

A Quality Assessment Initiative through Empirical Outcome Research in Long-Term

Care for Older Persons:

Experiences from National Level Mandatory Surveys in

Facility Care in Japan and Family Care in Chile

高齢社会におけるケアの質のアウトカム評価

一介護保険制度中心の日本と家族介護中心のチリにおける考察一

by

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1 Chapter 1: Introduction

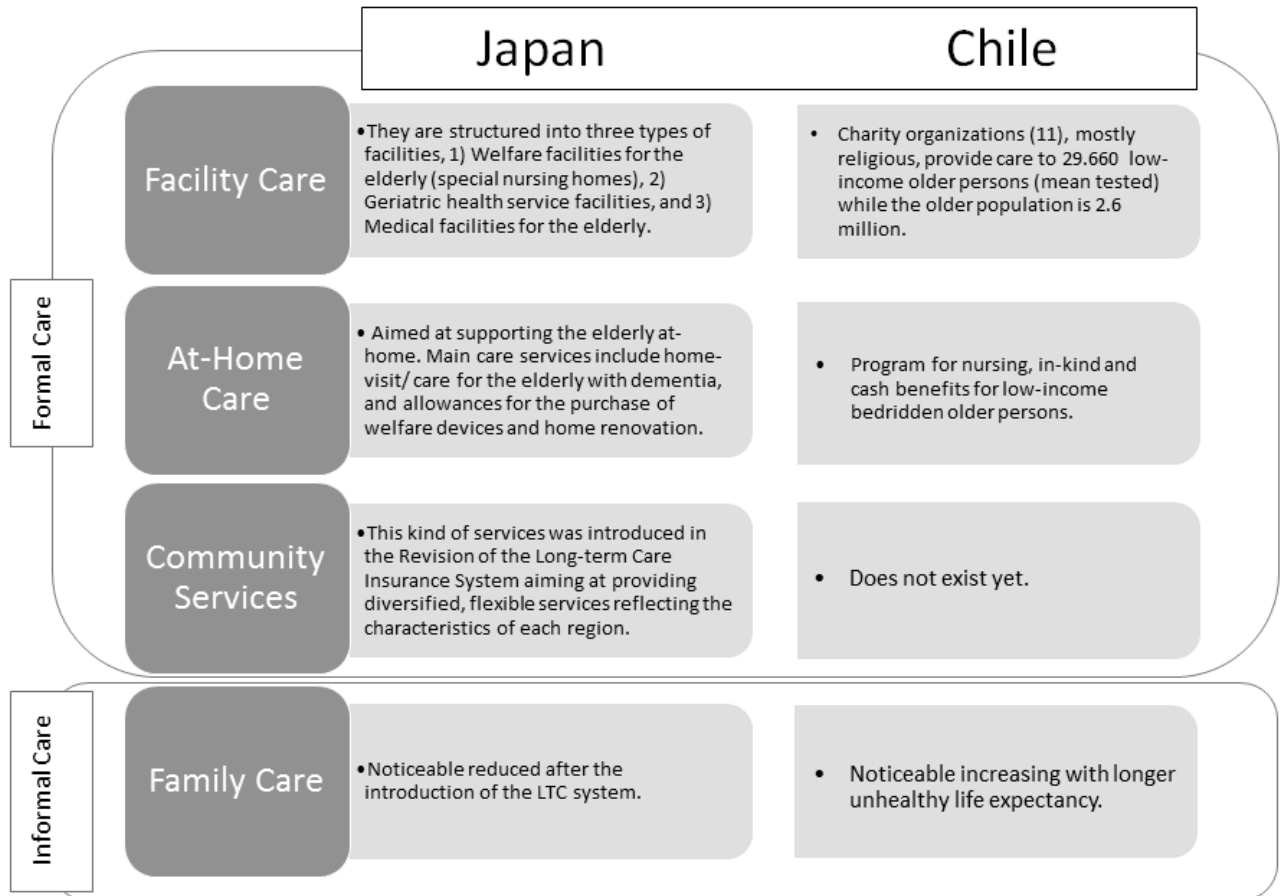
An ageing world and the provision of care

The world is ageing at a fast pace. Today there are around 1 billion people aged 60 and over in the world. This figure will double by 2050¹. While, developed countries have the highest proportions of their population being elderly people, developing countries are ageing rapidly as well. Additionally, developing countries have the highest numbers of elderly persons in the world, which by 2050 will represent 80 percent of the total elderly population in the world. A detailed revision of the demographic situation in the world is discussed in *Chapter 1: Background*. Under these circumstances, the provision of care to older persons will become an even more important aspect of public policies than it is today.

The provision of care for the elderly presents a range of different systems that varies by country. More developed countries have pioneered the implementation of policies regarding the provision of long-term care. To date, many countries have implemented long-term care systems. However, a few have implemented insurance systems, all of them located in the developed world. One example of these countries is Japan, the proportionally most aged country in the world. Details on the demographic characteristics of Japan and its arrangement of long term care provision are presented in *Chapter 2: Aging in Japan*.

On the other hand, developing countries are faced with a fast-paced aging process. This fast-paced aging process is characterized by the lack of resources to deal with the alleviation of aging-related implications, such as higher use of public funding for health, pension and social services, along with the ongoing challenges of previous developmental stages, for example, poverty, prevalence of communicable diseases, and lower levels of education. Despite these challenging future scenarios, developing countries have started to realize the importance of an early preparation for the future to come. That is the case of the Republic of Chile, which has started to develop policies for the provision of care for the elderly. However, the situation of the provision of care in Chile seems to be generalized in most of the developing world. In fact, in Chile is characterized by the scarce provision of formal care, which is mainly led by private institutions, such as religious organizations and for profit entities, with a low contribution on behalf of the state. This kind of arrangement relies heavily on the provision of informal care by family members, friends and neighbours of the older persons, usually referred to as family care. See figure 1.

Figure 1. Differences in the provision of care in Japan and Chile.



Source: Facilities as described on the *Survey of Institutions and Establishments for Long-term Care*²

When compared to more developed and aged countries, this dissimilar arrangement of the provision of care in Chile, a country which is seen as one of the most aged countries in Latin American, has been acknowledged by the state, and has started to work progressively in improving the quantity and quality of the services provided with support of the state. Details on the demographic characteristics of Chile and its arrangement of long-term care provision are given in *Chapter 3: Aging in Chile*.

The provision of care and its quality

With the increasing attention in the provision of care, the concept of the quality of care is one of many aspects that will continue to receive attention.

There are two main arguments for focusing on quality of care³; first, even where health

and long-term care systems are well developed and funded there is clear evidence that quality remains a crucial concern, with expected outcomes not being met and with notorious differences in delivery standards ³. Additionally, the need to maximize resources and expand coverage must be based on quality in order to achieve the best possible results ³, particularly in developing countries. With increasing restraints of funding and economic constraints to facility care, along with the changes in the care provision of family care, the quality of care received by older persons in the world has become an important aspect of the care provision as a whole. Details on the framework and rationale behind quality assessment initiatives are given in *Chapter 4: Quality assessment framework*.

Regarding facility care, concerns about quality have been widely documented for decades. Occasionally, we are informed of blatant cases of poor quality at some facilities for the elderly somewhere in the world. In different settings, increasing budget constraints, reduction on the scope and number of services, lack of staff, and high turnover rates have been reported and linked to poor quality.

Regarding family care, concerns about quality of care arises from an ever decreasing number of family members able or willing to provide care, along with the increasing number of older persons living alone with a number of chronic conditions and diminished functionality. Those who are able to provide care are faced with a demanding task that frequently leads to poorer health and quality of life. The physical and mental deterioration of caregivers may also lead to poor care, violence against the elderly, along with a significant trade-off of opportunities for those caregivers and the society as a whole.

In many developed countries, initiatives to assess the quality of care provided under the health and long-term care systems have become a central point of attention not only for the government, but also for the older persons and their families.

The need of research

Under the need of paying attention to the provision of care and its quality, this doctoral thesis is founded on four guiding principles:

- 1) Developed countries, like Japan, have great amounts of experience to share on policy implementation. Recipients of this experience may be countries that will follow progressive steps of development of such policies like Chile, to create services they do not provide at present. Chile, which is deeply interested in learning about facility care

could use this evidence to develop its own systems.

- 2) Even where provision services are well developed, the challenge of providing high quality outcomes remains a challenge ⁴, especially in countries where outcome assessment of formal care have not been systematic, for example in Japan.
- 3) Developing countries, like Chile which are in advanced stages of the demographic transition could also help to create evidence for countries that need to strengthen their informal care settings based on the assessment of care outcomes. That is the case of countries like Japan which are increasing their interest in promoting deinstitutionalization by strengthening their informal care.
- 4) Developing countries and developed countries alike need to have a thorough understanding of their present conditions regarding outcomes of care present in their informal and formal care provision, aiming at providing the best quality of care based on evidence

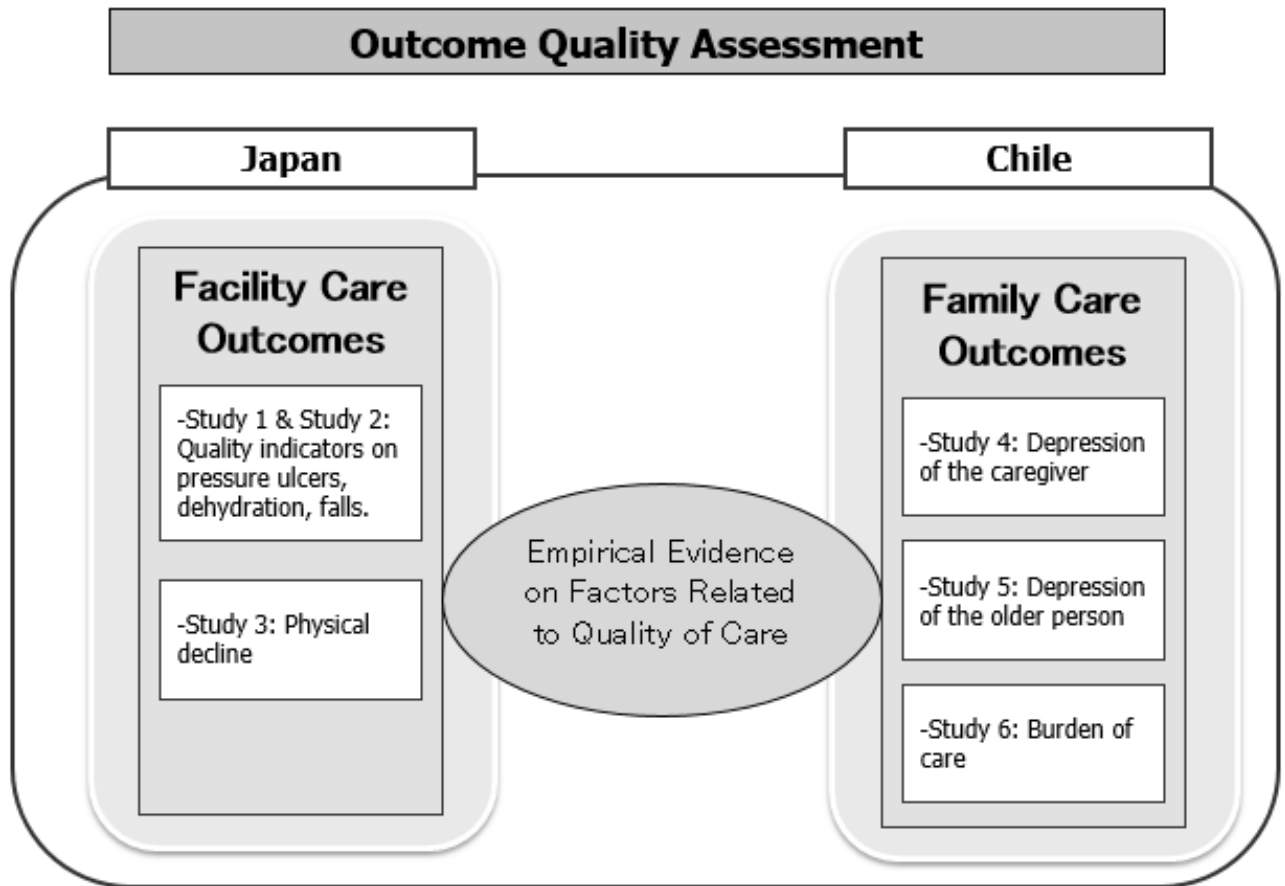
In the case of Japan there are no systematic instruments to assess quality of care at geriatric health services facilities before the beginning of this research⁵. Previously, initiatives to improve quality were only aimed at disclosing information regarding structural characteristics. However no link could be established between those structural characteristics and the subsequent outcomes of care. Following the aforementioned principles, three studies will take place focusing on studying outcomes of facility-care at geriatric health services facilities. Details on the characteristics of the studies aimed at assessing the quality of care in Japanese long-term care facilities are presented in *Chapter 5: Studies in Japan*.

In the case of Chile, as it is the case of most developing countries, evidence on ageing remains very low, being quality of care among those concepts that are rarely addressed. Following the aforementioned principles, three studies will take place focusing on studying outcomes of family care, both in older persons receiving care, and those persons providing care. Details on the characteristics of the studies aimed at assessing the quality of care in Chile are presented in *Chapter 6: Studies in Chile*.

To summarize, the present thesis project represents a quality assessment initiative using empirical outcome assessment in both long term and family care for older persons, in two different locations, Japan and Chile, by using nationally representative mandatory secondary data aimed at creating empirical evidence on factors related to quality of care through outcome assessments, both for internal and external references. The characteristics of evidence and implications as reference are discussed in *Chapter 7: Overall Discussion and Conclusions*.

The design of the thesis follows the structure shown in figure 2:

Figure 2. Thesis design.



1.1 Background

1.1.1 Demographic trends in the world

The world is ageing rapidly. Today, one in nine people in the world is aged 60 years or over, however, by 2050 this number would have increased to be one in five. Furthermore, the elderly population will reach 1 billion people within 10 years ¹ which not only inform us about the magnitude of the challenge, but also about the speed of it. When we observed this phenomenon in terms of more developed and less developed regions, we noticed that the fastest pace takes place in the more developed regions, where the population aged 60 and over will continue to increase by 2.4 percent annually by 2050 and 0.7 percent annually from 2050 to 2100 ⁶. This implies that in the next 40 years the aged population would have increased by more than 50 percent, going from 274 million in 2011 to 418 million in 2050 ⁶. In less developed regions over the next thirty years the aged is expected

to increase at a 3 percent rate per year, going from 510 million people in 2011 to 1.6 billion in 2050 and to 2.4 billion in 2100 ⁶. Until 2011, population ageing was considerably slower in less developed regions because of the high fertility rates.

This phenomenon of population ageing, which is taking place for the first time in the human history, can be considered as one of humanity's greatest achievements, as is it the result of increasing longevity. People nowadays are able to live longer thanks to improved nutritional intake, extended sanitation, medical innovation, extensive health care coverage, improved education and economic wellbeing. However, population ageing is not only driven by one component, but by two; increased life expectancy and fertility decline.

The definition of an aging society is rather general. As defined by the Department of Economic and Social Affairs of the United Nations Secretariat, the ageing of society is "the result of lower mortality (combined with reduced fertility) and longer longevity." ⁷. Underlying the ageing of a society is a process known as the "demographic transition" which is caused by a longer life expectancy and a reduced fertility rate ^{7,8}.

1.1.1.1 Life expectancy in the world

One of the components of population ageing, along with fertility decline is an increased life expectancy. Between 1950 and 1955, life expectancy at the world level was 48 years, however, this expectancy reached 68 years between 2005 and 2010 (more developed regions continue to have a higher life expectancy compared to less developed regions (77.1 years). Furthermore, life expectancy is projected to increase to 76 years between 2045 and 2050, and to reach 81 years between 2095 and 2100 ⁶. This trend, which has been considered as one of humanity's greatest achievements, witnessed an incredible period during the 20th century in terms of velocity. However, the sustained improvement started in the 18th century as a result of better hygiene, improved nutrition and medical practices based on scientific evidence in developed countries. As for developing countries, the turning point took place in the 1950's with the arrival of antibiotics, vaccines and insecticides ⁹. Between 2005 and 2010, the share of world population living in countries with a life expectancy of at least 70 years, reached 57 percent and greatly evolved in the 1990's by China ⁹.

1.1.1.2 Fertility in the World

Regarding our lower fertility rates, when we look at the human history of world population we noticed that it grew slowly most of the time. World population started to

increase slowly during the 17th and 18th centuries as the mortality rate started to decrease. Fertility reached a peak of 2 percent per year in between 1965 and 1970, and since that time, we have only observed a decelerating growth, especially marked by the fall of fertility rates in the more developed world. Between 2005 and 2010, the population growth rate at the world level was 1.16 percent per year. This growth is projected to decline to 0.44 percent per year between 2045 and 2050 and to further decrease to 0.06 between 2095 and 2100. However, it must be noticed that population growth does not follow a uniform pace across regions, particularly if we consider the level of development⁶. For example, while the most developed regions growth is at a 0.41 percent annual rate, less developed regions almost fourfold this at 1.33 percent and the least developed regions at 2.21 percent annually. We can expect this trend to continue until 2050. If developed regions follow a medium variant we can expect their growth to stagnate by 2050 whereas the population in less developed regions will continue to increase at an annual rate of 0.50 percent and the least developed regions at 1.42 annually⁶. These trends tell us that the less developed regions will remain younger for a longer time.

1.1.2 Development of long term care in the world

Developed and developing countries, which are at different stages of economic development, respond differently to the aforementioned ageing process of their populations, depending on what stage of the demographic transition they are in as well. Additionally, among countries of equal economic group, there are different approaches on how to deal with the need of long-term care.

When the world was much younger, long-term care was provided by families of those with impaired functionality or those who presented a chronic disease¹⁰. Exceptional cases, in which there was no family or social networks to provide that care, were dealt with in hospitals or religious facilities¹⁰. However, the availability of such facilities was limited. The beneficiaries of these services were mainly the poor or those who have been abandoned by their families or did not have one. By 1970s, the demand for long-term care began to increase considerably among high income countries¹⁰. Subsequently, these high income countries began the implementation or extension of available benefits, which were funded by existing public financing methods¹⁰. Chronic care programmes, including long-term care, are now covered, at least partially by public health financing schemes in most countries of the Organisation for Economic Co-operation and Development (OECD)¹⁰.

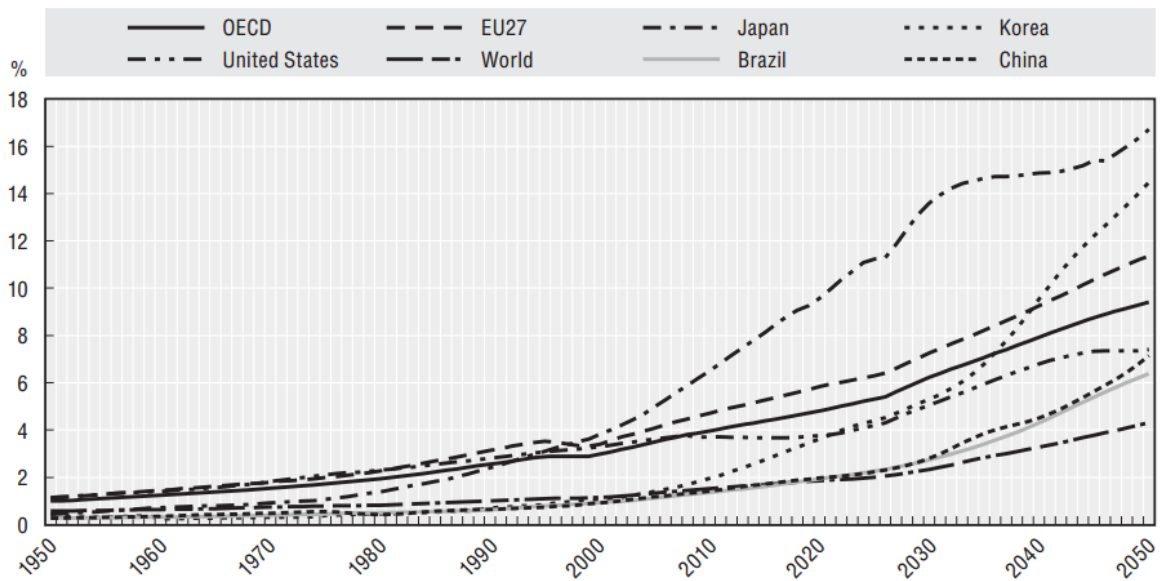
However, in low and middle income countries, the reality is very different, especially due

to resources that may go towards supporting long-term care are not satisfactorily high and therefore could not be easily extended, including those for the implementation of research and policy studies¹¹. While home and community care may be strengthened in these countries, a proper provision of long term care has not yet been included¹⁰.

In the present, the provision of long term care does not only include facility care, but also, home and community care. While some countries seem to prioritize some particular arrangement of these three elements, it seems clear to the author that balance must be achieved to ensure sustainability. The experiences of developing and developed countries and the results of their respective arrangements of these three elements seem to be considered of vital importance in a world that will continue to pressure governments for sustainability.

Sustainability will be at the core of care provision for the years to come. For example, OECD countries, which are among the most developed countries in the world, will continue their ageing trend that will result in levels of older persons never seen before in human history. Particular aspects of this ageing trend will represent those aged 80 or older. Persons aged 80 years or over will even present a heavier burden on society due to their frailty. In 1950, less than 1 percent of the global population was aged over 80 years. By 2050, this share is expected to reach 4 percent¹². The most important increase is expected for OECD countries, where by 2050 almost 10 percent of the total population will be very old (compared to 1 percent in 1950)¹². See figure 3.

Figure 3. The share of the population aged over 80 years old.

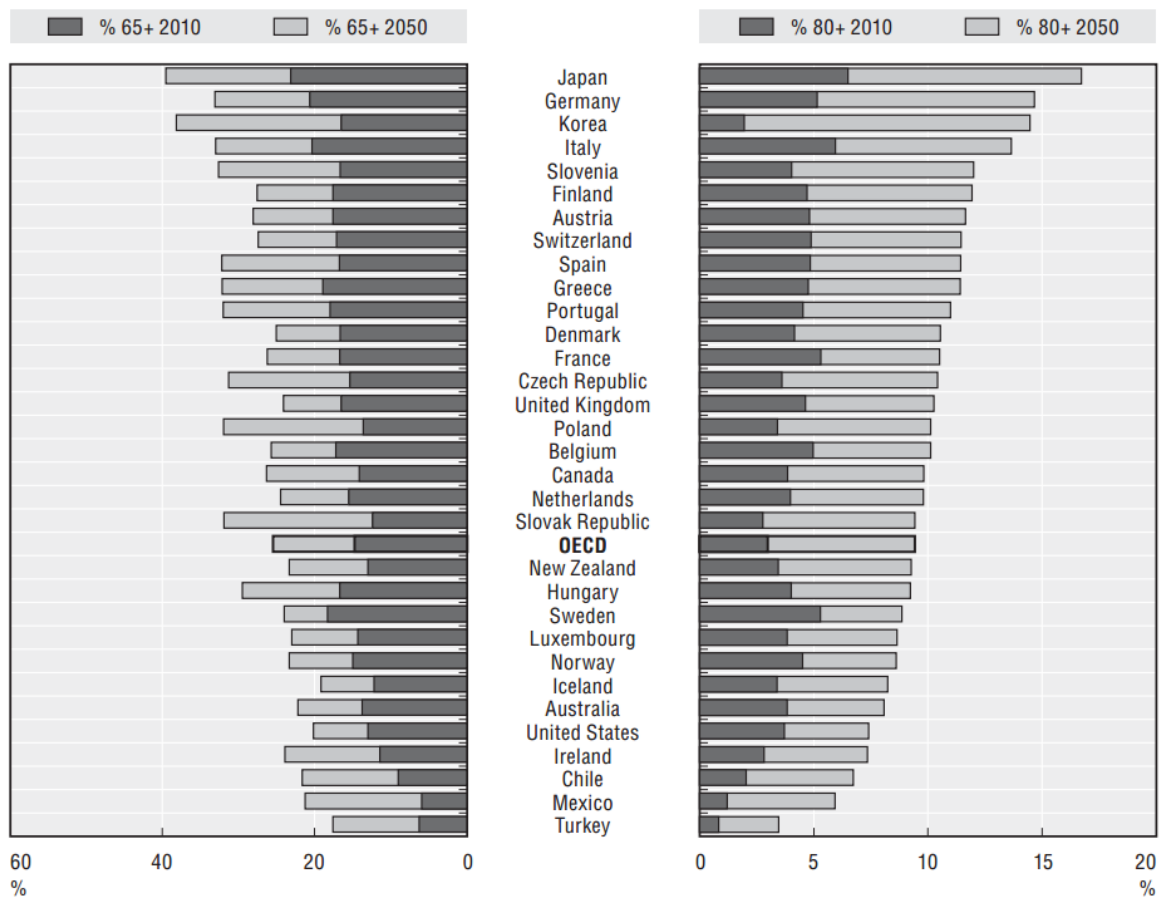


Source: OECD Labour force and demographic Database, 2010, as found in Future Demographic Trends and Long-term Care Costs, 2011¹².

This increased pressure on sustainability may compromise the quality of care provided if we think that long-term care may become more expensive as frailty increases. Therefore, the concept of sustainability and quality of care must be considered carefully if lessons are to be drawn from more experienced countries, such as countries that already have arranged long-term care systems and higher proportions of older persons.

For the purpose of this thesis on sharing experiences, it is particularly interesting to observe differences that exist regarding long-term care provision, along with demographic and epidemiological transitions even among countries of the OECD. In the following figure we can observe that even in this group of advanced economies there are marked differences in terms of population compositions.

Figure 4. The shares of the population aged over 65 and 80 years, OECD by 2050



Source: OECD labour force and demographic database, 2010, as found in Future Demographic Trends and Long-term Care Costs, 201112.

In the figure above we can observe clear differences between countries. Regarding older persons aged 65 years or over, Japan, which is placed at the top, more than doubles countries like Turkey, Mexico and Chile. Regarding those aged 80 years and over, the differences are even stronger for both 2010 and the projections for 2050.

It is the opinion of the author that our ongoing demographic and epidemiological changes of the population will lead us to inevitable modifications of our current allocation of government resources. In this scenario, reviewing the experiences of countries dealing with population challenges, both in developed and developing countries will help us better understand possible counter-measures based on evidence.

1.1.2.1 Developed countries

Developed countries have begun earlier in history the development of services aimed at providing assistance and care to their older populations, in order to face the

aforementioned aging of their population. Generally this set of services receives the name of long-term care (LTC). LTC can be defined in a variety of ways¹³. The populations of developed countries are proportionally much older than the ones in developing nations. The author has searched for experiences on developing long-term care systems among developed countries. The context of the selection is given by the Organization of Economic Development (OECD). Member states of the OECD have been chosen since the OECD is a group of countries committed to exchange and improve good practices regarding public administration, which may facilitate the exchange of practices and recommendations. In the following passages, we briefly analysed some experiences on the provision of long term care in developed countries.

1.1.2.2 Germany

Germany has a population of over 80 million people¹⁴ with about 15 percent aged 65 years or older. It is argued that before 1994 the German long-term care system particularly focused on facility care, mean-tested and heavily controlled by the state¹⁵.

In Germany three main issues have been argued to have led to the creation of the German universal social insurance program for long-term care: First, increasing fiscal pressures, a growing sense of social solidarity which was unable to be possible if the system was mean-tested and the quality of the supply and services was decreasing¹⁶.

The Social Dependency Insurance (SDI) was created for long-term care, which was founded on mandatory insurance based on an income scale. 70 million persons are enrolled in the SDI through public insurance and an additional 8.5 million by purchasing private insurance¹⁷.

Users must contribute with 1.7 percent of their income. From this 1.7 percent, half is paid by the employer or by a pension fund¹⁶ that has been arranged to cover the expenses of people who have retired from work. However, in order to be able to use the benefits of this system, one must be assessed by an examination committee. This committee assigns the applicant to one of the three following categories. First, cash benefit for a client at home; second, cash benefit for home care paid for the provider; and third, cash benefit for institutional care paid to the provider.¹⁶

It is important to notice that in the case the benefits are not sufficient to cover the cost of needed care, the individual is granted social assistance in the form of a benefit after being income tested¹⁷.

The implementation of the German system followed a series of chronological steps. First, home care was transferred to the SDI system in 1995 and institutional care followed in 1996. The system was implemented in order to give more attention and priority to the home care¹⁷.

