

Volunteers and informal caregivers' contributions and collaboration with formal caregivers in Norwegian long-term care

Authors:

Marianne Sundlisæter Skinner, PhD¹, Håkon Wergeland Lorentzen, dr.philos¹, Laila Tingvold, PhD,¹ Oddrunn Sortland, MSc, RN², Nina Beate Andfossen, MCC, RN¹ and Magnus Jegermalm, PhD^{3,4}.

¹Centre for Care Research, NTNU – Norwegian University of Science and Technology, P.O. Box 191, 2802 Gjøvik, Norway.

² Centre for Care Research, Western Norway University of Applied Sciences, P.O. Box 7030, 5020 Bergen, Norway.

³Jönköping University, School of Health & Welfare, Department for social work & Institute of Gerontology, Box 1026, 551 11 Jönköping, Sweden.

⁴Ersta Sköndal Bräcke University College, Department of Social Sciences, Box 441, SE-128 06 Sköndal, Sweden.

Corresponding author: Marianne Sundlisæter Skinner, Centre for Care Research, NTNU – Norwegian University of Science and Technology, P.O. Box 191, 2802 Gjøvik, Norway. Tel: +47 611 35 430, e-mail: marianne.skinner@ntnu.no.

Abstract

The article illuminates and discusses the realism of policy-makers' goals to increase involvement of volunteers and informal caregivers in long-term care services in Norway. Drawing on multiple data sources, the article investigates how commonplace volunteering and informal care are in long-term care, and it explores challenges experienced in collaboration between formal caregivers and *volunteers* and *informal caregivers*. The results show that only 4.4 percent of the Norwegian population carry out unpaid, voluntary work in long-term care. Twenty percent regularly provide informal care to someone with special care needs.

Knowledge/information gaps and lacking coordination are common collaboration challenges between formal caregivers and volunteers/informal caregivers. The limitations identified in the current collaboration environment should be used actively by both policy makers and the practice field to critically assess goals and strategies for involvement and improving collaboration practices.

Keywords: Caregivers; informal care; intersectoral collaboration; health personnel; long-term care; municipalities; volunteers; unpaid work; Norway; Nordic

Introduction

The challenges presented by population ageing have made western governments look for new, innovative ways of providing social care. Stimulating for increased use of volunteers in service provision is one solution put forward by governments across Europe and beyond (Hoad, 2002; Hussein & Manthorpe, 2014; Musick & Wilson, 2008; Pick, Holmes, & Brueckner, 2011). In many countries, the policy emphasis on increased unpaid contributions extends beyond volunteers to informal caregivers. Co-production of services with networks of family, friends and neighbors is also seen by politicians and administrators as pivotal in tackling the demographic and social changes that are set to characterize the 21st century (Dahlberg, 2006; Fast, Keating, Otfinowski, & Derksen, 2004; Philp, 2001; van Dijk, Cramm, & Nieboer, 2013).

The Nordic welfare model, characterized by universal rights to services and benefits, is under increasing pressure, due to population ageing, falling birth rates and shortages of health and care workers. In Norway, successive governments have advocated increased voluntary contributions and improved integration of voluntary and informal care provision with public care service provision as one means of meeting these challenges. Expectations are expressed in a range of government documents, such as white papers (Ministry of Health and Care Services, 2006, 2013, 2018) and Official Norwegian Reports

(e.g. Norwegian Official Report [NOU], 2011:11). In political rhetoric and policy documents we can trace three (implicit) assumptions. First, that there is a potential of contributions by volunteers that can easily be mobilized in long-term care services. Second, that formal caregivers and volunteers are well-suited for harmonious collaboration in long-term care. And third, that challenges in formal caregivers' collaboration with informal caregivers are different from challenges experienced in volunteer-formal caregiver interaction.

So far, there has been little research that illuminates and discusses the realism of such assumptions and policy-makers' goals with regard to increased involvement of volunteers and informal caregivers in long-term care services. In this study, we use data that provide us with possibilities to elaborate on, and give new insights into, unpaid care work involving volunteers and informal caregivers and their collaboration with formal caregivers. What is at stake here, is that politicians and policy-makers use "top-down" strategies to increase the extent of unpaid work in long-term care, without providing any concrete strategies or solutions for the practice field, besides vague policies and rhetoric. The aim of this article is to investigate the validity of policy-makers' assumptions and goals, focusing on Norway as a case. To do this, we formulate four research questions (RQ): 1) How common is volunteering in long-term care? 2) How common is informal caregiving? 3) What kinds of collaboration challenges are experienced in formal caregivers/*volunteer* interaction, and in 4) home care workers/*informal caregiver* interaction? Using population survey data on the prevalence and scope of voluntary and informal caregivers' contributions in long-term care, we present an overview of the scope of unpaid care work in Norway. This provides the basis for the discussion of the assumed potential of voluntary contributions. Additionally, by analysing data from two qualitative studies of collaboration between 1) formal caregivers and volunteers and 2) home care workers and informal caregivers, we explore collaboration challenges in interaction between formal and unpaid caregivers.

Context on long-term care volunteering and informal caregiving in Norway is given in the following section. Subsequently, the article offers definitions of key terms and details of the conceptual framework used in the study. In the third section, the methods are presented, and the fourth section reports on the findings. In the discussion, we discuss the implications of the results for social policies.

The Norwegian Context

As a representative of the Nordic welfare model, Norway's welfare state is characterized by universal rights and extensive public funding and service provision (Esping-Andersen, 2002). Whereas public expenditure on long-term care averages at less than 1 per cent of gross domestic product (GDP) globally, in Norway, public expenditure is among the top three in Europe, at 2 percent (Sweden and the Netherlands ≥ 3.5) (OECD, 2011; United Nations, 2016).

The provision of long-term care is typically divided into institutional and home care and is the responsibility of the municipality. Currently, there are approximately 420 municipalities, but the number is declining, due to an ongoing municipal reform. Formal long-term care provision is influenced by national government via policies, legislation, monitoring and block-grant funding, but municipalities can, to a considerable degree, organize and adapt services to local conditions (Vabø, 2012). Whether and how to organize collaboration with volunteers and informal caregivers in the provision of services is up to the individual municipality.

The Municipal Health and Care Services Act (Helse- og omsorgstjenesteloven) and the Patient and User Rights Act (Pasient- og brukerrettighetsloven) form the legislative framework for interaction between formal and informal caregivers. The former act sets out that long-term care for the elderly is the responsibility of the municipality. Thus, informal caregivers' contributions are, at least on a legislative level, based on voluntarism. Formal

caregivers cannot assume or expect informal caregivers to contribute in care provision (Molven, 2017). The latter act specifies that the long-term care services are to be targeted and tailored toward the care receiver's needs (Molven, 2017), as communicated by the care receiver or observed by formal caregivers in the health and care services. The same conditions apply in Sweden, where informal caregivers have no legal obligation to contribute in care provision; filial obligation was removed from social care in 1956 and from family legislation in 1979. This means that care for older people is primarily the legal responsibility of public welfare (Jegermalm & Jeppsson Grassman, 2012).

The latest Living conditions survey indicates that a total of 15 percent of the adult Norwegian population regularly carries out unpaid care work for others; two percent provides help or personal care for someone they live with, while 13 percent helps someone outside their own household (Statistics Norway, 2016). According to the Time use surveys, an average of five percent provided personal care or help to adults they live with, while nine percent provided help to other households. The survey results indicate that the time use on informal care in one's own household is considerably lower than time spent helping people in other households (average 46 minutes vs. 95 minutes per day) (Vaage, 2012, p. 86).

But how common is volunteering in the long-term care services in Norway? Findings from a survey of nursing homes and home care services in 50 municipalities carried out in the long-term care services in 2015 show that collaboration with volunteers in long-term care is commonplace: Eighty-three percent of the long-term care units surveyed (mostly nursing homes and home care units) reported that they had one or more activities which involved volunteers (Skinner, Sogstad, & Tingvold, 2018). Nevertheless, results from the same survey indicated that only 20 percent of activities involving volunteers were subject to a joint coordination effort between voluntary organizations *and* the municipality. The rest was coordinated by voluntary organizations *or* the municipality (Skinner, 2018).

