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Patterns of care and support in old age

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Abstract

This study describes the situation for community living older people, 65 years of age and older in Iceland, analyzing their needs for care and services and how these needs are met. The study analyzes the relationship between the main providers of help and care, the formal caregivers and the informal carers. The study further depicts what kinds of care and support older informal caregivers provide and receive themselves and analyze what factors are related to providing care alone or in combination with other caregivers, informal and formal. The study also analyzes the relationship and mutual support between grandparents and grandchildren and whether there are gender differences in intergenerational relations and support. As little research has been conducted on informal care in Iceland, it is important to show the importance of the informal carers in the care paradigm.

Two Icelandic studies were used for the descriptions and analysis. The main data source is the ICEOLD survey (Icelandic older people), based on a random representative national sample of 700 non-institutionalized persons in ages 65 – 79 years and 700 persons aged 80+. The final sample consists of 1,189 older persons to which an introduction letter was sent. They were contacted by phone a few days later and 782 persons, 341 men and 441 women, agreed to participate, giving a response rate of 66%. A study carried out among college students in Iceland, The Grammar School study, was also used to retrieve information on intergenerational relations between grandparents and grandchildren.

The study indicates that older people in Iceland are receiving help and care from both informal and formal carers but informal help provided by family members seems to play a major role in supporting older people in their home. The great majority of the respondents with Instrumental Activities of Daily Living (IADL) limitations and Personal Activities of Daily Living (PADL) limitations received either informal or formal help but not both. The care and help provided is more often help with domestic tasks than with personal care. However, when the need increases the formal system steps in. It is not clear whether the informal care is a substitute for the formal one. As the formal help provided is rather sparse, it is suggested that when the need for personal care increases, the older person moves into a nursing home instead of increasing the formal care in the home. Women more often than men are the sole carers, and daughters are more important carers for older people than sons are.

Older informal caregivers were alone in their caregiving in almost half of the cases and women more often than men. One third provided help with several tasks, such as help with errands and surveillance or keeping company

in addition to ADL help. Older caregivers provide care even when they need help themselves.

The results indicate that grandparents and grandchildren exchange more emotional than practical support. The emotional support provided and received by the generations is of great value. Gender influences the contact frequency between the generations, as women more often cultivate ties between grandparents and grandchildren.

Original studies

The thesis is based on the following studies, which are referred to by their Roman numerals in the text:

Study I

Sigurðardóttir, S.H.; Sundström, G.; Malmberg, B. and Ernsth Bravell, M. (2012). Needs and care of older people living at home in Iceland. *Scandinavian Journal of Public Health*. 40, 1, 1-9.

Study II

Sigurðardóttir, S.H. and Ernsth Bravell, M. (2013). Older caregivers in Iceland: providing and receiving care. Accepted for publication in *Nordic Social Work Research.* To be published in issue 1/2013 in June 2013.

Study III

Sigurðardóttir, S.H. and Kåreholt, I. Factors associated with informal and formal care of older Icelandic people. Submitted to *Health and Social Care in the Community* on 7th October 2012.

Study IV

Sigurðardóttir S.H. and Júlíusdóttir, S. (2013). Reciprocity in relationships and support between grandparents and grandchildren: An Icelandic example. Accepted for publication in *Journal of Intergenerational Relationships*. To be published in Vol. 11(2) in June 2013.

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1. Introduction

When doing research to understand care of older people, two main streams can be followed: the macro-level with the emphasis on studying the division of care between the state and the family, and the micro-level where the needs of the older individual are described, as well as who are receiving and providing care. In this dissertation, the micro-level stream will be followed. However, as these levels always influence each other, a dialog between them can hardly be avoided.

The aim of this dissertation is to generate knowledge about the care and support that older people in Iceland need, provide and receive. The relations between care receivers and care providers will be studied but also the interplay between formal and informal providers of help. It is important to identify and analyze if and how these providers of help work together to ensure that the needs of the older persons are met. Understanding the various means patterns, interaction and adequacy is vital in planning for the future eldercare. The intergenerational relationships between grandparents and grandchildren will also be studied. Because of a longer shared lifespan and healthier grandparents, these relations have received increased attention and are of importance for the well-being of both the grandparents and the grandchildren (Arber and Timonen, 2012).

The Icelandic care- and pension systems will be described to give some details on the society the older respondents live in. Iceland is in many ways a typical Nordic welfare state, even if it divides from the other Nordic countries in its social security structure by flat rate benefits and a higher degree of income-testing to other earnings (Ólafsson, 2011). Its welfare system is associated with high social expenditure, publicly funded services and high taxes. The public welfare provided is largely based on the needs of older persons but not on their economic situation. Iceland had for several years the highest institutionalization rates in old age care among the Nordic countries, but in spite of these high rates there has been a perceived lack of institutional care. The reasons for this have been discussed by authorities and academics (Broddadóttir, Eydal, Hrafnsdóttir and Sigurðardóttir, 1997; Heilbrigðis- og tryggingamálaráðuneytið [Ministry of Health and Social Security], 2003). The ideological shift from institutional care to home care occurred later in Iceland than in the other Nordic countries and the care model has until recently been more medical than social. Now there are signs of changes. Emphasis is put on respecting the older citizens' right to self-

determination and supporting them to live in their homes for as long as possible.

As little research has been conducted on care and support of older people living at home in Iceland, it is important to study how the needs for care and services are met. The ICEOLD study was conducted in 2008 with the main aim of illuminating needs and care of older people living at home in Iceland.

1.1. Aim of the thesis

The overall aim of the thesis is to study the old age care situation and how the needs of older people are met. More specifically, the research questions are as follows:

To investigate how factors such as gender, health, ADL-limitations and cohabitation affect the needs of older people.

To examine the public services (formal care) provided and the care provided by family, friends and neighbours (informal care), and study the relationship between these spheres.

To describe older informal caregivers and analyse the care and support they provide to others and receive themselves.

To study intergenerational relationships between grandparents and grandchildren, and the reciprocal support provided between the generations.

2. Care of older people in Iceland

2.1. The population

The population in Iceland is 320,000, of whom almost 13% are 65 years of age or older. Compared to most other European countries, where the average percentage of the population 65 years and older is 17%, the population is relatively young, but increasing longevity and declining fertility have resulted in a trend towards an older population (Eurostat, 2011; Hagstofa Íslands [Statistics Iceland], 2012a; Hagstofa Íslands [Statistics Iceland], 2012b). The oldest part of the population, 80 years and older, is growing fast and is expected to be 8.3% of the population in 2050, compared to 3.2% in 2008 (Hagstofa Íslands [Statistics Iceland], 2008a). There is great local variation between the 76 municipalities, where older persons 67+ make up from 5% to 25% of the population (Landlæknisembættið [Directorate of Health], 2011). In January 2012, foreign citizens were 6.6% of the total population. The average life expectancy of the newborn in Iceland is now 83.6 years for females and 79.9 years for males. Almost two thirds of the population (63%) live in the capital region (Hagstofa Íslands [Statistics Iceland], 2012a). The employment rate of working age population in Iceland is 79% compared to 65% in the OECD countries (OECD, n.d.).

2.2. Legislations and social policy

The Icelandic old age care system is universal; it is available to all people in need of the services. The official goal is to support older people to live independently for as long as possible (Lög um málefni aldraða [Act on the Affairs of the elderly], no.125/1999). The ideological shift from institutional to home care occurred later in Iceland than in the other Nordic countries. The main reason for this is perhaps the influence of the private sector. Eldercare has to a large extent been built up by private organizations and associations and the boards of the nursing homes decided who was admitted to nursing homes, even if the state was paying the running costs (Broddadóttir et al., 1997; Ólafsson, 2011).

A special Act on the Affairs of the Elderly was first implemented in Iceland in 1982 (Lög um málefni aldraða, no. 91/1982) but the current Act is from 1999. The purpose of the Act was to ensure that older people had access to health care and social services that they needed and to guarantee

that such service was provided at the most appropriate level based on the needs and condition of the elderly person. The purpose is to ensure that older people are able for as long as possible to enjoy a normal domestic life and that they are guaranteed institutional care when needed. The Municipalities Social Services Act [Lög um félagsþjónustu sveitarfélaga], no. 49/1991 also states the services older people are entitled to, including any assistance in the running of the home, such as social home help and assistance with personal hygiene. The State has been responsible for the expenses of institutional care and the home health care, but the municipalities provide and pay for social home help and other community services. These special laws on affairs of the elderly have been debated and it is discussed whether there is a need for a special act on the matters of older people.

The planning and the responsibility of home help services belonged between 1982 and 2011 to two different ministries. The Ministry of Social Affairs and Social Security was responsible for the social home help and other community services, such as meals-on-wheels and social activity, and the Ministry of Health was responsible for the home health care and institutional care. This led to many difficulties and made the home help services less successful, as the service was not coordinated. In 2011 these two Ministries were merged into the Ministry of Welfare, which is responsible for planning and providing all the services. The plan is to merge the services further, so all services will be organized and provided by the municipalities by 2014. This reorganization is expected to result in more individualized eldercare.

A plan for the care of older people in Iceland was submitted in 2003, but in 2008 the government put forward a new plan emphasizing the rights of older people to receive appropriate individual support to be able to live in their homes as long as possible. In addition it should be made easier for older people and their relatives to get proper information on rights and services, increase number of nursing homes beds, day-care-services and respite care. The quality standards for the services will also be improved and older people should be able to live in single rooms in nursing homes instead of sharing a room with another person, which is the reality in many nursing homes in Iceland (Félags- og tryggingamálaráðuneytið [The Ministry of Social Affairs and Social Security], 2008).

The expenditure on financing of services, pensions and other cash benefits for older people in Iceland was 5.3% of GDP in 2009, compared to 7.6%-12.7% in the other Nordic countries. One of the explanations to the low rate of expenditure in Iceland is the high rate of employment among older people (NOSOSCO, 2011). In 2011 the labour force participation of older workers 55-64 years of age was 79% compared to 54% of the participation of their counterparts in the OECD countries. Within the Nordic

countries Iceland is in a class of its own when it comes to employment among seniors (OECD, n.d.).

2.3. Service for older people

Older citizens living in their home in Iceland are entitled to home help services which are based on individual need assessment (Lög um málefni aldraðra [Act on the Affairs of the elderly], no.125/1999). Home help services is used as an overall description for formal services provided to older people living in ordinary households such as social home help, home health care, day care services, etc. The social home help includes help with domestic tasks (IADL) and meals on wheels and the home health care, personal assistance with daily living (PADL) and home care nursing. The purpose of the home help services is to strengthen the capacity of the person involved to help himself/herself and make it possible to live in one's own home as long as possible. The municipalities are responsible for providing the social home help and may charge fees for the services (Lög um félagsþjónustu sveitarfélaga [The Municipalities Social Services Act], No. 40/1991). From 2008, private companies providing home help services have been established, giving the older people in need of help an opportunity to choose other care providers than the official.

The home health care is organized somewhat differently than the social home help services. The country is divided into seven health regions and the home health care is usually provided by the health care centres in every region and is free of charge (Lög um heilbrigðisþjónustu nr. 40/2007 [Health Service Act], no. 40/2007); Reglugerð um heilbrigðisumdæmi [Regulations on health regions], no.785/2007).

Some municipalities, such as the Municipality of Reykjavík, have taken over all the responsibilities of home health care and social home help according to special contracts between the state and the municipality (Reykjavikurborg [The Municipality of Reykjavik], n.d.). In the plan of the future eldercare the municipalities will be responsible for all services from 2014. This expanding coordination of domestic services for older people is expected to result in better quality of services and increasing possibilities for them to live longer in their own homes.

Of all persons 65 years and older, 21% received home help services in Iceland in 2010 compared to 6.5-17.5% of their counterparts in other Nordic countries. The average help received was 2.2 hours per week (Hagstofa Íslands [Statistics Iceland], 2011; NOSOSCO, 2011).

An assessment for admission to institutions was implemented in 1990 with the main purpose to ensure that only those in need would be admitted to nursing homes. In 2008, the assessment became stricter and the purpose of the more stringent regulations was to ensure that every individual was provided services at the most appropriate level and that different community services, such as home help and home health care, had been undertaken before an older person moved to a nursing home. Only those in extreme need are admitted. Due to the more stringent assessment regulations, the waiting lists have become shorter (Landlæknisembættið [Directorate of Health], 2011). In a report from The Icelandic National Audit Office (Ríkisendurskoðun) (2012), there has been an increase in new placements in nursing homes, fewer are on waiting lists and the time people reside in nursing homes has also decreased. This indicates that people have worse health when they move into the institutions.

In 2006, 10% of older Icelanders (67+) and 25% of the population aged 80+ lived in nursing homes or retirement homes (Hagstofa Íslands [Statistics Iceland], 2008b). These numbers are decreasing and in 2009, 9% of older Icelanders (67+) and 23% of persons 80 years or older were living in nursing homes or retirement homes. The rate is somewhat higher in rural areas, or 12% compared to 9% in the capital region. Of all the beds, 54% were in the capital region and 46% in the rural areas (Hagstofa Íslands [Statistics Iceland], 2010).

In spite of these high rates, there has been a perceived lack of institutional care, even if the situation is getting better the last few years. In December 2008, when the ICEOLD study was conducted, 392 older people were on waiting lists for nursing homes, 223 in the capital region and 169 in the provinces. Similar numbers for December 2010 were 215 older people on waiting lists for nursing homes in Iceland, 79 in the capital region and 136 in rural areas (Landlæknisembættið [Directorate of Health], 2011).

The effect of those long waiting lists on older people and their families has for many years been highly debated in media and also academically (Björnsdóttir, 2002; Sigurðardóttir, 1985). As the municipalities have been responsible for the social home help while the state has been responsible for the institutions and the home health care, it has been suggested that the high rate of institutional care is due to municipalities being tempted to refer older persons to institutions in order to reduce their own expenses (Broddadóttir et al., 1997).

In Iceland the ageing-in-place ideology has met many obstacles. When the regulations on assessment for admission to institutions were first implemented, there was a discussion in the media about frail older people living at home without adequate formal services.

In 2006 the Directorate of Health conducted a survey to examine the situation of those on the waiting lists which were assessed in very urgent need for institutional services in Reykjavik. Of the 242 persons on the waiting list, 166 older persons and/or their relatives participated. The respondents were between 75 and 95 years of age, more than half were 80 years and older. 18% were living alone, 26% were living with their spouse and 16% with another relative, 20% in service facilities and 20% were in hospitals. Altogether 73% received social home help, of whom 13% received social home help every day and 59% received home health care, of whom 54% every day. Of the respondents, 42% claimed that they were in less need of institutional care than when the assessment was issued, and 54% considered themselves to be able to stay in their homes receiving the same community services as for the time being. This group also claimed that they were seeking institutional care due to encouragement from their relatives. 90% of the respondents claimed that they received visits or help from their relatives five times per week or more often a week (Landlæknisembættið [Directorate of Health], 2006). The family plays an important role in caring for the oldest old (90+) living at home in Iceland, both in the capital and in the rural areas (Guðmundsdóttir, 2004).