Beneficiaries are eligible to receive in-home care in the form of in-kind services, cash, or a combination of both¹⁸. Responsibility for administering non-means tested coverage is incorporated into a separate part of the existing sickness fund structure¹⁸. One element that sets the German system aside is that beneficiaries have no restriction of age as long as they meet the minimum functional eligibility criteria (i.e. need for assistance with at least 2 ADLs and some IADLs)¹⁸.

The health insurance companies are in charge of the administration of this system. Under their system, one of the conditions is that the user should have both an acute and long-term care insurance.¹⁶ This may be understood by some as a restrictive manoeuvre over the consumer rights to choose the provider, especially considering that the acute and long-term care systems are separate. Because of this separation the communication between these two organizations seems rather difficult;

Moreover, having to sign a contract with the same company, it is said that citizens are concerned that a cost shifting may take place between long-term and acute care, particularly among those services related to rehabilitation¹⁹.

In 1970s, Germany created the “social stations”, known as Sozialstation in German. Social stations have the role of providing community services for older persons. The reason why they were built was to reduce the burden caused by inpatient care¹⁷.

Generally, staffs who are employed at social stations include nurses and social workers. Nurses and social workers are in charge of providing a wide range of services, including: consulting, transport, shopping, rental, and distribution of food, among others.¹⁹

There are around 4,000 of these social stations. The people they serve range from 20,000 to 50,000 in cities and from 15,000 to 25,000 in rural areas¹⁹. Since the introduction of the SDI funding for these stations has declined. Despite this decline, one innovative form of care provision is the "senior citizen cooperative", which combines volunteers and paid staff. Among the many activities of these groups of people we can find neighbourhood assistance in housework, transport, visits, and telephone reassurance, among others.

Since the introduction of the system, the emphasis of activities has moved from institutionalization to the encouragement of home care, thus the specific-purpose housing with necessary services is expanding¹⁹. The cost of the housing endeavour is paid by the government or by a combination of social benefits¹⁹.

To date, the system has achieved a significant budget savings. The influence of regulators, insurance companies and providers has gained vitality thanks to the entitlement to benefits and payments¹⁹. However, as standardisation and consolidation of insurance funds' costs is preferred rather than looking for the most appropriate method of providing services, a rather inflexible system still prevails¹⁹. There is a visible absence of case management and integration between providers is a great challenge¹⁹.

1.1.2.3 England

In England, the long term care system is defined as a safety net that is mainly focused on those who cannot afford the arrangement of services by their own means²⁰. Although long term care system has evolved with the past of the time, the English system still maintains its means tests aimed at helping the needy. The philosophy behind this long term care experience is that the main responsibility for the long term care relies on the persons in need and their families. Only those who fail to meet the means-tested level receive publicly funded social care. In addition, the system pays special interest in focalizing the services towards those who live alone and do not receive informal care²⁰. As of the moment of writing this thesis, a major reform has been announced to take place in 2016 following a government's Green Paper published in 2009.

Reform in England has been guided through the work of a Royal Commission that reviewed the system and made a series of recommendations to the government²⁰. While the Royal Commission has been interested in a wide range of topics to be solved, the system of LTC funding in England, however, has remained almost unchanged, except for nursing care being made free to all those who need it and some small changes to the means tests²⁰. These means tests consist of an assessment of care needs and the preparation of a set of care required to meet those needs. This arrangement varies from region to region²⁰. In this process, there exists the possibility for a care manager to participate in the coordination or arrangement of the services for care.

In England, despite the fact that there is no national definition of the need for care, individuals are classified according to their needs using the eligibility bands of the Fair Access to Care initiative, a national framework for eligibility criteria that was

implemented to deal with problems of inconsistency among different places.²⁰.

In England, and in the United Kingdom to a greater extent, long term care is provided in a wide range of settings, including the community. Nursing homes are aimed at providing care that are in more need of direct care. Their provision has been in charge of several stakeholders, such as the private sector, voluntary and local governments²¹. In 2009, 8.6 percent of places were provided directly by local authorities. This is almost half the number found in Scotland²¹.

Services which are considered as long term care services belong to domestic tasks, such as shopping and meals and personal care tasks, such as dressing and bathing. In England there is the possibility for the older person to receive cash instead of services²⁰.

The main long-term care services available in the UK for individuals living in their own home are home care or home help services, private home help, community nursing services, day care in day hospitals or centres, meals on wheels or in lunch clubs, chiropody, therapy services and private domestic help²⁰.

The main institutional services are residential homes and nursing homes²⁰. Few persons access long-stay in hospitals and the government has recently invested in the development of extra-care housing, described as a kind of sheltered housing²⁰.

Regarding funding, the cost of providing long-term care is shared between private and public sectors. In the public sector, long-term care is largely the responsibility of local government. In the UK, local governments are able to collect just about 20 percent of the total amount it spends. The remainder comes from grants. Grants are provided in England by the UK parliament. The total expenditure in long term care as a percentage of the GDP is 1.37 percent, which is a little higher over the average of the OECD at 1.25 percent. As expenditure is divided into public and private expenditure, we find that 0.89 percent is provided by the public sector and 0.48 percent by the private²².

Regarding the challenges for this kind of system, beyond funding for a greater number of people in need and with no means, is the fact that there is one kind of facility that is available in Japan but not available in England. This kind of facility is the intermediate facility. There are plans to introduce intermediate facilities to fill the gap between health care and home care, with the purpose of rehabilitation²⁰. Another challenge is to better coordinate health care and long term care when discharging people in need of care. An intermediate facility aims to help in this regard²⁰. Additionally, the full establishment of a new Care

Quality Commission, which was created when the Health and Social Care Act of 2008 was enacted²⁰. The new Care Quality Commission is expected to improve the quality of the services overall.

Finally, the debate on long-term care funding in England is an ongoing process as this thesis is being written, and consultation is underway for a major reform of the system in 2016²³. The reform has been announced to give a lifetime cap for care²³. After the cap is reached by the paying user the government will take responsibility. The lifetime cap is expected to be £75,000 in 2017. Also, the upper capital threshold in residential care will be increased and is expected to reach £123,000 in 2017. Residential care, hotel costs will remain means tested and are expected to be £12,000 in 2017²³.

1.1.2.4 Sweden

The long term care in Sweden works under the philosophy of providing services for the elderly to achieve a high quality, independent life²⁴. The management of the system is provided by three stakeholders: the central government, the county councils, and the local authorities. The stakeholders decide the funding of the system by levying taxes and fees according to the Social Services Act²⁴. The services provided are solely determined based on needs, such as in the case of Japan. This means the services are not means tested.

Figure 5. Methods for assessment.

Katz ADL (activities of daily living) index	ADL taxonomy	'ADL steps'
EQ-5D	Functional Independence Method (FIM)	Gottfries-Bråne-Stein Scale (GBS)
Residential Assessment Instrument (RAI)	SF-36 Short Form Questionnaire	The Swedish National Study of Ageing and Care (SNAC)
Carers outcome agreement tool (COAT)	Camberwell assessment of need (CAN)	Mini Mental State Examination (MMSE)
Geriatric depression scale (GDS 20)	-	-

However, to avoid unnecessary use there is a monthly limit. Unlike England, the philosophy of the system takes away some responsibilities from the family and places them on the shoulders of the state, in a similar way as to the socialization of care in Japan²⁴.

The long term care system in Sweden provides the following services²⁴: institutional care, home care, and home nursing care. It also provides, day activities, meals services, personal safety alarms, home adaptation, and transportation services. These are additional services provided by the municipalities and are also regulated by law²⁴.

Funding

The cost of facility care in Sweden has been estimated to be around 3000 euros per older person aged 65 years and over. In the case of home care, it is nearly half of the cost of the facility. The total expenditure on long term care is nearly 3.5 percent of the GDP. Among this amount, less than 5 percent is privately funded²⁴. Due to the great burden on the state, there is an increasing interest in voluntary family care, however, evidence on family care provision remains very low²⁴.

A summary made of issues of the system, in terms of integration with the health system, are²⁴:

- Lack of communication between care levels
- Lack of chain of care or structural care network
- Lack of Professional steer-management
- Lack of coordination between the local municipalities and the county councils

- Difficulties in making the district nurses visit the elderly in their own home or at the nursing homes
- Coordination of financial matters between the two governmental bodies.

1.1.2.5 Netherlands

Netherlands is one of the first countries, along with Germany, to implement a care initiative based on cash assistance. This cash-based initiative is known as the Person-Centred Budget. It was introduced in 1995 by the government of the Netherlands¹⁷. Initially established as a demonstration, this cash assistance program was designed to promote greater choice and higher quality of care for consumers, as well as to encourage increased competition among providers¹⁸.

Cash payments, which are provided and funded through the country's exceptional medical expense insurance program, allow the users to buy ADL- and IADL-related services from the provider of their choice, including informal caregivers or private agencies; a small amount is set aside for flexible use.¹⁹ However, this is not the only cash benefit people receive. Since 1985 people can receive the so called “personal budget” available for certain disabilities.

Again, as in the same spirit of the German system, eligibility is extended to consumers of any age who need ADL and/or IADL assistance. This means there is no boundary related to age, but only regarding the needs of care, although nursing care is unable to exceed 3 hours of work daily¹⁷. If the users are too young or present cognitive impairment they need to provide a surrogate to take decisions.

Each client's monthly benefit level is determined by multiplying the hours in a professionally developed care plan by standard, national rates; income-related deductions are then taken. An independent fiscal agent has the responsibility for paying individual home care workers¹⁸. The exceptional medical expense insurance program in the Netherlands has proved to be an effective and important way to protect older persons from high expenditure in nursing homes, and since 1997 also in retirement homes, facilities for the disabled and stays in hospitals in the case where older persons need to be there for more than a year¹⁹. Their contribution amounts to 8.8 percent to 9.6 percent of the user's outcome. However, the major share is the responsibility of the employer, and once older persons retire they do not need to pay¹⁹.

One of the main critics to the way the system works is the poor coordination between primary health care and the long-term care¹⁹. This may be due to the provision of health care services as a joint work of the national and private sector¹⁹.

It is often argued that one of the distinctive features of the Dutch system in the world is that the beneficiaries are expected to join the organizations that provide services of home care, along with the long tradition of cash benefits aforementioned.

Despite its tradition, the Dutch system is constantly evolving. Just around 10 years ago the concept of case management and client-oriented service under the umbrella of “trans-mural care” has been imported from USA and UK¹⁹.

1.1.2.6 Japan

In 2000, Japan implemented the Long-Term Care Insurance (LTCI). The LTCI is a public mandatory insurance system aimed at providing institutional, community and at-home based care²⁵. The original system did not include Community based care. This was added in the revision of 2005²⁶.

The system aims at providing support to every elderly aged 65 or older based only on physical and mental disability^{27,28}. This a clear difference to the systems in Germany and The Netherlands mentioned previously, where there is no limit of age and needs of care are based purely on functional disability. While the system in Japan is based on the assignation of services on the functional challenges of the users, it requires them to be 65 years and older for the services to be used; or over 40 years old if the disability is caused by senescence.

Another difference is since its introduction, the emphasis was put in providing facility care. Unlike Germany, that actually went from Facility-oriented to Home-care oriented. Prior to the implementation of the system, Japan promised the socialization of care, removing the burden from the shoulders of the family and sharing it with society. However, with the past of the years the sustainability of such imbalance has made it evident that the burden of care cannot be merely maintained by the formal care, as there are no enough formal resources to cope. An evident fact is that the majority of care is provided by the family. In the case of developed countries the proportion of care provided by the family goes over 90 percent.

The Japanese LTCI is composed of three main elements presented by the providers in the

form of types of services: At-home services, Community Services and Facility Services.

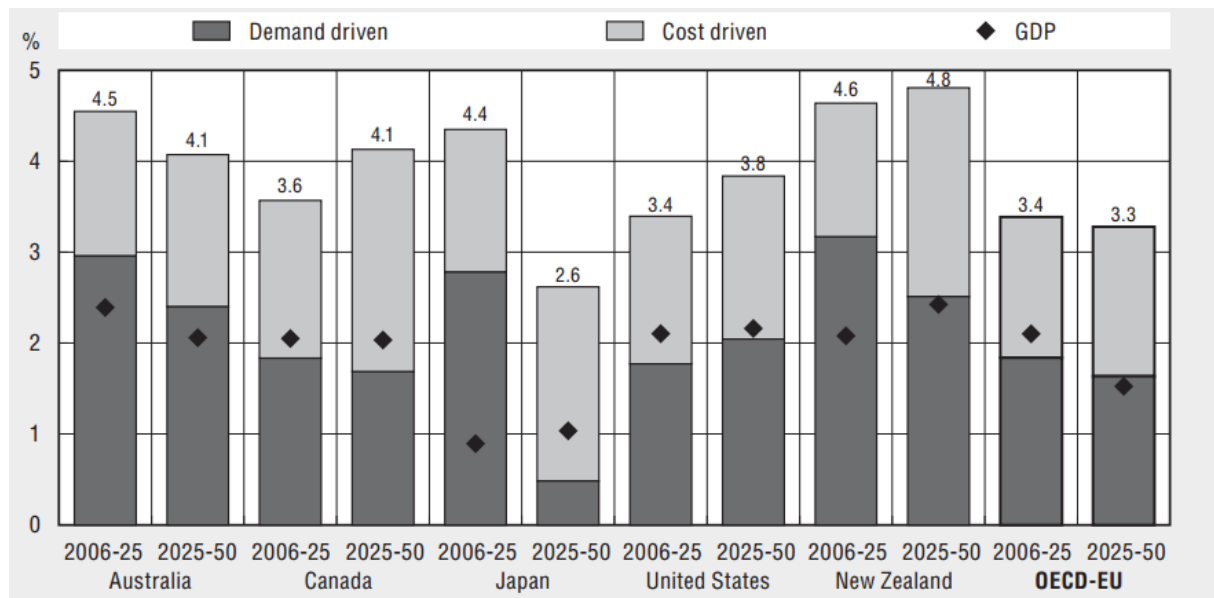
One distinctive element in Japan is that there are no cash benefits. This is a remarkable difference compared with Germany, The Netherlands, Austria, Korea and other countries around the world.

The main reason argued to avoid giving cash benefits, was the stigmatization of women, who represent the majority of caregivers in an environment of dependency and economic constraints.

1.1.2.7 Discussion

Long term care provision is a very complex issue. It can be observed that long term care arrangements varies in different countries in key aspects such as benefits, coverage, financing, benefits and limits to those benefits, and so on. It seems apparent to the author that these countries changed, and continue to change fundamental aspects of their socioeconomic structures when deciding what kind of long-term care to build, going in some cases from market-based to public provision; from home and family-care to institutionalization, from fiscal balance to threats to sustainability, and from lack of responsibility on the standards of quality to quality assurance efforts.

Figure 6. The average annual growth of LTC expenditure and real projected GDP growth



Source: Source: OECD calculations based on OECD Health Data 2010; European Commission (2009), Ageing Report; OECD Labour Force and Demographic Database, 2010; and Duval and de la Maisonnette (2009), as found in Future Demographic Trends and Long-term Care Costs, 2012.

The most prominent difference among countries and their arrangements of long-term care seems to be more evident in the table below, based on Karlsson et al¹³.

It is this different way to arrange a long-term care system what will greatly influence its cost and ensuing sustainability. In Germany, there is a tradition to fund support for the frail and dependent elderly with taxes¹⁷. The following change was to modify their criteria to grant benefits according to means-tests. However, some authors still considered that it might have been a better idea to increase the mean tested benefits instead of the present and more bureaucratic system of needs assessment¹⁷. On the other hand Japan is said to have broken way from its tradition¹³. The implementation of the Japanese system has moved away from their tradition of family care toward facility care. It has been argued that the Japanese system is different from the German system in that, first, the Japanese system offers complete compensation. Second, the method to assess the needs of the beneficiaries is more sophisticated. Third, it only reimburses formal care¹³.

Table 1. International Comparison of Long-term care Arrangement

	Germany	Japan	United Kingdom	Sweden	USA
Before LTC	Centralized, means-tested, facility-centered	Selective, relief, means-tested, family-centered	facility-care, means-tested, non-contributory	Domiciliary, volunteer, universal, public monopoly	Mean-tested, facility centered
After LTC	Decentralized, need-tested, home-centered	Universal, need-tested, preventive, facility-centered	decentralized, free of charge, Assets means-tested	Need-tested, purchaser/provider, private	Mean-tested, private
Financing	Pay-as-you-go, pooled risk, benefits independent of contributions	50% taxes, 50% insurance premiums (10% copayment care cost)	9% local authorities	20.57% Local income taxes, 5% out of pocket, rest by central government	Means-tested by Medicaid, medicare by premiums, private insurance or out of pocket.
Benefits	Preventive and rehabilitating measures, domiciliary over institutional care, cash benefits	Facility, home and community care (no cash benefit)	facility, community, and residential care, cash benefits	Facility and home care, home help, community activities, special accommodations, cash benefit	Medicaid=hospital, residential, home care (varies by state). Medicare: Hospital stays (3+ days), skilled nursing, hospice care. Private varies.
Coverage	90%	80%	100% if lack of resources (11.5% private)	100%	100% if lack of resources (15.9% effective)
Requirement	Need of LTC	Need of LTC and aged 65+ (40 if has an age related disease)	Means-tested	Need of LTC	Means-tested

Source: Self-made from an international comparison of long-term care arrangements: an investigation into the equity, efficiency and sustainability of long-term care systems in Germany, Japan, Sweden, the United Kingdom and the United States, Karlsson et al 2004.

Regarding the aspect on what scheme would be more recommendable to a particular country remains an open question. Developing countries that may apply this system have not only very low rates of taxation on income and other revenues, but additionally have high rates of tax evasion. This means that they are very ineffective in collecting the taxes the state should perceive. To the author, it seems that in countries with low taxation it may seem more appropriate the use of co-payments for all services. That would be the case of Japan and the Netherlands¹⁷. Co-payments are also usually used as tools of cost-containments, by limiting the utilization. In the case of Japan, the existence of these co-payments is said to prevent a steep increase of taxes¹³. However, the detrimental effect of these limitations must be carefully assessed to avoid social injustices, like preventing access when needed. Additionally, a system where not only taxes would be used by the contribution of employers, but also by the users themselves through premiums, which may serve to make the system sustainable in the long run, while protecting the provision of cheaper home and family care.

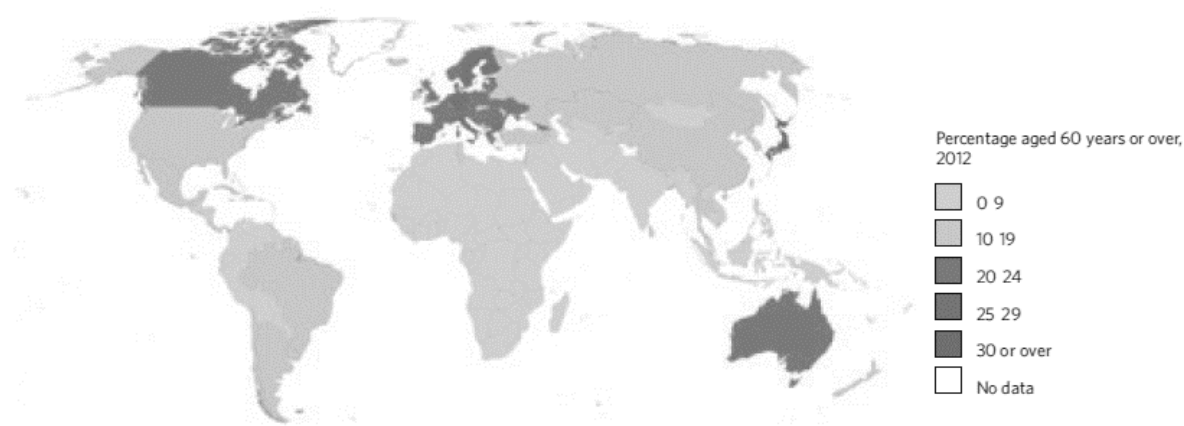
Based on these preliminary findings on the characteristics of long term care systems

around the world, the author of the present thesis dissertation has decided to focus on the Japanese system as a more feasible way to be implemented in a developing country like Chile, where family care is still the most important element of provision, taxation is low, tax evasion is high and where the co-payment and premium that may help sustain an incipient system may be more readily implemented, while maintaining the social justice that may be threatened by a full free-market provision.

1.1.2.8 Developing countries

Developing countries, unlike developed countries, have been considered for a long time to be countries with a high proportion of young persons, particularly children. While the differences between the developed and developing countries are clear, we also find among developing countries a heterogeneous distribution of their ageing process. In 2012, 6 percent of the population in Africa was 60 years and over, compared with 10 percent in Latin America and the Caribbean, while Asia reached 11 percent, and 15 percent in Oceania. In more developed regions the situation was different, reaching 19 percent in Northern America, and 22 percent in Europe²⁸.

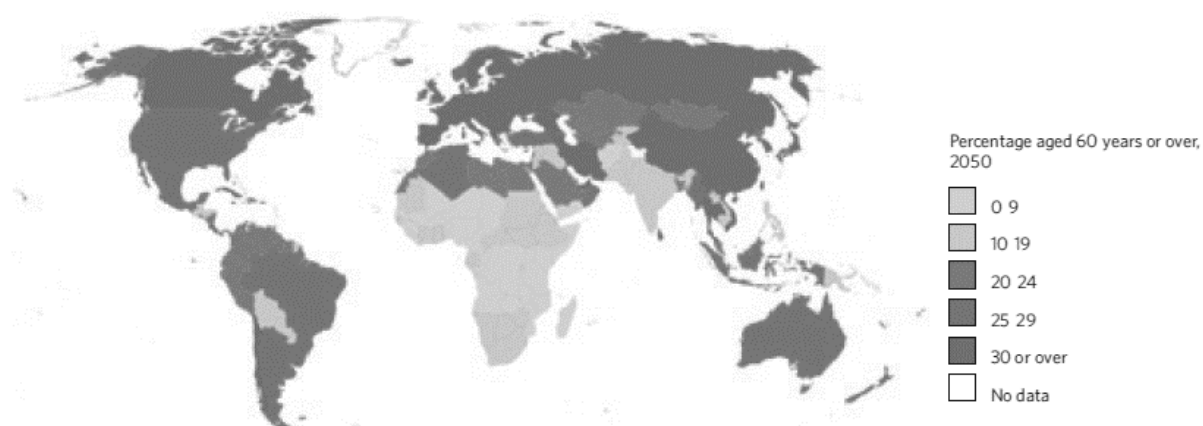
Figure 7. Proportion of population aged 60 or over in 2012



Source: UNDESA, Population Ageing and Development 2012, Wall Chart

However the demographic scenario has changed considerably in the last decades due to the decrease of fertility and the increase in their life expectancy in the developing world^{29,30} and will continue to change. By 2050, 10 percent of the population in Africa will be 60 years and over, compared with 24 percent in Asia, 24 percent in Oceania, 25 percent in Latin America and the Caribbean, while in more developed regions we can observe up to 27 percent in Northern America, and 34 percent in Europe.

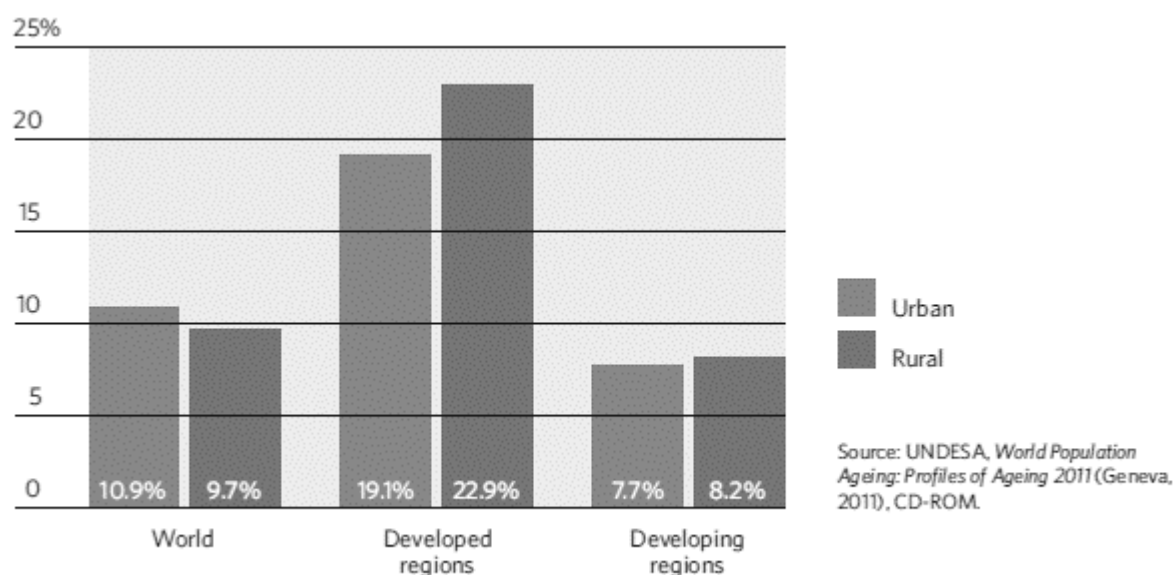
Figure 8. Proportion of population aged 60 or over in 2050



Source: UNDESA, Population Ageing and Development 2012, Wall Chart

As mentioned above, population ageing does not only present differences among different levels of development, but also within and between regions, and within nations as well, partly due to urbanization and migration³¹. This takes place when younger groups move in search of job opportunities to cities, leaving behind a much older group in the rural areas³¹.

Figure 9. Percentage of the population aged 60 or over in rural and urban areas in 2005



Source: UNDESA, World Population Ageing: Profiles of Ageing 2011

As can be observed in the figure above, due to the fact that developed countries are more urbanized and most of the developing world still presents a high proportion of the

population living in rural areas, the proportion of older persons by area at the global level is higher in urban than in rural areas ³¹.

The population ageing we have described above takes place, along the modernization of societies in developing countries that among its many traits affects family support. Modernization presents the following characteristics: Lower fertility translate into fewer children available for family care and provision of care. Higher education levels increase the information gap between old parents and children, which may lead to differences in attitudes and perceptions towards obligations to provide familiar support. Increased female labour force participation decreases the number of caregivers, although it may increase the purchase power available for care. Finally, rural urban migration draws younger people out of rural and into urban areas, and therefore decreasing the number of people able to provide daily care and support to the elderly. The changes in the demographic transition of developing countries has led to arrangement of incipient services for the elderly and a more diverse structure of families³⁰.

The first coordinated effort to cope with these changes, and leading to the creation of long term care services, was carried through the adoption in 1992 of the International Plan of Action on Ageing, adopted at the first World Assembly on Ageing in Vienna. In the previous year, an important documents on aging was adopted by the General Assensbly of the United Nations entitled Implementation of the International Plan of Action on Ageing and related activities. The Macao Plan of Action on Ageing for Asia and the Pacific ³² was one of the first international and regional efforts to address this challenge. It identified major areas of concern and priorities for action on ageing.

The Macau declaration³² was adopted during the Regional Meeting on a Plan of Action on Ageing for Asia and the Pacific convened by the ESCAP, Economic and Social Commission for Asia and the Pacific, Secretariat at Macau in a meeting that lasted from 28 September to 1 October 1998. 45 representatives and observers from governments and non-governmental organizations participated in the adoption of this declaration. The Plan of Action has seven areas of concern: a) Social position of older persons, b) older persons and the family, c) health and nutrition, d) housing, transportation and the built environment, e) older persons and the market, f) Income security, maintenance and employment, g) social services and the community³². These areas of concern were thought to recognize the imminent arrival of the ageing process, along with its long-term care implications and challenges.

a) Social position of older persons. This point of concern states the negative image of

ageing and the aged population, where the elderly appears frail, disabled and dependent, while actual research shows a different situation. It also acknowledges the increasing life expectancy and therefore the necessity to arrange a productive and meaningful life for this increasing group.

- b) Older persons and the family. In this point, the important role played by the family in Asia and the Pacific, especially for providing support to older persons, is recognized by the governments and support initiatives for care-giving are stated.
- c) Health and nutrition. States that while older persons are prone to age-related diseases this does not mean that ageing is synonym with poor health. Also, it highlights the importance of primary and secondary health care, along with education on healthy ageing.
- d) Housing, transportation and the built environment. The important of the family house in Asia and the Pacific is emphasized, along with necessity to improve their housing conditions, and transportation to allow their independence and mobility.
- e) Older persons and the market. The elderly should be protected from abusive market schemes, while promoting private initiatives and the establishment of minimum standards.
- f) Income security, maintenance and employment. The importance of income security for old age is acknowledged in the Asia and the Pacific region, highlighting that saving should be encouraged, or implemented in those countries where there is no security system, especially for vulnerable groups.
- g) Social services and the community. This point emphasizes the necessity of having external support such as day-care rehabilitation, counselling, among others. This support varies across countries and across settings. In addition, older persons as beneficiaries can also share information and be valuable resources in the community.