Compared to most other western countries outside the Nordic region, the total volume of voluntary work in Norway is high. In a population survey from 2017, 63 percent reported to have done some kind of voluntary work in the last year, of which the majority of the work was related to sports and leisure (Fladmoe, Sivesind, & Arnesen, 2018). Around 6 percent reported having done voluntary work in organizations classified as “health, care and rescue work” and “social services and substance abuse-related care”, respectively, and results from a 2014 survey indicate that an additional 1.1 and 0.6 percent do voluntary work for public institutions in the areas of “old-age care” and “other care” (Andfossen, 2016, p. 9; Fladmoe et al., 2018). The above studies investigated how common it is to do voluntary work within the broad categories of health and social care, but they do not capture the scope of voluntary work in the long-term care services accurately, as “care” was part of wider categories.

Despite the strong policy emphasis on the importance of volunteers and informal caregivers’ contributions in long-term care on the political agenda, there is limited knowledge about the scope of voluntary and informal care work in Norwegian long-term care. While civil society scholars have thoroughly examined the magnitude of volunteering in Norwegian society at large (e.g. Fladmoe et al., 2018; Wollebæk, Selle, & Lorentzen, 2000), several scholars point out that there is little available data on volunteering in long-term care (Førland, 2015; Rønning, Schanke, & Johansen, 2009). This is why it is so important to find answers to our questions: How common is informal caregiving and volunteering in long-term care, and what kinds of collaboration challenges characterize the interaction between unpaid and formal caregivers?

Conceptual framework

We define voluntary work in long-term care as *unpaid* contributions that are given freely to benefit individuals or groups outside pre-existing relationships and personal networks, without (expectation of) monetary reward or other compensation (Musick &

Wilson, 2008; Snyder & Omoto, 2008; Wollebæk et al., 2000). In accordance with recent trends in volunteer mobilization, we include voluntary work for both voluntary organizations and public institutions such as nursing homes and home care services in our definition.

Informal help and care given to members of one's family, friends or neighbors with special care needs is usually not defined as voluntary work. The terminology used to describe the nature of informal help does, however, depend upon research tradition. One tradition of research connects to studies in nursing care and/or social care, wherein informal help and caregiving (or family care) often involve personal care tasks such as dressing, feeding and administering medication (Brown & Brown, 2014; Jegermalm, Malmberg, & Sundström, 2014; Plagnol & Huppert, 2009). Another tradition has discussed informal help and care in a civil society context, using a broad definition of informal care, often including the provision of practical help such as housework, gardening or transport services, typically representing a low number of hours per week (Henriksen, Koch-Nielsen, & Rosdahl, 2008; Jegermalm & Jeppsson Grassman, 2013; Wilson & Musick, 1997). In this article we will focus on receivers of informal care that have special care needs, which reveals whether the caregiver helps someone who is sick, disabled or an older person, and unable to look after themselves in certain ways.

In the literature, the idea of universal welfare is often contrasted with the idea of voluntary and informal care work, as public welfare is expected to cover the population's care needs (Jegermalm & Jeppsson Grassman, 2012). However, studies from Scandinavia suggest that there is no straightforward conflict between a universal welfare state and mobilization of informal resources in welfare provision. Quite the contrary, a relatively extensive welfare state seems to be a precondition for much informal care in Scandinavia (Jegermalm, Hermansen, & Fladmoe, 2018). The conclusions drawn in these studies suggest that there is a unique "Scandinavian model" of informal care, whereby the division of care is task-specific:

Informal caregivers provide care when recipients' needs are limited, while the welfare state steps in when the informal resources and efforts become insufficient or unsustainable (Jegermalm et al., 2018; Jegermalm & Jeppsson Grassman, 2012). Some researchers have described these relations in terms of a partnership or mutual substitution (Chappell & Blandford, 1991; Jegermalm & Sundström, 2015; Litwak, 1985). Our study does not allow us to draw any conclusions about the extent of overlap, complementarity or substitution of tasks, but earlier studies have indicated that caregivers with heavy care commitments receive relief services which complement the type of care they already provide (Jegermalm, 2004). Moreover, in the Nordic countries personal care tasks are often provided by public services rather than by informal or voluntary sources, reflecting a clear division of tasks in this area (Kröger, 2005).

In analysing the findings from the qualitative studies of collaboration challenges between formal caregivers and volunteers/informal caregivers, we draw on the organizational institutionalist perspective of institutional logics. Institutional logics can be understood as “socially constructed, historical patterns of cultural symbols and material practices, assumptions, values and beliefs by which individuals produce and reproduce their material subsistence, organize time and space, and provide meaning to their daily activity” (Thornton, Ocasio, & Lounsbury, 2012, p. 51). Whereas formal caregivers in the municipal care services operate within a public service logic, the efforts of volunteers and informal caregivers are situated within the institutional orders of the family and/or community (Alford & Friedland, 1985; la Cour, 2014; Thornton et al., 2012). The public service logic in the Nordic welfare model is based on professional standards, accountability, equality and bureaucracy. The family and community logics, however, are characterized by commitment to community or family values, loyalty and reciprocity, emotional connection and amateurism (Lorentzen, 2013; Thornton et al., 2012).

In our analysis of the population survey data on the prevalence of long-term care volunteering and informal care, we use the life-course perspective as an interpretive frame. In this perspective, life is conceptualized as a chronology, a path characterized by significant events, transitions, family connections and cultural and societal influences. People's behavior is influenced by where they are on this path. Simultaneously, life course scholars acknowledge that "time is only one dimension of human behavior; characteristics of the person and the environment in which the person lives also play a part" (Hutchison, 2008, p. 9). Since the life course perspective focuses on "how chronological age, relationships, common life transitions, and social change shape people's lives from birth to death" (Hutchison, 2008, p. 9), it can help explain why people do more volunteering and informal caregiving in some life phases than others. Thus, it can help shed light on the prevalence of volunteering and informal care in our study.

Methods

This article is based on three studies from a project about voluntary work in Norwegian long-term care. The studies were conducted over a three-year period (2014-2016) and were designed to generate knowledge about unpaid caregivers in long-term care, with focus on prevalence and interaction with professionals. Our four research questions about prevalence and collaboration challenges presupposed different research methods. Thus, data from different settings and different actors was used to answer the questions. First, Study 1 – a population survey – was conducted to map the prevalence of care volunteering and informal care in the population, addressing RQ 1 and 2. Subsequently, two separate qualitative studies were conducted to explore collaboration challenges, answering RQ 3 and 4. The research questions and the relationship with the studies and methods used to answer them are presented in Table 1.

Table 1 Research questions and methods

RQ1	How common is volunteering in long-term care?	Study 1: Population survey (N=4000)
RQ2	How common is informal caregiving?	Study 1: Population survey (N=4000)
RQ3	What kinds of collaboration challenges are experienced in formal caregivers/ <i>volunteer</i> interaction?	Study 2: Qualitative semi-structured interviews with municipal managers and volunteer activity leaders in both nursing homes and home care
RQ4	What kinds of collaboration challenges are experienced in home care workers/ <i>informal caregiver</i> interaction?	Study 3: Qualitative interviews and observations of nine elderly persons, their informal caregivers and home care workers.

Study 2 was conducted to dig deeper into findings from a 2015 survey of frontline leaders and volunteer coordinators, in which respondents identified suboptimal conditions for collaboration as the most important barrier to successful interaction between formal caregivers and volunteers in long-term care (Lorentzen & Skinner, 2019). Study 3 focused on collaboration practices and the division of tasks and responsibilities between informal caregivers and home care workers as one of its main themes from the outset.

The strength of our multi-methods approach and our use of population survey data and qualitative data from different settings and actors to answer different research questions, is that we can examine several aspects of one of the key issues currently facing ageing and social policy. Not only does it reveal the scope of unpaid efforts in the population, it also provides insights into different actors' perspectives on challenges involved in integrating volunteers and informal caregivers in welfare provision. A related strength of the approach is its comprehensiveness. The main *challenge* involved in using such an eclectic approach is that the different settings and methodological approaches inevitably generate different kinds of data, which limits comparison between actors and across settings.

Below, we present the three substudies in more detail.