It seems that even if the aging-in-place ideology is on the agenda, the attitude of the Icelanders is not following it. One reason suggested is that people do not rely on the formal services when needed. A survey studying the working situation of care workers in Iceland conducted in 2009 shows that they do not perform as multifaceted tasks as their counterparts in the other Nordic countries and most of them only work daytime jobs. The results can indicate that older people in Iceland with different needs do not get various and sufficient service at home that could encourage them to move into nursing homes (Karlsdóttir, 2011).

In recent years, several sheltered apartments have been built on the initiative of older people's associations, often in the neighbourhood of a nursing home. These apartments are mostly privately owned, and different services and security alarms are provided by the neighbouring nursing home or the municipality. Moving into such apartments could be the older people's way to ensure that they receive proper services when needed.

Surveys conducted in Iceland in 1999 and 2007, studying older persons' opinion on community services, contact with children, housing and well-being show that most of the service recipients found the service they received to be adequate. In these surveys more women received social home help/home health care than men, who get help more often. Between 90 and 93% of the respondents in these surveys met their children once a week or more often and 13% (in the survey 1999, not asked in the survey 2007) received help from their children once a week or more often

(Félagsmálaráðuneytið, Landssamband eldri borgara, Reykjavíkurborg og Öldrunarráð Íslands [Ministry of Social Affairs, The Federation of Seniors, The Municipality of Reykjavik and The Geriatric council of Iceland], 2007; Heilbrigðis- og tryggingamálaráðuneytið [Ministry of Health- and Social Security] 1999).

2.4. Pensions

Everyone who has lived in Iceland for at least three calendar years between 16-67 years of age is insured by the Icelandic Social Insurance System. At the age of 67 they can apply for an old age pension, regardless of occupation or marital status. Sailors (mainly fishermen) can start drawing their old age pension at age 60, after fulfilling certain conditions regarding sailing. Some other professions, such as nurses, are also entitled to leave employment earlier.

The Icelandic pension system is based on three pillars, 1) a tax-financed public plan, 2) a mandatory occupational or private funded pension scheme and 3) a voluntary person's savings scheme. In 1997-1998 a wide-ranging pension reform took place affecting both the mandatory occupational or private funded pensions and the supplemental pension savings. Tax incentives were established and the pension system strengthened (Guðmundsson, 2001; Ólafsson, 2011).

Old age pensions and various types of compensation paid along with it are linked to income with the aim of equalizeing the earnings (Pillar 1). As the pension system is work-related, all individuals working in Iceland are obligated to pay certain minimum premiums into a mandatory occupational or private funded pension scheme, managed by the labor market partners. The right to payments depends on the paid-in premiums of fund members and the length of the payment period. Payments from these funds impact social security payments (Pillar 2).

There is also a possibility of supplemental pension saving beyond the minimum premium into a personal pension fund or into the pension savings account of a financial company. The wage payer pays a certain matching contribution, which varies according to wage agreements. Payments from a personal pension fund have no effect on social security payments (Pillar 3).

The pension system is rather complicated and though the Icelandic society is similar to the other Nordic countries it deviates from them in the structure and amounts of benefits. The use of income-testing in the social security system is also more common in the Icelandic system (Eydal and Ólafsson, 2006).

After the financial collapse in Iceland in October 2008, the welfare system faced cuts in pensions. The occupational pension funds and personal pension funds lost significant sums of their assets (20-25%) but in 2010 many of the occupational pensions funds had already regained their pre-crisis assets level (Ólafsson, 2011).

Even if all inhabitants have suffered after the crisis, the strong welfare system sheltered the low and middle-income groups, which suffered less reduction of their purchasing power, Pensioners, families with children and the unemployed have received some softening of the cuts in living standard from the system. According to Ólafsson (2011:p.3), the welfare system has therefore proved to be an important asset in the crisis and the "pension system remains shaken but basically intact".

3. Theoretical background

The need for different services increases with higher age; both home care services, institutional services and needs for medical treatment. Different theories and models related to informal and formal care have been put forward to understand the relationship between these spheres, how support is provided and how it affects the relations between the older persons and their caregivers. These theories can increase the understanding of processes behind receiving and giving support and care within the family and social interaction between individuals, both instrumental and emotional.

In modern societies families are the main source of care and support for older family members (Lowenstein, Katz and Gur-Yaish, 2007; Silverstein, Conroy, Wang, Giarrusso, and Bengtson, 2002). The informal care is extensive in the Nordic countries, with their well-developed health- and social services (Daatland and Herlofsson, 2004; Jegermalm, 2006; Szebehely, 2005a). Therefore, informal care and support provided by relatives and friends of older people has received increased attention in the gerontological literature in recent years (Hirst, 2001; Jegermalm and Jeppsson Grassman, 2009; Jeppsson Grassman, 2001; Sundström, Malmberg and Johansson, 2006).

Research in this area aims at understanding the aspect of care, who is providing it and how the informal care affects both the provider and the older help receiver. An attempt has been made to describe the role of the informal care in the welfare society, whether it is complementary to the

public service, where the state and the informal care system carry out different tasks and services, or seen as a substitution where the informal care is a resource that can fill gaps caused by cutbacks in the formal care system (Jegermalm and Jeppsson Grassman, 2009).

There is some evidence that the care provided by state and municipalities will not be able to meet the expected needs of dependent older people because of limited common financial resources to be used in the eldercare (Sundström et al., 2006; Szebehely and Trydegård, 2011). This can lead to informal caregivers playing an increasingly important role in many countries, including the Nordic states, in caring for their older relatives (Hirst, 2001; Jegermalm and Jeppsson Grassman, 2009). This calls for more comprehensive discussion on the caregivers situation and what support they might desire themselves or for the cared for person (Johansson, Long and Parker, 2011).

3.1. Needs

Disability is one of the most common indicators used to understand the needs of older people for help and care. The most universal measures used are different forms of ADL activities describing what kind of help the older person needs. The ADL instrument was originally designed for use in long-term care but now it is used both to measure health in medical studies and community-based studies describing the needs of older people (Parker and Thorslund, 2007).

In this dissertation the ADL measurement scale is divided into IADL (instrumental activities of daily living), limitations with cleaning, shopping, washing clothes and cooking and PADL (personal activities of daily living) limitations with activities such as bathing, using the toilet, getting in and out of bed and dressing. This division is often used in earlier Scandinavian studies or elsewhere (see e.g. Ekvall, Sivberg and Hallberg, 2004; Sundström et al., 2006).

The different forms of ADL activities are standardized to some degree but it can still be difficult to compare ADL between studies because of different wording and different activities included. As an example some studies ask whether the respondent experiences *difficulty* in performing the activity and others ask whether the respondent *needs help* with certain tasks (Parker and Thorslund, 2007). In the ICEOLD study, the older participants were asked whether they needed help or assistance with different IADL and PADL tasks.

3.2. Help and care

As the boundaries between the concepts *care, help, support* and *service* are often unclear, they are used partly interchangeably to describe the support to older people in need of help. The Norwegian sociologist Wærness (1982) was one of the first to define what care is and how it is practised. She makes a distinction between personal *service* and *caring* work. *Service* is provided to someone who is able to perform the task him/herself, but *care* is assistance given to a person who is not able to do things him-/herself or carries them out with great difficulty. In the ICEOLD study, the Icelandic term "aðstoð" was used both when asking the respondents whether they needed help with domestic tasks such as cleaning IADL (help) and when asking whether they needed help with dressing and other personal activities of daily living PADL (care). The needs of assistance with different tasks explain whether *help* or *care* is provided.

The use of the concepts may be difficult to translate between languages. In the British research environs, the concepts "care" and "caring" were used in the eighties to describe unpaid informal care mainly directed to the elderly and did not originally include caring provided by professionals. The Nordic concept "omsorg" has been considered more flexible than the concept "care" (Anttonen and Zehner, 2011). It demonstrates both care (sw/no. omtanke, medkänsla; icel. umhyggja, samkennd) which all of us are in need of and help which refers to assistance with diverse tasks (Daatland, Veenstra and Lima, 2009). In Study III, the term *help* was used to describe help with IADL activities but the term *care* was used to describe help with personal assistance (PADL). In the following, the term *care* will be further discussed.

It was women who traditionally took care of children, the disabled and older people and the increased participation of women in the workforce is one of the most important factors explaining why care has become a theoretical and political issue[1]. The theoretical care discussion stems from feminist scholars who wanted to make the value of unpaid work done by women visible (Anttonen and Zechner, 2011). Knijn and Kremer (1997) defined care as paid or unpaid work that involved psychological, emotional and physical assistance to people in need of support. The term *care* is a useful framework to compare issues for social policy and analysis of the welfare states (Knijn and Kremer, 1997).

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[1]The employment rate for women in Iceland 15-64 years old is 77% compared to 57% in the OECD countries (OECD, 2011).

Daly (2002:p.252) uses the concept *care* referring to "looking after those who cannot take care of themselves" and defines it as "the activities and relations involved in caring for the ill, elderly and dependent young". This understanding of the concept regarding helping older people is used in this dissertation.

Anttonen and Zechner define *care* as: "a multilayered and complex concept that refers to the emotional, economic, personal and social aspects of care. It is characterized by a broad perspective and ambigous boundaries in relation to other closely linked concepts such as housework, mothering and nursing. In addition, the broad perspective means that caring includes care for children as well as for older people. It also refers to the broad range of potential needs for care" (Anttonen and Zechner, 2011:p.15).

Care can also be divided into different categories such as *care* or *help* with instrumental activities of daily living (IADL), where the elderly receive help with shopping, cleaning, washing and cooking, or care in performing personal activities of daily living (PADL), where help is provided with personal care, such as clothing, bathing, getting in and out of bed and feeding (Sundström et al., 2006). The concept "care" has a multidimensional nature and can include both formal and informal care (Daly and Lewis, 2000). It can also be used to describe the development and variations of the welfare state, not discussed further in this dissertation (Daly and Lewis, 2000; Sipilä, 1997). It is also sometimes unclear what may be perceived as care or just help received as normal exchanges or support between spouses and family members as a part of an ordinary family life (Daatland et al., 2009).

The concept *care* thus refers to a broad range of different needs and brings together different dimensions of care-giving and care-receiving. Even if caring is universal, the concept has multiple meanings, and can be imprecise and vary depending on time and culture, social values and norms (Anttonen and Zechner, 2011). The concept has its limitations and needs to be elaborated further to provide a useful theoretical tool. Daly and Lewis (2000) suggest that the definition of care must be broadened for a more general understanding of the relationships to the welfare state.

3.3. Informal care

Informal care is the assistance a person in need of care or support receives from their spouse, children, other relatives, friends or neighbours (Jegermalm and Jeppsson Grassman, 2009; Lewinter, 1999; Sand, 2005). It may be the only help the person receives or help provided together with formal support from municipalities or the state. The informal care is mostly

unpaid and refers to different tasks of unregulated activities (Bettio and Plantenga, 2004; Hirst, 2001; Kröger, 2005).

In this dissertation, the term informal care is generally used. It is defined as support provided to an older person by relatives, neighbours or friends both with practical things but also with more extensive IADL and PADL help and care. It can also include mutual help between the informal caregiver and the care receiver.

The concept "*family care*" is integrated in the term "*informal care*" and can be used both in theory and research to further analyse the care expanding from an individual caregiver to the family as a whole (Kahana, Kahana, Randal Johnson, Hammond and Kercher, 1994). Informal care is a wider term and includes both family members, neighbours and friends, but family care refers to relatives, most often children and/or a spouse. The definition of the two concepts is sometimes unclear (Jegermalm, 2005).

An informal caregiver is a person who regularly provides informal, unpaid help and care for others (Jegermalm and Jeppsson Grassman, 2009). Usually the term is used in the sense of describing someone who helps persons in need of assistance with the activities of daily living which they are unable to perform or have difficulties in carrying out themselves. But it can also refer to a person providing surveillance or keeping someone who is sick or old company (Bettio and Plantenga, 2004).

Informal care provided by the family is one of the most important types of intergenerational exchanges (Antonucci, Birditt, Sherman and Trinth, 2011). Informal caregivers can be categorized in different ways depending on living conditions, frequency of caregiving and whether he/she provides care alone or not. Jeppsson Grassman (2001) divides informal caregivers into two groups based on whether they live with the care receiver or not: 1) family caregivers who take care of someone in their own household and 2) care providers who take care of a person who does not live with them. Szebehely (2005b) divides informal caregivers into three groups based on the groups defined by Jeppsson Grassman (2001) but adding the frequency of caregiving: 1) family caregivers who take care of someone in their own household and provide help daily or several times a week; 2) care providers who take care of a person who does not live with them, daily or several times a week; and 3) helpers who assist someone within or outside their own household once a week at the most. These categories provide more details in terms of describing the frequency of care. This Nordic categorizing does not fit in all cultures, as classifying informal caregivers may sometimes involve culture-specific terms or roles that vary in different parts of the world (Corcoran, 2011; Dilworth-Anderson, Williams and Gibson, 2002).

Lyons, Zarit and Townsend (2000) classify informal caregivers according to whether the informal caregiver provides care alone or in combination with

another caregiver, either informal or formal. They describe three categories of caregivers: 1) isolated caregivers, who receive no assistance with caregiving; 2) family dependent caregivers, who receive assistance from other family members but not from the formal care system; and 3) caregivers who also receive support from formal caregivers, sometimes in combination with informal care. Classifying informal caregivers by different methods is helpful in understanding and clarifying how informal care is provided and how it affects both the care provider and the caregiver.

Attempts have also been made to develop typologies for various help to better understand different parts of the informal care and how the informal caregivers perceive their situation. According to Nolan, Keady and Grant (1995) Bowers identified five different typologies describing how help providers distinguish their support to the help receivers. She defined the typologies by purpose rather than on the tasks provided The typologies are *anticipatory caregiving*, based on anticipated future need, being prepared on helping, which affects the activities of the future caregiver and often conducted from a distance, *preventive caregiving*, also conducted from a distance, where the main purpose is to prevent illness and physical and mental decline, *supervisory caregiving*, which is help in arranging different things for the person, *instrumental caregiving*, which is hands-on caregiving, and *protective caregiving*, where the emphasis is on protecting the person's identity and taking care of their emotional needs. The observations of these different typologies explain how the care can affect the caregivers in different ways (Ekwall et al., 2004; Nolan et al., 1995).

Nolan et al. (1995) made an attempt to develop Bowers typologies to further improve the understanding of how families define care. Their work is consistent with Bowers except that they divided Bowers's anticipatory care category into two groups; speculative anticipation and informed anticipation. By doing so, they wanted to stress that the protective care can only be considered for short periods of care and used preservative care (maintenance care) instead, to maintain the resident's self-esteem. What separates Bowers and Nolan et al. typologies is that Bowers saw the categories as phases or stages in chronological order, while Nolan "saw care in terms of process, with a chronological and hierarchical order between the dimensions". Nolan et al. also adds a new typology that goes through the entire care process, namely reciprocal care (mutual care) (Ekwall et al., 2004: p.240).