The participant governments and associate members were asked to take prompt actions to implement the Plan of Action, and at the same time requested the Executive Secretary of ESCAP, Economic and Social Commission for Asia and the Pacific, to provide full support and assistance.

The Macao Plan of Action on Ageing for Asia and the Pacific was followed by the Second World Assembly on Ageing that took place in Madrid, Spain in 2002. The final product of that assembly was a rights-based and policy relevant Political Declaration and Plan of Action on Ageing to manage the challenges of population ageing in the 21st century ³¹ that came to be known as the Madrid Plan³³. The Political Declaration and Plan of Action are aimed for major problems that affect the lives and well-being of older persons and recommend concrete policy actions in the three priority areas of older persons and

development, advancing health and well-being into old age, and ensuring enabling and supportive environments ³¹.

The three directions are known as the three pillars of the Madrid International Plan of Action on Aging³³:

Pillar I. Old Persons and Development

- a) Active participation in society and development.
- b) Work and the ageing labour force
- c) Rural development, migration and urbanization
- d) Access to knowledge, education and training
- e) Intergenerational solidarity
- f) Eradication of poverty
- g) Income security, social protection/social security and poverty prevention
- h) Emergency situations

Pillar II. Advancing health and well-being into old age

- a) Health promotion and well-being throughout life
- b) Universal and equal access to health-care services
- c) Older persons and HIV/AIDS
- d) Training of care providers and health professionals
- e) Mental health needs of older persons
- f) Older persons and disabilities

Pillar III. Ensuring enabling and supportive environments

- a) Housing and the living environment
- b) Care and support for caregivers
- c) Neglect, abuse and violence
- d) Images of ageing (1 objective, 8 actions)

When the governments adopted the Madrid Plan, it was the first time that they agree on the need to link ageing with human rights. It is argued that this was because the human rights approach to development was gaining increasing importance on the international stage³¹. The Political Declaration ratifies the promise on the promotion and protection of all human rights and fundamental freedoms, including the right to development³³.

Based on the plan of actions and key policy identification, governments started to apply the indications contained in the declarations as some of examples given below³⁴.

1.1.2.8.1 China

China began working their National Working Commission on Ageing established in 1999 by grouping 26 government and non-government organizations; areas of focus include:

- Establishing an Old-age Insurance System in Urban Areas
- Probing the Establishment of an Old-age Security System in Rural Areas
- Establishing Aid System for Impoverished Elderly People
- Working Committees on Ageing and Old Persons' Associations at both central and local level;
- Law of the People's Republic of China on Protection of the Rights and Interests of the Elderly (1996)
- The 10th 5-year Plan on Ageing (2001-05)
- The 11th 5-year Development Plan on Ageing (2006-10)
- Local regulations to protect rights and interests of older people at provincial, regional and municipal level.

China has been particularly keen to work on cultural and civic programmes to ameliorate social isolation³¹. Chinese older persons are active through the Chinese Older Persons' Chorus Festival and national associations of senior citizens. In 2009, China also organized the First National Sports Meeting for the Elderly, and in 2008, three ministries sponsored Olympic Games for older persons³¹.

1.1.2.8.2 Malaysia

Malaysia began working with their National Policy for the Elderly adopted in 1995 and whose main point of interest are:

- National Advisory and Consultative Council for the Elderly (NACCE) formed in 1996 to make recommendations to the government in population ageing.
- Elderly Health Care Program established by Ministry of Health (1996)
- Older Persons Aid Scheme provides modest stipend to elderly destitute since 1979
- Public Health Care Services for persons 60+ are mostly free and heavily subsidized
- Federal and state-funded homes for elderly that require shelter
- Geriatric wards and related services introduced in pilot general hospitals
- Specialized training in aged care and scholarships for further studies in geriatrics
- Incentives to encourage filial responsibility in form of tax rebates and deductions
- Incentives to employers who hire retirees

1.1.2.8.3 Thailand

Thailand established their National Commission for the Elderly in 1999 which created the current Second National Plan for Older Persons (2002-2021); the main areas of this effort are:

- Act on Older Persons (2003) to provide policy framework for welfare promotion, protection and empowerment of older persons;
- Government provides social welfare assistance for destitute elderly;
- Created an Older Persons Fund
- Tax exemptions for adults that take care of their old parents
- 30 baht Universal Health Care Scheme to support health care for the elderly
- Ministry of Health is encouraging community hospitals to run elderly clinics and provide home health services for elderly.
- Other initiatives focus on strengthening income security, life-long education, day centres for health care and promotion, family assistance, social activities for elderly, etc.

As observed in the examples above, an important element of the declaration of Madrid is the fact that governments, the United Nations system and civil society aim to participate in a “bottom-up” participatory approach. This approach is also applied to the way the interventions are evaluated. A set of indicators for the review and appraisal of the Madrid Plan to assist the “bottom-up” approach was developed by the United Nations Programme on Ageing of the Department of Economic and Social Affairs³¹.

Discussion

Despite national efforts following the international commitments on ageing, the creation of fully functional, nation-wide, long term care systems is still a hard objective for developing countries, where competing challenges are still much in place. The challenges that population ageing poses to economies have been object of extensive discussion among politicians, policy makers and researchers³¹. One of the most heard notions is that the ageing of the population will affect economic output, or even lead to deflation³¹. Due to this, it questioned how nations of the world, especially the poorer ones would be able to afford social security as their populations grow older. While developed countries have experienced economic growth, a considerable part of the peoples of the world still live in poverty. The challenges of these disadvantaged peoples can be represented in many factors that hinder the implementation of long term care services, creating a vicious circle

of neglect. Among these challenges we can cite some below:

Disparities in labour force participation

Labour force participation rate, as defined by the International Labour Organization, is the proportion of the population ages 15 and older that is economically active³⁵. However, when we talk about the participation of the elderly, the definition only applies to those aged 60 or older. In the world, it is estimated that nearly 35 percent of the elderly population works. Working at advanced ages it is a complex issue, as the individual ageing process poses many challenges that make it harder to have a stable income. Among the many factors we can find for the usually lower participation of the elderly are poor working conditions, ill health, low job satisfaction, pension arrangements and negative perceptions about older workers. However, we must consider that in developing countries up to 90 percent of older people work. The highest rates of labour participation of older citizens take place in Africa. This is likely to happen because of the absence of social security systems³⁶.

When we look at the gender differences we also find disparities between genders. While 47 percent of older men actively participate in the workforce, only 24 percent of older women do so³⁷. This fact poses further challenges to the aforementioned feminization of ageing.

If we take the situation of Asia as an example we observe how the labour participation of the older changes by gender, we can observe that the proportion of males working at old age goes up to 52 percent and women to 23 percent. If we look at the sub-regions, we find that Eastern Asia present a 48.4 percent for men and 22.1 percent for women. In South-Central Asia men proportion goes up to 57.4 percent and women 20.4 percent. In South-Eastern Asia the proportion of men reaches 59.4 and women 36.6. Finally, Western Asia presents the lower proportions with 35.8 percent for men and 12.8 percent for women.

Another important aspect of the participation of older people in the labour force is that most of them are employed in the informal economy. This would mean they are self-employed or that they receive payment, but without secure contracts, worker benefits or social security. Furthermore, a lot of women endure many challenges while provided with a lot of work at their household; this is not recognized by labor-force surveys. Some of these important roles are caregiving and household tasks.

Lack of pension coverage

Pensions are regularly provided income provided to individuals having reached a certain age and who are no longer earning a steady income. This type of pension is called old-age pension to differentiate it from other branches of social security. They can be classified in many different ways: contributory or non-contributory, meaning that the beneficiaries are only those who contributed to the system or not. They can also be mandatory or voluntary, public or private, social, occupational or personal, basic or supplementary. However well defined, these pensions constitute as part of the national pension system. The particular characteristics or arrangement of the pension system usually reflect the policy view of the state or the levels of development of the country.

Old people of both genders present diminished physical and, commonly, mental capacities, and thus, have fewer opportunities for employment. As a consequence, there is a higher reliance on other sources of support such as pension schemes.

Coverage

We need to distinguish among different definitions about pension coverage. Here we will discuss two of them: Legal coverage, also known as statutory coverage, and effective coverage. Legal coverage is made of the statutory definitions (legal provisions) made by the law of the different countries, while the effective coverage is the actual number of those contributing or receiving the benefits stipulated in the legal provisions³⁶ (ILO, 2010). By definition, effective coverage can only be equal or lower to the mandatory. In actuality, effective coverage is substantially lower than the legal coverage^{36,38}. This difference can be explained by many factors, such as incomplete implementation and enforcement of the legal framework, non-compliance and trends towards more unstable and precarious forms of employment³⁸.

Legal coverage

In the world, it is thought that only 42 percent of the population of working age is legally covered by contributory old-age pension schemes³⁶, including voluntary schemes.

However, due to the previously mentioned low proportion of formal sector employment, in many countries, low numbers of older people have access to a pension and the growing incidence of informal work led to stagnant or even declining rates of coverage³⁸.

Moreover, we also need to consider the enormous regional differences. In North America and Western Europe the percentage of the working-age population legally covered almost double the one of the world (42 percent) with 75.4 percent and 77.4 percent, respectively.

In Sub-Saharan Africa the percentage go as low as 26.1 percent. In the case of Asia and the Pacific, the percentage remains under the world average with 31.9 percent.

Effective coverage

It is necessary to distinguish among different classifications of effective coverage. For this paper, we focus on two types: Effective old-age coverage in percentage of the working-age and effective old-age coverage in percentage among the retired population.

Effective old-age coverage in percentage of the working-age

In this indicator of coverage that considers in the numerator and denominator the actual number of people contributing and receiving the benefits, excluding voluntary schemes, is that the percentage in the world is 25.8. In this case, the percentage of legally covered working population of 42 percent worldwide went down to a 25.8 percent of those actually using the system. Even this kind of coverage remains high for North America with 72.4 percent of coverage for those of the working age. Western Europe follows with 65.3 percent and central and Eastern Europe with 48.4 percent. Latin America has a 28.1 percent of coverage, followed by North Africa with 24.3 percent of coverage. In the last three positions we find Asia and the Pacific with 18.7 percent, Middle East with 17.8 and Sub-Saharan Africa with only 3.9 percent.

Effective old-age coverage in percentage among the retired population

Regarding particularly to Asia, based on available data (35 countries), we observe that the proportion of effectively covered population above legal retirement age in receipt of a pension (percent) varies greatly, going from the 100 percent of coverage in countries like Kyrgyzstan and Uzbekistan to numbers as low as low as 0.5 percent in Bhutan. Countries of the former Soviet Union have high percentages of coverage, but low social security expenditure in some of these countries as well as other evidence indicates that actual pensions paid are very low³⁶.

As we can observe, the great majority of the world population still lacks access to social security coverage, even by legal standards. Very few countries have non-contributory pension systems. Moreover, women, who comparatively have a low participation in the work force, at all age groups, are usually affected by the contributory characteristics of most of the available pension schemes in the world, and thus are particularly at risk of poverty and exclusion. One of the reason is that the labour participation of women is more diverse, having periods of leave due to maternity, and caregiving activities in general, and ensuing part-time or no activity at all, which may prevent them from fulfilling eligibility criteria of pension systems designed for men³⁹. Additionally, the

informal sector, mainly composed of women does not qualify for contributory systems designed for formal workers³⁹. There is also a gender gap in pension coverage with women not only having lower coverage but also lower pension benefits³⁶.

Furthermore, in the world, existing public pension systems are, and will continue to be, under increasing pressure because of the growth in the number of older people and the longer retirement periods due to an ever increasing life expectancy³⁶. In recent years, the economic crisis and economic instability in general, have put further pressure on pension schemes. Lack of economic growth, budget deficits and debt crises, as well as financial instability and low employment, have made traditional pension systems increasingly unsustainable in many countries³¹. As a consequence, some countries have reformed, or are considering reforming, their pension systems³¹.

2 Chapter 2: Aging in Japan

2.1 Demographic transition

Japan's total population according to the 2010 Population Census as stated in the Statistical Handbook of Japan 2011 was 128.06 million ⁴⁰. The Japanese accounts up to 1.9 percent of the world's total population.

In 1950, the proportion of elderly people was about 5 percent of the total population ⁴⁰. However, since 1950 the proportion of elderly population in Japan has been increasing continuously. By 1970, the proportion of those aged 65 years and over went up to 7 percent and to 17.4 percent by 2000 ⁴¹.

This high-speed trend continues until now. As of 2010, the elderly population in Japan had already exceeded the 23.0 percent (29,246,000 people) of the total population ^{40,42}. Moreover, statisticians predict that by 2040 this number will rise to 36.3 percent ⁴³. Japan is considered as a super-aged society and with the highest proportion of elderly people in the world ^{6,41}

2.1.1 Life expectancy in Japan

In 1950, according to the population census, Japanese life expectancy was 59.75 years old

for both sexes; for the male population was 58 years old and 61.5 for women ⁴⁴, but as of 2011, it is 83 years old for both sexes; 80 years for men and 83 years for women according to the Life tables for 2009 noted in the World Health Statistics 2011 ⁴⁵ by the World Health Organization. It can be noted that Japanese women's life expectancy is the highest in the world.

The main source for the improvement in life expectancy can be related to the longer survivorship of senior citizens in Japan. This remarkable achievement has been attributed, among other reasons, to favourable risk factor behaviours, health system performance, and universal coverage of the health care system, among other public health interventions⁴⁶.

Moreover, this high life expectancy at birth is thought to increase even more, to reach 90.34 years for women and 83.67 years for men by the year 2055, according to projections by the National Institute of Population and Social Security Research ⁴⁷.

2.1.2 Fertility in Japan

Japanese total fertility rate is 1.39 as of 2010 ⁴⁰, which is very low compared to what it was back in 1950 when it was 3.65 ⁴⁴. This rate is much smaller than the rate of 2.1 which is needed to maintain the current population among industrialized countries⁴⁸⁻⁵⁰.

This declining fertility has been interrupted twice by periods referred to as baby-booms, which are marked increases in the fertility rates. The Japanese has experienced two identifiable baby booms and they have been very short^{40,44,47,49}. The first one occurred between 1947 and 1949 for a period of three years. Following this short period of higher birth numbers Japanese fertility went down again. After 1949, Japanese fertility went down by 50 percent within the following ten years⁵¹.

Between the years 1971 and 1974, there was the second short baby-boom period encouraged by the economic bubble Japan was living in those days with favourable economic conditions, however, it started to decrease again after the oil crisis of 1973⁵¹.

2.2 Development of the Long Term System

2.2.1 Law for the welfare of the elderly

The beginning of a systematic approach to the social welfare and protection of the elderly can be dated back to 1963, when the government implemented the law for the welfare of the elderly^{50,52} as the Japanese elderly population reached up to 5.7 percent of the

population. By enacting this law, the Special Nursing Homes (as of 2011 referred to as Welfare facilities for the elderly requiring long-term care) and the law for home helpers were created.

2.2.2 Universal and free health care for the elderly

In 1973, a major policy was enacted. It was the universal and free access of the elderly to medical treatment^{50,52}, when the elderly population represented 7.1 percent of the total. However, despite its clinical and positive influence on the medical conditions of the elderly users, this policy opened the door to a long-standing problem in the Japanese society. This phenomenon is the so called “Social hospitalization”. Social hospitalization could be defined as hospitalizing and elderly people for non-medical reasons under the responsibility of the health care system^{50,53-55}. Among the reasons, it is mentioned the lack of appropriate intermediate facilities in charge of long term care activities⁵¹ and the increasing impossibility of the family to take care of the elderly. Then, in a society under a Confucian tradition, stigmatization because of failing to comply to filial obligations of care were avoided by the hospitalization of the elderly instead of the use of Long Term Care Facilities (LTCF)^{51,55,56}.

2.2.3 The gold plan

In 1989, another major change was introduced: the creation of the “Gold Plan” officially referred to as the “Ten-Year Strategy to Promote Health and Welfare for the Aged”⁵⁴, to promote in-home care. to reverse the increasing phenomena of “Social Hospitalization” and over utilization of facilities by promoting home care for the elderly through the expansion of social services such as home helpers and care facilities⁵⁴. Another important feature of this system is that the support was mean-tested and it varied accordingly to the availability of family caregivers²⁷.

2.2.4 Long term care insurance system

In 2000, when the elderly population reached 17.3 percent of the total population, Japan implemented the Long-Term Care Insurance (hereinafter as LTCI). LTCI is a public mandatory insurance system aimed at providing institutional, community and at-home based care²⁵. The original system did not include Community based care. This was added in the revision of 2005²⁶. The system aims at providing support to every elderly aged 65 or older based only on physical and mental disability^{27,28}. The following content has been obtained from the official website of Welcome to Ministry of Health, Labour and Welfare

in English.

The objectives of the LTCI are ²⁵:

- A) To socialize the support to those in need of long-term care by making it a responsibility of the society as a whole.
- B) To establish a transparent system where the relationship between benefits and burdens was clear to the public and easily understood.
- C) To establish a horizontal relationship between the health, medical and welfare services, so the users of the system would be able to choose services from different institutions of their choice in a holistic approach.
- D) To divide the expenses generated by the long-term care and the health care insurance, and to establish a system aiming at decreasing the cases of "social hospitalization".

Stakeholders: The system is composed of three main actors a) The insured, b) the insurer and c) the provider ²⁵.

a) The Insurers

The insurers are the municipalities, and wards in the case of the metropolitan area. The central and prefectural governments, health care insurers and pension insurers are encouraged by law to provide continuous support and assistance to the municipalities.

b) The insured

Every Japanese citizen aged 40 years old or more becomes the insured after starting compulsory contributing to the payment of the premiums to the system.

They are divided into two groups:

Group one: The person who is 65 years old or more in need of long-term care (bedridden or demented elderly people) or people requiring support (frail elderly people). This group represents about 28,380,000 people ⁵⁷.

Group two: Any person over 40, and under 65years old suffering from an age related disease such as early-stage dementia, cerebrum-vascular disease, and others. This group represents about 42,400,000 persons ⁵⁷.

c). The provider:

The providers give three types of services: At-home services, Community Services and Facility Services.

At-home services: Aimed at supporting the elderly at-home, the main categories of at-home care services include home-visit/ care for the elderly with dementia, and allowances for the purchase of welfare devices and home renovation ⁵⁷.

In detail the list of available services is as follow ²⁵:

- Home-visit care (home help service)
- Home-visit bathing service
- Home-visit nursing care
- Home-visit rehabilitation
- Commuting rehabilitation service (day care)
- Management guidance for in-home care
- Commuting for care (day service)
- Short-term stay at a care facility (short stay)
- Medical care service through a short-term stay
- Daily life care for elderly in specific facilities
- Sales of specific welfare instruments
- Lending welfare instruments

Community Services: This kind of services was introduced in the Revision of the Long-term Care Insurance System aiming at providing diversified, flexible services reflecting the characteristics of each region ²⁶

- Night time home-visit care
- Commuting care for elderly with dementia
- Small-sized multifunctional at-home care
- Daily life care in communal living for elderly with dementia
- Community-based daily life care for elderly in community-based specific facility
- Community-based daily life care for elderly in welfare facilities for the elderly requiring long-term care

Facility Services: They are structured into three types of facilities, 1) Welfare facilities for the elderly (special nursing homes), 2) Geriatric health service facilities, and 3) Medical facilities for the elderly.

The Three Types of Long-Term Care Facilities as defined in the Survey of Institutions and Establishments for Long-term Care by the Ministry of Health, Labour and Welfare of Japan ² are:

1) Welfare facilities for the elderly (special nursing homes):

A 'Special nursing home for the elderly' (only those with capacity of 30 residents or more) prescribed in the Act on Social Welfare Service for Elderly, which was designated by a prefectural governor based on the Long-term Care Insurance Act, and aims to provide assistance in activities of daily living such as care for bathing, toileting, eating, functional training, health control and recuperative care to their residents requiring long-term care based on a facility service plan.

2) Health Care Facilities for the Elderly Requiring Long-Term Care (HCFE):

A facility which was established with the prefectural governor's permission based on the Long-term Care Insurance Act, with the purpose of providing nursing care, long-term care under control of medical management, functional training and other necessary medical treatment, and assistance in activities of daily living to their residents requiring long-term care based on a facility service plan.

3) Sanatorium-Type Medical Care Facility for the Elderly Requiring Long-Term Care

A medical facility prescribed in the Medical Care Act, that was designated by a prefectural governor based on the Long-Term Care Insurance Act, and aims to provide recuperative management, nursing care, assistance including long-term care under control of medical management, functional training, and necessary medical treatment to their residents requiring long-term care based on a facility service plan. This type of facilities was planned to disappear by the end of the fiscal year 2011.

3 Chapter 3: Aging in Chile

3.1 Demographic transition

In 2014, Chile can be described as a country in an advanced stage of the demographic transition. According to the preliminary results of the last population and housing census in 2012, in Chile there were about 1.7 million persons aged 65 years and over, representing approximately 10 percent of the total population. This proportion represents an increase of 41 percent over the previous 2002 census. The results of the population and

housing census of 2012 were questioned in 2013 due to procedure problems ⁵⁸ and planned to be done again in 2017. However, projections were made to provide temporary information on population characteristics ⁵⁹. According to these projections, by 2014, older persons aged 65 years and older represent 10 percent of the total population ⁵⁹.

It must be noted that, unlike Japan, the definition of old age by the state is set at 60 years old and will be the definition used in our studies. By 1970, people aged 60 years old or over accounted for 8 percent of the population. According to the 2002 population and housing census this number increased to 11.4 percent and, according to data from the 2006 Survey of Socioeconomic Characterization (Casen), older persons aged 60 years and over reached 13 percent of the total population ⁶⁰. By 2014, projections ⁵⁹ show 14.5 percent of the population to be 60 and over and 17.3 percent by 2020 ⁵⁹. By 2025, 3,825,000 persons are projected to be older, which represent 20 percent of the total population ⁶⁰.

3.1.1 Life expectancy in Chile

In the period 1952-1953, according to the Institute of National Statistics ⁶¹, Chilean life expectancy at birth was 54.85 years old for both sexes; for the male population was 52.95 years old and 56.83 for women ⁶¹, but as of 2002, it increased to 77.08 years old for both sexes; 74.37 for men and 80.40 for women. In 2014, life expectancy is 80 years for both sexes; 77 years for men and 83 for female, according to the World Health Statistics 2014 by the World Health Organization ⁶².

The main source for the improvement in life expectancy can be related to the longer survivorship of senior citizens.

Moreover, this high life expectancy at birth is thought to increase even more, to reach 83.86 for women and 77.64 for men by the period 2025-2030, and for the period 2045-2050 it is estimated to reach 85.40 years for female and 79,00 for males, according to projections by the Institute of National Statistics ⁶¹.

3.1.2 Fertility

Between the period 1990-1995, women in the age group between 20 and 24 years had, in relative terms, the highest fertility rates by age group. This stage is known as "early" fertility. Subsequently, during the period between 1995 and 2000, the age group between 20-24 and 25-29 years, have almost the same relative total contribution on births. This stage is referred to as "delayed" fertility. Recently, in the period 2001-2002, the structure

becomes a "late" fertility, characterized by a relative contribution to the total fertility of women driven mainly by females between 25 and 29 years old.

Regarding total fertility rate (TFR), it has consistently declined in Chile from 4.95 in the period 1950-1955 to 2.0 in the period 2000-2005, when it went below the so-called *replacement rate*⁶¹. In 2012, the TFR in Chile is 1.8 as reported by WHO⁶². It is projected a decrease for the period 2015-2020 to reach 1.8⁶¹. However, it is projected that this level will remain stable at 1.85 until the period 2045-2050⁶¹.

3.2 Development of a long term care system

3.2.1 Commission for the elderly

The Commission for the Elderly was created in 1995 by the President Eduardo Frei. The Commission was directed by the wife of the president, Mrs. Marta Larraechea Frei, and consisted of 38 persons from various public and private organizations, including parliamentarians, government agencies, academics, members of social organizations and unions. The work done by the Committee led to the creation of the National Committee for the Elderly, which was responsible for coordinating and articulating the National Policy for the Elderly⁶³. The commission took a more relevant role in the creation of policies for the elderly and it became a national committee.

3.2.2 First Government Policy on Older Persons

The creation of the national committee was followed in 1996 with the creation of the first "Government Policy on Older Persons". This government policy was created to provide the theory framework for policy-making and was founded on two values: equity and intergenerational solidarity. Equity aims to address the high levels of inequity that Chilean society presents. Poverty becomes exacerbated in old age, precluding resources to satisfy basic goods and services. The state aims to give all older persons regardless of socioeconomic status a better quality of life by supporting those older persons with less resources⁶⁴. In this point on equity, it is the first time that improvement of quality of life is mentioned. Secondly, intergenerational solidarity recognizes the contribution of older persons to society and expects younger generations to provide a retribution on aspects such as social, economic, cultural and political development⁶⁴. This retribution is argued to provide justice, a life with dignity and better quality of life.

This first government policy on older persons was founded on 4 pillars: independence and

active ageing; prevention; policy making flexibility and, decentralization and subsidies from the state, having the general objective of "achieving a cultural change of the entire population on the assessment and treatment of the older persons, which implies a different perception on aging and achieving better quality of life for all older adults."⁶⁵.

3.2.3 National Agency for Older Persons

In 1999, the government started the transformation of the National Committee for the Elderly into a new National Agency for Older Persons. In July 2002, the National Congress approved the bill creating the National Agency for Older Persons, under the law 19828 law, enacted two months later, on September 17, 2002. In January 2003, SENAMA began its operations⁶⁵.

The National Service for the Elderly, is responsible for guaranteeing and promoting knowledge and exercise of the rights of older people, in order to promote their full integration into society and establish a system of social protection through coordination, implementation and evaluation of policies, plans and specific programs ⁶⁶.

The agency is created as a functionally decentralized public service, with legal persona and own assets, subject to the control of the President of the Republic through the Ministry of Social Development. The agency defines an elderly person as those aged 60 years or over and argues that the main task is "to improve the quality of life of older people in the country." ⁶⁷.

3.2.4 Long-term care facilities

The definition for long-term care facilities in Chile is provided by the Ministry of Health through the resolution 134 in 2005, and defined as places: "where older persons live, for biological, psychological or social reasons, and require a protected environment and differentiated care for the maintenance of their health and functionality, and which are authorized to operate as such by the Regional Ministerial Secretariat of Health according to their location". This definition excludes the informal and therefore unauthorized facilities.

The users are defined as older persons aged 60 years and over, excluding those who suffer from severe illnesses and that would require constant medical care.

One of the early attempts to obtain the number of older persons institutionalized was carried out in 2004 by Marin et al ⁶⁸. At that time there was no reliable information about the number of institutionalized elderly subjects. The authors developed a proxy indicator of the percentage of institutionalized elderly (those living in collective residences with more than 5 elderly persons and in which they represent more than 25 percent of the residents). This proxy was argued to have a $R^2=0.9859$ with the real number of institutionalized older persons in Latin-American countries ⁶⁸. Using this proxy applied to national housing and population censuses from 1992 and 2002 (In Chile censuses takes place every 10 years) to calculate the number of institutionalized older persons, they found that the elderly population had increased from 14114 (1992) to 26854 (2002) and it was projected to reach 83500 (2025). In 2002, there were 1.668 institutions (37.4 percent were institutions providing informal care). In the Metropolitan Area, there were 804 institutions (with 14178 elderly persons) and 40.3 percent of these were registered at the Ministry of Health as formal facilities⁶⁸. As there is no official census results for 2012 ⁵⁸, this method cannot be used to update these figures.

The results of that study shows that the proportion of institutionalized elderly subjects was 1.56 percent of the total elderly population⁶⁸. The proportion increases with age: 0.87 percent in subjects aged 60 to 74, 2.5 percent among those aged 75 to 84 years and 6.1 percent in subjects 85 and over. Older persons in institutions were 60.9 percent women, 21 percent were married, 35 percent were single, approximately 50 percent receive a pension and around 15 percent were handicapped ⁶⁸. One the recommendations of this study it is the necessity to have a formal register of institutions providing care.