Study 1: The population survey

To investigate the prevalence of long-term care volunteering and informal caregiving, a nationally representative survey was conducted in Norway in 2014. Data were collected through telephone interviews with survey respondents aged 16 years and older, i.e. representing the entire adult population. Due to challenges posed by falling response rates in national surveys, the goal was at the outset to recruit 4,000 respondents in order to attain a representative sample and avoid biased results. In total, a random sample of 20,000 was drawn from the national population register. The data was collected March-October 2014.

The questionnaire used a structured multiple-choice approach, and voluntary work was defined as “work you do for organizations or individuals without being regularly paid for this”. The survey items on informal care/help were modelled on items used in Swedish population studies (von Essen, Jegermalm, & Svedberg, 2015) to facilitate comparative analysis of informal care in Denmark, Norway and Sweden (published as a chapter in an anthology, see Jegermalm et al., 2018). The survey items used in this study are presented in Table 2.

A weakness of our survey items and categorization is that the volunteering categories potentially capture help or care work for individuals or groups outside of long-term care, such as refugees and child services.

Since the aim of the survey was to identify the prevalence and scope of unpaid work in the long-term care services, descriptive statistics were used in the analysis. Relationships between care volunteering/informal help/care and gender/age were investigated by crosstabulations with exact chi square tests (2-sided). The software used was IBM SPSS Statistics.

The final sample drawn from the national register consisted of 19,761 individuals. A total of 2,024 were interviewed in spring 2014 and 1,976 in the autumn, giving a response rate

Table 2 Survey measures

Care volunteering in voluntary organisations
<i>In the last 12 months, have you carried out voluntary work for voluntary organisations in the following areas...</i>
<i>5. Health, care and rescue work? YES/NO</i>
<i>6. Social services and substance abuse-related care? YES/NO</i>
<i>If yes, what kinds of tasks within [area 5 and/or 6] have you carried out?</i>
<i>9. Help or care work directed at individuals or groups [e.g. visiting service, refugee guide, counseling, help with practical tasks] YES/NO</i>
<i>If yes to 9, have you carried out voluntary work for voluntary organisations within [area 5 and/or 6] in the last four weeks? If yes, approximately how many hours?</i>
Care volunteering for municipal or public institutions
<i>Have you in the last 12 months done voluntary, unpaid work for a municipal or public institution? [e.g. nursing home, school, nursery, other eldercare, leisure association, museum, child services, blood donation, firefighting, rescue operations] YES/NO</i>
<i>For what types of institution have you carried out voluntary, unpaid work?</i>
<i>2: Old age care (nursing home, home care, senior citizens' community center, etc.) YES/NO</i>
<i>3: Other care (substance abuse-related, physically disabled, child services) YES/NO</i>
<i>If yes, approximately how many hours did you spend in the last four weeks doing voluntary, unpaid work within [old age care and/or other care]?</i>
Care volunteering through volunteer centers
<i>Have you in the last 12 months done voluntary, unpaid work for a volunteer center? YES/NO</i>
<i>If yes, what kinds of tasks within did you carry out for the Volunteer center?</i>
<i>9. Help or care work directed at individuals or groups [e.g. visiting service, refugee guide, counselling, help with practical tasks] YES/NO</i>
<i>If yes, approximately how many hours did you spend in the last four weeks doing voluntary work in a volunteer center?</i>
Informal help/care to persons with special care needs outside household
<i>Do you provide, on a regular basis, help to relatives you do not live with, neighbours, friends or colleagues [e.g. help with transportation, food shopping, gardening, tidying, cleaning, looking after, care or other help]? YES/ NO</i>
<i>If yes, does the person you help (the most) special care needs? By this, we mean comprehensive support to older, sick or physically disabled people. YES/NO</i>
<i>If yes, approximately how many hours did you spend in the last four weeks helping this person?</i>
Informal help/care to persons with special care needs in same household
<i>Do you provide, on a regular basis, help to someone in your own household with special care needs? [e.g. help to older, sick or physically disabled people]? YES/NO</i>
<i>If yes, approximately how many hours did you spend in the last four weeks helping this person?</i>

of 20.2 percent (n=4,000). The subgroups of non-respondents were: those who refused to participate in the study (42.9%), those who did not answer the phone (31.2%), those whose

phone number was incorrect (15.8%), those who were in an institution or were ill (8.3%), and finally, those who were unavailable or away during the interview period (1.8%) (Arnesen, 2015). Younger age groups and people with low levels of education were somewhat overrepresented among the non-respondents. Otherwise, there were no major structural differences between non-respondents and those interviewed. Immigrants were also underrepresented in the sample as a result of the low response rate, so the results are primarily representative of the majority population in Norway. There was some missing data in the hours variables. The cases with missing data have been included in the analysis where possible.

Study 2: The qualitative interview study of volunteer activities

In order to identify barriers for successful integration of volunteer activities in long-term care, we carried out an interview study with managers and activity leaders with first-hand experience of collaboration. We selected eight research sites from three of the most common types of volunteer activities in Norwegian long-term care (cf. Skinner et al., 2018). These were two cultural activities (in nursing homes), two physical activities (offered to service receivers in both nursing homes and home care) and four visiting schemes (two in nursing homes and two in home care).

Other criteria for selection were that the activities had been in operation for more than one year, that there was a considerable degree of coordination between the municipality and the voluntary organization and that they represented different municipal contexts (urban/rural, large/small). This was to strengthen transferability across different activity types and contexts. Our sampling approach was in line with the principles of purposive sampling, whereby settings (and informants) were chosen deliberately and strategically (Pope & Mays, 1995).

The third author searched for volunteer activities that fulfilled the criteria described above by contacting voluntary organizations, searching the internet and attending seminars

where voluntary work in long-term care was discussed. Twelve potential research sites were initially considered, but ultimately only eight research sites were selected and included in the study. This was so that time and resources would allow for representatives from both voluntary organizations and municipalities to be interviewed, instead of just voluntary organization activity leaders. To recruit informants to the study, volunteer activity leaders and managers of the long-term care unit at each research site were contacted by e-mail to ask for their participation. All the activity leaders/managers in the eight selected research sites agreed to participate. The final sample included 25 informants: 11 from eight voluntary organizations/centers (of which five were male) and 14 from 12 municipal long-term care units (of which all were female). Site visits were arranged in all the eight sites. A site visit lasted for one to two days, depending on location, transportation alternatives and availability of respondents. The purpose of the site visits was primarily to conduct interviews, but the researcher also observed settings, activities and actors to gain a fuller understanding of the collaborative aspects of activities. A total of 21 qualitative interviews were carried out on-site by the second and third author in autumn 2016. The interviews were carried out in the informants' offices or place of work and lasted from 45-80 minutes. All the interviews followed a structured set of topics with probing questions to ensure comparability between interviews. The five main topics were: volunteers, care receivers, organizational procedures, mobilization and coordination. The interview protocol was informed by a review of existing literature in the field and eight hours of observation in two volunteer visiting schemes, carried out by the third author in advance of the interview study. The preparatory observation study was unstructured and carried out without an observation guide. Its sole purpose was to inform the design of a survey and the topics for the qualitative interview guide (for more information about the survey, see Lorentzen & Skinner, 2019; Skinner et al., 2018).

Study 3: The qualitative study of informal care

In order to explore hindrances in the cooperation between home care workers and informal caregivers (family members) in long-term care, we use data from a larger qualitative study including nine elderly care receivers, their informal caregivers and home care workers in one urban and one rural municipality in the west of Norway. Drawing on data collected through conversations and semi-structured interviews with home care workers and informal caregivers, this article focuses on formal and informal caregivers' experiences of collaboration in the home care setting. The subgroups of home care workers recruited to the study were registered nurses, assistant nurses, students and managers with long and short experience in the field. The aim of the recruitment strategy was to maximize the richness of the data material. Some home care informants were recruited by managers, others by the researcher during observations of daily activities at the home care offices (the data from the observation did not form part of the analysis for the article). Interviews with home care workers were conducted in a separate room in the home care offices.