In a Swedish study among persons who were 75 years and older, Ekwall et al. (2004) examined dimensions of care activities based on the work of Nolan et al., (1995). They noted that the model was relevant and pointed out that health care is a process that is important to understand in order to support caregivers in their roles. The different typologies can be in effect simultaneously without barriers between them.

Many researchers have stressed the negative consequences of informal caregiving, such as confinement, but recent research emphasizes that caregiving also has positive aspects, such as meaning and appreciation (Sand, 2005). According to Anttonen and Zechner (2011), Hilary Rose argued that caring is not just work done for someone but has to do with positive emotions, to give something of oneself to one that needs assistance. This emotional relationship has been referred to as a "labour of love". Other researchers emphasized that care also could lead to a negative experience, such as violence (Anttonen and Zechner, 2011). It may be noted that not all relatives are suitable as carers, and older people dependent on the help of their relatives can be at risk of domestic violence. Those relatives considering caring as a burden can become too exhausted if they don't receive support which can lead to a risk of violence against their old family member (Cohen, 2007).

3.4. Formal care

Formal care is defined as the care services provided by professionals employed by formal organizations, public authorities such as the state and municipalities and private for-profit or non-profit organizations (Kröger, 2005). Formal care is provided by institutions, Home Help professionals and other additional service providers. It is usually carried out in accordance with laws and regulations and is generally paid for by the care receiver or by the state and municipalities (Lewinter, 1999). In this dissertation, formal care is defined as the care and help performed by persons employed by the state or municipalities, and the assistance they provide is usually paid for by officials or the care receiver him-/herself. As the participants in the ICEOLD study received no services from private organizations, the definition used here does not cover these bodies.

The formal care can be divided into care provided in the homes of the persons in need, in institutions or in special housing. Examples of formal care provided to older people are home care, home health care, daycare and meals-on-wheels. When the formal care is well organized it can be a great support for informal carers (Szebehely, 2005a).

Research on care in the Nordic countries focused in the beginning mainly on formal care but in the 1990s, informal care received increased attention (Kröger, 2005). As described in chapter 2, this is also the case in Iceland.

3.5. Relationships between informal and formal care, substitution vs. complementarity

Within the Nordic countries, the relationship between formal and informal care providers has received increased attention in research. Caring for older people is often a mix of care given by these two main providers in a complementary relationship to each other (Johansson, 2007; Lingsom, 1997). Both these forms of care are important but some tasks can better be performed by either the formal or the informal carers. It is therefore important to analyze the different spheres of care and how the care is provided.

Whether the two forms of care replace or complement each other has been discussed by many Nordic researchers (see e.g. Kröger, 2005). The substitution issue as introduced by Daatland and Herlofsson (2001; p.54) indicates "that there is an inverse relationship between service provision and family care. When service levels are high, family care is low and vice versa". But more input from one of the providers does not need to imply less services from the other, and the authors indicate that this either-or explanation is too simple. Formal care does not need to replace the care provided by the family but can be seen as a desirable addition, or complementary, especially when different qualities are needed. Sometimes it is not easy to see whether substitution or complementarity is taking place when discussing care from these two sources. Research indicates though most often some form of complementarity between formal and family caregiving (Daatland and Herlofsson, 2001; Kröger, 2005).

The complementarity theory as presented by Lingsom (1997) includes the family support theory, which states that the formal services can strengthen the family care by sharing the burdens of caregiving, and the task-specific model indicating the two parties providing different kinds of support (Daatland and Herlofsson, 2001; Kröger, 2005). Both these sources have a certain role to play in caring for older people.

While the state and municipalities have taken over some of the assistance that families used to provide, the family members are able to take over other kinds of support, such as helping the older person to find out what kind of service is available and making contact with authorities. According to Daatland and Herlofson (2004), the formal care does not replace the service that the family gives, but it can give families more time to do other tasks, such as providing emotional support which can be difficult for formal helpers to give. The welfare state has thus changed the way solidarity and support is shown in today's society.

It seems that where the responsibility for care is on the family the formal services are considered supplemental. According to Davey et al. (2005), formal services in the United States seem to supplement the informal services, but in Sweden the formal and informal services are complementary. Lingsom (1997) found no substitution effects in her research in Norway but states that the substitution issue is complex and has many facets. Lyons et al. (2000) suggest that supplementation and substitution can be seen as parts of the same continuum of formal utilization. With supplementation, formal and informal helpers are providing identical care to the older person, but the researchers see substitution as a special case of supplementation when the formal helper provides the care that an informal helper used to provide.

How the care responsibilities for older people should be divided among the family, the market and officials is an ongoing discussion, as well as whether the formal care is substituting the informal care or vice versa. Nordic research seems to confirm that there is a difference between tasks provided by informal carers and formal carers. The formal care focuses on long-term care and personal care, while the informal care concentrates more on practical tasks. As the goal is to support older people to live at home for as long as possible, the care has been increasingly shared between the family and the formal care providers. The main issue is not whether one type of care is replacing the other, but what the effects are of shared care or cooperation between the formal and informal care (Kröger, 2005). The formal care can be an important support for informal carers and may contribute to more willingness to take care of older relatives.

3.6. Gender and care

Recent care studies have noted that care within the intimate family often involves mutual dependency and it can be difficult to define who the care-receiver is and who the care-provider is. In a relationship between older couples it can be impossible to define because these positions are exchanged over time or even daily (Daatland et al., 2009; Mikkola, 2009 in Anttonen and Zechner, 2011). This can affect the results of studies on gender differences in the care relationship.

According to Anttonen and Zechner (2011) there is a gender difference between women and men in defining what providing care means which can cause women's efforts to be underestimated but men's care to be overestimated. Assistance by women to spouses and other relatives is likely to be regarded as tasks provided but the same acts are considered caring if provided by men (Jegermalm, 2005).

Many researchers argue that informal caregivers of older people are most often women; spouses and middle aged daughters (Bettio and Plantenga, 2004; Lyon and Glucksmann, 2008). Other researchers have pointed out that there is no gender difference in providing care (Russel, 2001). Kahn, McGill and Bianchi (2011) state that women are more likely than men to provide emotional support, but as men retire from the workforce, they become more involved in helping their children and grandchildren and the gender difference vanishes when they are in their 60s. The most frequent care provided by older people is the care of spouses, equally men and women (Anttonen and Zechner, 2011). Research in Sweden shows that the informal caregiver within the household is usually between 75-84 years of age and the receiver of care is usually a spouse or cohabitant (Ulmanen, 2009). Informal care for men is mostly provided by their wives, but informal care for women is mostly provided by daughters. Older wives are more often than their male counterparts alone in their informal caregiving to their spouses (Szebehely, 2005b). As men's mortality declines, their role in caregiving is predicted to increase (Russel, 2001).

According to Daly (2002), men are viewed as choosing to care but there seems to be an obligation on women in many societies to be the caregivers. Men and women, however, seem to experience their roles as caregivers in different ways and men get more support from the environment than women do (Johansson, 2002). Suitor and Pillemer (2006) report that older people rely rather on their daughters than their sons, for both instrumental and emotional support, supporting the thesis of gender difference in caregiving.

3.7. Legal issues in providing care

In many countries (such as Germany, Italy and France), children have a legal obligation to take care of their older parents and ensure that they receive the services they need. In many Mediterranean countries, only those who have no relatives able to pay for their care are eligible for support from the State (Millar and Warman, 1996). But even if this contract is by law, norms and values also exists in the latter countries, which can be seen as a contract between generations, where adult children are paying back the care they received as children (Johansson, 2007; Millar and Warman, 1996; Sundström, 2002).

Within the Nordic welfare states, the care of older people is important, based on the principle of citizenship and intended for everybody in need of care, regardless of income or social status (Sipilä, 1997). It guarantees free universal health care and personal social services which are mostly financed through general taxation. Former laws on adult children being responsible

for their parents were abolished in the Nordic countries from 1956 onwards (Daatland and Herlofsson, 2004; Johansson, 2007; Winquist, 1999). In Iceland, such laws were abolished in 1991 (The Municipalities Social Services Act, no. 40/1991). Both the legal and economic responsibility has been passed from family to society, which has clear obligations to provide care for older people (Eydal and Sigurðardóttir, 2003; Szebehely, 2005a; Winquist, 1999). The Nordic States and the municipalities are providing different services, such as domestic home help, home health care, meals on wheels etc. but also institutional care if needed. Comparing to similar countries, older people in the Nordic countries are probably among those receiving most formal services in the world (Sundström et al., 2008).

Although there are no laws in the Nordic countries requiring the adult children to care for their parents, there is a great solidarity between generations and the families make an enormous contribution in helping and supporting their older family members (Szebehely, 2005a).

The European multidisciplinary study SHARE (Survey on Health, Aging and Retirement in Europe) shows that in countries where there are no laws on children being responsible for care of their parents, children provide less care for their parents than in countries where they are obliged to by law. The level of care provided by the family is almost four times higher in countries where there are such laws. In southern European countries there seems to be a class difference in relation to the care of parents, where the rate is lower among those who have more education. Haberkern and Szydlik (2010) argue that this may be due to the traditional family norms being more pronounced in the lower classes than among the educated. Family responsibility for older people depends therefore both on the legal obligations and cultural standards. An increase in other service options may not lead to changes in informal care. How the informal care will affect the well-being of persons providing care has been discussed. Researchers suggest that informal care will probably affect older people with shorter education more than those with higher education (Szebehely, 2005b).

3.8. Family relations and intergenerational solidarity

Relations between generations are an important source in providing support and affecting emotional wellbeing. The intergenerational roles of individuals change during the live course as people cross different periods from childhood to old age. Changes in demographics of families are occurring, and increasing longevity extends the time the generations of grandparents

and grandchildren spend together. Decreasing fertility leads to fewer grandchildren and the generations create longer and potentially stronger ties (Connidis, 2010). It is more likely that children have grandmothers than grandfathers and on average grandparents are healthier and better off economically than before (Arber and Timonen, 2012). The increased frequency of divorce has also affected the connections within families with sometimes broken ties or including new step-grandparents and step-grandchildren (Ahrons, 2006; Júlíusdóttir, Arnardóttir and Magnúsdóttir, 2008). Due to these changes, the research on intergenerational relationships has increased and is important in understanding the bounds and support provided between the generations. The support provided can be of different kinds, such as social support which refers to diverse support that individuals provide to each other (aid, affect and affirmation) or instrumental, financial and emotional support.

Bengtson and colleagues (see e.g. Bengtson and Roberts, 1991) put forward a framework of an intergenerational solidarity model showing six different types of solidarity within families. This model has been used to provide understanding on the relationships between an older parent and an adult child but also on the relationships between grandparent and grandchild. The model explains associational solidarity (frequency of contact), affectual solidarity (sentiments toward family members), functional solidarity (giving and receiving practical support within families), consensual solidarity (agreement over attitudes and key issues), normative solidarity (valuing of family cohesion) and structural solidarity (geographical distance) (Arber and Timonen, 2012).

Within families there are forces of commitments between family members. Often these forces are called "invisible loyalties" meaning that family members are ready to offer help to those they have an emotional and ethical relationship with and consider it their duty. Behaviour of individuals is determined by the moral power inherent in human relations and the environment (Boszormenyi-Nagy and Spark, 1973). Blood relations encourage family members to offer something to the others as a "gift" or they sacrifice their own interests for the benefit of other family members (Júlíusdóttir, 1997).

Thus generations have important roles to play in the lives of each other. The grandparents transmit knowledge and core values to younger generations and the grandchildren provide knowledge on new technology and contribute in integrating their grandparents into new facts in a changing society (Delerue Mathos and Borges Neves, 2012). The majority of grandparents report relationships with grandchildren as among the most important relationships they have and these feelings are positively related to wellbeing (Clarke and Roberts, 2004).

Silverstein and colleagues (2002) state that children who spend a great deal of time in shared activites with their parents offer more support to their parents later in life. This could be seen as one part of reciprocity.

3.9. Models and theories of social support and care provided

Many researchers have discussed who is likely to become the provider of help and care to older people and in what order the caregiving appears. Different models have been introduced to understand the relationship between the care provided by the informal and the formal care systems. They are also used to describe the relationship between the older person in need of care and those who are providing support. This dissertation goes from empirical data to theories which therefore are used to shed light on the results of the four studies.

The hierarchical-compensatory model put forward by Cantor in 1975 (as cited in Lyons and Zarit, 1999) states that the caregiving preferences are based on social relationships, meaning that the care should be provided by a family member who is available and most closely located. The closest relatives, spouse and children are preferred but if they are not available, substitutes can be found (Connidis, 2010; Lyons et al., 2000). However, easier access and better standards of the provided formal care have resulted in a majority of older Scandinavians preferring care from official resources. Receiving such care is no longer seen as a socially stigmatic (Daatland and Herlofsson, 2001).

The task-specificity model introduced by Litwak in 1985 (as cited in Lyons et al., 2000), also called *the family specialization theory* suggests that the tasks of caregiving are divided between the informal and formal caregivers on the basis of what kind of help and care the older person needs and who is best suited to performing the tasks needed. It allows the family to provide other forms of support not available from the formal care system. These tasks are stronger predictors of formal service use than the relationship to the older person and suggest the importance of diversity in social networks (Connidis, 2010; Daatland and Herlofsson, 2001). Personal touches by informal caregivers might be better suited to maintaining the emotional wellbeing of the care-receiver than help from a formal one.

The *Convoy model of social relations* includes characteristics of networks and support aspects which are influenced by personal and situational characteristics which together influence well-being and health. The convoy

can be described as a network of important individuals moving through time and changing through the lifespan, to whom a person is connected by the giving and receiving of support. The model states that the protective base provides the person with practical help but also subjective and perceived support, which is even more important than objective and actual support. It can be used to describe the relations between members in the family and the changing of long-lasting intergenerational roles (Antonucci, Birditt, Sherman and Trinh, 2011; Antonucci, Jackson and Biggs, 2007; Connidis, 2010).

The *social exchange theory*, which is mostly used on the micro-level, is based on economic theory from the 1930s emphasizing the wish of the individuals to maximize rewards (material and non-material) and minimize costs in relationships with others (Bengtson, Burgess, Parrott and Mabry, 2002; Lowenstein et al., 2007). The theory has its roots in sociological exchange theories introduced by Homans and Blau and in social psychological exchange theories launched by Thibaut and Kelly. The theory was introduced within gerontology to explain the relationship between young and old, especially the relationships between parents and their adult children. The interaction is reciprocal in the way that when receiving help or other forms of assistance, something is expected to be given instead to maintain a balance between receiving and giving support (Bengtson et al., 2002; Dowd, 1975). Persons with better resources are considered to have greater social impact and are therefore better off in social interaction. The theory is used to investigate the provision of assistance and intergenerational support within the family. The theory has further been used to describe social interaction between individuals, both emotional and financial, sometimes in relation to the equity theory, which emphasizes that if both partners in the exchange relationship are equally dependent on each other, the balanced relationships contribute to higher levels of well-being (Lowenstein et al., 2007). "Exchange includes assumptions of reciprocity, and reciprocity or balance in a relationship enhances life satisfaction for adults of all ages" (Connidis, 2010:p.155).