A formal cadastre on the number of facilities for older persons took place in 2012 as an update to a previous cadastre from 2007. The cadastre report published in 2013 shows that there are 756 long term care facilities (LTCs), of which 229 are NPOs (31.5 percent), 478 are For –Profit (65.8 percent) and 16 are public organizations (2.6 percent).

4 Quality assessment framework

4.1 Quality assessment in the long term care

4.1.1 In Japan

In the Revision to the Long Term Care insurance in 2005 a very important concept was introduced to the system. This important concept was quality assurance. To the

knowledge of the author, the concept of maintenance and improving quality has not been mentioned explicitly in the Long Term Care system and no previous measures were enacted before. This new incorporation was referred to as “maintenance and improving of quality service” and it was one of the six main components (basic perspectives of the reform) of the revision to the LTCI of 2005 ²⁶.

The concept of “maintenance and improving of quality service” aims to assure quality of service by promoting the choice of users and the competition of the providers. The way to do this was by obliging the providers to disclose information about the services provided in the context of the LTCI, service experience and living environment, along with a review of the regulations ²⁶. Moreover, the care management staff is reviewed to promote “comprehensive and continuous management, improvement of care managers’ quality and expertise”²⁶.

The concept of “maintenance and improving of quality service” is composed of four elements as detailed in the Overview of the Revision of the Long-term Care Insurance System ²⁶:

1) Disclosure of Care Service Information:

- Service providers are obliged to disclose information regarding their companies.

2) Improvement of Expertise in Services and Living Environments:

- Improvement of expertise in home-help services and promotion of Unit Care.

3) Review of Regulations for Service Providers:

- Review of reasons for disqualification (introduction of the renewal system).

4) Review of Care Management:

- Introduction of the renewal system for care manager accreditation, requiring them to participate in training programs.

- Reducing the standard number of the cases (workload) each care manager takes charge in, strengthening punishment against unfairness.

This revised law, including the disclosure system of care service, was implemented in April 2006 as part of the third term of the LTCI.

4.1.2 In Chile

The concept of quality for long-term care facilities was first mentioned in 2007, and it was contained in a final report entitled “Study for the design of a system and quality improvement plan of the service provided by nursing homes or long-term care facilities”⁶⁵. This study states the necessity to deviate to a quality management model for the services

offered in these facilities. This report is divided into six parts: Introduction, method, international experiences (Canada, France, Spain and New Zealand), quality assurance initiatives in other sectors (pre-school, tertiary education, labour, etc., current state of long-term care facilities in Chile and guidelines for a quality assurance initiative). The study found 8 areas where quality improvement was possible: human resources, infrastructure, social integration, organizational planning, administrative and financial management, community outreach, leadership and management⁶⁹. However, this report aims to provide guidelines and recommendations and not to set particular standards of quality.

Under the first government of the president Michelle Bachelet (2006-2010) the administration tried to focus on their quality interest, by changing the perspective of older persons from objects of social security to subjects of rights⁶⁵, a change that has been documented overseas⁷⁰. When the government created the National Agency for Older Persons it defined its main task as “to improve the quality of life of older people in the country.”⁶⁷, although there were no specific quality assurance or quality improvement indications.

In 2010, Chile implemented the first structural guidelines for long-term care facilities (LTCFs). These guidelines were instructions on the characteristics of the LTCFs and staff composition. These structural guidelines define the number of registered nurses, licensed practical nurses and care workers, along the qualifications of the legal and technical representative. However, no mention of quality was made.

4.1.3 In the world

In many countries, particularly in the United States of America, and for a long time, the long-term care sector has been closely observed regarding its quality, cost, and adequate control and related laws. The quality of the long-term care system has received much attention, not only from local governments, but also from the central government. This interest comes not only from the policy makers, but also from the citizens, including the users of the system and their beloved ones, due to quality related problems attributed to the system as early as 1956 when the Commission on Chronic Illness called attention to problems with the quality of care in nursing homes⁷¹. These problems have been successively reflected in government reports, court trails, and news reports. The focus on the problems in the quality of the long-term care system persists despite the efforts made to improve quality⁴.

4.2 Quality measurement

Since there are several definitions of quality of care, it is hard to agree on a particular way to define it. Despite its ambiguity, most people tend to agree on a very general definition of quality given by the IOM, stating that "quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" ^{72,73}. While agreeable, this generic definition cannot be transformed into empirically applicable tools to assess quality as it is. It is because of this that the necessity to surrogate actual quality with quality indicators.

4.3 The Donabedian model

With many quality measures available, a model for its organization is necessary. In this regard, in conceptualizing and organizing quality measures, the approach of Donabedian⁷⁴⁻⁷⁷ is important and pervasively accepted⁷⁸. Originally created to assess the care provided by physicians or hospitals^{75,76}, Donabedian proposed that quality could be measured in terms of structures (S), processes (P), and outcomes (O). Structural measures are the organizational characteristics associated with the provision of care. Process measures are characteristics of things done to and for the resident. Outcome measures are the desired states one would (or would not) like to achieve for the resident⁷⁸⁻⁸¹. Donabedian proposed that quality indicators are causally linked: "good structure increases the likelihood of good process, and good process increases the likelihood of a good outcome." ⁷⁹.

4.3.1 Quality Indicators

Definition

Quality indicators are a quantitative form to express quality ⁷⁴. The first steps to create empirically these verifiable indicators of quality were provided by the health sector which borrowed the idea from the industrial quality control sector with the ethos of continuous quality improvement⁷⁴.

History

The first set of quality indicators were implemented in the United States of America,

when the Public Health Service issued the Nursing Home Standards Guide, after finding some quality problems reported by the Commission on Chronic Illness ⁷¹. This guide recommended “basic minimum standards applicable to all nursing homes”. The recommendations consisted of 77 health and safety standards—55 of these were structural quality indicators ⁸². No process or outcome indicators were included.

In the United States of America the care for the elderly was basically carried out by poorhouses and charitable or immigrant organizations until 1935, when the Social Security Act was enacted following the Great Depression to provide cash benefits for the elderly starting a new era of for-profit nursing homes ⁸³. However, nursing homes, as we know them today, were further encouraged by the creation of the Medicare and Medicaid programs by former US president Lyndon Johnson in 1965 ⁷⁴. Medicare covering expenditures derived from the discharge from acute hospital, whereas Medicaid is a cost sharing program of medical assistance aimed at the indigent or recipients of public assistance. Medicare and Medicaid represent until now a fundamental umbrella for funding of the long-term nursing care ⁸⁴. In addition, the creation of the Medicaid and Medicare programs brought along a certification process, which was required for nursing homes to receive reimbursement for Medicare or Medicaid users. This certification, that assesses the quality of care whether the facility meets standards defined by the programs, motivated the creation of new standards and by 1974, 90 health and safety standards existed, with 59 of these as structural quality indicators ⁸⁵. Furthermore, by 1987, the certification included 136 health and safety standards, with 98 of these being structural quality indicators and including for the first time process indicators, 38 of them ^{4,85}. No outcome indicators were included at this point.

As the nursing home industry continued its development and growth, and despite the implementation of the above mentioned nursing home standards, concerns about poor quality of care continued increasing. In 1984, a committee of the Institute of Medicine (IOM), called Committee on Nursing Home Regulation, began researching the quality of care in nursing homes. Their shocking findings of poor quality of care ⁴ that were published in 1986 and their subsequent confirmation by the General Accounting Office (GAO) in 1987 ⁸⁶, led to the issue of the Omnibus Budget Reconciliation Act of 1987 also known as OBRA-87, which created a minimum set of standards also known as Resident Assessment Instrument (of which the Minimum Data Set (MDS) is a major component) ^{83,85,87} that moved the focus from assessment of structure and process to the assessment of outcomes. By MDS 2.0, a revised version of the original, 17 of the outcome indicators were outcome related indicators. The last modification to this measurement tool is the creation of the MDS 3.0.

Rantz et al. concluded, "QIs derived from MDS data can serve as a reasonable first step in determining what level of quality exists in a facility" ⁸⁸.

4.3.2 Review of Literature on National Quality Assessment Overseas

A systematic search for relevant articles and reports, published in English, was performed to take a look into what was the state of the art regarding the use of quality indicators applied systemically as part of national assessment system of quality of nursing care in the world. The search procedures are described below.

4.3.2.1 Operational definitions

Outcome indicators are defined as those describing quantitatively the effects of care on health status ⁷⁹.

Long-Term Care Facilities were defined as a range of institutions that provide health care to people who are unable to manage independently in the community. Facilities may be able to provide short-term rehabilitation care as well as chronic care management as defined by the Centers for Medicare & Medicaid Services (CMS) ⁸⁹.

The most prevalent and the oldest of institutions providing long term care are the nursing homes.

Nursing homes are defined as facilities licensed with an organized professional staff and inpatient beds that provides continuous nursing and other services to patients who are not in the acute phase of an illness.

Search parameters

An electronic search was carried out in PubMed using the terms "quality indicators" or "quality measures") in combination with "Long-Term Care" and several keywords aiming at institutional care such as: Institution, facility, residences or nursing homes. The abstract of the articles and reports were first read to find whether they met the inclusion criteria.

Inclusion criteria: Material was restricted to the English language, published in the last 10 years. The documents found were considered for a deeper review of their content if they mentioned the implementation or use of quality indicators for care in Long-term Care facilities (LTCFs) for the elderly. Reviews were first retrieved, and then additional papers and national published documentation was accessed. Hand searches in reference lists from relevant documents found were also carried out.

Exclusion criteria: In this review National quality assessment on hospitals or any other

acute care facilities were not considered. Clinical indicators not applied in a Long term care setting were not considered either.

In detail, the key words for the search were the following:

("quality indicators" OR "quality measures" OR "quality of care")

AND

(("Long-Term Care")

AND

(Institution OR facility OR Facilities OR Institutions OR Residential OR Residence OR "Nursing home"))

The search string returned 462 hits published in the last 10 years mentioning the implementation or use of quality indicators for care in Long-term care facilities (LTCFs).

4.3.2.2 Results of Review on National Quality Assessment Overseas

Countries

Most of the literature and actual empirical use of quality measures came from the Anglo-Saxon world (USA, England, Australia and New Zealand).

The system that began this usage was the one used in USA, called MDS, from where MDS-based Quality Indicators were derived. The England's Single Assessment Process for Older People (SAP) and Norway's Individual care needs data set (IPLOS) are said to have been influenced by the one in the United States ⁹⁰. The English assessment subsequently inspired the systems in Australia and New Zealand.

National Quality Assessment and the Three Concepts (SPO)

Among these systems, there are clear differences in the emphasis they put on the measures in terms of what aspect of the quality assessment they want to examine more carefully. As stated before, the analysis of the quality indicators, according to Donabedian model, can be focused on three components: Structure, Process and/or Outcome.

As seen in Table 1, in the case of the US, the emphasis of the MDS-based indicators is put on Outcome Quality Indicators, followed by Process Quality Indicators. However, in the case of Australia, England and New Zealand this emphasis is clearly put in the processes.

Table 2. Quality Aspects on each National System.

Country	Structure n(%)	Process n(%)	Outcome n(%)
USA	0 (0%)	10 (42%)	17 (71%)
Australia	3 (7%)	38 (86%)	4 (9%)
England	12 (32%)	26 (68%)	0 (0%)
New Zealand	8 (14%)	50 (88%)	1 (2%)

As show in table 2, we can see that even among those countries that are focused on Process Quality Indicators there is space for some Outcome Quality Indicator and that these domains are sometimes shared among the systems.

a) We can see, for example, that the Domain of Skin Care is shared by USA and Australia. In both countries this measurement is an Outcome Quality Indicator.

b) Another case of shared interest in the form of Outcome quality indicators is in the domain of Nutrition and Eating. This interest is shared by USA and New Zealand. In the case of New Zealand, this item can be considered either as an outcome quality indicator or as a process quality indicator. This is because the distinction between a process and outcome quality indicator is not always straightforward⁷⁸. Sometimes, the quality indicator is a mix of an outcome and a process measure, because it reflects both aspects. A very well-known example comes from USA and their quality indicator of symptoms of depression (outcome) with no treatment (process). Sometimes, like in the case of New Zealand, the quality indicator can be considered either an outcome or a process indicator, depending on the perspective taken by the measuring organization, according to their measuring needs. As explained by Zimmerman, “this kind of quality indicators can be considered to reflect the status (outcome) of the resident (i.e. the resident is not able to or chooses not to engage in activities). Alternatively, it may be understood as a process quality indicator (i.e. the facility staff elects not to provide or arrange for the activities)”⁷⁸.

Table 3. Quality Indicators by Domain

Outcome Quality Indicators' Domains		
Skin Care		
Australia	Skin care	Outcome
USA	Prevalence of stage - pressure ulcers	Outcome
Accidents		
USA	Prevalence of falls	Outcome
USA	Incidence of new fractures	Outcome
Nutrition and eating		
USA	Prevalence of dehydration	Outcome
New Zeland	Nutrition, safe food, and fluid management	Process OR Outcome
USA	Prevalence of weight loss	Outcome
Health and personal care		
Australia	Palliative care	Process AND Outcome
Australia	Sleep	Outcome
Behavioral and emotional patterns		
USA	Prevalence of behavioral symptoms affecting others	Outcome
USA	Prevalence of symptoms of depression	Outcome
USA	Prevalence of depression with no antidepressant therapy	Process AND Outcome
Cognitive patterns		
USA	Incidence of cognitive impairment not risk-adjusted.	Outcome
Elimination and continence		
USA	Prevalence of bladder or bowel incontinence	Outcome
USA	Prevalence of occasional or frequent bladder or bowel incontinence without a toileting plan.	Process AND Outcome
USA	Prevalence of fecal impaction	Outcome
Infection control		
USA	Prevalence of urinary tract infections	Outcome
Physical functioning		
USA	Prevalence of bedfast residents	Outcome
USA	Incidence of decline in late-loss ADLs	Outcome
USA	Incidence of decline in ROM	Outcome
Quality of life		
USA	Prevalence of little or no activity	Process OR Outcome

Source: Nakrem S, Vinsnes AG, Harkless GE, Paulsen B, Seim A: Nursing sensitive quality indicators for nursing home care: international review of literature, policy and practice. *Int J Nurs Stud* 2009, 46(6):848-857.

As a summary, we can observe the pervasive effect of the system used in the USA. Therefore the next step is to go deeper in the understanding of the historical and technical process that led to the assessment tool we know today. This experience is presented in the following passage.

Outcome Quality Indicators: The US Case.

The MDS-based Quality Indicators were developed by a team of researchers at the Center for Health Systems Research and Analysis (CHSRA) at the University of Wisconsin-Madison ⁷⁸ and consist of 24 quality indicators, divided into process and outcome quality indicators, as shown in Table 3.

The MDS-based Quality Indicators are based on resident-level data collected from the Minimum Data Set (MDS). These indicators represent 11 of the original 12 domains of care ⁷⁸.

Table 4. Twenty-four quality indicators (Process and Outcome)

Domain	Quality indicators	Process/Outcome
Accidents	Incidence of new fractures	Outcome
	Prevalence of falls	Outcome
Behavioural and emotional patterns	Prevalence of behavioural symptoms affecting others*	Outcome
	Prevalence of symptoms of depression*	Outcome
	Prevalence of symptoms of depression * without antidepressant therapy	Both
	Use of nine or more different medications	Process
Cognitive patterns	Incidence of cognitive impairment*	Outcome
Elimination and continence	Prevalence of bladder/bowel incontinence	Outcome
	Prevalence of occasional bladder/bowel incontinence without a toileting plan	Both
Clinical management	Prevalence of indwelling catheters	Process
	Prevalence of fecal impaction	Outcome
Infection control	Prevalence of urinary tract infections	Outcome
	Prevalence of weight loss	Outcome
Nutrition and eating	Prevalence of tube feeding	Process
	Prevalence of dehydration	Outcome
Physical functioning	Prevalence of bedfast residents	Outcome
	Incidence of decline in late loss ADLs	Outcome
	Incidence of decline in range of motion	Outcome
Psychotropic drug use	Prevalence of antipsychotic use in the absence of psychotic and related conditions*	Process
	Prevalence of antianxiety/hypnotic use*	Process
	Prevalence of hypnotic use more than two times in last week*	Process
Quality of life	Prevalence of daily physical restraints*	Process
	Prevalence of little or no activity*	Either
Skin care	Prevalence of stage 1-4 pressure ulcers	Outcome

Source: Zimmerman DR: Improving nursing home quality of care through outcomes data: the MDS quality indicators. *Int J Geriatr Psychiatry* 2003, 18(3):250-257.

The assessment tool for quality of care used in the USA is the most extended beyond their frontiers, probably due to the fact that it is a very well documented assessment tool and it is the only one of the assessment system found in the review to have validity and reliability publications. However, while Zimmerman ⁷⁸ asserted that validity and reliability have been shown ⁷⁸, others found inconclusive results ^{88,90}

From a conceptual point of view, the analysis suggests the importance of analysing outcome indicators in the context of the Donabedian model as a reflection of the whole chain of care. Donabedian says that: “The assessment of outcomes, under rigorously controlled circumstances, is, of course, the method by which the goodness of alternative strategies of care is established”⁷⁹ adding that “outcomes do have, however, the advantage of reflecting all contributions to care, including those of the patient.” The list of outcome quality indicators derived from the MDS is presented in Table 4.

Table 5. Only outcome quality indicators

Incidence of new fractures
Prevalence of falls
Prevalence of behavioral symptoms affecting others
Prevalence of symptoms of depression
Prevalence of depression without antidepressant therapy
Use of nine or more different medications
Incidence of cognitive impairment
Prevalence of bladder or bowel incontinence
Prevalence of fecal impaction
Prevalence of urinary tract infections
Prevalence of weight loss
Prevalence of dehydration
Prevalence of bedfast residents
Incidence of decline in late loss ADLs
Incidence of decline in ROM
Prevalence of little or no activity
Prevalence of Stage 1–4 pressure ulcers

Source: Castle NG, Ferguson JC: What is nursing home quality and how is it measured? *Gerontologist* 2010, 50(4):426-442.

In addition, as a result of the revision of this very extended assessment tool, it seems necessary to give a further step on deepening our knowledge of those outcome quality indicators that appear to be common among the countries using National Quality Assessments. Since, this shared interest is mainly based on outcome quality indicator as shown in Table 2 the focus will be put in this type of quality indicator.

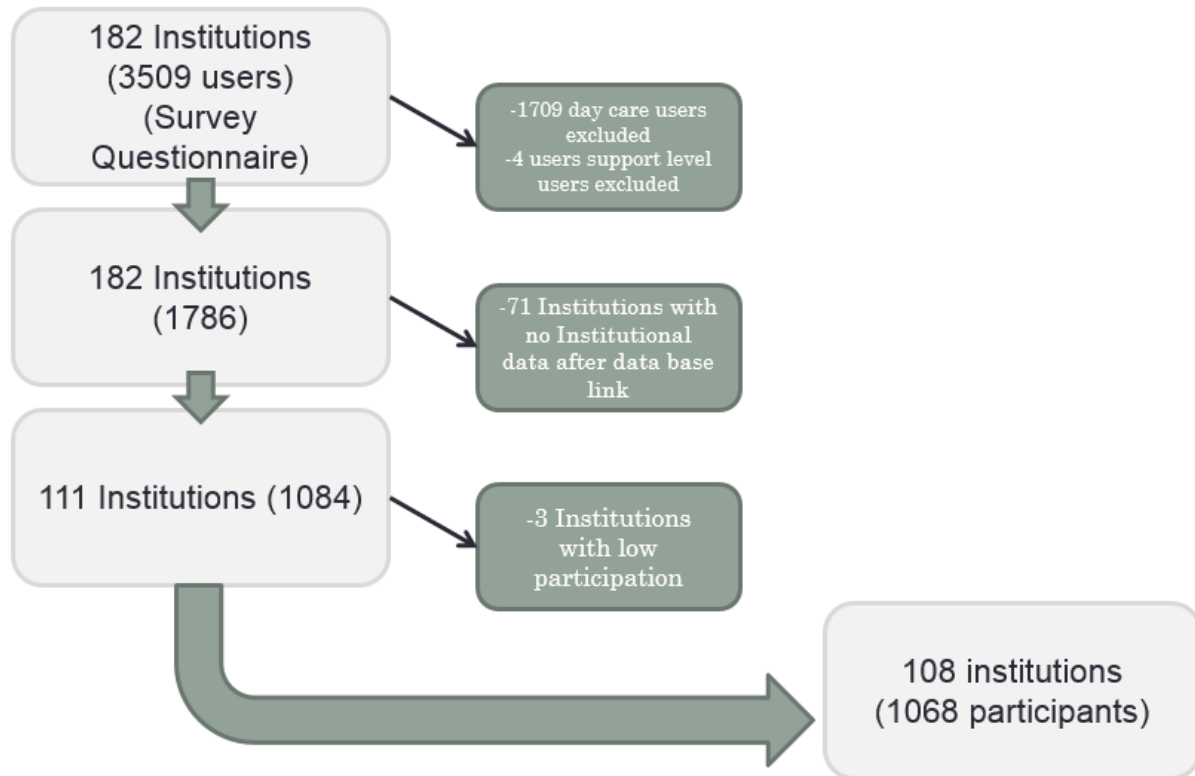
5 Chapter 5: Studies in Japan

5.1 Data source

We have analysed secondary data from the “survey to verify indicators for chronological index of status and individual characteristics of user of the long term care facility for the elderly” carried out in March 2009. This data was merged with a data set of institutional data. They were merged by the user ID.

Sample: Selected subjects (cases and non-cases that provide data to the study): Around 10 randomly selected institutionalized users from 108 institutions accounting up to 1068 residents. This number of subjects was obtained after applying the exclusion criteria described in the figure below.

Figure 10. Sample flow



5.1.1.1 Review of the Three Outcome Quality Indicators: Falls, Pressure Ulcers and Dehydration

A systematic search for relevant articles and reports was performed to find out the importance and characteristics of our three selected major quality indicators: Falls, pressure ulcers and dehydration, in terms of the impact on the users and the system, and what kind of risk factors or predictors are associated to them. The search procedures are described below.

5.1.1.1.1 Search parameters

An electronic search was carried out in PubMed using negative outcomes as keywords (fall OR pressure ulcer OR dehydration) AND several keywords aiming at institutional care (Institution, facility, residences OR nursing homes). The abstract of the articles and

reports were first read to find whether or not they met the inclusion criteria.

Inclusion criteria: Material was restricted to the English language and published in the last 10 years. The documents found were considered for a deeper review of their content if they mentioned the characteristics of the outcome in relation to facilities or institutionalized users. Reviews were first retrieved, and then additional papers and national published documentation were accessed when possible. Hand searches in reference lists from relevant documents found were also carried out.

Exclusion criteria: Documents not describing the importance or the related risk factors or predictors of the outcome.

5.1.1.2 Results for the Review of the Three Outcome Quality Indicators

The results are presented below by outcome quality indicator, divided by their relevance as a measurement item and the associated main risk factors.

5.1.1.2.1 Importance and risk factors for falls

Importance:

A common problem worldwide ^{91,92}
A leading cause of injury for those over 65 ^{91,93,94} .
A leading cause of death in persons over age 65. ⁹⁵
Important contributing factor in nursing home admissions (OPHA1998)
One-third to one-half of persons over 65 fall each year ⁹¹
Important cause of morbidity and functional impairment ⁹¹

Main Risk Factors:

Gait impairment ^{91,92,96}
Cognitive decline. ^{91,92,96}
Polypharmacy ^{91,92,96}
Poor visual acuity ^{91,92,96}

5.1.1.2.2 Importance and Risk Factors for Pressure Ulcers

Importance:

Pressure ulcers are common. The reported prevalence of pressure ulcers among residents in nursing homes ranges from 7 percent to 23 percent in the US ⁹⁷ .
They are largely preventable
At early stages are very responsive to treatment ^{97,98}
At advanced stages are hard to treat, expensive and prolonged ^{97,98}
Cause of morbidity and complications. ⁹⁸

Main Risk Factors:

Bedridden status ⁹⁷⁻⁹⁹
Mobility problems ⁹⁷⁻⁹⁹
Malnutrition ⁹⁷⁻⁹⁹
Incontinence ⁹⁷⁻⁹⁹

5.1.1.2.3 Importance and Risk Factors for Dehydration

Importance:

It may cause serious clinical outcome in the elderly ¹⁰⁰
Common reason for hospitalization. In the US, 6.7 percent of admitted patients to hospitals suffered from dehydration. 1.4 percent as the main reason. Of these 50 percent died within a year. Costs \$446 million for Medicare a year. ¹⁰⁰
It is significantly associated to longer stay in rehabilitation settings ¹⁰¹

Main Risk Factors:

Cognitive impairment ^{100,102}
Mental disorders ^{100,102}
Dysphagia ¹⁰²
Chronic illnesses, such as diabetes ¹⁰⁰
Medication ¹⁰⁰

The main inferences from this review was that these are very common problems with a heavy burden on the users and the system to a greater extent, yet maybe more importantly, these kinds of problems are highly preventable and with low cost solutions. When not addressed is a wise time frame, all of them result to be costly and dangerous for the wellbeing of the people affected.

5.1.1.3 The Relationship between Structure and Outcome Quality Indicators at Long Term Care Facilities in the Literature.

The importance of structure characteristics on outcome quality indicators has been studied extensively in terms of ownership ¹⁰³⁻¹⁰⁵, and staffing levels ¹⁰⁶⁻¹⁰⁸ and their numbers are increasing as time goes by ¹⁰⁸. It is because of this significant amount of evidence documented in the literature that we have decided to pay attention to these aspects of structural characteristics (ownership and nurse staffing) in relation to our three selected quality indicators (falls, pressure ulcers and dehydration for the purpose of this review. It should be noted however, that other aspects that are important in a Japanese context of Long Term Care are not found in the literature overseas, such as cooperating institutions, availability of 24-hour nurse staffing, etc. Information not found in the literature published in English was kindly obtained through consultation with Japanese members of the Department of Health Services Research of the University of

Tsukuba. In this regard, participant members who contributed with information were the academic advisor of the author of this thesis, Prof. Nanako Tamiya; deputy advisor, Prof. Masayo Kashiwagi, and fellow doctoral classmate and medical director of a long-term facility Dr. Sumiko Miyata. Additionally every study contained in this product was kindly advised and commented by all the members of the department led by Prof. Tamiya during every step of the research process through open debates during research presentations.

5.1.1.3.1 Ownership

It must be mentioned that the concept of ownership in this study differs significantly to the practical definition given in other regions outside Japan, especially in the USA. Ownership is seen overseas as the difference between profit and non-for-profit facilities. In the USA, two thirds of the nursing homes are for profit¹⁰³. Most of the studies there suggest that quality of care is better in not-for profit facilities^{103,109-111}. Generally, the authors, generally, speculate about the influence of the profit maximisation goal of for-profit facilities (hiring less skilled personnel, outsourcing, agency use, etc.), in contrast to the professional skill approach of those not-for profit (Hiring more specialized personnel, smaller turnover rates, etc.), and how this would affect quality of care, reflected on the outcome indicators.

However, in Japan, in the context of LTCI, the majority of the institutions are not-for profit organizations. In this study, the term points to the fact of knowing what kind of institutions owns the facility in terms of their professional profile. The option varies from, medical institutions to welfare ones.

5.1.1.3.1.1 Ownership on Outcome Quality Indicators

Pressure ulcers:

- Some studies have found a lower prevalence of pressure ulcers in Non-profit facilities compared to those for-profit facilities ^{103,111}.

Dehydration:

- To the knowledge of the authors there is not research done on how ownership would affect dehydration.

Falls:

- To the knowledge of the authors there is not research done on how ownership would affect falls.

5.1.1.3.2 Nurse Staffing

These studies state that, in general terms, there seems to be a beneficial effect of a higher staff number on negative outcome. However, it is evident that there are mixed results

among the main reviews of this dimension. Bostick et al.¹⁰⁷ state that “there is a proven association between higher total staffing levels (especially licensed staff) and improved quality of care”.

On the other hand, Spilsbury et al.¹⁰⁸ while finding a tentative positive effect of increased total staffing levels and increased ratios of registered nurses on quality of care, concluded that: “The existing evidence base does not enable any firm conclusions to be drawn when considering the relationship between nurse staffing and quality of care for residents in nursing homes”. Despite this difference, they agree that there are mixed results if we look at specific indicators, and that the construction of the measures to carry out the studies varies greatly among the studies, not only in the outcome measurement, but also in the exposures. What the review of Spilsbury et al contributes is the notion that “there is tentative evidence that total nurse, registered nurse and nurse assistant staffing are more often positively influencing quality of care for residents.”¹⁰⁸.