In order to recruit informal caregiver informants, an information letter was distributed to care receivers by home care workers, asking for permission for the researcher to come to their home and present the study. Inclusion criteria for receivers of home care services were elderly persons with chronic physical impairments, and exclusion criteria were different kinds of cognitive impairment. Care receivers' consent to participate included agreeing that the researcher could interview close family members. Upon obtaining care receivers' consent, their informal caregivers were given written information about the study and asked if they were willing to participate. Interviews with informal caregivers were conducted in the location of their choice: their place of work, their home or the researcher's office. The interview-guides were semi-structured and covered background information and questions

regarding help from and collaboration with family members/home care workers. All fieldwork and interviews in Study 3 were conducted by the fourth author.

Qualitative data analysis

All interviews were recorded and transcribed in full by the interviewing researchers. Four researchers were involved in the data analysis. The second and third author were in charge of the data analysis in Study 2, and the fourth author led the data analysis in Study 3. In addition to coordinating the different components of the research project, the first author had a central role in final stages of the data analysis, merging and comparing themes across the two studies. Only the interview material related to the informants' experiences with collaboration, coordination and organization was included in the analysis for the article. Using thematic analysis (Braun & Clarke, 2006), the text was read several times in order to gain an overall impression of the data, focusing on both manifest and latent content. Afterwards, different content areas were identified in the text and the content areas *coordination challenges* and *collaboration challenges* were included in the next stage of the analysis. Using a summary of themes (produced by the lead researchers from each of the two studies) as the starting point, the four authors arrived at the themes that were elaborated on in the article. The

Table 3 Themes

Challenges in cooperation between formal caregivers and volunteers/informal caregivers			
Category	Volunteers-formal caregivers	Common challenges	Informal caregivers - home care workers
Themes	<i>Poor communication</i>	<i>Unclear responsibilities and expectations</i>	<i>Legislation</i>
	<i>Negative attitudes among formal caregivers</i>	<i>Lack of system</i>	<i>Unfulfilled potential</i>
	<i>Increased workload</i>	<i>Need to acknowledge and appreciate</i>	
	<i>Recipients too poorly</i>		
<i>(Un)-suitability</i>			

themes were produced inductively; there were no predefined codes shaping the analysis. An overview of the themes is presented in Table 3.

Findings

This section is divided into three parts. The first part presents results from the population survey and answers research questions 1) and 2) about the prevalence of volunteering and informal caregiving. The second and third parts address research questions 3) and 4) about challenges experienced in formal caregiver-volunteer and home care worker-informal caregiver interaction.

Study 1: The scale of unpaid care work

The results show that the prevalence of care volunteering is modest, while informal help and care for people with special care needs is a little more widespread in the Norwegian population. Only 4.4 percent engage in voluntary work in long-term care, while around 20 percent regularly provide help to family, neighbors, friends or colleagues with special care needs.

Table 4 Prevalence of care volunteering and informal help/care in Norway by gender. Percent (n=4000).

Gender	Men	Women	Total	P
Care volunteering in voluntary organisations	1.7	2.8	2.3	.026
Care volunteering for municipal or public institutions	1.4	2.5	2.0	.022
Care volunteering in volunteer centres	0.3	0.9	0.6	.106
<i>Total long-term care volunteering</i>	<i>3.2</i>	<i>5.5</i>	<i>4.4</i>	<i><.001</i>
Informal help/care outside household	11.3	18.3	14.9	<.001
Informal help/care in household	6.4	6.7	6.6	.655
<i>Total informal care</i>	<i>16.8</i>	<i>23.2</i>	<i>20.1</i>	<i><.001</i>

Source: *Respons* survey 2014

As Table 4 shows, care volunteering and informal care *outside* the household are more widespread among women than men, but there is little difference between the sexes when it comes to the prevalence of informal help and care in one's own home. As shown in Table 5,

volunteering in long-term care is more widespread in the highest age groups, whereas informal care outside the household is most prominent in the 50-67 age group and care for someone you live with is more common in the highest age group (>67).

Table 5 Prevalence of care volunteering and informal help/care in Norway by age group. Percent (n=4000).

Age group	16-24	25-49	50-66	>67	Total	P
Care volunteering in voluntary organisations	2.1	1.6	3.0	3.0	2.3	.036
Care volunteering for municipal or public institutions	1.2	1.6	2.5	2.4	2	.165
Care volunteering in volunteer centres	0.5	0.6	0.4	1.1	0.6	.735
<i>Total long-term care volunteering</i>	<i>3.7</i>	<i>3.3</i>	<i>5.4</i>	<i>6.0</i>	<i>4.4</i>	<i>.005</i>
Informal help/care outside household	10.2	13.3	19.9	13.5	14.9	<.001
Informal help/care in household	5.3	6.3	6.5	8.0	6.6	.296
<i>Total informal care</i>	<i>15.1</i>	<i>18.1</i>	<i>25.2</i>	<i>19.8</i>	<i>20.1</i>	<i><.001</i>

Source: *Respons* survey 2014

Our results indicate that the weekly contribution by volunteers is modest, at just 1 hour 20 minutes per week on average (see four-week averages in Table 6). The magnitude of informal help and care is more considerable, at 4 ¼ hours per week for care and help outside the household, and 9 ½ hours inside the household. The high standard deviation values for the bottom two categories show that there is much variance in time spent among informal caregivers.

Table 6 Average hours of volunteering/help given in four weeks. (N) is original sample size.

	Average hours	St. Dev.	N=
Care volunteering in voluntary organisations	5	7.9	92 (92)
Care volunteering for municipal or public institutions	7	17.8	75 (79)
Care volunteering through volunteer centres	4	4.1	23 (25)
Informal help/care outside household	17	35.3	526 (596)
Informal help/care in household	37.5	37.6	187 (262)

Source: *Respons* survey 2014

Rønning et al. (2009) estimated in 2009 that informal caregivers' contributions equal 100,000 full-time equivalents. This estimate is widely cited in both policy documents and

academic literature in Norway (e.g. Ministry of Health and Care Services, 2013; Tønnessen, 2016). The estimate is based on simple calculation of the average number of minutes spent on informal care into FTEs applied to the population as a whole.¹ If we adopt the same approach and take our respondents' retrospective estimate of their monthly contribution at face value and use them to calculate full-time equivalents for the whole population,² we arrive at 77,500 FTEs of informal care to different households and 75,500 to the same household: 153,000 in total. The corresponding figure for care volunteering is 8,500 FTEs. It is, of course, questionable how valid these recalculations of the scope of volunteering and informal caregiving are, as any sources of error in the data are multiplied. The estimates nevertheless give an indication of the scope of unpaid work in long-term care, comparable to other estimates based on other survey data (Holmøy, Haugstveit, & Otnes, 2016; Rønning et al., 2009). We will now turn to the question of challenges in collaboration between formal caregivers and unpaid care providers. The next section deals with formal caregivers-volunteer interaction.

Study 2: Collaboration challenges between formal caregivers and volunteers

In nearly all the cases, we found examples of failing information chains between the voluntary organization/volunteer and the services/formal caregivers. Lacking or poor routines were the most important reasons for this. Formal caregivers on duty were responsible for keeping track of appointments with volunteers. While some used lists, others used diaries to exchange necessary information about activities between the different formal caregivers. There were examples of formal caregivers forgetting, or not having been informed about planned activities. So, when volunteers arrived to visit or take care receivers out, formal caregivers and care receivers were unprepared, something that could lead to frustration for both volunteers and formal caregivers. Several nursing homes lacked routines for information exchange about volunteer activities.

Interaction between volunteers and formal caregivers sometimes required sharing of work. Friction would sometimes arise because it was not clarified who was doing what. In some instances, it was particularly challenging to achieve smooth coordination of tasks in preparing and accompanying care receivers to activities. However, all activities did not require the same amount of coordination. Activities such as individual indoor visiting schemes, serving of meals or entertainment events for care receivers required less coordination than activities for which care receivers were required to travel outside of their own home or the nursing home. The poorer the health of care receivers, the more help was required from formal caregivers. Care receivers commonly needed help with getting dressed, personal hygiene and being escorted to the activity, and care receivers with dementia often needed formal caregivers to repeatedly explain the purpose of activities.

Unclear roles and blurred responsibilities was a recurring issue in the interviews. It was often unclear what tasks were the professionals' domain and what tasks could be carried out by the volunteers. Generally, volunteers were not involved in traditional professional care tasks, such as personal care or medication, and the volunteers were viewed as a supplement to the services provided by the professionals. Volunteer visitors, for example, were not delegated any tasks or responsibilities that had to do with personal care, illness, medication or feeding. Their role was supplementary to that of formal caregivers. As one informant from the long-term care services put it: "the volunteer compensates for all the things auxiliary nurses and nurses feel bad about [due to lack of time:] that good conversation or that walk".

