregivers' well-being may be enhanced by the Expert Caregiver intervention as it offered the participants, mostly older bereaved spouses, a social context and a sense of belonging with the other participants. The training course and the available support from the intervention organizers contributed to most participants feeling confident and safe as volunteers. When volunteering, the participants got a chance to not only use their caregiving past as a resource but also to take advantage of other personal skills and resources. Offering peer support to current caregivers offered the participants a meaningful, therapeutic, and even joyful activity. However, risks of negative effects were noted among the participants in terms of not having enough distance from one's own caregiving experience, in situations of malfunctioning peer support groups, too high expectations on one's contribution, or too high demands of the peer support recipient. Our results, in terms of the mainly positive impact but also risks of adverse effects, are in line with previous findings exploring the experiences of former caregivers volunteering to support current caregivers [20,21]. Indeed, in a Norwegian study, the peer supporters appreciated using their past as a resource but also experienced the need for safeguarding their free time and setting limits, as providing peer support was experienced not only as rewarding but also exhausting [21]. Similar results in terms of mostly positive effects such as emotional gains and new social contacts were reported from a peer support program in England, but the participants stressed the need for the right timing of transitioning into the peer supporter role to avoid awakening negative emotions [20].

The participants reported high levels of SOC and SLWS throughout the intervention, although no statistically significant differences were found across the three timepoints of study. A future study with a larger group of participants should continue to assess the effects on well-being outcomes and analyse whether this type of intervention is more suitable for certain subgroups of individuals with experience of informal caregiving. Previous research on former caregivers in general suggests that the post-caregiving experiences and outcomes may depend on, amongst other things, the characteristics of the past caregiving situation such as pre-loss levels of social support [8,9], pre-loss levels of depressive symptoms [7,9], and whether the care recipient died in the preferred setting [44].

It is noteworthy that most of the participants in the Expert Caregiver intervention were of female gender and holding an upper secondary education. While the evidence is not completely consistent, caregiver well-being and care characteristics seem to depend on sociodemographic features in terms of high caregiving intensity and adverse effects being more associated to female gender, lower education levels, and lower income [4,6,45,46]. Most of the participants in the Expert Caregiver intervention had provided care to someone who did not have cognitive disorders. Providing care to a spouse with cognitive disorders is generally considered the most burdensome care context [4], possibly requiring a longer time to recover from potential adverse effects. The share of male participants was small given the less gendered caregiving role among older adults [47] especially among older Finns encompassed by the public Informal Care Allowance [25]. However, previous examples of volunteering programs for former caregivers in other countries have also been more represented by female participants [19–21].

The participants in the intervention reported high scores on well-being throughout the intervention. This is in line with the results of a study in England assessing, amongst other things, the impact of a volunteering program on the peer supporters of current caregivers [19]. The fact that the participants reported high scores on well-being is also in line with previous studies on post-caregiving health in general suggesting that for most former caregivers, adverse effects associated to intensive caregiving diminish with time [8,9,45]. Still, studies have also found that for some post-caregivers, negative health effects [7–9,44,45] such as insomnia, depressive symptoms, and feelings of guilt may prevail, even for as long as up to 10 years [7]. The specific needs of such vulnerable former caregivers should be further studied and met in interventions where they are the end-users. Nonetheless, the Finnish Expert Caregiver intervention showed promising results in terms of training former caregivers with sufficient distance to one's caregiving past to become volunteers to support current caregivers.

4.2. Strengths and Limitations

Limitations include a small sample size as well as the absence of results from a control group. Collecting questionnaires on-site could affect the validity of the quantitative data, as participants may have been influenced by the presence of other people when filling in information about their well-being. Another limitation is the exclusion of data collection from the peer support recipients about their experiences and perceived effects of the intervention. This should be further investigated in a future study.

The implementation of the intervention was affected by the COVID-19 pandemic and causes difficulties in interpreting the results of the intervention in terms of demand and perceived effects in comparison to if the intervention had been organized in normal circumstances with an emphasis on face to face rather than technological peer support situations. On the other hand, the idea of technological solutions for supporting informal caregivers being bound to their homes because of remoteness or caregiving demands is nothing new [25]; the COVID-19 pandemic only contributed to a digital leap. The COVID-19 pandemic also resulted in a relatively low number of focus group interview participants. Only participants who had tried volunteering participated in the focus group interviews, contributing to a lack of qualitative data collected from participants who chose to not try volunteering. A future study could collect more data from participants who enroll in the program but withdraw or do not try volunteering.

Strengths of the study include the use of mixed methods and the adherence to validated recommendations for intervention development and implementation description. Another strength of the study is that three of the researchers were involved in the development and implementation of the intervention, thus possessing extensive knowledge on the intervention assessed and the focus group interview participants. However, this could have influenced the results in the focus group interviews, as the participants may have hesitated to share information about negative experiences of the intervention. On the other hand, the participants were informed about their important role as sources of information in this feasibility study to improve future interventions. Furthermore, the results from the focus group interviews are aligned with written feedback collected anonymously during the intervention (not presented here).

5. Conclusions

The findings of this study imply that the Expert Caregiver intervention was feasible, as it resulted in a co-designed training course consisting of 30 h with 25 participants enrolling and 19 of those trying volunteering activities. The participants reported high scores on well-being throughout the intervention. The analysis of the focus group interviews revealed that the Expert Caregivers experienced the intervention as meaningful and offered them a sense of belonging with the other participants. Apart from using their caregiving past as an asset, the participants also took advantage of other personal skills and resources. Risks of adverse effects were related to high expectations on one's contribution, demanding peer support recipients, poorly functioning groups, and insufficient distance to one's caregiving past. Therefore, continuing support from intervention providers may be deemed necessary. Future studies with larger samples should investigate whether the effects of the intervention differ between subgroups of participants as well as explore the perspectives of the peer support recipients.

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Sarah Åkerman

Informal Care in the Light of Well-Being – the Case of Finland

The thesis examines informal care among older adults in the light of well-being. The life course perspective, capability approach, caregiver stress process model and the WHO healthy ageing-paradigm are used in the four original studies to shed light on various aspects of well-being. Informal care and well-being are placed in a Finnish societal context, where the demographic, economic, political, and social context is outlined. More specifically, the thesis investigates care recipients' care preferences, care recipients' care arrangements across time, the relationship between individual resources and subjective caregiver burden among older spousal caregivers, and the feasibility of a co-designed intervention utilizing the experiences of former informal caregivers.

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