5.1.1.3.2.1 Nurse Staffing on Outcome Quality Indicators

Study designs

Most of the designs were cross-sectional and cohort studies. The data used to describe the nurse staffing was mainly secondary⁹⁴.

Nurse staffing measures

As noted by Dellefield in her review, historically, nursing homes have used a predominance of paraprofessional nursing staff, including NAs and LPNs, rather than RNs¹¹². The nursing staff skill mix, meaning the different educational background of the nursing staff, is thought to be a key element for the quality of care in nursing homes¹¹³.

As reported recently by Spilsbury et al¹⁰⁸ there are sixteen studies that document the relationship of pressure ulcers and nurse staffing of different backgrounds.

Pressure ulcers:

- Registered Nurse (RN)

Eleven of them report the relationship of RN and pressure ulcers, however, with mixed results. This means that there was positive association, a negative association or no association at all in these eleven studies.

- Licensed Practical Nurse (LPN)

Regarding the influence of LPN, no significant evidence was found. This seems to corroborate the literature where LPN usually has not significant relationships¹⁰⁸.

- Registered Nurses and Licensed Practical Nurses (RN+LPN)

There is mixed evidence for the association between the combination of RNs and LPNs staffing and pressure ulcers (four studies). This means that there was positive association, a negative association or no association at all in these four studies.

•Licensed Practical Nurses and Certified Nurse Assistants (LPN+NA)

According to the review of Spilsbury et al.¹⁰⁸, there were two studies that used this staffing combination to explain the pressure ulcers prevalence. However, no association was detected.

Dehydration:

Reported by Spilsbury et al¹⁰⁸ there seems to be only one previous study reporting on the relationship of dehydration and nurse staffing. However this relation proved to be insignificant.

Falls:

To the knowledge of the authors there is not research done on how nurse staffing would affect falls.

Main discussion points from three systematic reviews on nurse staffing

While there seems to be evidence on particular studies on the relationships of staffing characteristics and outcome, from the point of view of a meta-analysis, that allows drawing general conclusions on the matter, there are some common difficulties stated by the reviewers of the literature about Structure characteristics and Outcome quality indicators. They can be summarized in two: 1) Different use or construction of Structural variables, 2) Different use of risk adjustment.

In the literature review by Dellefield on nurse staffing and their relationship with quality indicators, Dellefield noted that “Researchers have not been consistent in their categorization and use of variables as structure, process, or outcome quality indicators.”¹¹². This means that researchers have used some variables as either Structural, process or outcomes indicators in different studies. For example, nurse staffing levels have been used as either the response or explanatory variable and total nursing staff have been defined and measured differently. Moreover, studies also present nursing staff skill mix defined and measured differently¹¹². Dellefield also noted that the risk adjustment for outcome variables has been applied differently and that this lack of adjustment may lead to different results and misleading conclusions^{112,114}.

The same difficulty in comparing the result of the different studies carried so far in relation to assess quality through nurse staffing characteristics of the facilities was noted by Bostick et al ¹⁰⁷ in their review of 2006. They noted the difficulties in comparing different type of measurements, but also noted how there is not mention of which kind of measurements could be better over other. They also noted that “several studies suggest that a consistent case-mix system is needed; however, no consensus was reached as to what this case-mix method should be¹⁰⁷”. Case-mix is used for risk adjustment purposes.

Spilsbury et al ¹⁰⁸, in their review of 2011, also noted these difficulties, stating that “the literature presents 1) a wide range and varied mass of findings that 2) use disparate methods for defining and measuring quality and nurse staffing.” making hard to draw firm conclusions out the different studies existing on the subject of measuring quality through staffing levels.

The difference in the variable utilization is attributed to the building of the staffing variable. They are created in different ways as explained in three rather recent systematic reviews carried out by Dellefield in 2000¹¹², Bostick et al. in 2006¹⁰⁷ and Spilsbury et al. in 2011¹⁰⁸. According to these reviews, this composition is made of two elements:

- 1) Educational and Skill Background ¹⁰⁸:
 - a) Total nurse staffing (RN, LPN and NA).
 - b) First level nurse staffing (RN).
 - c) Second level nurse staffing (LPN).
 - d) First and second level nurse staffing (RNs and LPN).
 - e) Nurse Assistant (NA)
 - f) LPN and NA.

- 2) Staffing Measures ¹⁰⁷:

Structural Characteristics varies from one another in the staffing measurement. There are basically two ways to measure the staff:

- a) The ratio of staff to residents (i.e. number of full-time equivalents (FTE) per resident or bed)
- b) The number of hours per resident (i.e. hours per resident per day (HPRD))

Therefore, to create a staffing variable it is important to join: Educational and Skill Background, plus a Staffing Measure. Since, most of the literature comes from the USA,

and the use of national assessment tools such as OSCAR, the most commonly found measure is HPRD.

5.1.1.4 Need of the research

At this point, it must be noted that Japan's efforts to assess quality, introduced with the revision of the LTCI in 2005, can be considered as early steps to grasp and regulate some structural characteristics of the system compared to much more advanced approaches in other countries with similar challenges regarding their ageing demands. Existent quality measurements are aimed at presenting information of institutions, but no standards of quality for comparison purposes are given. It should be considered that analysing only these structural indicators alone have disadvantages: while structural quality as a standard can be achieved by LTCFs, not necessarily this means providing quality care. Donabedian stated that "from these (structural) characteristics, we can only infer that conditions are either inimical or conducive to good care. We are unable assert that care, in fact, has been good or bad ⁷⁹".

Ownership

Due to the particular characteristics of the ownership entitlement in Japan, no relation can be made with previous studies on ownership prediction of outcome described above. The Japanese case focuses on the profile of the owning corporation of the facility from a professional/skill point of view. They can be 1) Medical corporation, 2) Socio-Medical corporations, 3) Socio-Welfare corporations 4) NPOs or 5) Others. We may presume that a medical-related condition of the ownership may have some effect of Outcome Indicators.

Cooperating Institutions

A unique characteristic of the Japanese Facilities is their association with a Cooperation Institutions to provide assistance on particular aspects of care and/or referral. To the knowledge of the author, this kind of analysis has not been carried out and there is no analysis of this element as a structural characteristic on outcome quality indicators. The available options for this relationship in Japan are: 1) Regional hospital, 2) Clinic with beds, 3) Clinic with no beds 4) Others. We may guess that an association with a Cooperating Regional Hospital may induce better referral processes and availability of highly specialized medical consultations, leading to better clinical outcomes, especially reflected on these indicators. This particular characteristic of the Japanese system, may be associated with the particular case mix of users (Need of care, disability, number of medical condition, etc) and thus may influence the allocation of human resources (RNs, LPNs, etc), skill mix determination, and, as a result, the inherent reflection on certain

quality indicators.

Nurse staffing

It must be pointed out that the Japanese system defines the staffing levels by law using the concept of ratio of staff to residents, more specifically the number of Staff per 100 users. In the literature the most found measure is the number of hours per resident. Since, most of the literature is from USA, this is: Hours per Resident per Day, also known as HPRD. Therefore, it is necessary to evaluate this kind of approach in contrast with outcome measures, every time these kinds of measurements have been left behind due to measurement reliability as stated by Bostick et al: “Less variance is seen when measuring staffing hours per resident day as compared to FTEs per resident or bed”¹⁰⁷.

In a context of assessment and underlying reforms, the question of whether or not Japan can socially support the elderly at low cost and at the same time provide good quality services is one of Japan’s biggest challenges. Cost-containing reforms and a high demand for institutionalization may suggest the surge or existence of quality care problems at all of the three LTC facilities mentioned before (Welfare facilities for the elderly, Health Care Facilities for the elderly and Medical Type Long Term Care Facilities). This study focuses on the second one.

To the knowledge of the author, no previous studies describing the quality conditions at this type of facility in Japan have been carried out in relation to structural characteristics. Despite that assessing quality of care through quality indicators is an extended practice worldwide, in Japan this trend has not been reflected in actual national initiatives to measure quality systematically.

5.2 Study 1:

Relationship between Structural Characteristics and Outcome Quality Indicators at Health Care Facilities for the Elderly Requiring Long-Term Care in Japan from a Nationwide Survey

5.2.1 Abstract

Aim: To clarify what is the performance situation of selected quality indicators (QIs): falls, pressure ulcers and dehydration, at Health Care Facilities for the Elderly (HCFE) in Japan, and what structural characteristics are related to these QIs.

Methods: The operational population consisted of around 10 randomly selected institutionalized users from 107 facilities with a total of 1057 residents from a survey answered by the care staffing. The facilities were divided into two groups according to their prevalence of negative outcomes (falls, pressure ulcers, dehydration): the best 25 percent (the very good performers) and the remaining 75 percent (not so good performers). Logistic regression analysis was conducted to examine the relationship between the structure characteristics of the facilities and their performance regarding each quality indicator.

Results: After controlling for gender, age of the facility and average age of the users, our results revealed a beneficial significant relationship between falls and the total number of nurses per 100 users with an Adjusted Odds Ratio (AOR : 95 percent CI) = 0.77 : 0.593 to 0.979 ; On the other hand, for pressure ulcers, a harmful association between a higher number of registered nurses (RNs) (1.306 : 1.089 to 1.069) was found. Marginally, the availability of 24-hour nurse staffing 3.404 (0.98 to 13.081); regarding dehydration, we did not find any staffing characteristics related.

Conclusion: Nurse staffing may be considered as a potentially related variable in the quality of care in health care facilities for the elderly. This study is the first to demonstrate a relationship between structural characteristics and quality outcomes in the HCFE.

5.2.2 Introduction

In Japan, despite the increasing threat to quality of care at long term care facilities (LTCFs) that the high demand and ensuing cost containment that may be posed by the oldest population of the world under the long term care insurance (LTCI), it was not until the implementation of the revision of the LTCI in April 2006 that the concept of quality assurance (QA) was strengthened. This addition, referred to as “maintenance and improvement of quality service” consisted of mandatory information disclosure by the service providers, the improvement of service experience and living environments, and the revision of the regulations for service providers and care management²⁶. However, because these concepts mainly address structure regulations, little is known about the relationship between the structure characteristics of the LTCFs and the quality outcomes of the care provided and how they differ across facilities. In Japan, there are three types of LTCFs: long-term care hospitals, health care facilities for the elderly (HCFEs), and special nursing homes. In this study, we are focused on HCFEs because it is an intermediate facility between those focalized mainly on medical therapy and the ones focalized mainly on shelter, thus providing a varied care mix¹¹⁵.

By applying the pervasive structure-process-outcome model to analyze aspects of quality of care by Donabedian^{79,80}, we use the experience of the USA to hypothesize that structure characteristics of the LTCFs are important predictors of quality outcomes^{103,107,116} by using quality indicators (QIs). These QIs have been developed to provide starting points for both external and internal QA and quality improvement activities.¹¹⁴

In this study, we have selected: prevalence of falls, pressure ulcers and dehydration as outcome variables for QIs, according to the literature review conducted in the English language. Falls were selected for being a common problem worldwide, a leading cause of injury and death for those over 65, an important contributing factor in nursing home admissions, and an important cause of morbidity and functional impairment^{91,95,117}. Pressure ulcers were selected because they are common, costly, and they are largely preventable at early stages and very responsive to treatment. However, at advanced stages they are difficult to treat, expensive and prolonged, causing morbidity and complications^{97,98}. Dehydration was selected as it may cause serious clinical outcomes in the elderly, being a common reason for hospitalization, costly and significantly associated to longer stays in rehabilitation settings^{100,101,118-120}, like the HCFE. Furthermore, pressure ulcers and dehydration are considered to be sentinel health events, due to their serious nature, representing the extreme of poor performance that requires investigation¹²¹.

The present study aims to clarify two main questions:

- 1) What is the performance situation of selected major QIs (falls, pressure ulcers and dehydration) regarding quality of care across HCFE in Japan?
- 2) What structural characteristics are related to these QIs?

5.2.3 Method

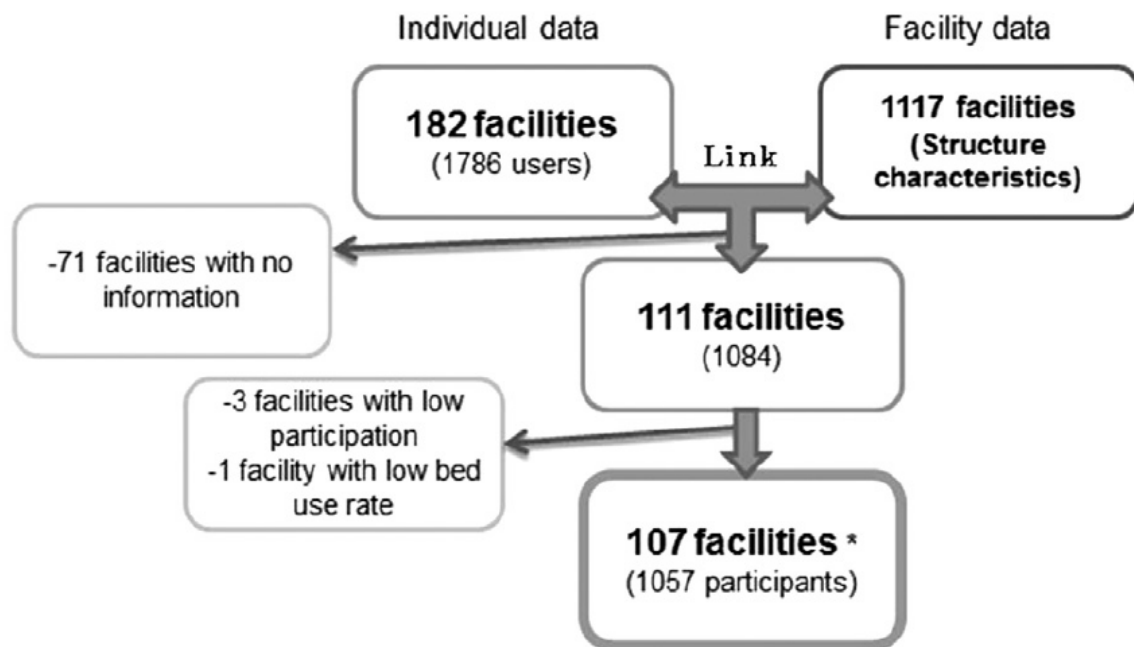
Design

This study is an observational and cross-sectional study, using secondary data from a national survey carried out in March 2009 by the Japan association of health care facilities for the elderly requiring long-term care (JAHCFE) and covering the previous six months to its execution.

Participants

The operational sample consisted of approximately 10 randomly selected institutionalized care-level users from 107 institutions from all over Japan with a total of 1057 residents. The flowchart is presented in figure below.

Figure 11. Flowchart of sample enrolment.



Data collection

The data was collected by means of a postal survey sent to 331 member facilities of the JAHCFE. One hundred and eighty two replied (55 percent). It was answered by nurses

(44 percent), care workers (46 percent), rehabilitation specialists (8 percent), and unknown staff (2 percent).

Participant characteristics

Main medical conditions, proportion of gait impaired users per facility and proportion of bedridden users per facility.

Facility characteristics

Information about facility characteristics was collected from the members' database of the JAHCFE for the pertinent fiscal year. They are ownership, cooperating institutions, availability of 24-hour nurse staffing, age of the institution and number of staff in different specialties allocated per 100 users,

Dependent variables

The methodology for comparing quality among LTC facilities was developed by researchers at the Center for Health Systems Research and Analysis, University of Wisconsin-Madison¹¹⁴ with the name of Quality Indicators (QIs). At a facility-level, QIs are calculated by dividing the number of residents with negative outcomes in each facility by the number of those at risk, while adjusting for case-mix differences. In this study, adjustment for case-mix is carried out using covariates, such as gender, co-morbidities, gait impairment, bedridden status, among others, in the multiple logistic regression analysis.

The distributions of the prevalence rates were positively skewed, and all of the tests rejected the null hypothesis of normality for the three outcome variables. To face this, the QIs were modeled as a binary response variable by dividing the groups into the very good performing facilities (the first quartile, representing the best 25 percent) and the not so good performing ones (the remaining 75 percent) because of their skewed distribution. A logistic model was used to explain the poorer performance of the latter.

Statistical methods

For statistical analyses we carried out a logistical regression to clarify which structural factors of the facility were associated with our selected quality indicators. The logistic regression analyses were carried out with the logistic procedure in SAS version 9.1 on a Windows XP environment. The variables were included in the models using a combined approach of forward stepwise logistic regression with forced variables, also known as hierarchical or sequential logistic regression. The forced variables or locked terms to be entered in all models are gender, age of the facility, average age of users and number of

users, for adjustment purposes. On SAS we use the option *INCLUDE=n* for this objective. The INCLUDE option requests that the first n explanatory variables in the MODEL statement be included in every model. The stepwise criteria for other variables to enter and leave the model are as follow: entry of 0.20 and a stay of 0.20 as the significance levels for the procedure, to obtain parsimonious models. Observations with missing data were excluded from the analysis. Adjusted Odd Ratios (AORs) with 95 percent confidence intervals (CIs) were obtained ~~after adjusting for gender, age of the facility and average age of the users.~~

We obtained written permission from the JAHCFE to analyse the data this secondary data. The data does not include personal identifications. Due to commitments on the storage of the data, this study is approved by the ethical committee of the University of Tsukuba (#23-222).

This study was supported by the Grant-in-Aid for Scientific Research of the Ministry of Health, Labour and Welfare (H24-Chikyukibo-ippan-001) Challenges of global ageing without borders, ,and the H26 Geriatric Health Promotion Research Grant from the Japanese Ministry of Health, Labour and Welfare.

5.2.4 Results

Bivariate analysis

After discarding correlations, we tested relationships using chi-square test for categorical variables and t-test for continuous variables. The characteristics of these relationships and significance per each outcome are presented below.

Table 6. Structural characteristics of the facilities by grouping prevalence of falls.

Categorical Variables	Very good performers		Not so good performers				Total		<i>P</i> -value		
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)			
Non-medical ownership (ref)	5	4.81	17	16.4	22	21.2					
Medical ownership	29	27.9	53	51	82	78.9			0.2618		
No 24-h nursing care (ref)	6	5.66	13	12.3	19	17.9					
24-h nursing care	28	26.4	59	55.7	87	82.1			0.9592		
Other cooperating institutions (ref)	15	14.4	28	26.9	43	41.4					
Cooperating hospital	19	18.3	42	40.4	61	58.7			0.6892		
Continuous variables	Mean	SD	Min	Max	Mean	SD	Min	Max	<i>n</i>	(%)	<i>P</i> -value
Female proportion	79.2	14.1	40	100	73.9	15.7	40	100	107	100	0.0974
Years of operation	12.1	4.5	3	21	11.7	4.4	2	21	104	97.2	0.6576
Average age of the users (years)	84.7	2.3	77.8	89.6	84.2	3.4	77.3	91	107	100	0.4392
No. users	91.9	14.1	61	140	84.8	24.2	45	145	105	98.1	0.1206
Nurses per 100 users	12.7	2.0	8.9	16.2	12.0	2.1	7.9	17	105	98.1	0.1003
RN per 100 users	5.4	3.1	1	12.9	5.0	2.7	0.6	14	100	93.5	0.4761
CNA per 100 users	34.9	4.9	26.1	47.5	33.7	4.9	24.8	46	104	97.2	0.2493
PT per 100 users	2.0	1.4	0.2	6.6	2.1	1.0	0.1	4.8	94	87.9	0.6570
OT per 100 users	1.6	0.8	0.5	3.3	1.9	1.5	0.5	8.2	90	84.1	0.3553
Nurse skill mix	2.8	0.5	1.8	3.8	2.9	0.6	1.8	4.7	105	98.1	0.6443
Rehabilitation staff per 100 users	0.8	0.4	0.2	1.5	1.4	1.1	0.1	5.5	34	31.8	0.1482
Nutritionist per 100 users	1.6	0.7	1	4.5	1.6	0.9	0.7	5.1	100	93.5	0.9570
Dietitians per 100 users	1.3	0.4	1	2.3	1.4	0.6	0.7	3.9	101	94.4	0.3731
Proportion of gait impaired users	94.3	7.0	75	100	93.5	9.2	50	100	107	100	0.6689
Proportion of bedridden users	23.0	18.6	0	60	17.1	15.5	0	60	107	100	0.0863
Proportion of brain disorder	47.9	17.9	0	80	51.3	17.6	0	80	107	100	0.3450
Proportion of heart disease	8.3	8.4	0	30	8.6	9.9	0	40	107	100	0.9077
Proportion of respiratory disease	2.1	4.8	0	20	2.4	4.3	0	11	107	100	0.7744
Proportion of renal urological disease	1.2	3.3	0	10	1.8	4.2	0	20	107	100	0.4605
Proportion of endocrine metabolic disorders	3.0	5.3	0	20	4.2	6.9	0	30	107	100	0.3803
Proportion of muscle bone disorders	10.8	10.4	0	40	12.3	12.1	0	50	107	100	0.5275
Proportion of mental disorder	17.1	15.3	0	60	11.5	13.3	0	50	107	100	0.0581
Proportion of digestive disorders	1.8	4.6	0	20	2.2	4.9	0	20	107	100	0.6351

The χ^2 -test for categorical variables and *t*-test for continuous variables. SD, standard deviation.

Table 7. Structural characteristics of the facilities by grouping prevalence of pressure ulcers

Categorical variables	Very good performers		Not so good performers				Total		<i>P</i> -value		
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)			
Non-medical ownership (ref)	7	6.73	15	14.4	22	21.2					
Medical ownership	38	36.5	44	42.3	82	78.9	0.2221				
No 24-h nursing care (ref)	11	10.4	8	7.55	19	17.9					
24-h nursing care	36	34	51	48.1	87	82.1	0.1892				
Other cooperating institutions (ref)	17	16.4	26	25	43	41.4					
Cooperating hospital	28	26.9	33	31.7	61	58.7	0.5187				
Continuous variables	Mean	SD	Min	Max	Mean	SD	Min	Max	<i>n</i>	(%)	<i>P</i> -value
Female proportion	75.3	14.0	40	100	75.9	16.5	40	100	107	100	0.8616
Years of operation	12.0	5.1	2	21	11.7	3.9	4	20	104	97.2	0.7682
Average age of the users (years)	84.0	3.1	77.6	91.3	84.6	3.0	77.3	90	107	100	0.3286
No. users	91.6	24.8	45	145	83.7	18.6	49	144	105	98.1	0.0649
Nurses per 100 users	11.8	2.1	8.5	16.4	12.5	2.0	7.9	17	103	96.3	0.1122
RN per 100 users	4.3	2.4	0.6	9.8	5.8	3.0	1.3	14	100	93.5	0.0090
CNA per 100 users	34.0	4.9	25.3	45.7	34.2	4.9	24.8	48	104	97.2	0.8706
PT per 100 users	2.1	1.4	0.2	6.6	1.9	0.8	0.1	3.9	94	87.9	0.3717
OT per 100 users	1.5	0.9	0.5	3.9	2.0	1.5	0.5	8.2	90	84.1	0.0879
Nurse skill mix	2.9	0.5	1.8	4.3	2.8	0.6	1.8	4.7	105	98.1	0.4263
Rehabilitation staff per 100 users	1.4	1.4	0.1	5.5	1.2	0.5	0.5	2.2	34	31.8	0.5427
Nutritionist per 100 users	1.4	0.7	0.7	4.5	1.7	0.9	0.7	5.1	100	93.5	0.1474
Dietitians per 100 users	1.2	0.4	0.7	2.2	1.4	0.6	0.7	3.9	101	94.4	0.0604
Proportion of gait impaired users	92.6	8.0	70	100	94.7	8.9	50	100	107	100	0.2081
Proportion of bedridden users	11.0	14.1	0	60	25.2	15.9	0	60	107	100	0.0001
Proportion of brain disorder	47.0	18.6	0	80	52.8	16.6	10	80	107	100	0.0950
Proportion of renal urologic disease	1.1	3.1	0	10	2.0	4.4	0	20	107	100	0.2220
Proportion of muscle bone disorder	14.4	12.8	0	50	9.9	10.2	0	40	107	100	0.0459
Proportion of mental disorder	14.1	15.7	0	60	12.6	12.9	0	40	107	100	0.5757

The χ^2 -test for categorical variables and *t*-test for continuous variables. SD, standard deviation.

Table 8. Structural characteristics of the facilities by grouping prevalence of dehydration

Categorical Variables	Very good performers		Not so good performers				Total		<i>P</i> -value		
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)			
Non-medical ownership (ref)	12	11.5	10	9.62	22	21.2					
Medical ownership	49	47.1	33	31.7	82	78.9	0.6594				
No 24-h nursing care (ref)	11	10.4	8	7.55	19	17.9					
24-h nursing care	53	50	34	32.1	87	82.1	0.8071				
Other cooperating institutions (ref)	27	26	16	15.4	43	41.4					
Cooperating hospital	35	33.7	26	25	61	58.7	0.5795				
Continuous variables	Mean	SD	Min	Max	Mean	SD	Min	Max	<i>P</i> -value		
Female proportion	74.0	16.3	40	100	78.0	13.7	50	100	107	100	0.1945
Years of operation	11.6	4.2	3	21	12.2	4.8	2	21	104	97.2	0.5025
Average age of the users (years)	83.8	3.1	77.3	91.3	85.2	2.8	78.4	90	107	100	0.0151
No. users	86.4	20.6	45	145	88.0	23.5	46	144	105	98.1	0.7077
Nurses per 100 users	12.3	2.2	8.5	17.2	12.1	1.8	7.9	16	103	96.3	0.6940
RN per 100 users	4.9	2.6	0.6	12.9	5.4	3.1	1.3	14	100	93.5	0.3547
CNA per 100 users	33.8	4.6	25.8	41.9	34.6	5.3	24.8	48	104	97.2	0.3651
PT per 100 users	2.1	1.2	0.1	6.6	2.0	1.1	0.5	6.2	94	87.9	0.6469
OT per 100 users	1.6	0.9	0.5	3.9	1.9	1.7	0.5	8.2	90	84.1	0.2498
Nurse skill mix	2.8	0.6	1.8	4.3	2.9	0.6	1.9	4.7	105	98.1	0.2584
Rehabilitation staff per 100 users	1.3	1.1	0.1	5.5	1.4	0.9	0.5	3.7	34	31.8	0.7422
Nutritionist per 100 users	1.5	0.7	0.7	4.5	1.7	1.0	0.7	5.1	100	93.5	0.1863
Dietitians per 100 users	1.3	0.4	0.7	3.2	1.4	0.6	0.7	3.9	101	94.4	0.2243
Proportion of gait impaired users	93.6	7.7	70	100	94.0	9.8	50	100	107	100	0.8363
Proportion of bedridden users	16.1	15.5	0	60	23.3	17.5	0	60	107	100	0.0283
Proportion of brain disorder	49.9	17.4	0	80	50.7	18.2	10	80	107	100	0.8314
Proportion of heart disease	8.4	8.7	0	30	8.7	10.4	0	40	107	100	0.8861
Proportion of respiratory disease	2.1	4.5	0	20	2.6	4.5	0	11	107	100	0.5590
Proportion of renal urologic disease	0.9	2.9	0	10	2.6	4.9	0	20	107	100	0.0354
Proportion of endocrine metabolic disorders	3.3	6.8	0	30	4.5	6.0	0	20	107	100	0.3667
Proportion of muscle-skeletal disease	12.4	12.3	0	50	11.0	10.5	0	30	107	100	0.5308
Proportion of mental disorder	13.1	14.7	0	60	13.5	13.4	0	40	107	100	0.8945
Proportion of digestive disorders	2.1	4.8	0	20	2.1	4.7	0	20	107	100	0.9553

The χ^2 -test for categorical variables and *t*-test for continuous variables. SD, standard deviation

Logistic Regression

Falls

One variable was found to be a significant predictor of the facilities with higher falls: nurses per 100 users with an AOR of 0.77, with a *p*-value of 0.039. The estimate was negative, meaning the higher the number of nurses per 100 users the less likelihood the facility to have a higher prevalence of falls.

Pressure ulcers

According to the results, four variables were found to be significant variables of the facilities with higher prevalence of pressure ulcers: “number of users”, “proportion of bedridden users”, “availability of 24-hour nurse staffing”, and “RN per 100 users” with AORs of 0.97, 1.07, 4.95 and 1.23 respectively. Regarding their *p*-values, they were 0.02,

0.0004, 0.04 and 0.05 respectively.