The OASIS study (Old Age and Autonomy: The Role of Service Systems and Intergenerational Solidarity), a cross-national study of Norway, England, Germany, Spain and Israel, reports that it is important for an older person's life satisfaction to be an active provider in exchange relations between generations. Using the social exchange framework, the authors state that reciprocity between older parents and their adult children is of great importance. The emotional component in intergenerational family relations is also of importance to the older generation. Lowenstein et al. (2007) state that older parents who gave more to their adult children than they received experienced higher levels of well-being. However, when physical functioning was accounted for there were no differences found regarding life

satisfaction between respondents giving more or giving less than they received. As reciprocity is an important component of satisfying social relationships, older disabled people have the same desire to reciprocate as others (Ingersoll-Dayton and Antonucci, 1988) and try to find ways of doing so (Beel-Bates, Ingersoll-Dayton and Nelson, 2007).

Even if the social exchange theory provides the social gerontology with important explanations on social relations and exchange between individuals, it has its limitations. It cannot explain why individuals evaluate things differently. Further research is needed to follow the changes on roles and dependency within the family (Bengtson et al., 2002).

4. Methods and samples

4.1. Two different studies

The sub-studies in this thesis are based on data from two different surveys. The main work is based on the ICEOLD study (Icelandic older people) conducted in 2008. In Study IV, also the Grammar School study carried out among college students in Iceland in 2006 was used. The first study, *Needs and Care of older people living at home in Iceland,* the second study, *Older caregivers: Providing and receiving care,* and the third study, *Factors associated with informal and formal care of older Icelandic people,* solely used data from the ICEOLD survey. In the fourth study, *Reciprocity in relationships and support between grandparents and grandchildren: An Icelandic example,* the ICEOLD survey and the Grammar school study were used.

4.2. Ethical considerations

Ethical considerations are important when doing research concerning people's situations and attitudes. The main rule to follow is not to cause any harm to those participating. In the planning and implementation of the two studies used in this dissertation, ethical guidelines have been followed. The respondents in the studies could not be identified and participation did not involve positional dependency for the respondents participating neither for the time being nor in the future. The studies are important to provide new knowledge concerning needs and care of older people and the relations between grandparents and grandchildren. The reason for gathering the information weighted more than the demand put on the persons participating.

The two studies were conducted according to the ethical regulations stated in the Act no. 77/2000 on the Protection of Privacy as regards the Processing of Personal Data. In accordance with Icelandic law, ethical approval was not obtained for the studies but The Icelandic Data Protection Authority (Persónuvernd) was notified of them according to regulations. The questionnaires used in the two studies were adjusted for the respective groups bearing in mind showing full respect and not tiring the participants with too long and demanding questioning. The registration number for the ICEOLD study is S4522 and the registration number for the Grammar School Study is S2113.

In the ICEOLD study, a national sample of older people received an introduction letter on the aims of the study and how the results would be used, stating that participation was voluntary. They were also informed that they would be contacted by phone. The letter also contained contact information about the person responsible for the study. When contacted by phone, the participants were informed that data collected would be analysed without identifying participants and that the information was only accessible to authorised persons. After they had been reminded that participation was voluntary, those giving oral consent were included in the study.

In the Grammar School study, the young people were informed about the study, how the results would be used and that participation was voluntary. If they agreed to participate, they received a questionnaire to fill in. This acceptance was considered informed consent for participation.

The articles in the dissertation are written following the ethical requirements of the journals in which they are published.

4.3. The ICEOLD study

4.3.1. The data collection

In the Icelandic older people study (ICEOLD), a random national sample of 700 persons aged 65-79 years and 700 aged 80+, living in Iceland in year 2008, is used. As the aim of the study was to illuminate the care situation of older people living in the community, persons living in nursing homes were excluded (n=117). This was determinated from their addresses. Persons also excluded were those who had died (n=5), were living abroad (n=2), and did not speak Icelandic (n=3). Another 84 persons were excluded because it was later discovered that they lived in nursing homes or stayed in hospitals. The final sample consisted of 1,189 older persons, to which an introductory letter was sent.

The persons were contacted by phone a few days later and after being asked whether they were willing to participate, 782 persons agreed, giving a response rate of 66%. The interview was performed by trained interviewers informed especially about the study and on matters of older people. 292 persons declined to participate, 147 men and 145 women, with a mean age of 78. There were 115 persons that could not be reached, 64 men and 51 women with a mean age of 79. As no proxy interviews were used, the answers are based on the responses of the older participants themselves.

4.3.2. The data material

There were 341 men and 441 women who participated. The mean age of the participants was 77 years, 76 for men and 77 for women, with a range between 65 years to 98 years of age. The whole sample will be used for the analysis of the first, the second and the third articles. Since the fourth article discusses the relationships between youths and older people, only the responses of those 260 senior citizens who had grandchildren aged 17-25 will be used; around a third of the respondents. Of these, 54% were men and 46% were women and the average age of this group was roughly 74 years (SD=5.9). This is further discussed below.

The interview contained questions on social network, living arrangements, subjective health, and ability to perform activities of daily living (ADL), both IADL (instrumental activities of daily living) and PADL (personal activities of daily living). Respondents were also asked whether they received support from the community and/or from relatives, neighbours and friends. The interview also contained questions on the relationships and reciprocal support between the older respondents being grandparents and their grandchildren. The participants were asked whether they provided help or support to someone old, sick, or disabled on a regular basis. Information was collected about the person they helped, how often and in what way they provided help or support. They were also asked for their preferences for help and living arrangements if they became dependent and in need of long-term care.

Persons aged 80+ years were oversampled in the ICEOLD study, and therefore the sample has been weighted in Studies I, III, and IV. The weighting was conducted to represent the Icelandic population 65 years and older. No weighting was conducted in Study II, as the main analyses are based on the selected group of older people who themselves are caregivers. It should also be mentioned that in Study I only those who always or often needed care/help because of IADL and PADL limitations are considered in need of help/care. In Study III, all those who needed help with one limitation, even seldom, are considered in need of help/care.

As there is a difference in the number and percentage of participants who are always or often in need of help in Study I and Study III, the unweighted and weighted data is shown in Table 1 to illustrate the difference in numbers and percentage.

Table 1.
Number and proportion of persons always or often in need of help/care.

	Unweighted				Weighted			
	Need		No need		Need		No need	
Limitations	Number	%	Number	%	Number	%	Number	%
IADL	322	41.4	455	58.6	276	35.4	503	64.6
PADL	59	7.6	718	92.4	38	5.0	741	95.0
IADL or PADL	328	42.2	449	57.8	280	35.9	499	64.1

4.3.3. Limits of the data

Two limitations of the data material are a high non-response rate (66%) and the fact that no indirect interviews were conducted. These limitations could have the result that the proportion of older people in need of help and care is higher than estimated in the study. The non-responders in the study were older than the participants. This could have the disadvantages of losing information about the situation of more frail older people. In telephone interviews, hearing impairment could also be a hindrance.

4.4. The Grammar School study

4.4.1. The data collection

The cohort of people born in Iceland in 1987 counts 4.204 persons, and 74% of them are expected to be registered in the consisting 29 upper secondary schools, both general and vocational schools. In 2006 a cluster sampling was conducted and nine schools chosen with a random sampling method which reflects the schools, the number of students and where in the country they are located. A letter of information was sent to the principals, followed by a call to get approval for the study.

4.4.2. The data material

The Grammar school study was presented to 1,187 college students in their third year of study throughout Iceland in 2006. Most of them were born in 1987. 845 students participated, giving a 71% response rate. The analysis was limited to those 648 youths aged 17-25 (76%) who had grandparents 65 years and older. This group consisted of more young women (64%) than young men (36%) and the average age was 19 years.

The questionnaire included 80 questions on family values, attitudes and social situation. Two trained social workers presented the questionnaires to the students at school, either in class, between classes, or during lunch hours, with the assistance of the teachers.

4.4.3. Implications of the study design

The study reflects the answers of young people attending college, but not those who have dropped out of school. It is well known that more of those who have dropped out of school come from families with divorced parents and eventually have less contact with grandparents on the father's side (Júlíusdóttir et al., 2008). There might also be a difference between the socioeconomic position of younger people attending college and of those who do not.

4.5. Combining the studies

4.5.1. Investigated variables for both studies

The ICEOLD study and the Grammar School study are two independent surveys conducted in 2008 and 2006 in Iceland. The ICEOLD study used telephone interviews and the Grammar School study was performed by asking the students to fill out questionnaires in their schools. The responses of the elderly having grandchildren aged 17-25 were chosen. To be sure that answers do not refer to young children, elderly people with grandchildren aged younger than 10 years are excluded. This means that the answers could include information about 10-16 years old grandchildren. This can affect the results, as the age of the grandchild they have the most contact with is not known. Only the responses from youths having grandparents older than 65 years were considered.

Each grandparent was asked to evaluate his or her relationship with the grandchild with whom they had the most contact. Similarly, each grandchild was asked about his or her relationship with the grandmother or grandfather with whom they had the most contact. In both surveys, the participants were asked about who *initiated contact* and whether they provided/received *emotional support*. They were also asked whether they provided/received *practical help* from each other and whether they provided/received *financial help* from each other.

The college students were also asked about how frequent their relationship was with their maternal and paternal grandparents, which was not asked in the ICEOLD study.

4.5.2. Comparability and implications of combining the studies

When comparing two different studies, it is important to be aware of the differences in how the studies are made. Similar questions were asked in both studies and results were analyzed separately in the beginning. The older persons were asked about the contact and relations to their own grandchildren and the grammar school students were asked in the same way about the relations to their own grandparents. Bearing in mind that the results do not present a comparison between pairs of grandparents and grandchildren, the results can still give valuable information on ties between generations.

5. Results

5.1. Study I. Needs and care of older people living at home in Iceland

5.1.1. Introduction and aim

In the first study, the main aim was to describe the living conditions and needs of older people living in their homes in Iceland and to describe how their needs for care and services were met. The panorama of care was examined and the relationships between informal and formal care discussed.

5.1.2. Method and analyses

The ICEOLD study was used for description and analysis. The results are based on telephone interviews, including questions on social network, health, ADL, and received support from the community and/or from the informal care system. The respondents were also asked how they would prefer to be cared for if they became dependent and needed long-term care.

Descriptive analyses, independent samples t-test, chi-square test, and Pearson correlation analyses were performed for the descriptive part of the study. Nominal logistic regression models (also called multinomial logistic regression) were performed to explore associations among care patterns and factors of socio-demographics, health and ADL. As the older age group 80+ was overrepresented, the sample was weighted to represent the Icelandic population aged 65 years and older[2].

The social network situation was assessed by asking how often the respondent met his/her children and how often they had telephone contact with them. The possible answers to these questions were: 1) daily, 2) 4-6 times a week, 3) 2-3 times a week, 4) once a week, 5) 2-3 times a month, 6) once a month, 7) more seldom than once a month, and 8) never. The participants were also asked about the distance to their nearest child, with the

[2] The frequencies and percentages in Table 1 in the article are based on unweight data, while the p-values are based on weighted analyses.

alternatives: 1) living in the same household, 2) in the same house, 3) less than one km distance, 4) in 1-5 km distance, 5) 6-25 km distance, 6) 26-100 km distance 7) more than 100 km distance in Iceland and 8) living in another country[3].

Subjective health was assessed with a general question about how they rated their health, with response alternatives 1) very good, 2) good, 3) moderate, 4) poor and 5) very poor. The need for help to perform activities of daily living (ADL) was done both by asking whether the person needed help with instrumental activities of daily living (IADL), shopping, cooking, cleaning their home, and laundry and personal activities of daily living (PADL), bathing, using the toilet, getting in and out of bed and dressing. For each of the activities, both IADL and PADL, the possible answers were 1) always, 2) often, 3) sometimes, 4) seldom, and 5) never. Those who needed help were asked whether the help came from formal carers, informal carers, or from both.

The participants were also asked whether the care they received from informal and formal carers was in accordance with their needs, with the possible answers: 1) too much, 2) just right, 3) too little, and whether they preferred more help, with the possible answers: 1) yes, 2) no, 3) do not know. Wishes for future assistance were assessed by asking how they would like to be cared for if they became dependent, and in need for regular help and long-term care – whether they would prefer to be cared for in their own home, in a nursing home or in the home of a relative. The older person was also asked if he/she would prefer to be cared for by private, informal, or public carers.

5.1.3. Results

The results show that 58% of the respondents needed help with one or more activities of daily living but a majority only needed help with instrumental care (IADL). There is a significant gender difference in *needs of care*. Men more often than women reported need of help with only IADL activities while women more often reported need for a combination of IADL and PADL activities. Of the respondents with one or more ADL limitations, 82% needed help with IADL activity only and 18% were also in need of help with PADL. Of the latter group, two thirds are 80+ and two thirds are women.

[3] In article I, page 3, the left column, regarding distance to the nearest child – response category (6) should have been in 26-100 km distance, category (7) more than 100 km distance in Iceland, and (8) living in another country.

The results further show that among those who receive care, formal or informal, 58% received only informal care, only 8% receive only formal care and 34% receive both informal and formal care. (Note that the proportions presented in Study I are based on unweighted data but the p-values were based on weighted data.)

There are no significant gender differences in *received care* from different sources but those who are living with someone receive significantly more; often a combination of informal and formal care ($p < .01$)[4]. The oldest age group, 80+, receives significantly more care in all categories ($p < .001$). Of those receiving some kind of care, 10% received formal care four times a week or more often, but twice as many received informal care as often. The main caregiver of those receiving only informal care was the spouse, followed by the daughters. Almost half of the sample, 47%, receives some kind of care, with 27% receiving only informal care, 4% receiving formal care only, and 16% receiving both formal and informal care.

A significant difference was found between those living alone and those living with someone. The majority (78%) of those cohabiting and in need of help received help from their spouses ($p < .001$). Those living alone mostly received help from their children, children-in-law and grandchildren (76%).

In the nominal logistic regression we used "care received" as a dependent variable with "no help received" as a reference. The results showed that persons with bad subjective health were more likely to receive a combination of informal and formal care. It is also shown that the household structure and having children or not were significantly related to receiving informal care only, but gender and age were not. Only receiving formal care was associated with age and ADL needs[5]. Receiving both informal and formal care was also associated with age and subjective health.

Even if the majority is satisfied with the care they receive from formal and informal caregivers, 18% wish to receive more formal care, and among those receiving informal care 22% wish to receive more formal care.

Of the respondents, 68% prefer to be looked after in their own homes if they become dependent and 28% in long-term care institutions. Among those with at least one PADL limitation, about one third prefers to be looked after in their homes and more than half (57%) in an institution.

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[4] The χ^2 values regarding civil status, household structure, having children, need of care, and care received in Table 1 in the article are incorrect. The P-values are however correct.

[5] The ADL needs which are associated with help which is received from formal care only are significant p<0.01**, information missing in Table II.

When future wishes about receiving care from informal carers, formal carers or both were used as a dependent variable, the nominal regression showed that the only factor significantly related to wishes concerning future care was help received at the present time. The respondents who already received care preferred to be cared for by both informal and formal carers together.