Another key theme in the interviews was that formal caregivers thought involvement of volunteers was time-consuming and added to their workload. Quite often, volunteer activities were not aligned with routines in the care services, and formal caregivers therefore perceived them as wearisome. In some instances, the volunteer activity was rejected or constrained by formal caregivers' limited capacity. In others, contact between the voluntary

organization and the care services was the responsibility of *coordinators* employed by the care services. Coordinators were usually responsible for collaboration with the voluntary organization on the formal and general level, while the direct contact with volunteers on a day-by-day basis was the responsibility of formal caregivers on duty. Many interviewees viewed coordinators as having a key role in spreading enthusiasm among formal caregivers and acting as a driving force for volunteer activities at the location. Several of the frontline leaders expressed that negative attitudes among formal caregivers stemmed from a feeling of an added workload in an already hectic work situation. In some instances, the care services had to obtain written consent from family members before the care receivers could participate in volunteer activities. This task was assigned to formal caregivers, a task which could involve extra work. Several care service units had taken measures to improve attitudes among the formal caregivers, many through several years. The next section reports results from the qualitative study of informal caregivers' interaction with long-term care formal caregivers in two municipalities.

Study 3: Collaboration challenges between home care workers and informal caregivers

Referring to constrictions posed by the legislative framework, interviewed home care workers expressed that they had few expectations of what and how informal caregivers (family members) should contribute. Furthermore, they expressed reluctance toward taking the initiative to establish binding agreements with informal caregivers, as they did not want to be perceived as expecting and demanding or as putting a burden on them. They were positive toward cooperating with informal caregivers, and described the "ideal" informal caregiver as "engaged and involved". This was not necessarily because informal caregivers took on performing practical tasks, but rather that they did what they had said they would do and kept home care workers up-to-date. Moreover, home care workers emphasized that social contact

and support for care receivers were the most important contributions from informal caregivers, as this was not a prioritized task by the public services.

The home care workers spoke of differences of expectations among informal caregivers regarding how the services could, and could not, contribute in care receivers' day-to-day situations. This could be a source of mistrust and accusations between home care workers and informal caregivers, based on poor communication and a lack of clarified expectations between the two parties. Even though general information about available services was provided on the larger municipality's internet page, the municipalities in the study did not have any hand-outs with written information for care receivers and informal caregivers. It was up to them to find out how the services were organized, what kind of services they could apply for, and what kinds of tasks were prioritized by the long-term care services. This lack of information was expressed as a "missing link" by several of the informal caregivers in the study, as it was sometimes random what kind of information they received from home care workers. The home care workers, on the other hand, made personal judgements about what kind of services care receivers could and should apply for. They passed on information based on their personal experience, knowledge and values.

Although the otherwise expansive handbook in the small municipality did not describe how to create and maintain cooperation with informal caregivers, the municipality did have written documents for each individual care receiver, based on agreements made during the first home visit (initial assessment). The initial assessment was carried out by the manager, who was a registered nurse, and the document was reviewed and updated if/when changes occurred, either by a registered nurse, an assistant nurse or the manager. The document was available to all home care workers and explained what kind of tasks the informal caregivers would perform. The document was often based on information provided by the care receiver and not from informal caregivers, who were not necessarily present at the first home visit.

Other than this, cooperation with informal caregivers was based on home care workers' individual encounters with, and their knowledge of, the informal caregivers.

Conversely, the larger municipality did not have documents describing divisions of tasks between home care workers and informal caregivers. The home care workers assumed that care receivers' informal caregivers were responsible for taking care of issues that were not detailed on their work list. Thus, home care worker-informal caregiver interaction in the large municipality was more prone to suffer from unclear expectations and misunderstandings. Common for both of the municipalities were challenges connected to lack of structures and written routines regarding how to connect and cooperate with informal caregivers. Interviewed home care workers referred to the Health and Care Services Act to explain this, as the services were mainly oriented toward the *care receiver*. In effect, home care workers had to find and invent solutions on a case-by-case basis in their attempt to cooperate with informal caregivers.

Discussion

Our data show that only a small proportion of the Norwegian population carry out unpaid, voluntary work in the long-term care services. Informal caregiving to people who are likely users of municipal care services is more widespread; one fifth of the respondents report that they regularly provide help to family, neighbors, friends or colleagues with special care needs. These results diverge from the somewhat lower numbers reported by the latest Time use survey and Living conditions survey.

If viewed through a life-course lens, our data tell the same story as other informal care literature (Daatland, Veenstra, & Lima, 2009). People provide more informal care and help to spouses, parents, other family and friends as they grow older and their health situation requires it. The likelihood of having a parent or spouse who requires regular help and care increases with age (Daatland et al., 2009). Moreover, our results show that also care

volunteering is more widespread in the highest age groups. Hence, older people are not just care receivers; they are to a considerable extent also active as volunteers and informal caregivers. From the life-course perspective, the age gap in voluntary participation can be explained by a shift in focus from a desire to widen one's horizon when young, to an emphasis on reasons such as self-respect, social responsibility and social networks in older age (Musick & Wilson, 2008). In early middle age, people's focus is typically on their children, careers and buying a house; in middle life, people are more likely to do volunteering for their children's leisure activities, schools or local community (Musick & Wilson, 2008; Wollebæk, Sætrang, & Fladmoe, 2015), not nursing homes or residential care facilities. Notwithstanding, the life-course perspective represents a very static perspective on voluntary engagement. People do diverge from these patterns and may be motivated by other factors, internal (e.g. personality, religion) and external (e.g. asked by a friend, community characteristics).

We also found gendered differences in our study. The overrepresentation of women in informal caregiving was as expected. Studies across Europe show that most informal care is carried out by women (Sand, 2005), with daughters being the most common caregiver (Walker & Warren, 1997). Our results are also in line with other research which shows that the difference between the genders is more prominent when it comes to care for someone who is sick, handicapped or elderly in another household, than informal care within the household or informal care to healthy or young persons outside the household (Jegermalm, 2006). Interestingly, the gendered dimension of care extends to volunteering. Overall volunteering is more common among men (Fladmoe et al., 2018; Jegermalm & Jeppsson Grassman, 2009), but within the realm of care, female volunteers are in majority.

When it comes to challenges in collaboration between formal caregivers and unpaid volunteers and caregivers, our studies show that there are many similarities across the two

settings. For most formal caregivers (volunteer coordinators excepted), dealing with volunteers is not formally part of their job description. This is illustrated by the absence of formal routines for collaboration. And since healthcare professionals' responsibilities are primarily connected to the individual care receiver's needs (Molven, 2017), communicating with informal caregivers or volunteers is not on formal caregivers' daily task lists.

Notwithstanding, our study shows that managers and formal caregivers view both volunteers and informal caregivers as invaluable providers of care, especially when it comes to fulfilling care receivers' social and emotional needs. Both nursing homes staff and home care workers find themselves in a squeeze between the social needs of care receivers and their own limited time and resources. They will prioritize other, more pressing caring tasks over social activities. Due to recent reorganization of the provision of health and care services in Norway, formal caregivers have been expected to provide care for a higher total number of care receivers than previously, and care receivers have needs that are more complex and extensive than before (Gautun & Syse, 2017).

In both the volunteer and informal carer setting, missing routines for recording or collecting information, filing or sharing information hinder successful collaboration and seamless task division. Sometimes collaboration fails because assumptions and misunderstandings are allowed to develop into mistrust and resentment. For example, our study shows that at times, home care workers experience that family members have unrealistic expectations of what services the municipality can provide. This corroborates previous research that shows that the scope of care is a source of disagreement between formal and informal caregivers (Sims-Gould, Byrne, Tong, & Martin-Matthews, 2015). Thus, it could be argued that there is a discrepancy between the municipality's responsibility for care, as communicated to the ordinary citizen through legislation, policy and the media, and formal caregivers' capacity to provide statutory services (Tønnessen, 2016). Also in

volunteer-formal caregivers collaboration does volunteers' limited knowledge about the care services' organizational and financial limitations create friction. Volunteers who show little or no appreciation of formal caregivers' busy schedules and take it for granted that they are available at all times to get care receivers ready for activities cause frustration and negative attitudes.