Dehydration

According to the results, no structural characteristics were found to be significant predictors of the institutions with higher prevalence of dehydration.

Table 9. Factors related to the three negative outcomes

Predictor	Falls (<i>n</i> = 100)			Pressure ulcers (<i>n</i> = 95)			Dehydration (<i>n</i> = 100)		
	AOR	95% Wald confidence limits		AOR	95% Wald confidence limits		AOR	95% Wald confidence limits	
Intercept									
Female proportion (%)	0.98	0.95	1.01	0.99	0.95	1.02	1.01	0.99	1.04
Average age of the users	1.02	0.87	1.20	1.11	0.91	1.36	1.13	0.96	1.34
No. users	0.97	0.95	1.00	0.97	0.94	0.99*	1.00	0.98	1.02
Nurses per 100 users	0.77	0.59	0.98*	–	–	–	–	–	–
Mental disorders (%)	0.98	0.95	1.01	–	–	–	–	–	–
24-h nurse staffing (yes)	–	–	–	4.95	1.19	24.91*	–	–	–
RN per 100 users	–	–	–	1.23	1.01	1.54*	–	–	–
OT per 100 users	–	–	–	1.54	0.94	2.86	–	–	–
Bedridden users (%)	–	–	–	1.07	1.03	1.11**	1.70	0.77	4.04
Renal urological disorder (%)	–	–	–	–	–	–	1.11	0.99	1.27

P* < 0.05, *P* < 0.0005. AOR, adjusted odds ratio.

5.2.5 Discussion

Our study revealed that a significant beneficial factor for falls was the number of nurses per 100 users, and that significant detrimental factors for pressure ulcers were RNs per 100 users and availability of 24-hour nurse staffing. The reader must be aware that the use of the word detrimental refers to a positive association between the variables and not to value judgement on the staff figure. No significant relationship was found between structural characteristics and dehydration. In the following paragraphs we discuss each quality indicator.

Falls

Our results showed that there was a significant beneficial relationship between the QI of falls and the structural characteristic of total nurses per 100 users with an OR of 0.791, meaning that per every additional nurse in the total nurse staffing per 100 users, the probability of being a facility with a high prevalence of falls goes down to 79 percent.

Number of Nurses per 100 users: While this relationship has been found in hospitals¹²², to the knowledge of the author, there are no previous studies on the analysis of the relationship between the total nurse staffing-ratio to residents and the outcome indicator

of falls at long term care facilities (LTCFs)^{107,108,112}.

We speculate that the beneficial relationship of the number of nurses per 100 users may be due to their clinical formation and role in the facility that enables them to create nursing plans according to the needs of the users, plans that in turn may affect the prevalence of falls. These plans may include fall prevention plans aimed at frail elderly at risk, control plans addressed at risk factors or predictors of falls found in the facility, among others.

Pressure Ulcers

In the present study, our results revealed a significant detrimental association between a higher number of RNs per 100 users and the availability of 24-hour nurse staffing with a higher prevalence of pressure ulcers, meaning that the higher the number of RNs per 100 users the higher the prevalence.

a) RNs per 100 users: The kind of detrimental relationship shown in the present study for the RNs and pressure ulcers has been documented before, but along with other contradictory results that show a preventive association at LTCFs^{108,112}. Regarding this, the reader must be aware that the use of the word detrimental refers to a positive association between the variables and not to value judgement on the staff figure.

An opposing study found that LTCFs with the highest levels of RN staffing showed greater improvement in preventing pressure ulcers at nursing homes in the United States¹²³. The authors argue that the findings suggest that RN staffing contribute to improvement of resident outcomes because of their problem-solving and cognitive assets.

Another opposing study¹²⁴ also describes a significant association between more RN staff and a reduction of the prevalence of pressure ulcers. The study¹²⁴ argues that the beneficial effect of the RNs is given by their “staff time available for supervision and direction” of the care assistant staff, but warns that this may be closely related to the skill mix, as a higher number of RN may be harmful regarding other outcomes. Skill-mix can be defined as the “mix of skills or competencies possessed by an individual; ratio of senior to junior grade staff within a single discipline; or mix of different types of staff within a multidisciplinary team”¹²⁵.

A third opposing study is a report to the congress of the USA¹²⁶ that found that staffing numbers over the national average prevented pressure ulcers. It is speculated that a higher number of RNs would allow them to carry out more activities apart from directors of nursing¹²⁶.

On the other hand, some studies support the detrimental association of our study. Dellefield¹²⁷ found that an increased ratio of total RN hours per resident day was associated with a higher-than-expected prevalence rate of pressure ulcers. One

explanation is that licensed nurse staffing may be increasingly involved in the documentation of care and decreasingly involved in direct clinical assessment of residents¹²⁷.

This kind of mixed results in term of the direction of the association of RNs and pressure ulcers was reported in a review¹⁰⁸, where up to a total of eleven original publications reported mixed results. The review suggests that this may be due to the cross-sectional design of the studies¹⁰⁸. The cross-sectional characteristics of this study may preclude the possibility to determine if there is a causal relation between the higher number of RN and the higher prevalence of pressure ulcers, or if the higher prevalence of pressure ulcers makes necessary the presence of a higher specialized professional as the RN.

Another two possible explanations for the lack of evidence found of the benefits of the care given by RNs may be found in a different study¹²⁸. First, it is possible that none of the homes had enough licensed nurses, particularly RNs, to improve care quality. Second, licensed nurses in all facilities simply may be unaware of some care processes that define good quality, because of lack of specialized training focused on the NH population¹²⁸. The same warning is given by Bostick¹²⁴ concerning the low number of RNs in direct care and how this might be a reason for contradictory or insignificant results. This situation holds true in the Japanese context where the number of RNs is rather small compared to the rest of nurse staffing because the numbers of RNs per number of residents are not fixed by law while the total number of nurses is.

Availability of 24-hour nurse staffing: The detrimental relationship shown in the present study for the availability of 24-hour nurse staffing and pressure ulcers has neither been previously documented overseas nor in Japan at the HCFE level, due to the fact that, with the exception of the Japanese, a long term care facility is defined as an institution with 24-hour nurse staffing. It is in Japan where it is optional to have or not this service all day long. This type of detrimental relationship may be related to the aforementioned cross-sectional limitation of the study that precludes determining the direction of the causality, more plausible explained by the care mix in the facilities.

Dehydration

Regarding dehydration, we did not find any staffing characteristics related to this negative outcome. This may be due to the rather homogenously good performance of the facilities, where a quite noticeable part of the intuitions has no record of this kind of negative outcomes at all (60 percent of the facilities). However, since there is no official definition of dehydration¹²⁹, the criteria to define a status of dehydration may vary from one institution to another, and even among the staff. This may hinder the correct magnitude of the phenomenon. We can also speculate about the seasonal influence on

dehydration. The survey covered the coldest months of the year in Japan (Oct-March). Since dehydration decreases with colder weather, the effect of the characteristics of the facility may be diminished.

5.2.6 Conclusion

We conclude that the significance of the present results should prompt us to analyse more carefully the arrangement existing today for this type of facilities in terms of staff composition. Advances has been made in terms of minimum requirements for staffing levels, however, these results point to the necessity of paying more attention to the role of clinical awareness at the facility level and the conformation of workgroups in terms of its multidisciplinary characteristic.

As Dellefield¹³⁰ points out, the total nurse staffing levels are an important component of quality, however a deeper study is needed to grasp how the skill mix, also known as personnel mix, impacts QIs, such as the prevalence of pressure ulcers or falls in the LTCFs.

Our results show that, despite the generalized lack of licensed nurses in the long term care facilities, policies to increase the number of nurses per 100 users should be considered in order to reduce the prevalence of falls.

Finally, this first report about QIs in HCFEs shows the rather low prevalence of pressure ulcers and dehydration may account for the good quality and quite homogenous performance of many of the facilities in Japan.

Limitations

Analysing only structural indicators to outcomes has analytical disadvantages; while structural QIs as a standard can be achieved by HCFEs, this does not necessarily mean provision of quality care⁸². In Japan, the national structural standards are extensively fulfilled as the national regulations through funding are strongly influential. Thus, despite being indispensable, controlling institutional standards may not be enough to explain differences in quality of care⁸². Therefore, it seems necessary to go further into the description of not only staffing allocation and institutional characteristics, but also processes of care, which are intrinsically linked to quality⁷⁹. Additionally, we must pay attention to the fact that the measures of the users conditions are made in the form of aggregated data as proportions or average numbers per facility. We should avoid the possibility of ecological fallacies by making inferences about the nature of individuals deduced from the group to which those individuals belong¹³¹.

Finally, this study calls to research further the causal relationship of staffing levels and outcomes beyond the limitations of a cross-sectional approach.

5.3 Study 2:

Relationship between care processes and outcome quality indicators at Health Care Facilities for the Elderly in Japan

5.3.1 Abstract

Aim: In this study we determine 1) the relationship of selected processes of care with selected outcome quality indicators: falls, pressure ulcers and dehydration.

Methods: A nationwide cross-sectional study of 107 facilities reporting their attitudes towards processes of care, rated with a five-point Likert scale. Facilities were divided into those strongly agreeing with a positive attitude and the rest. An exploratory factor analysis was used to measure underlying factors in the items. Two factors, “physician’s leadership” and “management’s leadership”, were detected. We included these two factors and covariates in a logistic regression to analyse the likelihood to belong to the top best 25 percent performing facilities (a higher OR means better quality) regarding falls, pressure ulcers, and dehydration.

Results: No significant relations were found for falls. Regarding pressure ulcers, we found beneficial relationships with the factor “physician’s leadership” (OR 2.347; CI, 1.196~4.609) and “number of users” (1.028: 1.001 ~1.056). Also, detrimental relationships with “registered nurses per 100 users” (0.714: 0.566 ~0.900) and the “proportion of bedridden users” (0.944; 0.911~0.979) were found. Regarding dehydration, we found a beneficial relationship with the factor “management’s Leadership” (2.497: 1.390~4.796) and a detrimental relationship with “average age of the users” (0.820: 0.683~0.968).

Conclusion: Regarding pressure ulcers, a more proactive leadership of the physicians should be considered. Regarding dehydration, further attention should be paid at the way a proactive leadership of the management influence a better performance. For falls, the absence of significance may be because it is not directly influenced by leadership attitudes inside the facility.

5.3.2 Introduction

The entire world is aging rapidly and Japan is proportionally the most advanced aged country in the world ¹ and it is expected to age even more in the next 50 years ^{1,47} To face this ageing challenge, Japan started in the year 2000 the Long Term Care Insurance (LTCI) system ⁵⁴. This system provided, along with community-based care, facility services divided in three types of long term care facilities (LTCFs): long-term care hospitals, health care facilities for the elderly (HCFEs), and special nursing homes.

The demand for these LTCFs is high, set at 843,016 users per year ¹³² with a constant of around 400,000 available beds, but with already a waiting list reported to equal this number ¹³³ and argued to grow even more ¹³⁴. This increasing demand and ensuing cost containment may pose challenges on the quality of the service provided. The LTCI was revised in 2005 to include the concept of “maintenance and improvement of quality service” ²⁶; however, it only requested providers to disclose structural characteristics. To the knowledge of the authors, no national studies to link the process of care and outcomes have been done so far at LTCFs. In this study, we are focused on HCFEs because it is an intermediate facility between those focused on medical therapy and those focused on daily care, thus providing a varied care mix ¹¹⁵ being the rehabilitation one of its main objectives.

The aim of this study was to examine the relationship of processes of care related to self-reported attitudes of care and quality outcome indicators at facility level: prevalence of falls, pressure ulcers and dehydration and it builds on a previous study where only structural factors were analysed ⁵.

The outcome indicators to be included were the same as in the previous study: prevalence of falls, pressure ulcers and dehydration as outcome variables for QIs, according to the literature review, conducted in the English language. Falls were selected for being a common problem worldwide, a leading cause of injury and death for those over 65, an important contributing factor in nursing home admissions, and an important cause of morbidity and functional impairment^{91,95,117}. Pressure ulcers were selected because they are common, costly, and they are largely preventable at early stages and very responsive to treatment. However, at advanced stages they are difficult to treat, expensive and prolonged, causing morbidity and complications^{97,98}. Dehydration was selected as it may cause serious clinical outcomes in the elderly, being a common reason for hospitalization, costly and significantly associated to longer stays in rehabilitation settings^{100,101,118-120}, like the HCFE. Furthermore, pressure ulcers and dehydration are considered to be sentinel health events, due to their serious nature, representing the extreme of poor performance that requires investigation¹²¹.

Conceptual Framework

The framework is given by Donabedian^{79,80} and his pervasive ^{85,104,135-138} “structure-process-outcome” model to analyse quality. In this study the relationship observed is between processes and outcomes, using structure measures as covariates.

Process: Leadership is regarded as highly influential processes on quality of care¹³⁹⁻¹⁴². Leadership is thought to affect the conditions of the systems where they take place ¹³⁹, thus increasing a more active attitude of the leaders performance must reflect this in terms of better outcomes ^{139,143}, especially in settings where the number of unskilled staff (LPN, CNA) is vastly superior to those higher-skilled health professionals (facility directors, physicians, RN) as in the case of HCFEs in Japan.

Outcome: Quality is commonly accepted as a multidimensional duality of Quality of Life and Quality of Care ¹⁴⁴. In this study we are focused on the latter by using quality indicators (QIs) ^{78,114}. These QIs were created to give starting points for both external and internal quality assurance and quality improvement activities^{114,145}. For this study, with base on the literature analysed, we have selected: prevalence of falls, pressure ulcers and dehydration as outcome variables for QIs for their relevance in LTCFs. Falls is a common problem worldwide, a leading cause of injury and death for those over 65, an important contributing factor in nursing home admissions, and an important cause of morbidity and functional impairment ^{91,95,117}. Pressure ulcers were selected because they are common, costly and preventable at early stages^{97,98}. Dehydration was selected as it may cause serious clinical outcomes in the elderly, common reason for hospitalization, costly and significantly associated to longer stays in rehabilitation settings^{100,101,118-120}. Furthermore, pressure ulcers and dehydration are considered to be sentinel health events, due to their hazardous nature, reflecting the extreme of poor performance that requires investigation ¹²¹.

5.3.3 Method

This study is an observational and cross-sectional study that used two nationwide sets of secondary data of HCFEs.

Facility characteristics questionnaire: It was carried out in October 31, 2009 and it collected information from 1117 facilities on 1) self-reported attitudes towards care and 2) Structure characteristics of the facility (such as staffing levels, ownership, facility size, number of users, etc.).

User characteristics questionnaire: It was carried out in March 2009 covering the past 6 months to its execution, and it collected information on about 10 users per facility, up to a total of 1057 users and their characteristics, such as gender, age, prevalence of negative outcomes (fall, pressure ulcers and dehydration), main diseases, etc.).

Data linkage: Both data sets were link using the matching members' ID for a final sample of 107 facilities.

Data collection

Facility characteristics questionnaires were collected by means of a questionnaire sent to member facilities of the JAHCFE. One thousand and one hundred seventeen replied. It was answered by a panel of staff made up of the facility director, doctors, nursing care and rehabilitation staff, among other.

Variables used: Attitudes toward care, size of the facility, ownership, cooperating institutions, availability of 24-hour nurse staffing, age of the institution and number of staff in different specialties allocated per 100 users.

User characteristics questionnaires were collected by means of a postal survey sent to 331 member facilities of the JAHCFE. One hundred and eighty two replied (55 percent). It was answered by nurses (44 percent), care workers (46 percent), rehabilitation specialists (8 percent), and unknown staff (2 percent).

-Variables used: average age of users, proportion of female users, proportion of main medical conditions, proportion of gait impaired users per facility and proportion of bedridden users per facility, prevalence for the past six months regarding falls, pressure ulcers and dehydration.

Dependent variables

The Quality Indicators (QIs) for falls, pressure ulcers and dehydration were built by calculating the presence or absence of the negative outcomes at the user level and aggregated to represent their prevalence at a facility level, by dividing the number of residents affected by the number of those at risk (Zimmerman, 2003; Zimmerman et al., 1995). More details can be found our previous structural study (Sandoval Garrido et al., 2013).

The distributions of the prevalence rates were positively skewed, and all of the tests rejected the null hypothesis of normality for the three outcome variables. To face this, the QIs were modelled as binary response variables by dividing the groups into the top best 25 percent performers (the first quartile) and the not so good performing ones (the

remaining three quartiles).

Independent variables

Process items: We selected questions regarding processes of care from the facility characteristics questionnaire. The initial set consisted of 15 questions rated in a five-point Likert scale, ranging from the facilities that strongly agree to those who strongly disagree. Because the questionnaire on attitude towards care was reported by the same staff that provides the care, we saw the possibility of introducing bias through the under-report of less desirable behaviours. To cope with this possible under-report, we divided the groups into two groups: Those who strongly agree with a positive attitude towards care and the rest. The distribution of the answers and groups is presented in table below.

Table 10. Distribution of the answers to the items and groups

Item ID	Item Question	Group One		Group two							
		Strongly Agree		Agree		Neutral		Disagree		Strongly Disagree	
		n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Item 1	Do you practice the philosophy and role as a rehabilitation facility?	31	29.3	64	60.4	5	4.7	6	5.7	0	0.0
Item 2	Do you constantly develop your organization by repeatedly improving your bussiness	19	18.1	61	58.1	20	19.1	5	4.8	0	0.0
Item 3	Does the staff have an organization philosophy of "growing, studying more and more?"	19	17.9	61	57.6	22	20.8	4	3.8	0	0.0
Item 4	Does the facility physician guide (lead) the facility?	30	28.9	36	34.6	25	24.0	12	11.5	1	1.0
Item 5	President of the corporation is proactive in the operation of the facility itself, and shows a variety of considerations and strategies?	35	34.7	38	37.6	18	17.8	10	9.9	0	0.0
Item 6	Is the president of the corporation proactive about returning home?	18	18.2	29	29.3	41	41.4	8	8.1	3	3.0
Item 7	Have you been clearly shown various instructions on the user care and policy on management and administration by the facility director.?	37	35.6	38	36.5	21	20.2	8	7.7	0	0.0
Item 8	The physician (in charge) responds proactively to conferences and rounds, etc.?	54	51.4	36	34.3	9	8.6	5	4.8	1	1.0
Item 9	Physician is ambitious about rehabilitation and have a clear understanding of the state of the users?	34	32.4	43	41.0	22	21.0	6	5.7	0	0.0
Item 10	Does the doctor communicates proactively with the staff?	39	37.1	47	44.8	16	15.2	3	2.9	0	0.0
Item 11	Do you have enough coordination between consultation support and rehabilitation staff?	41	38.7	54	50.9	10	9.4	1	0.9	0	0.0
Item 12	Do you have enough coordination between nurses and care helpers	41	38.7	60	56.6	5	4.7	0	0.0	0	0.0
Item 13	Is the rehabilitation staff actively involved in the living conditions of residents in the medical treatment room?	41	38.7	53	50.0	9	8.5	3	2.8	0	0.0
Item 14	Is the counseling support enough to support the families of the residents?	39	36.8	58	54.7	6	5.7	3	2.8	0	0.0
Item 15	Upon admission, has been defined a duration for objectives and improvement?	27	25.5	55	51.9	19	17.9	5	4.7	0	0.0

Covariates

We use covariates to account for the care-mix of the facilities. The covariates included variables collected at a user-level such as gender, age, bedridden status, main disorders. In this case they were aggregated to create facility-level characteristics in the form of proportions per facility (dichotomous) o average numbers (Continuous). Other covariates

were: size of facility, staffing levels, availability of 24-hour nurse staffing.

Statistical methods

For statistical analyses we carried out a logistical regression to clarify which process factors of the facility were associated with our selected quality indicators. The logistic regression analyses were carried out with the logistic procedure in SAS version 9.1 on a Windows XP environment. The variables were included in the models using a combined approach of forward stepwise logistic regression with forced variables, also known as hierarchical or sequential logistic regression. The forced variables or locked terms to be entered in all models are gender, average age of users and number of users, for adjustment purposes. On SAS we use the option *INCLUDE=n* for this objective. The *INCLUDE* option requests that the first *n* explanatory variables in the *MODEL* statement be included in every model. The following stepwise criteria for other variables to enter and leave the model are as follow: entry of 0.20 and a stay of 0.20 as the significance levels for the procedure, with the aim of obtaining parsimonious models. Observations with missing data were excluded from the analysis. Adjusted Odd Ratios (AORs) with 95 percent confidence intervals (CIs) were obtained

We obtained written permission from the JAHCFE to analyse the data this secondary data. The data does not include personal identifications. Due to commitments on the storage of the data, this study is approved by the ethical committee of the University of Tsukuba (#23-222)

5.3.4 Results

Correlation

In the initial set of items we detected significant mild correlation in all the items ranging from coefficients of 0.39 to 0.68 using Phi-coefficients. Phi-coefficients were chosen over tetrachoric correlation coefficients¹⁴⁶ as they allow further statistical analysis.

Factor Analysis

Firstly, using the matrix created by the phi-coefficients, we examined the reliability of the Likert items, using Cronbach coefficient alpha to measure the internal consistency of the items in the original set of questions (15 items). We obtained a reliability coefficient of 0.84 (standardized Cronbach's alpha). Secondly, we carried out an exploratory factor analysis using unweighted least squares as the initial factor method, with varimax rotation to find the latent (underlying) factors that might explain the correlation of items. Orthogonal varimax was used in order to obtain a clear interpretation of each factor.

Setting the minimal initial prior communality estimates, using squared multiple correlations, at 0.25 we obtained a structure of 13 process-related questions. Item 13 and item 14 did not meet the inclusion criteria of initial prior communality estimates and were excluded. We obtained acceptable overall residuals of 0.068 for the model.

Factor solution

To obtain the factor solution, the factors loadings were set at absolute values greater than 0.30. To explain the variance in the variables, the number of factors was determined using the Kaiser criterion of eigenvalues greater than 1.0, obtaining two factors as a result. Using the Cattell scree plot criterion we observed the same two factors. The variance explained by these two factors accounts for 100 percent of the variation, confirming the suitability of this number. The first factor accounted for 79 percent of the total variation. All 7 items in this factor, with loadings greater than 0.35, had to do with the leadership of the physician. This factor therefore was labelled “physicians’ leadership”. The second factor, with 6 items, accounted for 21 percent of the variance and included items describing leadership in management, therefore it was labelled “management’s leadership”.

The remaining 13 items on the scale retained a good reliability ($\alpha = 0.84$). The Cronbach coefficient alpha for the two subscales (factors) were good for “physicians’ leadership” ($\alpha = 0.83$) and acceptable for “management’s leadership” ($\alpha = 0.70$).

Table 11. Latent factors detected in the questions’ scale by factor analysis (rotated factor pattern)

Item ID	Item Questions	Physician's Leadership (Factor 1)	Management's Leadership (Factor 2)
Item 1	Do you practice the philosophy and role as a rehabilitation facility?	0.24712	0.45641
Item 2	Do you constantly develop your organization by repeatedly improving your bussiness?	0.06051	0.49198
Item 3	Does the staff have an organization philosophy of "growing, studying more and more?"	0.12391	0.53569
Item 11	Do you have enough coordination between consultation support and rehabilitation staff?	0.36315	0.52488
Item 12	Do you have enough coordination between nurses and care helpers	0.10171	0.63833
Item 15	Upon admission, has been defined a duration for objectives and improvement?	0.15343	0.46722
Item 4	Does the facility physician guide (lead) the facility?	0.55323	0.24758
Item 5	President of the corporation is proactive in the operation of the facility itself, and shows a variety of considerations and strategies?	0.54979	0.14228
Item 6	Is the president of the corporation proactive about returning home?	0.36779	0.10674
Item 7	Have you been clearly shown various instructions on the user care and policy on management and administration by the facility director.?	0.74195	0.09971
Item 8	The physician (in charge) responds proactively to conferences and rounds, etc.?	0.75098	0.1118
Item 9	Physician is ambitious about rehabilitation and have a clear understanding of the state of the users?	0.74107	0.22578
Item 10	Does the doctor communicates proactively with the staff?	0.63051	0.38228
Variance Explained		79%	21%

Bivariate Analysis

We tested relationships using chi-square test for categorical variables and t-test for continuous variables.

To build a multivariable model for the logistic regression we considered those variables with a significance equal or higher than 0.20 in the bivariate analysis.

Logistic regression

We used the scores from the factor analysis for each facility regarding each factor of leadership to build a logistic regression model to analyse the relationship between these two leadership factors and quality outcome indicators (falls, pressure ulcers and dehydration) using forward stepwise previously described, while adjusting with significant care-mix factors obtained from the bivariate analyses. Proportion of female users, average age of the users and number of users were held constant in all the models for adjustment by using the INCLUDE option on SAS. See results in table below.

Table 12. Factors related to the three negative outcomes. Logistic regression.

Predictor	Falls (n=91)			Pressure ulcers (n=90)			Dehydration (n=93)		
	AOR	95% Wald		AOR	95% Wald		AOR	95% Wald	
	Confidence Limits			Confidence Limits			Confidence Limits		
Female Proportion (%)	1.025	0.990	1.065	0.994	0.959	1.031	1.000	0.969	1.031
Average Age of the Users	1.036	0.870	1.243	0.919	0.756	1.105	0.820	0.683	0.968 *
Number of users	1.025	1.000	1.052 *	1.028	1.002	1.057 *	1.015	0.993	1.038
Nurses per 100 users	1.208	0.946	1.565	—	—	—	—	—	—
Mental Disorders (%)	1.028	0.994	1.066	—	—	—	—	—	—
RN per 100 users	—	—	—	0.714	0.553	0.883 **	—	—	—
Bedridden users (%)	—	—	—	0.944	0.908	0.976 **	2.497	1.390	4.796
Renal Urological Disorder (%)	—	—	—	0.873	0.714	1.037	—	—	—
Physician's Leadership	0.63	0.356	1.082	2.347	1.236	4.850 *	—	—	—
Management's Leadership	1.61	0.858	3.244	0.592	0.291	1.144	2.497	1.390	4.796 **
Goodness-of-fit test:	$\chi^2=11.50$	DF=8	$\pi=0.18$	$\chi^2=3.91$	DF=8	$\pi=0.87$	$\chi^2=6.28$	DF=8	$\pi=0.62$

*P < 0.05, **P < 0.005

AOR, Adjusted Odds Ratio

Below, we present a detailed summary by quality outcome indicator.

Falls

According to the results, no process characteristics were found to be significant predictors of the institutions with higher prevalence of dehydration.

Pressure ulcers

According to the results, two variables had beneficial significant relationships with facilities with better performance: “physician’s leadership” and “number of users”, with AORs of 2.347 and 1.028 respectively. Regarding their *p*-values, they were 0.013 and

0.038 respectively. On the other hand, two variables had detrimental effects on better performance: “RN per 100 users” and “Proportion of bedridden users”, with AORs of 0.714 and 0.944 respectively. Regarding their p-values, they were 0.0043 and 0.0017 respectively.

Dehydration

According to the results, one variable had a beneficial significant relationship with facilities with better performance: “management’s leadership” with an AOR of 2.497 with a p-value of 0.013. One variable had a detrimental significance: “average age of the users” with AORs of 0.820 and p-value of 0.038.

5.3.5 Discussion

In the nursing home, or long term care facilities to a greater extent, the concept of leadership is usually attributed and expected from nurses, which is considered as the vital professional component and axis of the array of services provided and their ensuing success¹⁴⁷. This is reflected in the vast majority of the literature available on leadership in LTCFs¹⁴⁷⁻¹⁴⁹. Therefore, the importance of the leadership of physicians and the management used in this study seems a rather uncommon, understudied perspective.

Furthermore, it must be noted that LTCFs may differ substantially from setting to settings in term of the clinical leadership¹⁵⁰. In this respect, regarding the generalizability aspects found in the literature on quality of care in long term care, we observe that the vast majority of the literature comes from nursing homes in the United States of America. These nursing homes might present some variation with the long-term care facilities from other countries. In the case of Japan, the facility chosen for this study is an intermediate level facility, resembling a nursing home in the USA known as HCFE, a conveniently located facility in the middle of the spectre of three LTCFs available for the elderly under the Japanese LTCL. We believe that the characteristics of the HCFEs do not differ considerable from those of the nursing homes in the USA and therefore the implications of the American literature and other locations can be also expected in this setting.