5.1.4. Conclusion

The main aim of Study I was to describe the needs of older people living in their homes and illustrate how their needs for care and services are met. The family is the main provider of help to needy community-living older people in Iceland. The family makes important and vast contributions in helping older family members. The help provided by the family is more often with IADL-tasks than PADL-problems, alluding that the family helps especially when the care is not too demanding. Among cohabiting people, spouses are the main carers, especially for men. Even if women state that they need care more often than men do, there is no significant gender difference in receiving care.

A large group receives public services, but the majority only receives a few hours a month. Those living with someone more often receive a combination of informal and formal help. Older people prefer to be cared for in their homes, but when already in need of substantial help they wish to be cared for in institutions. The results suggest that when an older person is in need of help with PADL, institutional care is preferred rather than increased formal care in the older person's own home. This indicates that too little and inefficient community care encourages older people to seek institutional care when the need for assistance increases.

5.2. Study II. Older caregivers in Iceland, providing and receiving care

5.2.1. Introduction and aim

The aim of this study was to describe older informal caregivers (in comparison to non-caregivers) and to investigate the care and support they provide. The kind of care and support older caregivers provided was examined together with factors related to providing care alone or with other

caregivers, informal and formal. A second aim was to describe the care that older caregivers received themselves.

5.2.2. Method and analyses

Study II is based on responses to questions regarding help given and/or help received by the respondents in the ICEOLD survey, older people 65+ living at home. Those who responded positively to the question whether they helped someone old, sick or disabled on a regular basis were defined as older informal caregivers and included in the study, 157 persons or 21% of the participants of the ICEOLD survey.

The results are based on descriptive analyses and a limited group of respondents. Because of this we decided not to weight the data. Descriptive Chi-square analysis was performed to analyze differences between caregivers and non-caregivers. A binary logistic regression model analysis was performed to identify factors related to whether the older caregiver provided help alone or in combination with other caregivers.

Information about living arrangements and socio-demographic variables were used for the descriptive analyses. The subjective health was measured by asking the caregiver to rate their own health for the analysis re-coded to the variables as: 1) good/rather good, 2) medium and 3) bad/rather bad. The older caregivers were asked whether they needed assistance with ADL themselves. For each of the ADL activities, both IADL (cleaning, shopping, washing clothes and cooking) and PADL (bathing, using the toilet, getting in and out of bed and dressing) the answers were coded as: 1) always/often, 2) sometimes or 3) seldom/never.

Questions about age, gender and relationship to the main care recipient were asked. Information about how often the caregiver provided care and the reason why the main care recipient needed help was also collected, with three possible answers: 1) physical problems 2) psychological/cognitive problems and 3) both of these reasons.

The older caregivers were asked whether the main care recipient received other help than provided by them, by asking if he/she received 1) help only from the old caregiver, 2) other informal help or 3) formal help. They were also asked whether the formal help received was sufficient, and whether their employment was or had been affected by the care situation.

5.2.3. Results

The findings indicated that older informal caregivers provide care even when they need help themselves. Comparing the characteristics of older informal

caregivers with non-caregivers shows that the older informal caregivers are younger (mean age (± SD) of the caregivers was 74.1 ± 6.7 years, non-caregivers 77.4 ± 7.4 years ($p < .001$)) and more often co-habiting ($p < .01$) than non-caregivers. No significant differences were found between caregivers and non-caregivers in terms of self-rated health and ADL.

The mean age of those receiving help from the older informal caregivers was 78.1±14.10 (SD) years, about 60% of them were 80+ years old and two-thirds were women. Half of them received care only because of physical problems, and almost one-third received care only for psychological/cognitive reasons. About one-fifth of the care recipients needed help for both physical and psychological/cognitive reasons. Spouses received the most frequent care and they were helped mainly for physical reasons.

Of the older caregivers, one third provided help with several tasks such as help with errands, emotional support, surveillance and keeping company in addition to ADL help. They were the only care providers for almost half of the care recipients and two-thirds of these providers were women. Of the main care recipients, 38% also received help from the formal care system, 16% received help also from another informal caregiver and 46% received no other care than from the older caregiver. Of the older caregivers providing care in conjunction with the formal care system, 73% claimed that no further support was needed. There was a tendency ($p = .06$) for caregivers who provided care without support from the formal care system to want more help from formal care providers.

The older caregivers received only formal and combined informal and formal care more seldom than the non-caregivers, even if the differences were not significant. More non-caregivers needed help with both IADL and PADL but almost half of both groups needed help with IADL only. Of the older informal caregivers, 54% (n=85) needed help with ADL tasks themselves, and 6% (n=10) needed help with both IADL and PADL. Nearly half (47%) of the older caregivers who provided care alone also received care themselves. The logistic regression analyses indicated that women provided care alone significantly more often than men did. Needs of care for psychological/cognitive reasons among the main care recipients were significantly related to conjunction in caregiving between the older caregiver and other formal or informal caregivers.

5.2.4. Conclusion

The aim of this study was to describe older informal caregivers and to investigate the care and support they provide and receive. The results of this

study show that older caregivers are an important resource for providing care to other older persons, as the majority of the care recipients are 80 years and older. Emotional support, surveillance and keeping company was the most common type of help provided by older caregivers to others than their spouses, who received care most often due to physical reasons. There was no difference found in health and self-rated ADL function when comparing older caregivers and non-caregivers. This indicates that caregiving was not too demanding for the older caregivers. This could also indicate a reciprocal relationship between the caregiver and the care recipient.

Men significantly more often than women provided care in the interaction with another caregiver, formal or informal. The only other factor significantly related to more often providing care in interaction was when the care recipient needed care for psychological/cognitive reasons.

The findings further indicate that older informal caregivers provide care even when they need help themselves. More than half of the older informal caregivers needed help themselves because of ADL limitations. Even if the help provided is mostly emotional support, surveillance and keeping company, it is an important assistance for supporting older people living at home. It can also be perceived as important reciprocal assistance between older persons. Improved knowledge and understanding of the interaction between the different care providers, older persons, informal and formal caregivers is expected to contribute to better eldercare.

5.3. Study III. Factors associated with informal and formal care of older Icelandic people

5.3.1. Introduction and aim

Older people in the Nordic countries usually have good access to formal care but the informal care is still an important factor in supporting older people to stay in their homes in spite of diverse ADL needs. The main aim of this study is to analyze the patterns of informal and formal IADL help and PADL care, and how help and care varies depending on gender, the degree of limitations, and whether the care recipient is cohabiting or not. The aim is also to study the distribution of care, the proportion of older persons who receive only informal care, only formal care or both. This is discussed in terms of substitution and complementarity.

5.3.2. Method and analyses

The ICEOLD study was used to analyse the patterns of how often persons with limitations needed help with instrumental activities of daily living (IADL); shopping, cooking, cleaning their home and doing laundry; and with personal activities of daily living (PADL) such as bathing, using the toilet, getting in and out of bed and dressing. Questions were asked separately for IADL and PADL. The response options were coded as: 0) never, 1) seldom, 2) sometimes, 3) often or 4) always. Two summarized indexes were created to get approximate information on the total amount of IADL and PADL limitations. Each index was created by adding the score for the amount of help needed for each ADL activity (IADL and PADL separately), thus obtaining an index ranging from 0 (no need for help with any of the activities) to 16 (always needing help with all activities). The participants with IADL or PADL limitations were asked who the providers of help were and the variables given were re-coded into informal caregivers and formal caregivers. To obtain information regarding the gender of the main informal caregiver, the variables were collapsed into the groups 1) spouse, 2) daughter/daughter-in-law, 3) son/son-in-law or 4) other. Information about socio-demographic variables such as gender, age, marital status, having children and household structure was used for the analyses. As persons 80+ were oversampled, weighting was done for both figures and tables 2-4 in the article, to represent the Icelandic population 65 years and older, but the data used in table 1 and in table 5 is unweighted because the tables are descriptive and the data in table 5 is unweighted because of few observations.

Logistic regression was used to analyse the odds for informal and formal IADL help and informal and formal PADL care, respectively. Results on informal and formal help according to ADL limitations are based on moving averages using three adjacent data points, among those having a score of two or more limitations.

5.3.3. Results

About 60% of the sample had limitations with one or more IADL activities, more men (62%) than women (55%). About 10% had limitations with one or more PADL activities, more women (11%) than men (8%). The great majority of the respondents with ADL limitations received either informal or formal help but not both. This counts both for those in need of help with IADL (77%) and PADL (76%). Those having only informal help with IADL were 54% (n=243) and those who only had formal help with IADL were 22% (n=100). Those with PADL limitations receiving informal care only

were 34% (n=26) and those who received formal care only were 42% (n=32). The proportion of those receiving care from both informal and formal care providers was 24% (n=18).

Women have a higher likelihood than men of receiving formal and informal help because of IADL limitations, even if the difference is not significant.

When the need for help with IADL activities increased, the *informal* care increased for men but was almost constant for women. The *formal* help provided to women but not the one provided to men increased when the degree of IADL limitations increased.

When studying men and women together, the effect of the amount of PADL limitations has a different association to receivers of informal or formal care. The amount of formal care increases for needs for care up to a score of four out of 16 on the index of care needs, but the informal care remains constant. More people receive care from informal providers and the provision of care is nearly constant between persons with a different degree of PADL limitations.

The logistic regression shows that when controlling for age and degree of IADL limitations, no significant difference between men and women is found. Women have 39% higher odds for receiving informal IADL help than men (OR=1.39, $p = 0.189$). Age has a negative association to informal IADL help among both men and women. Men living with someone else more often receive informal IADL help than men living alone (OR=8.62, $p < 0.001$). Women cohabiting do not receive significantly more informal IADL help than women living alone (OR=1.27, $p < 0.524$). Among men, the rate for informal IADL increases significantly with increased IADL limitations (e.g. OR=1.18, p=0.002 in model 1) but among women, the corresponding association is not significant except when controlling for formal IADL help.

Controlling for age and the degree of IADL limitation the results did not yield any significant difference between men and women in the rate of receiving formal IADL help (OR for women=1.25, $p = 0.322$). The likelihood of receiving formal IADL help increases with age. Men living with someone else more seldom receive formal IADL than men living alone (OR=0.15, $p = 0.001$) but women cohabiting do not receive significantly less formal IADL help than women living alone (OR=0.57, $p = 0.163$).

The results further show that the effect of cohabiting on help received is of great importance, especially for men, who more often received IADL help from a spouse than cohabiting women did. This confirms that women are the main helpers of their spouses, especially regarding IADL help. Cohabiting women with some IADL help received more help from both their daughters/daughters-in-law and their sons/sons-in-law than men did, but also from other helpers, such as grandchildren, neighbours and friends. For those

living alone, a daughter/daughter-in-law was the main provider of informal help for both for men, 57%, and women, 68%. It can be expected that most of the children of the respondents in the ICEOLD study are of a working age.

All those with some kind of PADL limitations received care either from formal care providers only (42%), informal care providers only (34%), or both (24%). Age is not significantly related to the probability of receiving PADL care. Among men, there is a significant increase in the likelihood of receiving formal care when the need for help increases (OR=1.31, $p = 0.048$), but a corresponding increase is not significant for women.

When analyzing men and women together, there is a significant difference between those living alone and those cohabiting, those cohabiting receive more informal care with PADL (OR=2.77, $p = 0.037$) and less formal care with PADL (OR=0.34, $p = 0.039$). For a great majority of cohabiting men with informal PADL, the spouse was the main care provider (89%, n=8).

5.3.4. Conclusion

The results indicate that the majority of the respondents in the ICEOLD study received either informal or formal care but not both. The results further indicate that the two forms of care, informal and formal, are substituting or replacing each other, even if it is difficult to conclude in which direction the replacement is going. However, it is suggested that the informal care is substituting the formal care, as more people are receiving informal than formal care. This is especially clear among men, as fewer men than women get both formal and informal IADL help.

The informal help plays an important role in supporting older people to live as long as possible in their homes. For men, cohabiting is an important factor, as their spouses are the main helpers, especially regarding IADL help, and when the needs are higher they receive more help from both formal and informal caregivers. For older women, cohabiting is not as important, and married women do not get significantly more informal help than single living women.

5.4. Study IV. Reciprocity in relationships and support between grandparents and grandchildren: An Icelandic example.

5.4.1. Introduction and aim

In Iceland, little has been written and few studies have been conducted regarding relations within families and between generations. Because of transforming family structures and rapid social changes, it is important to study generational ties between grandparents and grandchildren. The role that grandparents play in the lives of teenagers and youths, and the role that teenagers and youths play in the life of grandparents, has been studied even less. Yet it is accepted that these different generations have roles to play in each other's lives. The aim of this study is to examine the intergenerational relationships between grandparents and grandchildren, and the reciprocal support provided between the generations.

5.4.2. Method and analyses

This study was based on descriptive analyses. Traditional chi-square tests were used to test for significant differences between gender groups. For all analyses, 95% confidence intervals were used to determine significance. Because persons aged 80+ years were oversampled in the ICEOLD study, the sample has been weighted to represent the Icelandic population 65 years and older. The analyses of data from the grandchildren were not weighted.

Data from two separate surveys was used for the study. The first survey, The Grammar School Survey, is based on questionnaires to 1,187 college students nationwide in Iceland, aged 17-25 years (mean age was 19 years) with a response rate of 71%. The analyses were limited to the 648 youths (76% of the respondents) who had grandparents older than 65 years. The second data source was a part of the Icelandic Older People (ICEOLD) study. The analyses were limited to grandparents having grandchildren aged 17-25 years old. To be sure that the answers did not refer to younger grandchildren, grandparents having grandchildren 10 years and very young were excluded, leaving responses from 206 grandparents for analysis.

Respondents in the independent surveys, grandparents and grandchildren respectively, were asked to evaluate their relationship with the grandchild/grandparent with whom they had the most contact. By looking at

the same questions, it was possible to develop a more complete picture of the interactions between the generations.

The participants were asked about *initiation of contact* with each other and whether they provided/received *emotional support*, *practical help* or *financial help* from each other. The response alternatives were the same for all of the questions: *always, often, sometimes, seldom and never.* The college students were also asked how frequent their relationship was with their maternal and paternal grandparents with the response alternatives: once a week or more often, once a month, or less often than monthly.

5.4.3. Results

The results from the study indicated that both the grandparents and the grandchildren experienced their intergenerational relationship as valuable. The relationships between the older grandparents and their grandchildren and the relationships between the youths and their grandparents were emotional rather than practical. However, the assessment of practical support seemed to vary according to age. Of the grandparents, about one fifth stated that their grandchildren always or often helped them with practical things, while a larger percentage of the grandchildren, about two fifths, stated that they always or often helped their grandparents. Only 4% of the grandparents stated that they helped their grandchildren financially, while 20% of the youths reported that they received financial help from their grandparents.