Unclear expectations as regards the division of tasks may cause frustration in both the volunteer and informal caregiver setting. It is often unclear which tasks are the responsibility of nursing home staff or home care workers and which tasks can (or should) be carried out by volunteers or informal caregivers. In both settings, formal caregivers are, at times, unwilling to delegate certain care tasks to volunteers or informal caregivers. This applies to personal care tasks in particular, which are viewed as the professionals' responsibility and domain. This might be seen as an expression of professionals defending their territory (Axelsson & Axelsson, 2009), but it can also be viewed as a result of the *voluntary* nature of the two forms of unpaid work. Formally and legally, both volunteers' and informal caregivers' contributions are based on voluntarism, through civil practices and informal interaction. Formal caregivers in the Norwegian care services cannot expect or demand that volunteers or informal caregivers contribute toward service provision. At times, this makes it difficult to establish workable structures for collaboration, as formal caregivers cannot enter into binding agreements with individual volunteers or informal caregivers.

There are also some distinct differences in how collaboration challenges are perceived across the two settings. First, in the volunteer setting, collaboration revolves around activities/events and their organization and execution. Recruitment and preparation of care receivers for participation in activities are added to formal caregivers' task lists and sometimes perceived as an unwelcome added workload. In the informal caregiver setting, we observe no such perceptions of interruptions or added workload. This might be because

dealing with family members forms part of home care workers' job description. However, we only studied the home care setting; perceptions might be different in institutions. A second major difference is the personal relationship factor. Informal caregivers do, in most cases, know the care receivers' lifestyle, habits and abilities better than home care workers, and they commonly carry out comprehensive care tasks that legally are the responsibility of the public services (Tønnessen, 2016). Volunteers, on the other hand, generally do not know care receivers when they volunteer, and voluntary organizations are not always well-informed about the abilities of care receivers when they plan or propose activities (Tingvold & Skinner, 2019). At times, formal caregivers find it difficult to manage the mismatch between the expectations of well-meaning volunteers and the reality of very frail or demanding care receivers (Tingvold & Olsvold, 2018).

We would argue that all the challenges in formal caregivers' interaction with volunteers and informal caregivers can be traced back to the differing logics of the professional, volunteer and informal caregiver spheres. It is unsurprising that friction arises when professionals and volunteers and informal caregivers join forces. The public services' preference for predictability, stability and continuity (Væggemose, Ankersen, Aagaard, & Bureau, 2017) inevitably clashes with the informal approach of volunteers, whose contributions are voluntary and more *ad hoc*. This was expressed by several informants in our data material. For example, one care manager expressed discontent with volunteers' *ad hoc* contributions in the area of dementia care, as the infrequency of volunteer visits were seen as at odds with the needs and preferences of the receivers: "The volunteer's commitment to do four hours a month is too little for the recipient! [...] There is a difference between the person with dementia's needs for contact and the activity companion's capacity."

In home care worker-informal caregiver interaction, bureaucratic aspects of home care services such as fixed care plans, rotating workers and time restrictions might clash with

informal carers' values, needs, preferences and expectations (Martin-Matthews & Sims-Gould, 2008; Sims-Gould et al., 2015; Sims-Gould & Martin-Matthews, 2010). However, research shows that when formal caregivers are able to navigate between the two logics, and in the case of informal caregivers display empathic awareness, successful collaboration and interaction can take place (Sims-Gould et al., 2015; Væggemose et al., 2017). A precondition for successful interplay between the two logics is, however, that all actors have information and knowledge about their counterpart and the values and practices that guide their daily activities.

Limitations

The non-response rate in the survey was considerable (79.8 percent). Nevertheless, research shows that high non-response does not necessarily equal biased results, and that surveys with response rates far below 20 percent may still produce scientifically valuable data (Groves, 2006; Hellevik, 2016). Another weakness in our data is that the magnitude of informal care may be more considerable than is suggested by our data. The survey items about hours spent providing informal care only asked about help and care for the person respondents helped the most. Since 74 percent of those who did informal care for someone with special care needs outside the household stated that they helped more than one person, it is clear that some unpaid care work has gone undetected in our study.

As regards the limitations of the qualitative study of *volunteer activities*, there were no cases of municipality-initiated activities in our study, so we have no data on the challenges they face. Nor do we have data on frontline staff and care receivers' experiences with coordination challenges. Moreover, data from the qualitative study of *informal care* presented in this article only took into account collaboration challenges that informal and formal carers in *home care services* face in two municipalities in Western Norway. Nevertheless, transferability in the qualitative studies was sought established by including different

activities and research settings in the study of volunteer activities, and both an urban and a rural setting in the informal care study. To ensure dependability and confirmability in the *volunteering* study, the second author examined the third author's processes of data collection and data analysis and the results in order to ascertain that interpretations were supported by the data. The findings were subsequently discussed with the first author. In the *informal care* study, respondents were sought included from different social strata and positions in order to maximize the variety of perspectives. Still, middle class respondents were overrepresented. Dependability was sought established by conducting long-term data collection that also included observations and informal conversations, which strengthened the researcher's insights into the actual cooperation practices and challenges. While the informal care study was conducted by the fourth author, the findings were examined by and discussed with the first author.

Conclusion

The results from the study supports the idea that there is a special model of Scandinavian social care which is characterized by a mix of formal care, volunteering and informal caregiving. However, less formal care does not necessarily imply more of informal caregiving and/or volunteering, as the actors largely carry out complementary tasks. Moreover, the findings from the population survey show that although informal caregivers' contributions in Norwegian long-term care are considerable, the current scope of voluntary contributions is scarce. Judging from this, it seems that social policy-makers have underestimated the obstacles that have to be overcome before "civil" resources can begin to meet future care demands. Moreover, the findings from the qualitative studies illustrate that the practice field is not sufficiently prepared for increased involvement of volunteers and informal caregivers. Current structural issues concerning the long-term care services' legal framework, (re)organization, capacity and operation hinder effective collaboration between

formal caregivers and volunteers/informal caregivers. Knowledge of limitations in the current collaboration environment will, hopefully, be useful to both policy makers and the practice field when assessing their goals and strategies for involvement and improvement of collaboration practices. Nevertheless, new strategies to involve volunteers and informal caregivers in the provision of long-term care services are by no means futile. Nor is it impossible for the care services to attract more volunteers in the future. But politicians and policy-makers need to acknowledge that involving volunteers in long-term care service provision is a costly venture: it requires education of both formal caregivers and volunteers, coordination and continuous recruitment efforts. To improve cooperation with informal caregivers, politicians have to be willing to take part in a more honest and open debate on the role of family care in the Nordic welfare state and to what extent informal caregivers have to take on a heavier care burden due to changing demographics and political priorities in the future.

Ethical considerations

The studies adhere to the ethical requirements governing Norwegian universities and research institutes and were approved by the Norwegian Centre for Research Data (NSD), reference numbers 38574, 43928 and 39204.

Conflicts of Interest

There are no conflicts of interest.

Source of Funding

This study was funded by the Research Council of Norway – grant number 222312. The funder played no role in the design, execution, analysis of data or writing of the article.

Acknowledgements

We would like to thank Tor Inge Romøren, Maren Sogstad, Dag Wollebæk and Audun Fladmoe for valuable contributions in various stages of the research project.

Notes

¹ FTEs of informal care=Percentage of adult population who provide informal care*size of adult population*minutes of informal care per day*365/60/1800.

² FTEs of informal care=Percentage of adult population who provide informal care*size of adult population*hours of informal care per four weeks/4*52/1750. Our survey is from 2014 and the study population was adults aged 16 and over, so we base our calculations on the group 16+ and population statistics from 1 January 2014, i.e. 4,115,195 (Statistics Norway 2014). We use Statistic Norway's definition of a FTE: 1750 hours (Statistics Norway 2018).