Falls

Trying to reduce falls and their related injures has been a great endeavour in the pursuit of quality in the long term care facilities. Fall prevention strategies have taken many forms, often with dissimilar results^{91,117}, proving to be a difficult task to implement quality improvement initiatives on this particular point. In our study, there are no significant relationships between the leadership factors and the likelihood to belong to

best performing group. This may be due to the fact that the known successful experiences on reduction of falls are multidisciplinary approaches^{91,92,117}. Thus, an explanation based on particular factors may be prone to insignificance. Especially because it has been argued that LTCFs are setting where multidisciplinary and multifactorial approaches are hard to implement ¹⁵¹. The reasons that likely hinder the implementation and sustainability of reduction strategies are common to many long term care facilities: high turnover, low motivation, low resources, and not risk-specific interventions, among others.

Pressure ulcers

In our study, leadership of the physician has been shown to increase the likelihood to belong to the best 25 percent performer with the lowest prevalence of pressure ulcers. This kind of beneficial experiences has been reported before ¹⁵² by means of multidisciplinary interventions. As it might be expected in the LTCFs, there have been other studies on the nurses' leadership ¹⁵³. However, to the knowledge of the authors there are no specific interventions on the particular role of the physicians. This takes place despite the recommendations given with the introduction of the MDS 3.0 section related to skin conditions that calls for the leadership of the medical doctors in education and collaboration in clinical matters ¹⁵⁴.

Dehydration

In this study a beneficial effect of leadership of the management on the likelihood to belong to the best performing group regarding dehydration is shown. This kind of positive effect of the management has been shown before ¹⁵⁵ as the management supervises the staff on the hydration strategies in the facility. However, no study on the direct effect of the management's leadership has been found through the literature review, conducted in English. We argue that while the management can have a supervising role on hydration policies, this task must be engaged by other elements of the care staff. The results of this study may be considered as a point made on the necessity for the management to be leaders in dealing with hydration.

5.3.6 Conclusion

Our results show that, despite the generalized low number of physicians, their leadership is a valuable process that affects directly the quality of care and institutional performance regarding pressure ulcers, and therefore it should be further analysed with respect to their interaction with other components of care. This study result is a

reinforcement call to their educational potential ¹⁵⁴, especially by using their leadership towards the unskilled staff members, despite that fact that even skilled member present deficiencies in their knowledge, attitudes and perceptions of barriers towards pressure ulcers ¹⁵⁶.

Although used as a covariate, the fact that a higher number of RNs per 100 users shows a detrimental effect on pressure has been documented before ^{5,112}, along with contradicting studies ¹⁰⁸. While some show a positive influence ¹²³ arguing about the RNs' problem-solving and cognitive assets. Another opposing study ¹²⁴ argues that the beneficial effect of the RNs is given by their "staff time available for supervision and direction" of the care assistant staff, but warns that this may be closely related to the skill mix, as a higher number of RN may be detrimental regarding other outcomes. A third opposing study is a report to the congress of the USA ¹²⁶ that found that staffing numbers over the national average prevented pressure ulcers. On the other hand, some studies support the detrimental association of our study. Dellefield ¹⁵⁷ argued that licensed nurse staffing may be increasingly involved in the documentation of care and decreasingly involved in direct clinical assessment of residents¹⁵⁷.

These kinds of contradictions have been reported in a review¹⁰⁸, suggesting that this may be due to the cross-sectional design of the studies¹⁰⁸. Another two possible explanations¹²⁸ is that homes do not have enough licensed nurses, particularly RNs, to improve care quality and that licensed nurses in all facilities simply may be unaware of some care processes that define good quality, because of lack of specialized training focused on the NH population¹²⁸. The same considered is posed by Bostick¹²⁴ concerning the low number of RNs in direct care. This also takes place where the number of RNs is not defined by law, like in Japan.

Limitations

This study calls to further investigate the causal relationship of staffing levels and outcomes beyond the limitations of a cross-sectional approach. The cross-sectional characteristics of this study hinder the counterintuitive possibility of a causal relation between the higher number of RN and the higher prevalence of pressure ulcers or vice versa. Additionally, we must pay attention to the fact that the measures of the users conditions are made in the form of aggregated data as proportions or average numbers per facility. We should avoid the possibility of an ecological fallacies by making inferences about the nature of individuals deduced from inference for the group to which those individuals belong¹³¹.

Finally, we consider that a sample of around 100 subjects at facility level may seem a

rather limited sample size for a factor analysis, however we must note that as an exploratory analysis it may be regarded as sufficient.

5.4 Study 3:

Adverse events and Physical Decline at Geriatric Health Services Facilities

5.4.1 Abstract

Objective: In this study we determined the relationship of user-related adverse events (falls, fractures, dehydration, decubitus, fever, infectious disease, aspiration, seizures, heart attacks and Paralysis) with diminished physical condition at Geriatric Health Services Facility in Japan

Method: This is an analytical, longitudinal hierarchical logistic regression study of elderly users of intermediate long term care facilities. Two waves of surveys in a lapse of ten months were used.

Questionnaires were sent to 331 member facilities. One hundred and eighty two replied (55 percent).

Questionnaires were answered by nurses (44 percent), care workers (46 percent), rehab specialists (8 percent), and unknown staff (2 percent). A total of 615 users from 86 facilities in both waves. Users included for analysis were those with valid physical measures (491 users), excluding those who could not get any worse and those who died.

Controlling for gender and age, the cluster effect of facilities were addressed using a multilevel model with inclusion significance from the bivariate analysis set at 0.20.

Results: Analyses of the relationship between adverse events with diminished physical condition shows that estimated variance of the facility intercepts is 0.3217 (SE: 0.1838) indicating there is facility effect on decline. Furthermore, those who fell increased their likelihood of physically declining to 1.82 OR (CI: 1,15-2,88).

5.4.2 Introduction

The world is ageing at a face pace⁶. Ageing of the population is considered an achievement of society, as it represent a decreased risk of premature death and mortality in general³¹. However, ageing brings new epidemiological challenges. A common scenario of old age is the loss of physical functionality. Functional impairment represents one of major causes for reduced quality of life and outcomes of care in general. Functional decline also implies,

through higher levels of dependence, a heavier burden of care on the provision of long term care services.

For these reasons, it has become essential for policy makers and researchers to investigate what factors may be associated to physical decline in order to prevent it and prolong physical functionality. This takes on a much more relevant positioning when the physical decline takes place inside facilities of long-term care, particularly in those facilities that aim at rehabilitation and social reinsertion. This is the case of geriatric health services facilities in Japan. They are intermediate facilities with rehabilitation as one of their more important roles.

In addition to natural physical decline in time, important factors that affect physical functionality are the so-called adverse events. Adverse events in this research are falls, fractures, dehydration, decubitus (pressure ulcers), fever, infectious diseases, aspiration (pulmonary aspiration), seizures, heart attacks and paralysis.

The present study aims at grasping the situation of physical decline using a longitudinal analysis, with a follow up of 10 months, using as exposure the effects of the aforementioned adverse events. The objective is to grasp what adverse events better predict physical decline and therefore precluding the possibility of rehabilitation and discharge that is one of the purposes of this kind of facilities. The rationale behind the setting of this exposure is given by the possibility to avoid, prevent or diminish the effects of such events.

5.4.3 Methods

Design

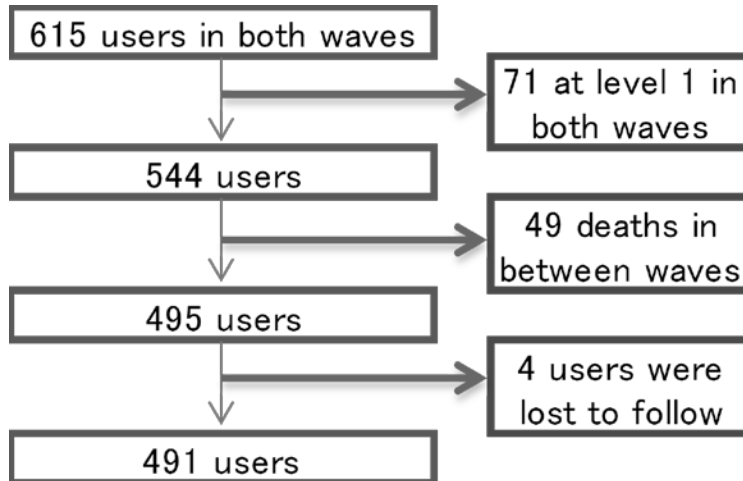
This study is an observational and longitudinal study, which uses secondary data from a national survey carried out in March 2009 by the Japan association of health care facilities for the elderly requiring long-term care (JAHCFE) and covers the previous six months to its execution. The surveillance period for the longitudinal analysis comprise 10 months, from March 2009 to January 2010.

Participants

The operational sample consisted of approximately 10 randomly selected institutionalized care-level users from geriatric health services facilities institutions from all over Japan with a total of 491 residents. The flowchart is presented in figure . The unit of analysis is the user. However, since every ten of them are drawn randomly from

the same facility, we may suspect a cluster effect of the facility on the measurements. To account for that cluster effect, a two-level multilevel logistic regression model has been used, with the facility as the cluster and the user as the unit of analysis.

Figure 12. Sample flow



Data collection

The data was collected by means of a postal survey sent to 331 member facilities of the JAHCFE. One hundred and eighty two replied (55 percent). The survey was answered by nurses (44 percent), care workers (46 percent), rehabilitation specialists (8 percent), and unknown staff (2 percent).

Figure 13. Study design and data collection flowchart



Participant characteristics (level 1 of the multilevel analysis)

Sex, age, physical condition at baseline, polypharmacy (more than 5 medicines), need of medical care, need of dementia care, need of nutritional care were used as characteristics of the users.

Facility characteristics (level 2 of the multilevel analysis)

Information about facility characteristics was collected from the members' database of the

JAHCFFE for the pertinent fiscal year. These characteristics are the number of staff in different specialties allocated per 100 users: MD (medical doctor) per 100 users, LPN (licensed practical nurse) per 100 users, RN (registered nurse) per 100 users, CW (care worker) per 100 users, and PT (physical therapist) per 100 users and OT (Occupational therapist per 100 users.

Independent variables

Adverse events were defined as dichotomous (binary) measurements. An event was registered if the event takes place at least once during the 10 months of follow up.

Adverse events for this study were: falls (yes/no), fractures (yes/no), dehydration (yes/no), fever (yes/no), infectious diseases (yes/no), aspiration (yes/no), stroke (yes/no), heart attack (yes/no), and paralysis (yes/no).

Dependent variable

Physical decline is defined as physical deterioration measured by using a five-stage scale of physical functionality. The higher the stage, the better the functionality. The five stages of physical functionality were: Level 5) He or she can be standing, Level 4) He or she cannot be standing, but can get off the bed, Level 3) He or she cannot get off the bed, but can sit on it, Level 2) He or she cannot get sit on the bed, but can change position and Level 1) He or she cannot change position because of bedridden status. Changes (worsening of maintenance/ improvement) were measured using the baseline level. We excluded those who dies, were lost to follow and those who were already at the lowest possible stage (level 1) and did not improve. For the logistic regression, our model will try to explain the decline (transition to a lower stage) by coding the negative transition as one (1), while improvement or maintenance is coded as zero (0).

We obtained written permission from the JAHCFFE to analyse the data this secondary data. The data does not include personal identifications. Due to commitments on the storage of the data, this study is approved by the ethical committee of the University of Tsukuba (#23-222)

This study was supported by the Grant-in-Aid for Scientific Research of the Ministry of Health, Labour and Welfare (H24-Chikyukibo-ippan-001) Challenges of global ageing without borders, ,and the H26 Geriatric Health Promotion Research Grant from the Japanese Ministry of Health, Labour and Welfare.

5.4.4 Results

The description of the transition for physical functioning showed that 328 users maintained or improved their condition, while 163 declined. As seen in figure below.

Table 13. Basic transition of physical decline from baseline and after 10 months

		Physical Decline										
		yes				no						
Baseline User Characteristics		n	%	min	max	n	%	min	max	total	p-value	
Level 1	Gender (1) ref=0	123	32.9			251	67.1			374	0.7943	
	Age	mean SD	86.3	8.1	60	99	84.1	8.5	40	99	491	0.0058
	Physical Cond. at baseline	mean SD	4.0	1.0	2	5	3.7	1.2	1	5	491	0.0052
	More than 5 medicines (yes)		62.0	32.8			127	67.2			189	0.8837
	Need of Medical Care (yes)		122	33.9			238	66.1			360	0.2923
	Need of Dementia Care (yes)		100	34.4			191	65.6			291	0.4121
	Need of Nutritional Care (yes)		98	33.9			191	66.1			289	0.6420
Level 2	Facility Characteristics	mean	SD	min	max							
	MD per 100 users	1.2	0.3	0.7	2.1	1.2	0.3	0.6	2.9	491	0.1080	
	LPN per 100 users	7.2	3.5	0	18	6.9	3.3	0	18	476	0.3478	
	RN per 100 users	4.6	2.8	0.6	14	5.1	3.0	0.6	19	476	0.0917	
	CW per 100 users	34.3	8.0	25	94	34.2	6.5	25	94	484	0.8390	
PT & OT per 100 users	2.9	1.3	0.8	7.6	2.9	1.5	0.8	8.6	472	0.8806		
Adverse Events		n	%									
	Falls (yes)	77	43.8			99	56.3			176	0.0002	
	fractures (yes)	12	57.1			9	42.9			21	0.0161	
	Dehydration (yes)	10	50.0			10	50.0			20	0.1031	
	Fever (yes)	62	36.1			110	64.0			172	0.3095	
	Infectious Diseases (yes)	7	38.9			11	61.1			18	0.6009	
	Aspiration (yes)	12	46.2			14	53.9			26	0.1419	
	Stroke or Seizure (yes)*	9	64.3			5	35.7			14	0.0184	
	Heart Attack (yes)	2	20.0			8	80.0			10	0.5096	
	Paralysis (yes)	5	45.5			6	54.6			11	0.5169	

* Fisher's exact

Table 14. Baseline characteristics of users by physical decline

Level	March 2009		Level	January 2010	
	n	%		n	%
Level 5 He/She is capable of maintaining a standing position	163	26.5	Level 5	91	14.8
			Level 4	48	7.8
			Level 3	7	1.1
			Level 2	3	0.5
			Level 1	2	0.3
Level 4 He/She is not capable of maintaining a standing position, but it is able to transfer	217	35.3	Level 5	16	2.6
			Level 4	127	20.7
			Level 3	39	6.3
			Level 2	21	3.4
			Level 1	3	0.5
Level 3 He/She is not capable of transfer but it is able to keep a sitting position	60	9.8	Level 5	3	0.5
			Level 4	15	2.4
			Level 3	16	2.6
			Level 2	12	2.0
			Level 1	11	1.8
Level 2 He/She is not capable of keeping a sitting position, but it is able to change his sleeping position	62	10.1	Level 5	5	0.8
			Level 4	6	1.0
			Level 3	7	1.1
			Level 2	19	3.1
			Level 1	17	2.8
Level 1 He/She is not capable of changing his/her sleeping position	113	18.4	Level 5	0	0.0
			Level 4	8	1.3
			Level 3	7	1.1
			Level 2	8	1.3
			Level 1	71	11.5
			Deaths	49	8.0
			Lost to follow	4	0.7
Total	615	100		615	100.0

A bivariate analysis, within a p-value of 0.2 of significance, on the existence of physical decline showed that regarding level 1 (user level), age and physical condition at baseline were significant. Regarding level 2 characteristics (cluster level), medical doctors and registered nurses were significant within a p-value of 0.2 of significance. Regarding our exposure of interest, we observed that falls, fractures and dehydration, aspiration and stroke were significantly related.

Table 15. Multilevel logistic regression model of physical decline by level model.

Fixed Effects		Empty Model (n=491)		Model 1 User Level (n=463)		Model 2 User level + Facility Level (n=448)	
		Variables	OR	(95% CI)	OR	(95% CI)	
Events	Falls (yes)	1.94	1.25	3.01	2.10	1.33	3.30 *
	Fractures (yes)	1.92	0.71	5.18	1.79	0.65	4.93
	Dehydration (yes)	1.42	0.52	3.89	1.24	0.43	3.58
	Aspiration (yes)	1.14	0.47	2.76	1.41	0.56	3.56
	Seizures (yes)	2.74	0.82	9.16	2.36	0.69	8.10
User Characteristics	Gender (female)	1.31	0.79	2.18	1.29	0.77	2.18
	Age	1.03	1.00	1.06	1.03	1.00	1.06 *
	Initial Physical Condition	1.23	1.04	1.47	1.27	1.06	1.52 *
Facility Characteristics	MDs per 100				0.55	0.26	1.16
	RNs per 100				0.93	0.87	1.00
Random effects		Estimate	Standard Error	Estimate	Standard Error	Estimate	Standard Error
τ^2	$\text{var}(U_{0i})$ variance	0.401	0.1874	0.3464	0.1912	0.3328	0.196

Notes Gender, age and baseline characteristics of users and facilities were use to adjust
* $p < .05$

Analyses of the relationship between adverse events with diminished physical condition showed that those who fell increased their likelihood of physically declining to 1.94 OR (CI: 1.25-3.01).

5.4.5 Discussion

The significance of falls in both model reinforce the importance of falls as a predictor of physical decline.

For this sample falls and fractures were not correlated. While both were significant in the bivariate analysis at $p > .05$, in the multivariate approach only fractures is significant.

Facility level characteristics (staffing) did not have a significant effect on physical decline in the multivariate model.

Fall prevention is a significant factor to avoid physical decline of institutionalized elderly people and should be further encouraged. Further studies on the relation of falls and

fractures are needed. The study of other facility characteristics may be further investigated. Other factors that affect quality should be considered, such as processes in the facility along with these structural characteristics.

6 Chapter 6: Studies in Chile

6.1 Data source

Secondary data entitled 2009 National Survey on Dependency of Older Persons in Chile commissioned by the National Agency for Older Persons in Chile.

The data consists of two target groups: (1) older adults aged 60 and older living in the community, and (2) their informal caregivers if any.

The data collection was conducted between November 2009 and January 2010.

The selection of the sample was conducted through a probabilistic sampling design, stratified geographically and by population size in urban and rural areas, with a multistage probability of selection. The sampling framework was based on the 2002 census characteristics of the elderly population, and an additional oversampling of the population aged 80 years and over, to compensate for their lower numbers.

Access to the data is granted to any Chilean citizen under the law 20,285 that grants access to information of any public institution.

6.1.1 Review of determinants

Previous studies have shown that perceived social support may be associated with better mental health ¹⁵⁸⁻¹⁶⁰ and higher quality of life ^{161,162}. Also, reduction of caregiver burden by social support has been reported ¹⁶³.

However, the level of evidence in Chile remain severely low despite the increasing proportion of older persons, with all the economic, social, cultural and political implications that this may bring ⁶⁹. Most of the available data consist of descriptive statistics for sociodemographic characteristics. As describes by Morris, in Chile, there is a serious shortage of current and specialized knowledge in the field of ageing, presenting all aspects of reality (differences in gender, age group, urban-rural, previous work history, etc.) regarding older persons ⁶⁹.

6.2 Study 4

The relation between perceived social support and depression among informal caregivers of community-dwelling older persons in the Republic of Chile

6.2.1 Abstract

Objective: The aim of this study was to examine the relation between perceived social support and depression among informal caregivers of community-dwelling older persons in the Republic of Chile.

Design: Cross-sectional secondary data was analysed from a nationwide survey in the Republic of Chile.

Methods: We used logistic regression on 377 dyads of community-dwelling caregivers and their informal caregivers from all over Chile. The Duke-UNC Functional Social Support Questionnaire (FSSQ) was used to measure perceived social support as exposure and the Center for Epidemiologic Studies Depression Scale (CES-D) for depression of caregivers as outcome. Gender, age, education, urbanization, carers' health insurance and kinship were used as covariates, along the dependency of the recipient.

Results: 76.9 percent of the caregivers perceived a higher level of social support; 46.9 percent presented depression. Logistic regression shows significant beneficial factors against being depressed are: a higher level of social support (Odds Ratio-OR: 0.311, 95 percent Confidence Interval, CI: 0.167~0.579) compared to lower support; and having taken vacations in the past 12 months (OR: 0.513, CI: 0.270~0.975) compared to others. Significant harmful factors that increase the likelihood of being depressed are: female gender of the caregiver (OR:2.296, CI:1.119~4.707), being uninsured (OR:4.321, CI:1.750~10.672), being the partner of the care-recipient (OR: 3.832, CI: 1.546~9.493), and hours of care (OR:1.053, CI:1.021~1.085).

Discussion: Higher levels of perceived social support were associated with lower prevalence of depression, along with having taken vacations in the past 12 months. The detrimental effect of being a female caregiver, the partner of the recipient, being uninsured, and extended hours of care, is also shown.

Conclusion: Interventions to enhance perceived social support might be helpful for improving mental health among informal caregivers. Additionally, support to female carers, those uninsured, and those caring for long hours, by considering providing respite from their caregiving role, particularly for the partner of the care-recipients.

6.2.2 Introduction

Depressive symptoms are one of the most important causes for disability in the world ¹⁶⁴ and leading contributor to the global burden of diseases¹⁶⁵. Depression is an important issue regarding the mental health of informal caregivers ¹⁶⁶.

Studies have shown that informal caregivers benefit from social support to improve mental health¹⁶⁷⁻¹⁶⁹, by allowing coping and adjustment to this role.

Evidence has demonstrated that lack of social support were associated with poorer mental health of caregivers¹⁷⁰. Additionally, perceived social support has the capability to diminish the detrimental effects of stress and improve general health ¹⁷¹.

In the Republic of Chile, despite being one of the most aged countries in Latin America ¹⁷², there is no evidence on how social support is related to the depression of caregivers of older adults. To the knowledge of the author, there is only one study on social support and caregivers^{173,174}. However, it was focused only on patients with schizophrenia and measuring burden, not depression, with a sample of 45 dyads of older persons and their caregivers living in the extreme northern region of Chile. An additional study analysed depression of caregivers¹⁷⁴, however there was no connection to the perception of social support by the caregivers as this was only measured among care-recipients, undergoing haemodialysis.

In most developing countries, where there are no national-level long-term care systems, the responsibility of care relies mainly on the family and network to provide support. This poses a great burden on untrained, lay caregivers. Despite this reality, evidence on caregiver's mental health and the significance of social support, in developing countries, remains low.

Social support is of special interest for caregivers because its absence may represent social ostracism and adverse events for caregivers of older persons, particularly in a country without long term care services as Chile.

We hypothesized that, in the absence of a long term care system, there may be a beneficial relation between perceived social support and the depression of caregivers, which has not been examined before, among general caregivers, using nationally representative data from a nationwide survey, in the Republic of Chile. In this study we also study previously documented demographic characteristics of the caregivers (age, female gender, education, health insurance) and caregiving characteristics (co-residing

with care-recipient, hours of care, and relationship with the recipient) and their association with depression in community-dwelling caregivers of older adults.

6.2.3 Methods

Study design

We conducted a secondary analysis of a nationwide survey data from a dual target (caregiver and older person) multistage probabilistic sample entitled *national survey on the dependency of older persons*. The sampling framework for the survey was taken from the *population and housing census* of 2002, aimed at collecting epidemiological data from persons aged 60 and over. Stratification was based on rural and urban settings (by population size) and geographical (to include subjects from all the regions in Chile). Units of analysis were, in descending order, cities, blocks, and houses. Primary sampling units were selected proportionally to the number of houses. Houses were randomly selected. One person aged 60 and over was selected per house, except those aged 80 and over, who were oversampled (always selected) to account for the increased prevalence of dependency in higher age groups. More details on the survey have been published by The National Agency for Elderly People in Chile in the form of a descriptive report ¹⁷⁵.

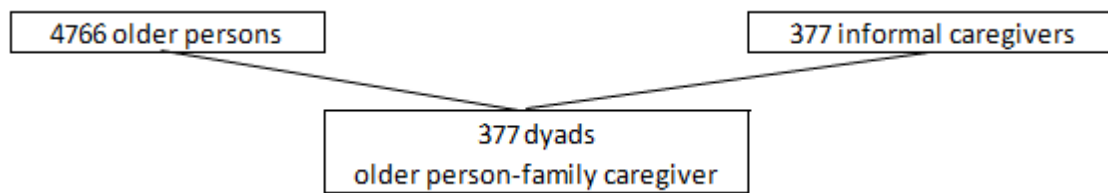
The survey on older persons consisted of 4766 respondents aged 60 and over and their family caregivers, if any. Ninety-one percent of respondents were the older persons themselves, while the remaining 9 percent were surrogates in case the older person had some degree of cognitive impairment measured using the Mini-Mental State Examination (short version) with a cut-off equal or less than 12 points. The surrogates needed to have no cognitive impairment, with a Pfeffer Functional Activities Questionnaire (PFAQ) score equal or greater than 6 points to be valid respondents. The survey was administered by 126 adults aged 18 and over, who had previous experience with complex surveys, and preferably with tertiary education. To minimize possible bias, the surveyors were trained on all the items of the survey and on how to use the PDAs to enter the responses. The PDA provides real-time validation of the entered data to avoid measurement errors. Data collection took place from November 2009 to January 2010.

Subjects

The sample consisted of 377 dyads of older persons and their informal caregivers. For this study, older persons are those aged 60 and older and living in the community who acknowledge the assistance of a main informal caregiver. Main caregivers are those who identified themselves as main caregivers and, at the same time, independently recognized by the older person as a provider of care related to ADLs and/or IADLS. This operational definition was set to avoid misclassification of the caregivers because of

confusion with legal or economic definitions of the role of the main caregiver.

Figure 14. Flowchart of older persons and informal caregivers to form the dyads



Measures

Outcome

For this study the outcome was depression as measured by the Center for Epidemiological Studies Depression Scale. The Center for Epidemiological Studies Depression Scale is an extensively used tool for measuring the degree of depressive symptoms among general population¹⁷⁶. This scale has been translated into Spanish and validated in Chile¹⁷⁷.

The 20 items were rated on a four-point scale ranging from zero (experienced rarely or none of the time) to three (experienced most or all of the time), with a total score range of 0–60 points.

For the 20-item Center for Epidemiological Studies Depression Scale, a score of 16 points or higher indicates some degree of depressive symptoms that could range from moderate to severe depression. For this study the depression status of caregivers was dichotomized following this cut-off point, between those with moderate to severe depression (coded as 1) and those with no depression (coded as 0).

Exposure

For the primary exposure of interest we used the Duke-UNC Functional Social Support Questionnaire (FSSQ) to measure perceived social support. This Questionnaire is used to measure perceived social support subjectively felt by the respondent. The 11 items were rated on a 5-point scale ranging from one (much less than desired) to five (as much as desired), and we calculated a total score (range 0–55). Higher scores indicated more perceived social support. For the FSSQ, a score of 32 or higher indicates a high degree of perceived social support. For this study the perceived social support felt by caregivers was dichotomized following this cut-off point, dividing the subjects between those with higher perceived social support (coded as 1) and those with lower support (coded as 0).

Due to the subjective nature of the perceived social support we also explored including binary questions of received social support in the bivariate analysis: “Have you taken vacations in the past year?”, “Have you received training on care?” and “Do you receive

community support?”

Covariates

Covariates were collected to identify potential confounding factors for depression. They have been divided into three categories: caregiver characteristics, caregiving characteristics and care recipient characteristics.

Caregiver characteristics

These characteristics included age, gender (female/male), years of education, marital status (married, divorced, widowed and single) and health insurance status (insured/uninsured).

Caregiving characteristics

Caregiving characteristics included hours of care, relation with the care recipients (partner, children or other), and their co-residential status (yes/no).

Care-recipient characteristics

Care-recipient characteristics were the ADL score (Katz Index), IADL score (Brody index) and cognitive impairment of the care-recipients.

The Katz Index of activities of daily living (ADL) measured independence in the care-recipient’s ADLs. The six items were rated dichotomously as zero (no) and one (yes), and we calculated a total score (range 0–6). Higher scores indicated more independence in activities of daily living.

The Lawton Instrumental Activities of Daily Living (IADL) Scale measured independence in IADL. The items were rated dichotomously as zero (no) and one (yes), and we calculated a total score (range 0–8). Higher scores indicated more independence in instrumental activities of daily living.

Cognitive impairment was measured using the short version of Mini-Mental State Examination (MMSE). The MMSE evaluates space-time location, short-term memory, and concentration. The total score for this short version of MMSE is 19 points. It is considered cognitive impairment if the score is less than 13 points.

Statistical methods

After using descriptive statistics to clean and describe our data in the univariate stage, we looked for correlations among the explanatory variables by using Pearson and Spearman’s correlation analyses, where only few mild correlations ($\rho < .7$) were found. For the bivariate relation among each one of the explanatory variables and the primary outcome of depression we used chi-square test for categorical variables and *t*-test for

continuous ones (Table 3).