Gender differences were observed in the relationships between grandparents and grandchildren. Grandmothers were more likely to initiate contact than grandfathers and were more likely to offer emotional support. More young women than young men stated that they always received emotional support from their grandparents, and stated that they were always more likely to initiate contact and give their grandparents emotional support. The experience of mutual support was more evident amongst the female than the male participants, both young and old. The young participants met with their maternal grandparents more often than with their paternal grandparents. About half of the grandchildren were in closer contact with their grandmothers than with their grandfathers, and 44% were equally close to both.

5.4.4. Conclusion

This study examined the relationships and mutual support between grandparents and grandchildren. It also analysed gender differences concerning intergenerational relations and support. The results of the study

indicated that the grandparents and grandchildren received more emotional than practical support from each other. The emotional support provided and received by the generations is of great value. Women; grandmothers, daughters and granddaughters seem to have a bigger role within families and are more likely than men to cultivate family ties. The reciprocal support between grandparents and grandchildren merits further study in order to determine the practical implications for social policy and the development of social welfare services.

6. Discussion

6.1. The interplay of needs and received care

The aim of this study is to generate knowledge about how the needs for care and support of older Icelandic people living at home are met. The study focuses on formal and informal caregiving, intergenerational relationships and how help varies depending on the degree of limitations, gender and cohabitation.

The conclusions indicate that older people in Iceland are receiving help and care from both informal and formal helpers, but the family and other informal carers seem to play the major role, especially when the need for help and care is not too severe. The informal care was provided to more old persons than the formal care was. The majority of older people with ADL limitations are receiving either informal or formal help but rather seldom both. This could point to a lack of interplay between the formal and the informal care. This could also indicate that there is a substitution in provided care, meaning that the formal care takes over instead of complementing the informal care.

Almost 60% of older people living at home in Iceland report that they often or always need help with one or more activities of daily living. Compared to other Nordic countries this is a high percent, but perhaps the questions are differently understood. The results further show that a majority only needs help with instrumental activities of daily living (IADL), such as cleaning, shopping, washing clothes and cooking. Among the older persons that receive care, formal or informal, 58% received only informal care from their spouses, relatives, neighbours, and friends. Only 8% of them receive only formal care, such as home help services and home health care provided by the state or municipalities, and 34% receive both informal and formal care. There are few persons who state that they need help but do not report any care[6].

The help provided by the family is rather with IADL-tasks than PADL-problems (such as bathing, using the toilet, getting in and out of bed and dressing), indicating that the family helps especially when the care is not too

[6] The numbers differs between Study I and Study III, since care and need are differently defined (see section 4.3.2).

extensive and demanding physically. Older persons are not only receivers of help but also active providers of help to others.

Those receiving formal help and care usually only receive a few hours of care. The care provided by informal caregivers is most often help with household chores and less often personal care. However, when the need increases, the formal system steps in and helps together with the informal system up to a certain level. As the formal help provided is rather sparse, it indicates that when the need for personal care increases, the older person moves into a nursing home rather than receiving more formal care in the home. The reason could be that even if the aging-in-place ideology is on the agenda older people and their relatives mistrust the formal home help services and prefer the safety within institutions.

Most of the older people interviewed are satisfied with the care they receive both from formal and informal caregivers. Among those receiving both informal and formal care, 18% wish to receive more formal care, and among those receiving only informal care, 22% wish to also receive formal care.

Even if older people prefer to receive help from both formal and informal carers, it is suggested that older people do not want to rely on their families too much and prefer to receive formal care when the needs become more demanding. Almost 70% of the older people in the study prefer to be looked after in their own homes if they become dependent and 30% prefer to move into nursing homes. The number of those preferring to be looked after in nursing homes increases up to almost 60% with the experience of needing care with at least one PADL limitation. There seems to be a lack of interplay between the formal and the informal care providers suggesting that a total substitution is preferred (institutionalization) instead of increasing the complementarity between the parties involved.

It could be suggested that these attitudes indicate that the existing formal care is perceived as too modest and ineffective. The results show that only 10% of the respondents in the ICEOLD study receive care because of PADL needs. It might be that the formal care system is not prepared to offer sufficient care to older people in their homes, and therefore the system encourages them to seek placement in institutions.

This result indicates that the relatively sparse provision and few hours of home help services can have consequences for older people’s demand for institutional care. The general attitude that institutional care is the best solution might also explain the relatively high proportion of older people living in institutions in Iceland. This result could also indicate that support for families and others who take care of older people in their homes is insufficient.

When looking at help provided between generations, i.e. grandchildren and grandparents, more emotional or social support compared to practical support is provided and received both from the grandchildren to the grandparents and from the grandparents to the grandchildren. It is seen as important by both generations.

6.2. The importance of informal care

As the formal care is provided to many care recipients but only a few hours to each of them, the main help is provided by the informal caregivers. Studies I, II and III show that the informal care, support and help provided by family, friends and neighbours is of great importance in care of older people in Iceland and enables them to live in their homes as long as the ADL limitations are not severe. These results are not a surprise, as research in other Nordic countries, which are comparable in culture, norms, and provision of health and social care, have shown similar results (Daatland and Herlofsson, 2004; Szebehely, 2005a; Sundström et al., 2006). As little is known about the patterns, types and volume of the informal care in Iceland, this study contributes with important knowledge on the provision of informal caregiving not least the role of women in caring for older people (discussed in chapter 6.4.).

According to *the Convoy model of social relations* the provision of practical help from family and friends is important but the subjective and perceived support can be even more important (Antonucci et al., 2011). This indicates that having someone to turn to and ask for help is as important as receiving the help.

In recent years, the informal caregivers; family members, neighbours and friends providing care for older people have received more recognition and have become more visible. More attention has been paid to the needs of informal caregivers for support. In Sweden, for example a new paragraph in the Social Service Act was passed in 2009 stating that the municipal social services are obliged "to provide support to persons caring for next of kin with chronic illnesses, elderly people, or people with functional disabilities" (SFS 2009:549; Johansson, Long and Parker, 2011). A number of studies seem to indicate that despite the new legislation, very few caregivers have received any kind of support, and nor did the vast majority desire any (The Swedish National board of Health and Welfare, 2012).

It is of great importance to observe the needs and circumstances of informal caregivers and to inform them about available support. Further research is also needed to create knowledge on what kind of support informal caregivers need and prefer. In the policy for care of older people in

Iceland it is emphasized that older people and their relatives should get proper information on rights and services. In addition to this the numbers of nursing home beds, day-care-services and respite care are also increasing. These actions can be seen as the first step regarding support to families of older people in Iceland and recognizing their involvement in care.

6.3. The relationship between formal and informal care

The formal and the informal care systems have different characteristics and some tasks can better be handled by informal carers and others by the formal carers. In the ICEOLD study, the informal care more often consists of help with ADL household tasks (IADL) than with PADL tasks. When the need for more help increases the formal system often steps in.

While the state and municipalities have taken over some of the assistance that families used to provide, the family members are able to take over other kinds of support, such as helping the older person making contact with authorities. According to Daatland and Herlofson (2004), the formal care does not replace the service that the family gives, but it can give families more time to do other tasks, such as providing emotional support, that can be difficult for formal helpers to give. The welfare state has thus changed the way that solidarity and support is shown in today's society. The reasons why people are committed in helping their relatives can be understood in the forces of "invisible lojalities". This means that family members are ready to offer help to those they are emotionally and ethically related to and consider it as their duty (Boszormenyi-Nagy and Spark, 1973; Júlíusdóttir, 1993). Also, the meaning of being in blood relation encoruages a family member to offer something for the other, as a "gift" (Titmuss, 1971).

The results of the ICEOLD study indicate that the two forms of care, informal and formal, are substituting or replacing each other even if it is difficult to conclude in which direction the replacement is going. It is however suggested that the informal care is substituting the formal care as more people are receiving informal than formal care. This is especially clear among men as even a smaller proportion of men receive both formal and informal care.

6.4. Gender differences

The results show that there is a gender difference in the reported need for help even if the difference is only significant on the 10 per cent level ($p < 0.10$, Study III). Women need more help both with IADL and personal activities of daily living (PADL) but men report more need for help with IADL activities only. Those in need of care because of PADL limitations are mostly women 80 years and older.

When the need for help with IADL activities increased, the informal care increased for men but was almost constant for women. It therefore seems that the family, mainly the spouses, is more willing to help men than women. The formal help provided to women but not the formal help provided to men increased when the degree of IADL limitations increased. This is probably due to the men to a larger extent get the care they need from informal sources.

The reason for men's need for help with household chores could be explained by the fact that some men of the older generations are not used to domestic work and therefore need help, especially when they are living alone. The next generation of older men will probably be better able to take care of themselves, as men and women are more equal in doing household chores due to changes of norms and attitudes in the society.

The reason for the gender differences regarding household chores could also be that women are not offered help with household tasks which they are used to perform, until their needs for help become severe. Keeping one's independence in one's own home could be more important to women than men.

For those living with a partner, the main informal caregivers providing help because of IADL and PADL limitations are spouses, especially wives often help their husbands. Wives more often than husbands provide care alone. For those living alone, daughters/daughters-in-law were the main providers of informal help both for men and women. The sons very seldom provided any help to parents living together. They helped their single living mothers more than they helped their single living fathers.

Even if the results indicate gender differences in relation to the need for help and support, there is no significant gender difference in the proportion that receives care. For men more than for women, informal and formal care seems to substitute or replace each other. For women, the results show that the family is the main helper when the need for help and care appears, but when the help becomes more burdensome the formal homecare system steps in. The formal help provided to women increased when the degree of IADL limitations increased.

When studying older persons who are caregivers and their contribution to caring for others, the results show that female caregivers were alone in providing care, without help from other informal or formal caregivers, for almost half of the care receivers. Being a male care provider was a factor significantly related to more often providing care in the interaction with another caregiver. Some of the older caregivers needed help themselves even if they were helping others. Nearly half of those who provided care alone received care themselves (46%, n=30). This result indicates that even if older people are in need of assistance, they are able to help others in some other regard. Even if the help provided is more of an emotional than an instrumental character, it is of importance for both the care receiver and the care provider.

One hypothesis is that daughters are more important caregivers for older people than sons. Other researches show that older people rely rather on their daughters than their sons, for both instrumental and emotional support, which supports the gender difference in caregiving (Suitor and Pillemer, 2006). Perhaps the daughters take after their mothers in caring and being available if assistance is needed. Study IV confirms the results of many other studies that gender greatly influences the bond between generations (see f. ex. Connidis, 2010). Grandmothers generally have more contact with their grandchildren than grandfathers do and are more likely to initiate contact with the grandchild. Grandmothers are also more likely than grandfathers to report receiving emotional support from their grandchild. The results show further that the youths meet with their maternal grandparents more often than with their paternal grandparents, showing that their parent's gender influenced the intergenerational ties. The ties between grandparents and grandchildren are obviously cultivated by the women in the families; grandmothers, daughters and granddaughters.

6.5. Reciprocity and social exchange

About 60% of those receiving help from older caregivers were 80+ years old and the majority were women. Half of them received care because of physical problems only, about one-third only for psychological/cognitive reasons and about one-fifth of the care recipients needed help for both physical and psychological/cognitive reasons. Older caregivers most often give care to their spouses. They were helped mainly for physical reasons.

The main help provided by older caregivers is emotional support. It is an important type of help, as it can prevent loneliness and increase the well-being of the care receiver. The older caregiver providing emotional help or keeping others company can also gain something from the relationship. The

help provided can be considered reciprocal, people gain something themselves by helping others, making them feel active and important. Emotional help was important support provided between grandchildren and grandparents and vice versa.

The social exchange theory indicates that when receiving assistance, it is important to be able to give something in return (Bengtson et al., 2002). In the study on the relationships between grandparents and grandchildren, it was shown that the experience of mutual support and relationships was more apparent between the female than the male participants, both young and old. The culture and traditions of relationship within a family have an impact on the determination of reciprocal help provided between the generations.

The grandparents do not state they offer their grandchildren financial support even if the college students report they do. It can be suggested that grandparents giving their grandchildren money are in fact eventually offering some compensation for a visit from the grandchild. This could be seen as one form of reciprocity as when receiving help or other forms of assistance something is expected to be given instead. In that way a balance is kept between receiving and giving support (Dowd, 1975; Bengtsson et al., 2002).

The reciprocal support between grandparents and grandchildren merits further study because of the changes in longevity and multidimensional variety in family relations. Older people can be an important source of support and models for the younger generations, which also offer meaningful support to their grandparents.

6.6. Cohabitation

Those who are living with someone receive significantly more informal help than those living alone. It is suggested that women are the major helpers of their spouses, especially regarding IADL help. The effect of cohabiting on received help is of great importance, especially for men, who more often received IADL help from a spouse than cohabiting women did. Men seem to gain more from cohabiting than women do. Cohabiting women with needs of IADL help received more help from their children than men did, but also from other helpers such as grandchildren, neighbours and friends. The social network has therefore different effects among men than among women, as mothers received more informal care from their children than fathers did, most likely because men receive more care from their spouses.

When living alone, more men than women are in need of IADL assistance only. Men living with someone, most often with their spouse, are

receiving more informal IADL help than men living alone. When needs for help with IADL activities increased, the informal care increased for men but was almost constant for women. Especially for men, cohabitation plays an important role in receiving help.

When looking at contact between generations, cohabiting grandfathers were more likely to initiate contact with their grandchildren and to offer them emotional support than grandfathers who lived alone. Grandfathers living alone also reported less contact with their grandchildren than grandfathers living with a partner.

6.7. Strengths and limitations of the study

The response rate in the ICEOLD study is 66%, and probably some of those not answering are too sick to participate. There were 292 persons (147 men and 145 women with a mean age of 78) who declined to participate. The number of persons who could not be reached at all was 115 (64 men and 51 women with a mean age of 79). As no indirect interviews with proxies were conducted, the answers give the responses of the older participants themselves. Using proxies, for instance by asking a close relative about the older people's situation, could have resulted in better response rate and additional information on the situation of the frailest group. However, asking the older persons themselves about their attitudes and experience gives information on their own understanding of their situation.

When calculating the needs of help and care, there is some inconsistence in the definitions of needs in Study I and Study III. In Study I only those who always or often needed care/help because of IADL and PADL limitations are considered in need of help/care. In Study III, all those giving the response of only seldom in need of help/care are included as in need of help. This means that those who are able to usually do the things themselves are considered as needing help. When comparing to other Scandinavian countries such as Sweden, this definition could indicate why more people in Iceland are considered in need of help.

In Study IV the analyses were limited to grandparents having grandchildren aged 17-25 years old as the respondents in the Grammar School Survey were at this age (mean age 19 years). To be sure that the answers did not refer to very young grandchildren grandparents having grandchildren 10 years and younger were excluded, leaving responses from 206 grandparents for analysis.

6.8. Conclusions

Informal help and care, e.g. provided by family members plays a major role in supporting older people with IADL or PADL limitations in their homes in Iceland. Women are the main informal carers and more often than men they provide care as the only carer. Older caregivers provide care to others even when they need help themselves.

The great majority of the respondents with IADL and PADL limitations received either informal or formal help but seldom both. The care and help provided is more often help with domestic tasks than with personal care. The formal care system steps in when the need for assistance increases, but the majority only receives modest care from formal care providers. It is suggested that when the need for personal care increases, the older person moves into a nursing home instead of increasing the formal care in the home.