References

- Alford, R. R., & Friedland, R. (1985). *Powers of Theory: Capitalism, the State and Democracy*. New York, NY: Cambridge University Press.
- Andfossen, N. B. (2016). The potential for collaborative innovation between public services and volunteers in the long-term care sector. *The Innovation Journal: The Public Sector Innovation Journal*, 21(3), 1-21. https://www.innovation.cc/scholarly-style/2016_21_3_3_andfossen_innovate-long-term-care.pdf
- Arnesen, D. (2015). *Undersøkelsene om frivillig innsats 1998-2014: Dokumentasjonsrapport* [The surveys about voluntary contributions 1998-2014: Documentation]. Oslo, Norway: Senter for forskning på sivilsamfunn og frivillig sektor.
- Axelsson, S. B., & Axelsson, R. (2009). From territoriality to altruism in interprofessional collaboration and leadership. *Journal of Interprofessional Care*, 23(4), 320-330. <https://doi.org/10.1080/13561820902921811>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>

- Brown, R. M., & Brown, S. L. (2014). Informal caregiving: A reappraisal of effects on caregivers. *Social Issues and Policy Review*, 8(1), 74-102. <https://doi.org/10.1111/sipr.2014.8.issue-1>
- Chappell, N., & Blandford, A. (1991). Informal and Formal Care: Exploring the Complementarity. *Ageing and Society*, 11(3), 299-317. <https://doi.org/10.1017/S0144686X00004189>
- Dahlberg, L. (2006). The complementarity norm: service provision by the welfare state and voluntary organisations in Sweden. *Health and Social Care in the Community*, 14(4), 302-310. <https://doi.org/10.1111/hsc.2006.14.issue-4>
- Daatland, S. O., Veenstra, M., & Lima, I. A. (2009). *Helse, familie og omsorg over livsløpet* [Health, family and care through life]. Oslo, Norway: NOVA.
- Esping-Andersen, G. (Ed.) (2002). *Why we need a new welfare state*. Oxford, UK: Oxford University Press.
- Fast, J., Keating, N., Otfinowski, P., & Derksen, L. (2004). Characteristics of Family/Friend Care Networks of Frail Seniors. *Canadian Journal on Aging*, 23(1), 5-19. <https://doi.org/10.1017/S0714980800016780>
- Fladmoe, A., Sivesind, K. H., & Arnesen, D. (2018). *Oppdaterte tall om frivillig innsats i Norge, 1998-2017* [Updated statistics about voluntary efforts in Norway, 1998-2017]. Oslo, Norway: Senter for forskning på sivilsamfunn og frivillig sektor.
- Førland, O. (2015). Oppsummering av litteraturen om frivillig innsats og samspillet med offentlige omsorgstjenester [Review of the literature about voluntary work and the interaction with the public care services]. In L. H. Jensen (Ed.), *Frivillighet i omsorgssektoren* (pp. 123-136). Tønsberg, Norway: Forlaget Aldring og helse.

- Gautun, H., & Syse, A. (2017). Earlier hospital discharge: a challenge for Norwegian municipalities. *Nordic Journal of Social Research*, 8, 1-17.
<https://doi.org/10.7577/njsr.2204>
- Groves, R. M. (2006). Nonresponse Rates and Nonresponse Bias in Household Surveys. *Public Opinion Quarterly*, 5(1), 646-675. <https://doi.org/10.1093/poq/nfl033>
- Hellevik, O. (2016). Extreme nonresponse and response bias: A "worst case" analysis. *Quality and Quantity*, 50(5), 1969-1991. <https://doi.org/10.1007/s11135-015-0246-5>
- Henriksen, L. S., Koch-Nielsen, I., & Rosdahl, D. (2008). Formal and Informal Volunteering in a Nordic Context: The Case of Denmark. *Journal of Civil Society*, 4(3), 193-209.
<https://doi.org/10.1080/17448680802559685>
- Hoad, P. (2002). Drawing the line: the boundaries of volunteering in the community care of older people. *Health and Social Care in the Community*, 10(4), 239–246.
<https://doi.org/10.1046/.1365-2524.2002.00361.x>
- Holmøy, E., Haugstveit, F. V., & Otnes, B. (2016). *Behovet for arbeidskraft og omsorgsboliger i pleie- og omsorgssektoren mot 2060* [The need for labour and sheltered housing in the long-term care sector toward 2060]. Oslo-Kongsvinger, Norway: Statistisk sentralbyrå.
- Hussein, S., & Manthorpe, J. (2014). Volunteers Supporting Older People in Formal Care Settings in England: Personal and Local Factors Influencing Prevalence and Type of Participation. *Journal of Applied Gerontology*, 33(8), 923-941.
<https://doi.org/10.1177/0733464812455098>
- Hutchison, E. D. (2008). A Life Course Perspective. In E. D. Hutchison (Ed.), *Dimensions of Human Behavior: The Changing Life Course* (3 ed., pp. 1-38). Los Angeles, CA: SAGE Publications.

- Jegermalm, M. (2004). Informal care and support for carers in Sweden: Patterns of service receipt among informal caregivers and care recipients. *European Journal of Social Work*, 7(1), 7-24. <https://doi.org/10.1080/136919145042000217465>
- Jegermalm, M. (2006). Informal care in Sweden: a typology of care and caregivers. *International Journal of Social Welfare*, 15(4), 332-343. <https://doi.org/10.1111/ijsw.2006.15.issue-4>
- Jegermalm, M., Hermansen, J., & Fladmoe, A. (2018). Beyond voluntary organizations and the welfare state: Patterns of informal helping in the Scandinavian countries In L. S. Henriksen, K. Strømsnes, & L. Svedberg (Eds.), *Civic engagement in Scandinavia: Volunteering, Informal Help and Giving in Denmark, Norway and Sweden* (pp. 95-11). Cham, Switzerland: Springer.
- Jegermalm, M., & Jeppsson Grassman, E. (2009). Caregiving and Volunteering Among Older People in Sweden - Prevalence and Profiles. *Journal of Aging and Social Policy*, 21(4), 352-373. <https://doi.org/10.1080/08959420903167066>
- Jegermalm, M., & Jeppsson Grassman, E. (2012). Helpful citizens and caring families: Patterns of informal help and caregiving in Sweden in a 17-year perspective. *International Journal of Social Welfare*, 21(4), 422-432. <https://doi.org/10.1111/j.1468-8602397.2011.00839.x>
- Jegermalm, M., & Jeppsson Grassman, E. (2013). Links between informal caregiving and volunteering in Sweden: a 17 year perspective. *European Journal of Social Work*, 16(2), 205-219. <https://doi.org/10.1080/13691457.2011.611796>
- Jegermalm, M., Malmberg, B., & Sundström, G. (2014). *Anhöriga äldre angår alla* [Elderly relatives concern us all]. Kalmar, Sweden: Nationellt center anhöriga.

- Jegermalm, M., & Sundström, G. (2015). Stereotypes about caregiving and lessons from the Swedish panorama of care. *European Journal of Social Work, 18*(2), 185-197.
<https://doi.org/10.1080/13691457.2014.892476>
- Kröger, T. (2005). Interplay between Formal and Informal Care for Older People: The State of the Nordic Research. In M. Szebehely (Ed.), *Äldreomsorgsforskning i Norden: En kunskapsöversikt* (pp. 243-280). Copenhagen, Denmark: Nordiska ministerrådet.
- la Cour, A. (2014). *Frivillighedens logik og dens politik: En analyse af den personrettede frivillige sociale indsats og statens frivillighedspolitik* [The logic of volunteering and its politics]. Frederiksberg, Denmark: Nyt fra samfundsvidenskaberne.
- Litwak, E. (1985). *Helping the Elderly: The Complementary Roles of Informal Networks and Formal Systems*. New York, NY: Guildford.
- Lorentzen, H. (2013). *Utdanning og kompetanse i idretten* [Education and competencies in sports]. Oslo, Norway: Institutt for samfunnsforskning.
- Lorentzen, H., & Skinner, M. S. (2019). Frivillige i omsorgssektoren – muligheter og barrierer [Volunteers in the care services - possible barriers and their significance]. *Tidsskrift for velferdsforskning, 22*(1), 4-24. <https://doi.org/10.18261/2464-3076-2019-01-01>
- Martin-Matthews, A., & Sims-Gould, J. (2008). Employers, Home Support Workers and Elderly Clients: Identifying Key Issues in Delivery and Receipt of Home Support. *Healthcare Quarterly, 11*(4), 69-75. <https://doi.org/10.12927/hcq>
- Ministry of Health and Care Services. (2006). *St.meld. nr. 25 (2005–2006) Mestring, muligheter og mening: Framtidas omsorgsutfordringer* [White paper no. 25 (2005-2006) Mastering, opportunities and meaning: the care challenges of the future] Oslo, Norway: Ministry of Health and Care Services.