The relationship and support between generations is more of an emotional or social nature than a practical one. Both grandparents and grandchildren consider the provided and received emotional support to be of great value. The gender influences the contact frequency between the generations, as women more often cultivate ties between grandparents and grandchildren.

Two main conclusions can be drawn from the results of the research. Despite government policy to support older people to live at home as long as possible only a small group receives substantial support from public service providers. Many older people receive help, but only few hours each and more help with household tasks than personal service. Caregivers play a vital role in supporting older people to live at home as long as possible.

It is a challenge issue for social policy in the elderly care to increase public services so it would be a real option for seniors to live in their homes, despite limitations. As the informal care providers; family, friends and neighbours, are the main helpers of older people with ADL limitations in Iceland, it is important to provide them with good support. The support can be in the form of day care, respite care or improved home help services, mainly indirect form of support for caregivers. To create confidence among the older care receivers and their caregivers, the formal system must be available and accessible when the need occurs. Further, it needs to be more flexible, taking into account the special needs of the older person in question.

6.9. Practical implications for providing qualities and further research

As modest research exists on services for older people in Iceland, this dissertation contributes important information on mapping the needs for care and support of older Icelanders and the care already provided by informal and formal caregivers. But as the results only show a cross-sectional aspect of the situation, further research is vital. It is important to focus on the on-going changes in society and monitor the provision of formal care and how it eventually affects older people's possibilities to "age in place" and the help and care provided by the family. It is also important to study how the relationships between the informal and formal caregivers change and how increased limitations influence the services in the future. The care situation can be seen as relationship between officials, the family and the older person involved. It is important to study the relationship between these actors from a holistic point of view.

After the financial collapse in 2008 there are signs of cutbacks in the welfare system (Félags- og tryggingamálaráðuneytið [The Ministry of Social Affairs and Social Security], 2009). The increasing workload of those working in the field of home help services must be considered as a risk for both older people and the providers of care themselves. It is also vital to be aware of the different needs of support for the family members who are involved in informal care. It is well known caregiving can be stressful and new methods are needed to improve support for informal caregivers. It is also important to observe older people who are helping others but are still in need for help and care themselves. As reported in Study II, this is a group whose situation is not well known and needs more attention.

As society is drastically changing the intergenerational relationship between grandparents and their grandchildren needs to be studied. Further gerontology research in Iceland should also emphasize the reasons for older people moving into nursing facilities, their social situation and whether they could be better supported in their homes by the formal care system.

Summary in Swedish

Syftet med avhandlingen är att beskriva och analysera vilka behov av omsorg och service som personer som är 65 år och äldre i Island har, samt hur dessa behov är bemötta. Relationen mellan de viktigaste givarna av hjälp och vård, den formella hjälpen som ges av stat och kommuner och den informella hjälpen som ges av partner, familj, vänner och grannar analyseras. Studien analyserar också den hjälp de äldre ger till andra och vilka faktorer som är relaterade till att ge vård ensam eller i kombination med andra vårdgivare, informella och formella. I studien analyseras relationen och det ömsesidiga stödet mellan mor/farföräldrar och barnbarn och om det finns könsskillnader i relationerna mellan generationer. Forskning om de äldres hjälpbehov i Island är begränsad. Därför är det viktigt att analysera vem som ger vård, vilken roll de informella och formella vårdgivare har och hur samspelet är dem emellan.

I avhandlingen används två isländska undersökningar för beskrivning och analyser. Den huvudsakliga datakällan är ICEOLD-undersökningen (Icelandic Older People), som gjordes hösten 2008 och är baserat på ett slumpmässigt representativt nationellt urval av icke-institutionaliserade personer, 700 i åldrarna 65 till 79 år och 700 i åldern 80 år och äldre. Det slutliga urvalet bestod av 1,189 äldre personer. Dessa informerades om studien med ett brev och kontaktades per telefon några dagar senare. 782 personer, 341 män och 441 kvinnor, deltog vilket gav en svarsfrekvens på 66%. Den andra undersökningen som gjordes bland gymnasieelever i Island år 2006 användes för att få information om relationer mellan generationer, mellan mor/farföräldrar och barnbarn. Samma frågor användes för analyser i båda undersökningarna.

Studien visar att äldre personer i Island får hjälp och vård från både informella och formella vårdgivare men att den informella hjälpen spelar en viktig roll för att stödja hemmaboende äldre. Den stora majoriteten av de svarande som har IADL (Instrumental Activitys of Daily Living) eller PADL-begränsningar (Personal Activities of Daily Living) fick antigen informell eller formell hjälp men inte båda. Den hjälp som de fick var oftare hjälp med hushållssysslor än med personlig omvårdnad. När behovet av vård och omsorg blev större ökade den formella hjälpen. Från resultaten kan man inte konstatera om den informella vården er ett substitut för den formella vården eller tvärt om. Eftersom den formella hjälpen är begränsad, verkar det troligt att när behovet av personlig vård ökar flyttar den äldre personen in i ett vårdhem i stället för att den formella vården i hemmet ökas. Kvinnor är

än män oftare enda vårdgivaren. Döttrar ger mer vård till sina föräldrar än söner.

De äldre som hjälper andra, var ensamma i sin roll som informell vårdgivare i nästan hälften av fallen och kvinnor oftare än män. En tredjedel hjälper till med flera uppgifter, till exempel både hjälp med ärenden och övervakning och ADL hjälp. De äldre vårdgivarna hjälper andra även när de själva behöver hjälp.

Vad gäller relationer emellan generationer så visar resultaten att mor/farföräldrar och barnbarn ger mer emotionellt än praktiskt stöd till varandra. Det känslomässiga stödet emellan generationerna är av stort värde för både barnbarnen och mor/farföräldrarna. Kontakten mellan generationerna odlas speciellt av kvinnor, både unga och gamla. Unga kvinnor har mer kontakt med sina mor- och farföräldrar än unga män och äldre kvinnor har mer kontakt med sina barnbarn än de äldre männen har. Det kan därför konstanteras att det är kvinnorna i familjen som odlar relationerna emellan generationerna.

En begränsning av studien är att de som inte svarar (svarsfrekvens 66%) kan vara sjukare och oftare funktionshindrade än de som svarat. Inga indirekta intervjuer (proxys) gjordes om den äldre personen, på grund av sjukdom, inte själv kunde delta i undersökningen. Detta kan medföra att andelen äldre som bor hemma och är i behov av hjälp underskattas i studien.

Samantekt á íslensku (Summary in Icelandic)

Tilgangur þessa doktorsverkefnis er að greina frá niðurstöðum fjögurra rannsókna, en markmið þeirra var að kanna hvers konar þjónustu eldra fólk sem býr á heimilum sínum á Íslandi þarfnast. Kannað var hverjir það eru sem veita þjónustuna, hvort það eru opinberir þjónustuaðilar (formal caregivers), sem eru opinberir aðilar, s.s. ríki og sveitarfélög, eða óformlegir aðilar (informal caregivers), sem eru fjölskylda, vinir og nágrannar. Enn fremur var athygli beint að því hvernig tengslum þessara aðila er háttað og hvernig þeir starfa saman að því að veita eldra fólki aðstoð. Þá er kannað hvaða áhrif kyn, heilsa, færni og búsetuform (hvort þeir öldruðu búa einir eða ekki) hafa á þá þjónustu sem þeir fá. Einnig var skoðað hvers konar aðstoð eldra fólk veitir öðrum öldruðum, fötluðum eða veikum reglulega og hvort eldra fólk veitir aðstoð eitt eða í samvinnu við aðra þjónustuveitendur, formlega eða óformlega. Þá er kannað hvort þeir eldri borgarar sem hjálpa öðrum þarfnast sjálfir aðstoðar. Tengsl og gagnkvæm aðstoð afa og ömmu og barnabarna eru einnig skoðuð og hvort kynjamunur sé á samskiptum milli kynslóða.

Notuð eru gögn úr tveimur íslenskum gagnagrunnum; annars vegar ICEOLD-rannsókninni (Icelandic Older People), símakönnun, sem framkvæmd var haustið 2008 og byggir á tilviljunarúrtaki á landsvísu, og hins vegar gagnagrunnur rannsóknar sem gerð var meðal framhaldsskólanema á Íslandi árið 2006. Í ICEOLD-rannsókninni voru aðstæður og þjónusta við aldraða sem búa í heimahúsum kannaðar. Í úrtakinu voru 1,400 einstaklingar á aldrinum 65 ára og eldri, en þar sem einungis var talað við þá sem bjuggu í heimahúsum var úrtakið 1,189 einstaklingar á aldrinum 65-98 ára. Alls tóku 782 manns (341 karl og 441 kona) þátt og var svarhlutfall því 66%. Svörin sem fengust í ICEOLD-rannsókninni eru notuð í öllum rannsóknum þessarar doktorsritgerðar.

Síðarnefndi gagnagrunnurinn sem notaður var er rannsókn sem var gerð meðal framhaldsskólanema og voru flestir þátttakendur fæddir árið 1987. Úrtakið var klasaúrtak 1,187 nemenda í níu framhaldsskólum. Alls tóku 845 nemendur þátt og var svarhlutfall 71%. Sömu spurningar voru notaðar í báðum rannsóknunum til að fá upplýsingar um tengsl og stuðning milli kynslóða, milli ömmu og afa og barnabarna. Svörin sem fengust í þeim gagnagrunni eru notuð í rannsókn um samskipti ungmenna og afa og ömmu í þessari ritgerð.

Doktorsritgerðin byggir á fjórum ritrýndum greinum á grundvelli þessara gagnagrunna. Þær tengjast allar þjónustu og stuðningi við eldra fólk og

samantekt á niðurstöðum þeirra. Hér verður gerð grein fyrir hverri grein fyrir sig og samantekt á niðurstöðum birt í lokin.

Grein I. Þarfir eldri borgara á Íslandi fyrir þjónustu og þjónustan sem veitt er.

Markmið rannsóknarinnar var að lýsa aðstæðum og þörfum aldraðra fyrir umönnun og þjónustu og kanna hvernig þörfum þeirra er mætt. Skoðað var hver það er sem veitir þjónustuna, óformlegir og/eða formlegir aðilar, og hvernig tengslum á milli þessara aðila er háttað.

Niðurstöður sýna að 58% svarenda þurfa aðstoð við eina eða fleiri athafnir daglegs lífs (Activites of Daily Living, ADL) en meirihlutinn aðeins við almenn heimilisstörf, þrif, þvotta, matseld og innkaup (Instrumental Activities of Daily Living, IADL). Það er marktækur munur á þörfum kynjanna fyrir aðstoð. Karlar þarfnast oftar aðstoðar við IADL, en konur þarfnast oftar aðstoðar bæði við IADL og persónulega aðstoð (Personal Activites of Daily Living, PADL), þ.e. að fara í bað, fara á salerni, komast í og úr rúmi og klæðast. Af þeim sem þörfnuðust aðstoðar við einn eða fleiri þætti ADL þörfnuðust 82% aðstoðar við IADL. Aðstoðar bæði við IADL og PADL þörfnuðust 18% og af þeim voru tveir þriðju 80 ára og eldri og tveir þriðju voru konur. Það er því ljóst að eldri borgarar sem búa í heimahúsum þörfnuðust frekar aðstoðar við heimilisstörf en við persónulega umönnun.

Niðurstöður sýna enn fremur að meðal þeirra sem þörfnuðust aðstoðar fengu 58% eingöngu aðstoð frá fjölskyldu sinni, vinum og nágrönnum, 8% eingöngu aðstoð frá opinberum aðilum og 34% aðstoð frá bæði frá fjölskyldu og opinberum aðilum. Greinilegt er að fjölskyldan, nágrannar og vinir eru ómetanleg aðstoð því eldra fólki á Íslandi sem þarf á hjálp að halda. Ekki er marktækur kynjamunur á þeim sem fá aðstoð frá formlegum og óformlegum þjónustuveitendum, en þeir sem eru í sambúð fá mun meiri aðstoð, bæði frá formlegum og óformlegum aðilum ($p < 0,01$). Stór hópur aldraðra fær formlega þjónustu en flestir fá aðeins nokkrar klukustundir í mánuði. Af þeim sem fá einhvers konar aðstoð fengu 10% formlega þjónustu fjórum sinnum í viku eða oftar, en tvöfalt fleiri fengu óformlega aðstoð eins oft. Þeir sem fengu eingöngu óformlega aðstoð fengu hana oftast frá maka sínum, oftar frá eiginkonu en eiginmanni, en dætur veittu mesta aðstoð á eftir mökum.

Næstum helmingur þátttakenda fékk einhvers konar aðstoð. Af þeim fengu 27% aðeins aðstoð frá fjölskyldu, vinum og nágrönnum, 4% eingöngu frá opinberum aðilum og 16% frá öllum þessum aðilum. Aðhvarfsgreinig var notuð til að meta áhrif heilsu á hvort þátttakendur fengu aðstoð eða ekki. Í ljós kom að einstaklingar sem mátu heilsu sína slæma voru líklegri til að fá bæði formlega og óformlega aðstoð. Niðurstöður sýndu einnig að þeir sem voru giftir eða í sambúð og áttu börn voru líklegri til að fá einungis

óformlega aðstoð, en ekki var marktækur munur á hópunum eftir kyni eða aldri.

Meirihluti þeirra sem fengu aðstoð var ánægður með þá þjónustu sem hann fékk, en 18% óskuðu eftir að fá meiri formlega þjónustu. Meðal þeirra sem eingöngu fengu aðstoð frá fjölskyldu, vinum og nágrönnum vildu 22% fá meiri aðstoð frá opinberum aðilum. Þegar þátttakendur voru spurðir hvar þeir vildu búa ef þeir þyrftu umönnun vildu 68% búa áfram á heimilum sínum og fá þjónustuna þangað. Þegar fólk þurfti aðstoð við a.m.k. einn þátt personulegrar aðstoðar (PADL) vildi meira en helmingur (57%) flytja á hjúkrunarheimili og fá umönnun þar. Eldra fólk kýs því frekar að fá þjónustu á heimilum sínum, en þegar hjálparþörf eykst vill fólk flytja á hjúkrunarheimili. Niðurstöður benda til þess að þegar þörf á persónulegri umönnun aukist sé frekar óskað eftir flutningi á hjúkrunarheimili en aukinni heimaþjónustu. Þetta gæti bent til þess að of lítil þjónusta sé í boði fyrir fólk í heimahúsum, sem leiðir til þess að þegar þörfin fyrir þjónustu eykst eru fáir kostir í boði aðrir en að leita eftir stofnanaþjónustu.

Grein II. Eldri borgarar á Íslandi bæði veita og þiggja aðstoð.

Markmið rannsóknarinnar var að kanna aðstæður þeirra eldri borgara sem hjálpa eða annast aðra aldraðra, fatlaða eða veika reglulega (þ.e. eldri óformlegir þjónustuveitendur). Kannað var hvers konar aðstoð þeir veita, hverjum þeir hjálpa og hvort þeir veita aðstoðina einir eða í samvinnu við aðra, óformlega eða opinbera umönnunaraðila. Annað markmið var að kanna hvort þeir sem aðstoða aðra þörfnuðust aðstoðar sjálfir.

Alls veittu 157 einstaklingar 65 ára og eldri, eða 21% þátttakenda í ICEOLD-rannsókninni, öðrum öldruðum, fötluðum eða veikum aðstoð eða umönnun reglulega. Niðurstöður bentu til þess að eldra fólk veitti öðrum aðstoð og umönnun þó svo að það þarfnaðist aðstoðar sjálft. Þegar þessi hópur er borinn saman við þá sem enga aðstoð veittu kom í ljós að þeir sem aðstoða aðra eru yngri en þeir sem ekki hjálpa en ekki er munur á heilsu þeirra og færni.

Meðalaldur þeirra sem fengu aðstoð frá eldri viðmælendum í rannsókninni var 78 ár, um 60% af þeim voru 80 ára og eldri og tveir þriðju voru konur. Helmingur þeirra fékk aðstoð einungis vegna líkamlegra ástæðna, og tæplega þriðjungur fékk aðstoð einungis vegna sálrænna og/eða andlegra ástæðna (t.d. einmanakennd, minnisskerðing). Um 20% þeirra sem fengu aðstoð frá öldruðum þörfnuðust aðstoðar bæði vegna líkamlega og sálrænna/andlegra ástæðna. Makar fengu oftast aðstoð og aðallega vegna líkamlegra ástæðna.

Tilfinningalegur stuðningur og eftirlit var algengasta hjálpin sem veitt var öðrum en maka, sem fengu umönnun oftast vegna líkamlegra ástæðna. Þriðjungur þess eldra fólks sem veitti öðrum aðstoð aðstoðaði við

margvíslega þætti, s.s. með innliti, með smá viðvikum og tilfinningalegum stuðningi auk þess að aðstoða við ADL. Þeir voru einu aðstoðarmenn þess sem þeir hjálpuðu í helmingi tilvika, en tveir þriðju af þeim sem hjálpuðu einir voru konur. Af þeim sem fengu aðstoð frá eldra fólki fengu 38% einnig aðstoð frá opinberum aðilum, 16% einnig frá öðrum óformlegum aðila en 46% fengu aðeins hjálp frá þeim aldraðra. Af þeim sem veittu aðstoð í samvinnu við opinbera aðila töldu 73% að ekki væri þörf fyrir aukna aðstoð frá opinberum aðilum. Það var tilhneiging ($p = 0,6$) hjá þeim sem veittu aðstoð án hjálpar frá opinberum aðilum að vilja fá aðstoð frá þeim.

Meira en helmingur þeirra eldri borgara sem aðstoða einhvern sem er aldraður, fatlaður eða veikur þarfnast sjálfur aðstoðar. Aðstoðar við ADL þörfnuðust 54% (n=85) og 6% (n=10) við bæði IADL og PADL. Enginn munur var á heilsufari þeirra eldri borgarara sem veittu aðstoð og þeirra sem ekki veittu aðstoð, sem bendir til þess að aðstoðin sé ekki of krefjandi. Jafnvel þótt sú hjálp sem veitt er sé að mestu tilfinningalegur stuðningur og eftirlit er þetta framlag mikilvægt til að styðja eldra fólk til að búa heima sem lengst. Niðurstöður gætu einnig bent til að um gagnkvæman stuðning væri að ræða á milli þessi sem veitir aðstoðina og þess sem þiggur hana, nokkuð sem báðir aðilar geta hagnast á.

Auka þarf þekkingu á þeim hópi aldraðra sem veitir öðrum þjónustu og auka skilning á samvinnu þeirra við aðra aðila sem veita öldruðum þjónustu, óformlega og formlega.

Grein III. Þeir þættir sem hafa áhrif á óformlega og formlega þjónustu við eldri borgara á Íslandi.

Meginmarkmið þessarar rannsóknar er að greina mynstur óformlegrar og formlegrar aðstoðar við athafnir daglegs lífs (ADL) og hvort aðstoðin er mismunandi eftir kyni, færni og hvort sá sem fær aðstoðina er í sambúð eða ekki. Markmiðið er einnig að kanna hlutfall aldraðra sem fá aðeins óformlega umönnun, aðeins formlega umönnun eða bæði formlega og óformlega umönnun. Þetta er skilgreint út frá því hvort annar hvor þátturinn kemur í staðinn fyrir hinn eða hvort hann er viðbót.

Um 60% úrtaksins þörfnuðust aðstoðar við einn eða fleiri þætti IADL, fleiri karlar (62%) en konur (55%). Um 10% þörfnuðust aðstoðar við einn eða fleiri þætti PADL, fleiri konur (11%) en karlar (8%). Mikill meirihluti svarenda með þörf fyrir aðstoð fékk annaðhvort óformlega eða formlega aðstoð, en ekki hvort tveggja. Þetta á bæði við um þá sem þurfa aðstoð við IADL (77%) og PADL (76%). Þeir sem einungis fengu óformlega aðstoð við IADL voru 54% (n=243) og þeir sem einungis fengu formlega aðstoð við IADL voru 22% (n=100). Þeir sem einungis fengu PADL-aðstoð frá óformlegum aðilum voru 34% (n=26) og einungis frá formlegum aðilum 42% (n=32). Hlutfall þeirra sem fengu umönnun frá bæði óformlegum og

formlegum þjónustuveitendum var 24% (n=18). Það eru meiri líkur á að konur fái formlega og óformlega aðstoð vegna IADL en karlar, þó að munurinn sé ekki marktækur.

Þegar þörfin jókst fyrir aðstoð vegna IADL jókst sú óformlega aðstoð sem karlarnir fengu en var nánast stöðug hjá konunum. Með aukinni aðstoðarþörf við ADL jókst aðstoð opinberra aðila við konur en ekki við karla. Menn í sambúð fá oftar óformlega IADL-aðstoð en karlar sem búa einir (OR=8,62, $p < 0,001$). Ekki var marktækur munur á þeirri óformlegu IADL-aðstoð sem konur fengu eftir því hvort þær bjuggu einar eða voru í sambúð. Niðurstöðurnar sýna að áhrif sambúðar á möguleika á að fá þjónustu eru afar mikilvæg, sérstaklega fyrir karla, sem fengu oftar IADL-hjálp frá maka en konur í sambúð fengu. Þetta staðfestir að eiginkonur eru helstu aðstoðarmenn maka sinna, sérstaklega varðandi IADL-hjálp. Konur í sambúð með þörf fyrir IADL-aðstoð fengu oftar aðstoð frá dætrum/tengdadætrum og sonum/tengdasonum en karlar fengu. Þeir sem bjuggu einir fengu aðallega óformlega aðstoð frá dætrum/tengdadætrum, eða 57% karla og 68% kvenna.

Allir þeir sem þarfnast einhverrar aðstoðar við PADL fengu aðstoð frá formlegum aðilum (42%), óformlegum aðilum (34%) eða bæði formlegum og óformlegum aðilum (24%). Aldur er ekki marktækt tengdur því að fá aðstoð vegna PADL. Meiri líkur eru á að karlar fái formlega aðstoð eftir því sem þjónustuþörf þeirra eykst, en ekki er að sjá slíka aukningu hjá konum.

Niðurstöðurnar benda til þess að meirihluti svarenda í ICEOLD-rannsókn hafi fengið annaðhvort óformlega eða formlega þjónustu en ekki aðstoð frá báðum þessum aðilum. Þetta bendir til þess að meiri samvinnu vanti á milli þessara aðila. Fram kemur að þessir tveir þjónustuaðilar, óformlegir og formlegir, koma í staðinn fyrir eða bæta hvor annan upp, þó að erfitt sé að staðhæfa á hvorn veginn það er. Hins vegar er líklegt að óformlega þjónustan komi í staðinn fyrir þá formlegu. Þetta á sérstaklega við um karla, þar sem færri karlar en konur fá bæði formlega og óformlega IADL-hjálp.

Óformlega þjónustan, sem veitt er af fjölskyldu, vinum og nágrönnum, gegnir mikilvægu hlutverki í að styðja eldra fólk til að búa eins lengi og mögulegt er á heimilum sínum. Fyrir karlana er sambúð mikilvægur þáttur, þar sem makar þeirra aðstoða þá mest, sérstaklega varðandi IADL. Þegar þörf þeirra fyrir aðstoð eykst fá þeir meiri hjálp frá bæði formlegum og óformlegum umönnunaraðilum. Konur í sambúð fá ekki marktækt meiri óformlega aðstoð en konur sem búa einar. Því má segja að sambúð sé ekki eins mikilvægur þáttur til að fá óformlega aðstoð fyrir konurnar og hún er fyrir karlana.

Grein IV. Gagnkvæmur stuðningur og aðstoð í samskiptum afa, ömmu og barnabarna.

Markmið rannsóknarinnar var að kanna tengsl og gagnkvæma aðstoð á milli kynslóða, þ.e. á milli afa og ömmu og barnabarna. Einnig var skoðaður kynjamunur varðandi tengslin og þann stuðning sem veittur er. Í rannsókninni er stuðst við gögn úr tveimur íslenskum rannsóknum, ICEOLD-rannsókninni og rannsókn sem gerð var meðal framhaldsskólanema. Báðir hóparnir fengu sömu spurningar um tengsl og gagnkvæma aðstoð milli kynslóða.

Niðurstöður rannsóknarinnar gefa til kynna að bæði afar/ömmur og barnabörn telja tengslin á milli kynslóða vera mikilvæg. Tengslin á milli afa og ömmu og barnabarnanna voru frekar af tilfinningalegum toga en í formi hagnýtrar aðstoðar. Hins vegar var matið á aðstoðinni mismunandi eftir aldri. U.þ.b. einn fimmti af öfum og ömmum sagði að barnabarnið sem þau höfðu mest samband við hjálpaði sér alltaf eða oft, en stærra hlutfall barnabarnanna, tveir fimmtu, taldi sig hjálpa afa og ömmu alltaf eða oft. Aðeins 4% afa og ömmu sögðust hjálpa barnabarninu fjárhagslega en 20% barnabarnanna sögðust fá fjárhagslega aðstoð frá afa og ömmu.

Kynjamunur kom fram í samskiptum afa/ömmu og barnabarna. Ömmurnar voru líklegri til að hafa frumkvæði að samskiptum við barnabarnið en afarnir, og voru líklegri til að veita þeim tilfinningalegan stuðning. Fleiri ungar stúlkur en ungir menn sögðust alltaf fá tilfinningalegan stuðning frá afa sínum og ömmu og voru líklegri til að hafa frumkvæði að tilfinningalegum stuðningi. Meiri reynsla var af gagnkvæmum stuðningi meðal kvenna en karla, bæði ungra og gamalla.

Unga fólkið í rannsókninni hitti móðurforeldra sína oftar en föðurforeldra. Um helmingur barnabarnanna var í nánara sambandi við ömmur sínar en afa, og í 44% tilvika voru þau jafn náin þeim báðum.

Konurnar innan fjölskyldunnar, ömmur, mæður og dætur sjá frekar til þess en karlarnir að tengslin innan fjölskyldunnar séu ræktuð. Gagnkvæm aðstoð milli afa/ömmu og barnabarna þarfnast frekari rannsókna í því skyni að skoða áhrif hennar á félagslega velferðarþjónustu.

Samantekt á niðurstöðum.

Niðurstöður rannsóknarinnar sýna að tæp 60% svarenda þörfnuðust aðstoðar við einn eða fleiri þætti athafna daglegs lífs (ADL). Meirihlutinn þarfnaðist aðeins aðstoðar við almenn heimilisstörf, þrif, þvotta, matseld og innkaup (IADL), fleiri karlar en konur. Fleiri konur en karlar þörfnuðust aðstoðar við einn eða fleiri þætti persónulegrar aðstoðar; að fara í bað, fara á salerni eða komast í og úr rúmi (PADL). Meirihluti svarenda með þörf fyrir aðstoð fékk annaðhvort óformlega eða formlega aðstoð, en ekki frá báðum þessum þjónustuveitendum. Þetta á bæði við um þá sem þurfa aðstoð við IADL og

PADL. Þegar þörfin jókst fyrir aðstoð vegna IADL jókst sú óformlega aðstoð sem karlarnir fengu en var nánast óbreytt hjá konunum.

Óformleg aðstoð fjölskyldu, vina og nágranna gegnir mikilvægu hlutverki í að styðja eldra fólk með færnisskerðingu til að búa á heimilum sínum. Þegar þjónustuþörfin eykst virðist sem fólk flytji frekar á hjúkrunarheimili en að þjónusta opinberra aðila sé aukin á heimilinu.

Aldraðir hjálpa öðrum öldruðum, fötluðum og veikum þó svo að þeir þarfnist sjálfir aðstoðar. Konur veita oftar óformlega aðstoð en karlar og eru oftar einar í hjálparhlutverkinu. Sambandið og stuðningur milli kynslóða er meira af tilfinningalegum eða félagslegum toga en hagnýtum. Bæði afar/ömmur og barnabörn telja að stuðningurinn sem kynslóðirnar veita hvor annarri sé mikils virði. Kyn hefur áhrif á sambandið milli kynslóða, þar sem konurnar rækta frekar samböndin en karlarnir.

Viðtöl voru einungis tekin við aldraða sjálfa, en ekki við ættingja eða aðra ef sá sem lenti í úrtakinu vildi ekki eða gat ekki svarað. Svarhlutfall í rannsókninni var 66%. Þetta getur þýtt að hlutfall eldra fólks sem býr heima og er í þörf fyrir aðstoð og umönnun gæti verið vanmetið í rannsókninni. Kosturinn við að spyrja aldraða sjálfa er hins vegar sá að þá fást raunveruleg viðhorf þeirra sjálfra til þjónustu, en ekki umsagnir annarra.

Tvær meginályktanir má draga af niðurstöðum rannsóknarinnar. Þrátt fyrir stefnu stjórnvalda um að styðja eldra fólk til að búa heima sem lengst er það lítill hópur sem fær umtalsverða aðstoð frá opinberum þjónustuveitendum. Margir fá hjálp en aðeins fáa tíma hver og einn. Sú hjálp sem fólk fær er oftar hjálp við heimilsstörf en persónuleg þjónusta. Aðstandendur gegna hins vegar veigamiklu hlutverki í að styðja aldraða til að búa heima sem lengst.

Það væri viðfangsefni stefnumótunar í málefnum aldraðra að efla vægi opinberu þjónustunnar þannig að það væri raunverulegur valkostur fyrir aldraða að búa á heimilum sínum þrátt fyrir skerðingu. Eins og kunnugt er getur því fylgt mikið álag, bæði fyrir aðstandendur og starfsfólk, að veita öldruðum viðeigandi aðstoð og þjónustu. Þannig er mikilvægt að þróa öflugri úrræði til stuðnings við þá aðstandendur sem veita eldra fólki umönnun og aðstoð í heimahúsum. Sömuleiðis er brýnt að huga að starfsaðstæðum þeirra sem starfa í hinni opinberu þjónustu.

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