- Ministry of Health and Care Services. (2013). *St.meld. 29 (2012-2013) Morgendagens omsorg [White paper no. 29 (2012-2013) The care of tomorrow]* Oslo, Norway: Ministry of Health and Care Services.
- Ministry of Health and Care Services. (2018). *Meld. St. 15 (2017 – 2018) Leve hele livet: En kvalitetsreform for eldre [White paper no. 15 (2017-2018) Live life: A quality reform for older people]* Oslo, Norway: Ministry of Health and Care Services.
- Molven, O. (2017). Rettigheter og plikter som pårørende i kommunale helsetjenester [Rights and duties as next of kin in municipal health services]. In S. Tønnessen & B. L. L. Kassah (Eds.), *Pårørende i kommunale helse- og omsorgstjenester: Forpliktelse og ansvar i et utydelig landskap* (pp. 28-51). Oslo, Norway: Gyldendal akademisk.
- Musick, M. A., & Wilson, J. (2008). *Volunteers: A Social Profile*. Indianapolis, IN: Indiana University Press.
- Norwegian Official Report [NOU]. (2011:11). *Innovasjon i omsorg [Innovation in care]*. Oslo, Norway: Departementenes servicesenter.
- OECD. (2011). *Help wanted? Providing and paying for long-term care*. Paris, France: OECD.
- Philp, I. (Ed.) (2001). *Family Care of Older People in Europe*. Amsterdam, the Netherlands: IOS Press.
- Pick, D., Holmes, K., & Brueckner, M. (2011). Governmentalities of Volunteering: A Study of Regional Western Australia. *Voluntas*, 22(3), 390-408.
<https://doi.org/10.1007/s11266-010-9161-5>
- Plagnol, A. C., & Huppert, F. A. (2009). Happy to Help? Exploring the Factors Associated with Variations in Rates of Volunteering Across Europe. *Social Indicators Research*, 97(2), 157-176. <https://doi.org/10.1007/s11205-009-9494-x>

- Pope, C., & Mays, N. (1995). Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *British Medical Journal*, *311*(6996), 42-45. <https://doi.org/10.1136/bmj.311.6996.42>
- Rønning, R., Schanke, T., & Johansen, V. (2009). *Frivillighetens muligheter i eldreomsorgen* [The opportunities of volunteering in eldercare]. (Vol. Report No. 11/2009). Lillehammer, Norway: Østlandsforskning.
- Sand, A.-B. M. (2005). Informell äldreomsorg samt stöd till informella vårdare – en nordisk forskningsöversikt [Informal eldercare and support for informal caregivers - a Nordic research review]. In M. Szebehely (Ed.), *Äldreomsorgsforskning i Norden: En kunskapsöversikt* (pp. 197-241). Copenhagen, Denmark: Nordiska ministerrådet.
- Sims-Gould, J., Byrne, K., Tong, C., & Martin-Matthews, A. (2015). Home support workers perceptions of family members of their older clients: a qualitative study. *BMC Geriatrics*, *15*(1), 1-9. <https://doi.org/10.1186/s12877-015-0163-4>
- Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: family caregivers' experiences of their older relative receiving home support services. *Health and Social Care in the Community*, *18*(4), 415-423. <https://doi.org/10.1111/hsc.2010.18.issue-4>
- Skinner, M. S. (2018). Frivillige aktiviteter i omsorgstjenestene: Omfang, typer og organisering [Volunteer activities in the care services: Scope, types and organization]. *Tidsskrift for omsorgsforskning*, *4*(2), 184-185. <https://doi.org/10.18261/.2387-5984>
- Skinner, M. S., Sogstad, M. K. R., & Tingvold, L. (2018). Voluntary Work in the Norwegian long-term Care Sector: Complementing or substituting formal Services? *European Journal of Social Work*, *22*(6), 999-1011. <https://doi.org/10.1080/13691457.2018.1462767>

- Snyder, M., & Omoto, A. M. (2008). Volunteerism: Social Issues Perspectives and Social Policy Implications. *Social Issues and Policy Review*, 2(1), 1-36.
<https://doi.org/10.1111/j.1751-2409.2008.00009.x>
- Statistics Norway. (2016). Ulønnet omsorgsarbeid, levekårsundersøkelsen, 2015 [Unpaid care work: The living conditions survey 2015], Retrieved from SSB
<https://www.ssb.no/helse/statistikker/omsarb/hvert-3-aar/2016-09-15#content>
- Thornton, P. H., Ocasio, W., & Lounsbury, M. (2012). *The Institutional Logics Perspective: A New Approach to Culture, Structure, and Process*. Oxford, UK: Oxford University Press.
- Tingvold, L., & Olsvold, N. (2018). Not just "sweet old ladies" - Challenges in voluntary work in the municipal long-term care services. *Nordic Journal of Social Research*, 9, 31-47. <https://doi.org/10.7577/njsr.2174>
- Tingvold, L., & Skinner, M. S. (2019). Challenges in the coordination of voluntary activities in long-term care services. *International Journal of Care and Caring*, 3(3), 339-358.
<https://doi.org/10.1332/239788219X15473078841850>
- Tønnessen, S. (2016). Pårørende: Usynlige bærebjelker i velferdsstaten [Next of kin: Invisible girders in the welfare state]. In H. Vike, J. Debesay, & H. Haukelien (Eds.), *Tilbakeblikk på velferdsstaten: Politikk, styring og tjenester* (pp. 76-101). Oslo, Norway: Gyldendal akademisk.
- United Nations. (2016). *Growing need for long-term care: assumptions and realities*. Retrieved from: https://www.un.org/esa/socdev/ageing/documents/un-ageing_briefing-paper_Long-term-care.pdf
- Vabø, M. (2012). Norwegian home care in transition – heading for accountability, off-loading responsibilities. *Health and Social Care in the Community*, 20(3), 283-291.
<https://doi.org/10.1111/hsc.2012.20.issue-3>

- van Dijk, H. M., Cramm, J. M., & Nieboer, A. P. (2013). The experiences of neighbour, volunteer and professional support-givers in supporting community dwelling older people. *Health and Social Care in the Community*, 21(2), 150-158.
<https://doi.org/10.1111/hsc.2013.21.issue-2>
- von Essen, J., Jegermalm, M., & Svedberg, L. (2015). *Folk i rörelse - medborgerligt engagemang 1992-2014* [Civic Engagement in Sweden 1992-2014]. Stockholm, Sweden: Institutionen för socialvetenskap.
- Væggemose, U., Ankersen, P. V., Aagaard, J., & Burau, V. (2017). Co-production of community mental health services: Organising the interplay between public services and civil society in Denmark. *Health and Social Care in the Community*, 26(1), 122-130. <https://doi.org/10.1111/hsc.12468>
- Vaage, O. F. (2012). *Tidene skifter: Tidsbruk 1971-2010* [The times are changing: Time use 1971-2010]. Oslo, Norway: Statistisk sentralbyrå.
- Walker, A., & Warren, L. (1997). *Changing services for older people*. Buckingham, UK: Open University Press.
- Wilson, J., & Musick, M. A. (1997). Who cares? Toward an integrated theory of volunteer work. *American Sociological Review*, 62(5), 694-713. <https://doi.org/10.2307/2657355>
- Wollebæk, D., Selle, P., & Lorentzen, H. (2000). *Frivillig innsats: Sosial integrasjon, demokrati og økonomi* [Voluntary efforts: Social integration, democracy and economy]. Bergen, Norway: Fagbokforlaget.
- Wollebæk, D., Sætrang, S., & Fladmoe, A. (2015). *Betingelser for frivillig innsats: Motivasjon og kontekst* [Preconditions for voluntary efforts: Motivation and context]. Oslo, Norway: Senter for forskning på sivilsamfunn og frivillig sektor.