Explanatory variables to be entered in the binary logistic regression analysis were those frequently mentioned in the literature to have a relation with the depression of caregivers and those that had relation strength in the bivariate analyses within 0.20 of significance (Table 3). Observations with missing data were excluded from the multivariable analysis. Odds ratios (OR) with 95 percent confidence intervals (CI) were reported as statistically significant (Table 4). Finally we conducted an analysis of multicollinearity (variance inflation factor was <10). Data was analysed using SPSS version 18.

A written consent to analyse this secondary data was obtained from the National Agency for Older People in Chile. There is no need for ethical clearance since the agreement with the government of Chile did not include any ethical requirement. Additionally, the data did not include any kind of personal information on the subjects. Also, no requirements are made regarding storage of the data, as it is readily accessible for any Chilean citizen.

6.2.4 Results

In the present study, 377 dyads of community dwelling caregivers and their care-recipient older persons were studied.

Univariate analysis

An extensive summary of descriptive characteristics of caregivers can be seen in Table 1. Previously an official report by the National Agency for Older Persons of Chile ¹⁷⁵ published descriptive data on the caregivers contained in the data analysed. However that report included the information of all the self-identified main caregivers, including those caregivers who were not recognized as involved in the provision of care related to ADLs and/or IADLs by the care-recipients, included in the operational definition for this study.

Regarding socio-demographic characteristics, caregivers in this sample had a mean age of 51.7 years. Most of them were female (85.1 percent) who had an average span of education of 8.2 years. In Chile, 8 years of education are equivalent to the complete elementary cycle of 8 primary years. Two thirds of the caregivers lived in urban settings. More than half (56.2 percent) were married. The second most common marital status was being single (30.8 percent). The majority of them had a national health insurance (84.9 percent), while only 2.4 percent and 2.1 percent had a private health insurance and other type of insurance, respectively. Uninsured caregivers amount to 8.5 percent.

Regarding caregiving characteristics, the mean hours of care was 15.6 (unit is hours). Less than half (43.8 percent) of the caregivers were the children of the older persons receiving the care. One fourth of them were the partner of the recipients. Only 6 out 377 caregivers were hired caregivers. A great proportion of the caregivers (84.9 percent) live

with the older persons they care.

Regarding the outcomes and exposure of interest shown in table below, we can observe that nearly half (46.9 percent) of the caregivers present depressive symptoms, while nearly three fourths perceived to have a higher level of social support. Measures of received social support show that nearly half (47.7 percent) of the caregivers share the task of caregiving with someone else, while one fourth (22 percent) had taken vacations in the past year.

Table 16. Univariate characteristics of the caregivers. n=377

Item	n (%)
Caregiver characteristics	
Carer Age [Mean±SD]	[51.73±15.4]
Carer Gender	
Male (ref)	56 (14.9)
Female	321 (85.1)
Carer Education (in years) [Mean±SD]	[8.22±4.2]
Setting	
Rural	127 (33.7)
Urban	250 (66.3)
Carer Marital Status	
Married	212 (56.2)
Divorced	28 (7.4)
Widowed	21 (5.6)
Single	116 (30.8)
Health Insurance	
Uninsured	32 (8.5)
National	320 (84.9)
Private	9 (2.4)
Other	8 (2.1)
Caregiving characteristics	
Hours of care [Mean±SD]	[15.6±8.3]
Relation with the care recipient	
Partner	88 (23.3)
Children	165 (43.8)
Stepchildren	4 (1.1)
Parents/Parents in law	2 (0.5)
Siblings/sibling in law	16 (4.2)
Children in law	26 (6.9)
Grandchildren	27 (7.2)
Other relatives	25 (6.6)
No relatives	18 (4.8)
Private care	6 (1.6)
Co-residence	
No	54 (14.3)
Yes	320 (84.9)
Care recipient characteristics	
ADL score of the care-recipient [Mean±SD]	3.39 (1.7)
IADL score of the care-recipient [Mean±SD]	13.8 (4.9)
Cognitive impairment	179 (47.5)

Table 17. Caregivers' measurements of interest. n=377.

Item	n (%)
Outcome and exposure	
Depression or carer (CES-D)	
Not depressed (<16)	200 (53.1)
Depressed (≥16)	177 (46.9)
Perceived Social Support (Duke-UNC)	
Lower (<32)	87 (23.1)
Higher (≥32)	290 (76.9)
Received Social Support	
Have you taken vacations in the past year? (yes)	83 (22)
Have you received care training? (yes)	28 (7.4)
Do you receive community support? (yes)	20 (5.3)

Bivariate analysis

As shown in table below, among those factors associated with being depressed in our bivariate analyses, we find that the perceived social support, having taken vacations in the past 12 months, the age of the carer, their gender, their education in years, being insured, the number of hours they provide care, relation with the care recipient, and co-residence, the scores on ADL and IADL were associated to depression within a statistical significance of .20. Also cognitive impairment, despite not been statistically significant in the bivariate analysis, was included because it appears commonly in the literature as related.

Table 18. Bivariate analysis of sociodemographic characteristics and depression (CES-D \geq 16)

Item	Depression			p-value
	Total n (%) 377 (100)	Not Depressed n (%) 200 (53.1)	Depressed n (%) 177 (46.9)	
Care giver characteristics				
Carer Age [Mean \pm SD]	[51.7 \pm 15.4]	[50.2 \pm 15.7]	[53.45 \pm 15]	0.042
Carer Gender				0.213
Male	56 (14.9)	34 (17)	22 (12.4)	
Female	321 (85.1)	166 (83)	155 (87.6)	
Carer Education (in years) [Mean \pm SD]	[8.2 \pm 4.2]	[8.3 \pm 4.5]	[6.7 \pm 4.2]	0.000
Setting				0.723
Rural	127 (33.7)	69 (34.5)	58 (32.8)	
Urban	250 (66.3)	131 (65.5)	119 (67.2)	
Carer Marital Status				0.431
Single	116 (30.8)	67 (33.5)	49 (27.7)	
Married	212 (56.2)	105 (52.5)	107 (60.5)	
Divorced	28 (7.4)	17 (8.5)	11 (6.2)	
Widowed	21 (5.6)	11 (5.5)	10 (5.6)	
Type of medical insurance				0.003
Insured	337 (91.3)	187 (95.4)	150 (86.7)	
Uninsured	32 (8.7)	9 (4.6)	23 (13.3)	
Care giving characteristics				
Hours of care [Mean \pm SD]	[15.6 \pm 8.3]	[13.6 \pm 8.2]	[17.9 \pm 7.8]	0.000
Relation with the care recipient				0.000
Partner	88 (23.3)	33 (16.5)	55 (31.1)	
Children	169 (44.8)	87 (43.5)	82 (46.3)	
Other	120 (31.8)	80 (40)	40 (22.6)	
Co-residence				0.012
No	54 (14.4)	37 (18.8)	17 (9.6)	
Yes	320 (85.6)	160 (81.2)	160 (90.4)	
Care-recipient characteristics				
ADL score of the care-recipient [Mean \pm SD]	[3.4 \pm 1.7]	[3.5 \pm 1.6]	[3.25 \pm 1.8]	0.140
IADL score of the care-recipient [Mean \pm SD]	[13.8 \pm 4.9]	[14.1 \pm 4.9]	[13.5 \pm 4.9]	0.160
Cognitive impairment				0.592
No	143 (44.4)	74 (43)	69 (46)	
Yes	179 (55.6)	98 (57)	81 (54)	
Social Support				
Perceived Social Support (Duke-UNC)				0.000
Lower (<32)	87 (23.1)	30 (15)	57 (32.2)	
Higher (\geq 32)	290 (76.9)	170 (85)	120 (67.8)	
Received Social Support				
Have you taken vacations in the past 12 months?				0.006
No	294 (78)	145 (72.5)	149 (84.2)	
Yes	83 (22)	55 (27.5)	28 (15.8)	
Have you received training on care?				0.737
No	349 (92.6)	186 (93)	163 (92.1)	
Yes	28 (7.4)	14 (7)	14 (7.9)	
Do you receive community support?				0.271
No	357 (94.7)	187 (93.5)	170 (96)	
Yes	20 (5.3)	13 (6.5)	7 (4)	

SD, standard deviation; n, number

Multivariable analysis

The final model for the dichotomous outcome variable of depression among caregivers

consisted of 11 explanatory elements. No multicollinearity among predictors was detected. In terms of our main variable of interest, the data showed that perception of a higher rather than lower level of social support by the caregiver reduced the likelihood of depression, with an OR of 0.311 and a CI of 0.167–0.579. Taking vacations in the past 12 months also reduced the likelihood of depression (OR: 0.513; CI: 0.270–0.975). The following factors increased the likelihood of suffering from depression: being female (OR 2.381; CI 1.136–4.988), being uninsured (OR 4.629; CI 1.838–11.656), and being the partner of the care recipient versus another relationship with the recipient (OR: 3.832; CI 1.546–9.493). In addition, the likelihood of reporting depression increased as a function of every additional hour of care provided (OR: 1.052; CI 1.017–1.087). When calculated based on the average of 16 h of care provided by Chilean caregivers using the exponentiating $\exp(B)$, the OR was 2.250¹⁶.

Table 19. Logistic regression of social support and depression (CES-D Score ≥ 16). n=315.

Variables in the Equation	Exp(B)	95% C.I. for EXP(B)	
		Lower	Upper
Perceived Social Support (ref= lower social support <32)			
Higher social support (≥ 32)	.311	.167	.579
Received support			
Have you taken vacations in the past 12 months?	.513	.270	.975
Age of the carer (in years)	.982	.959	1.005
Gender of the carer (ref= male)			
Sex of the carer (female)	2.381	1.136	4.988
Years of education (in years)	.943	.879	1.010
Health Insurance type (ref=insured)			
Uninsured	4.629	1.838	11.656
Relation with care recipient (ref=other)			
Partner (wife, husband, etc)	3.832	1.546	9.493
Children	1.387	.762	2.523
Hours of care (in hours)	1.052	1.017	1.087
Living in the same house (ref=no)	.939	.828	1.064
ADL Score of the care-recipient	.966	.902	1.034
IADL Score of the care-recipient	.996	.806	1.230
Cognitively impaired (ref=no)			
Yes	.765	.431	1.357
Constant	2.467		
Hosmer and Lemeshow Test			
Step	Chi-square	df	Sig.
1	2.125	8	.977

6.2.5 Discussion

The present study showed the complex process by which depressive symptoms among informal caregivers emerge. Specifically, perceived social support interacts with the sociodemographic characteristics of caregivers and the context in which the caregiving occurs. However, the characteristics of the care recipient did not seem to be a significant contributor to caregivers' depression according to this multivariate model.

A previous study on patients receiving hemodialysis in Chile reported that 43.82% of caregivers suffered from depression (CI 95%; 36.42–51.53) according to the CES-D ¹⁷⁴. This rate is close to that found in the present study (46.9%), although it is possible that caring for a patient receiving hemodialysis is more stressful than caring for those in the general population. Research in other countries using the same cut-off score of 16 found a lower prevalence of depression. One study in Japan found that 34.2% of informal caregivers of community-dwelling elderly persons suffered from depression according to the CES-D ¹⁷⁸. However, it should be noted that the sample consisted of users of Japanese long-term care insurance services, access to which may have reduced the burden leading to depression. A study of African-American women acting as informal caregivers of elders with dementia in the United States found a prevalence of depression of 18%, and a study in Canada found a prevalence of 21%, although dementia may impose more strain on caregivers, even though dementia may suppose higher strain ¹⁷⁹. In Spain, a sample of caregivers of disabled older persons reported a prevalence of 36.85% among both male and female caregivers, which was considered high by the authors. It can be argued that the prevalence of depression in the Republic of Chile is very high, even compared to other countries undergoing different demographic transitions involving populations at higher risk.

Regarding our main variable of interest, perceived social support appeared to have a preventive effect against higher levels of depressive symptoms. This beneficial effect of social support has been documented in previous studies ¹⁶⁸. Moreover, the effects of perceived social support are more strongly related to depressive symptoms than the social support received ¹⁶⁸. It has been argued that this may reflect the importance of quality of over quantity.

Regarding our covariates, in the present study, we found that female caregivers were nearly 2.4 times more likely than male caregivers to meet our criteria for depression. Indeed, previous studies have shown the detrimental effects of being a female caregiver^{180,181} and/or the partner of the care recipient ^{182,183}. Livingston et al. noted that the higher prevalence of depression among female caregivers contradicts the assumption that women adapt more naturally to the role of caregiver. The greater vulnerability of women to stress may be explained by other aspects of their gender role (e.g., less education, lower income, more economic vulnerability, higher rates of depression among

older adult women, more experience with violence) that render them more susceptible to the additional burden of serving as a caregiver.

Independently, other studies have found that spouses who act as caregivers have found to be at higher risks of being depressed^{182,184}. These scholars argued that this correlation may be attributed to the fact that stress increases as a function of the closeness of the bond between the provider and the caregiving recipient. This effect of proximity between members of the dyads may also explain the beneficial effect of being a caregiver other than the partner. This study found that spouses are also at higher risk than children or others (alternative analysis not included), which is consistent with the findings of other studies¹⁸¹. Thus, partners suffer from the detrimental effects of proximity. Nonetheless, it should be noted that, unlike many other studies, the present research did not find a significant correlation between the co-residence of the dyad and depression in the caregiver. This may be explained by the fact that the vast majority of dyads actually lived together (84.9%). This asymmetry may have statistically interfered with the emergence of any significant findings in this regard.

The lack of a significant association between diminished physical capabilities and depression has been previously reported¹⁸⁰. Livingston et al. asserted that this may be due to the maintenance or reinforcement of psychological benefits derived from a close relationship, when the recipient has diminished functional capabilities. In the present study, functional capabilities were reflected in ADL and IADL scores. However, the literature contains conflicting evidence on this topic. Other authors have found that increased functional impairment in the care recipient was related to higher levels of depression in the caregiver^{182,183}. Meshefedjian argued that the association between higher levels of depression according to CES-D scores and impaired ADLs may be explained by the increased physical burden of care, which may negatively affect the mental health of the caregivers. However, the authors noted the possibility of bias, because depressed caregivers may be more likely to report the impairment of their care recipients.

In terms of the weak significance of the influence of education on the depression of caregivers, it has been previously shown that the education of caregivers has a protective effect with respect to depression, possibly by enabling the caregiver to draw on a wider range of knowledge to cope with caregiving and stressful situations. However, it should also be noted that years of education may be strongly associated with the financial status of the caregiver. Thus, it is possible that the availability of economic resources serve as a coping method for dealing with this burden, as well as other stressful events or activities. This study did not include income data, which interferes with our ability to comment on this interpretation.

The detrimental effect of providing increasing hours of care has been previously shown in the literature¹⁸³. It can be argued that longer hours of care decrease the physical and

mental health of caregivers, because caregiving is a very physically and mentally demanding role. This may explain why vacations appeared to have a beneficial effect in our study.

Among the strengths of our study, is our use of a large, nationally representative dataset, which included, in its original state, an expansion factor that enabled the figures to be extrapolated to the national level. Previous studies examining the experiences of caregivers in Chile have had limited samples. This study also included a wide range of factors that were previously shown to be related to depression in caregivers. An additional strength of the present study was the more restricted definition of caregivers compared to that used in other studies, which only relied on self-identification. This definition allowed us to identify caregivers who were actually helping with ADLs and/or IADLs; however, it was unable to identify caregivers who did not view themselves as caregivers¹⁸⁵, which was an unavoidable weakness of the original data.

The principal limitation of this study is its cross-sectional design, which precludes concluding that the associations observed herein were causal. Furthermore, the use of depression as the outcome variable may render the results difficult to interpret, as the primary variable of interest was perceived social support. That is, the cross-sectional design prevented us from determining whether the caregivers were depressed, because of less perceived social support or whether they perceived less social support because they were depressed. We attempted to deal with this issue by including questions about the elements of the social support that were actually received, which improved the fitness of the multivariate model and made a statistically significant contribution.

Another limitation of the present study is the absence of measures of the economic resources of caregivers, care recipients, or households. It has been reported that economic health probably mitigates the stress of caregiving¹⁸³. Although it could be argued that the education of caregivers may act as a surrogate of income, the fact that, in Chile, primary education is mandatory and free for those without resources may preclude this assumption. Another factor that may reflect the economic status of the caregiver may be their enrollment in private health insurance, which is generally more expensive. However, the caregivers enrolled in the private system accounted for only 2.4% of the sample of this study. A much greater proportion (84.9%) was enrolled in the national insurance system, known to serve poorer segments of the populations. Their affiliation with the latter system may be explained by their inability to hold a paid job other than caregiving, which would preclude access to more expensive insurance..

6.2.6 Conclusion

Based on the findings of this study, we conclude that the beneficial effects of social

support should be further explored and may lead to initiatives to strengthen social networks. Such policies will be perceived by the caregivers of older adults as recognition of the importance of their role. Given that nearly half the caregivers in our study reported depression, it is crucial to develop ways to alleviate the burden placed on this population. Whereas the levels of perceived social support were high (according to three-fourths of the sample) when the survey was administered, we expect them to decrease as time passes, because the number of persons with whom informal caregivers share their caregiving role will likely decrease. In addition, the number of persons getting married is decreasing, leading to increasing numbers of single elderly individuals. Along with this reduction in marriage, the number of children is decreasing. Taken together, these trends are reducing the number of generations sharing a household. Because children and partners account for most of the caregiving force, the social support for caregivers will certainly decrease.

Another implication of these trends is the need for a long-term care system that will enable caregivers to experience respite and an alleviation of their burden. Particular emphasis should be given to female caregivers, who appear to have an increased vulnerability to the stress of caregiving. Additional ways to alleviate the depression of female caregivers should also be explored. These should be accompanied by more in-depth research regarding the obligation of spouses to adopt a caregiving role, as our data show that this role has a detrimental effect on loved ones. The benefits offered by respite programs should include respite care, which may allow informal caregivers to take vacations. Given that our study found that vacations are helpful, their benefits and characteristics should be further explored. Moreover, additional ways to encourage uninsured caregivers to enroll in a health insurance program should be explored. The Republic of Chile offers a non-contributory universal health insurance system, even for those who cannot afford it. Therefore, in theory, there should be no reason for lack of access to health services, which was shown to have a strong effect on depression in the present study.

6.3 Study 5

The relation of depression with health behaviours and social conditions of dependent community-dwelling older persons in the Republic of Chile, from a nationwide survey

6.3.1 Abstract

Objective: We examined associations of depression with health behaviors and social conditions among dependent community-dwelling older persons in the Republic of Chile.

Methods: This cross-sectional, inferential study relied on nationwide secondary data. We performed logistic regression analysis on data obtained from 640 dependent community-dwelling older persons throughout Chile who were not taking antidepressants. The Geriatric Depression Scale (GDS-15), a valid assessment instrument, was used to measure the outcome variable. We treated the health behaviors and social conditions of older persons as independent variables, and sociodemographic and physical conditions were included as covariates.

Results: A total of 44.5% of older persons reported depressive symptoms. The logistic regression revealed a significant effect of the following factors on the development of depression: visiting a doctor >4 times in the past 6 months due to acute conditions (odds ratio (OR): 2.9, confidence interval (CI): 1.1–7.5), living alone (OR: 2.1, CI: 1.1–4.0), feeling uncomfortable with one's living arrangement (OR: 3.7, CI: 1.1–12.0), and experiencing discrimination (OR: 2.2, CI: 1.4–3.6).

Discussion: In terms of health behaviors, the literature has shown that visiting the doctor due to acute rather than chronic conditions is associated with depression, possibly because both populations are accustomed to undergoing check-ups, but more stress is associated with acute episodes. With regard to social conditions, living alone, widely documented as being associated with depression, and feeling uncomfortable with one's living arrangement were also correlated with depression in this study. Consistent with the literature, experiencing discrimination also had a significant effect on depression.

Conclusion: Additional research regarding ways to help older persons who live alone avoid depression is needed. Studies examining the comfort of this population with their living arrangements are also necessary. Finally, approaches to prevent discrimination against older persons should be encouraged.

6.3.2 Introduction

Depressive symptoms are a leading cause of disability ¹⁶⁴, and it has been argued that depression is the most frequent cause of emotional suffering ¹⁸⁶. Depressive symptoms are more prevalent among older than among middle-aged adults ¹⁸⁷, and exert negative effects on the physical health, functioning ¹⁸⁸, and quality of life of elderly individuals who suffer from this condition ¹⁸⁹.

The Republic of Chile is among the most aged countries in South America, and is undergoing a demographic transition similar to that experienced by Argentina and Uruguay ¹⁷². Those aged 60 years and older accounted for 12.95% of the population in 2010, and this figure is expected to reach 20.11% by 2025 and 28.2% by 2050 ¹⁹⁰.

According to the nationally representative data used in this study and previously reported, 23.6% of both males and females aged 60 years and older were depressed

according to the Geriatric Depression Scale (GDS-15) ¹⁹¹. Depression was more prevalent among females (26.8%) than males (18.5%), which is consistent with the Survey on Health, Well-Being, and Aging in Latin America and the Caribbean (SABE). This study used the same scale, and found a prevalence of depression of 23% among females and 12% among males aged 60 years and older who were living in the capital city of Chile ¹⁹².

Old age is usually linked to dependency, and this affects 24.1% of those aged 60 years and older in Chile, whose level of dependency ranges from mild to severe. Dependency plays a dominant role in countries in the advanced stage of a demographic transition. Because depression is so closely related to loss of independence, it is necessary to develop a detailed understanding of this phenomenon.

A previous study on older persons associated complaints of depression with self-perceptions of impaired health and efficacy, lower instrumental support, and the presence of conflict ¹⁹³. However, the previous study of a sample of 394 persons living in an urban area of the capital city did not consider dependence. Because dependency is more common in rural areas and differs according to region and ethnicity ¹⁷⁵, it seems advisable to adjust for these characteristics when studying older individuals. The prevalence of depressive disorders also significantly differs among regions in Chile ¹⁹⁴. Similarly, a previous study focused on grandparents caring for grandchildren found an association between functionality and depression among men and between hours of care and depression among women¹⁹⁵. This study was limited to people aged 66–68 years who lived in low- or middle-income areas of the Santiago metropolitan area of Chile; therefore, the results may not be generalizable to a broader age range of older persons, those with different levels of income, those living in different settings, and those in different regions. Another study analyzed the relationship between depression and age in the city of Antofagasta in the northern part of Chile. The design of this study was correlational and not multivariate, sampling subjects from primary care centers, community sport groups, religious organizations, folkloric groups, and sociocultural associations. This design may explain why the prevalence of depression in this study was 4%, which is lower than other reported rates, as depressed people tend to not engage in these kinds of activity²⁹. The design of this study was correlational and not multivariate, sampling subjects from primary care centers, community sport groups, religious organizations, folkloric groups, and sociocultural associations. This design may explain why the prevalence of depression in this study was 4%, which is lower than other reported rates, as depressed people tend to not engage in these kinds of activity.

The present study builds on the initial report of the survey data used by the government ¹⁷⁵, which noted an association between depression and dependency after adjusting for age, gender, and years of education. We designed a more complex model of the interactions involved in the depressive status of dependent older persons, the outcome

measure, by examining the potential roles of the following health behaviors of elderly individuals as explanatory variables: number of visits to doctors for check-ups, numbers of visits to doctors due to acute and chronic conditions, smoking habits, and physical exercise. We also gathered data on whether respondents were living alone, their degree of comfort with their living arrangements, whether they worked during the last week, whether they had experienced discrimination, and whether they participated in volunteer activities. We adjusted for sociodemographic characteristics such as gender, years of education, urbanization, age, ethnic background, ability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs), number of falls, cognitive impairment, pain, number of chronic diseases, visits to doctors for acute and chronic conditions, and experience of falls in the past year.

We tested the hypothesis that depressive symptoms are associated with the health behaviors and social conditions of dependent community-dwelling older persons after adjusting for sociodemographic and physical variables. The results of the present study will contribute to a much-needed national overview of the contributors to depressive symptoms by analyzing data from a nationally representative randomly selected probabilistic sample of dependent older persons, including residents of both rural and urban areas, in the Republic of Chile.

6.3.3 Method

Study design

We conducted a secondary analysis of data obtained by the National Survey on the Dependency of Older Persons, which used a multistage probabilistic sampling design to gather nationally representative data. The sampling framework for the survey, which was taken from the population and housing census of 2002, was aimed towards collecting epidemiological data from persons aged 60 years and older. The sample was stratified by rural and urban settings (according to population size) and geographic region (to include subjects from all regions of Chile). Units of analysis were, in descending order, cities, blocks, and houses. Primary sampling units were selected in proportion to the number of houses. Houses were randomly selected. One person aged 60 years and older was selected per house; however, those aged 80 years and older were oversampled (always selected) to account for the increased prevalence of dependency of older groups. Additional details about the survey were published by The National Agency for Elderly People in Chile in the form of a descriptive report ¹⁷⁵.

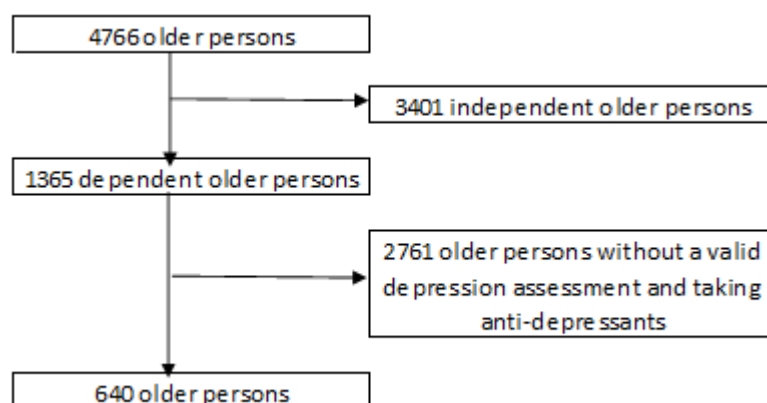
This survey included 4766 respondents aged 60 year and older. In total, 91% of the care recipients were the older persons themselves, whereas the remaining 9% were surrogates because the older person had some degree of cognitive impairment according to the short

version of the Mini-Mental State Examination (using a cut-off equal to or less than 12 points). The surrogates were free of cognitive impairments and scored at least 6 points on the Pfeffer Functional Activities Questionnaire (PFAQ). The survey was administered by 126 adults aged 18 and older who had previous experience with complex surveys, and preferably, tertiary education. To minimize possible bias, the surveyors were trained on all of the items in the survey and on how to use personal digital assistants (PDAs) to enter the responses. The PDA provides real-time validation of the data entered to avoid measurement errors. Data were collected from November 2009 to January 2010.

Participants

The sample initially consisted of 4766 older persons aged 60 years and older. Subjects with no level of dependency were excluded, leaving a final sample of 1365 respondents. Furthermore, subjects without a valid depression assessment and those taking medicine for depression were excluded. After the exclusion criteria were applied, the final sample consisted of 640 individuals. The sampling flowchart is presented in the figure below.

Figure 15. Flowchart of the sample by exclusion criteria



Dependency

The operational definition of dependency followed the one used in the original survey. Dependency was determined by the functionality of the person, and by the amount, type, and level of assistance received from others. The two components of this definition are functional limitations and need for human assistance due to impaired functionality. Thus, the general definition of dependent persons used in this study was based on the following considerations:

1. Bedridden people.
2. People with any level of dementia, defined by a MMSE score lower than 13 points and a PFAQ score higher than 5 points.

3. Inability to perform one ADL
4. Inability to perform one IADL
5. Needing always help or almost always to do one ABVD
6. Needing always help or almost always to do two IADL

Measures

Outcome

The outcome variable in this study was the score on the 15-item short form (GDS-15) of the Geriatric Depression Scale (GDS), which was created in 1986 by Yesavage et al. [please note citation], and tested on and extensively used with older populations. Of the 15 items, affirmative answers to 10 reflect the presence of depression, whereas negative answers to the remaining questions (numbers 1, 5, 7, 11, 13) reflect depression. Scores of 0–4 are considered normal, and scores of 5–15 indicate mild to severe depression. Thus, a cut-off of 5 is used to identify depressive symptoms. Accordingly, we divided the sample into those with mild to severe depression (coded as 1) and those with no depression (coded as 0).

Exposure

Health Behaviour

The number of visits to the doctor in the past 6 months was divided into visits due to acute conditions and those for a periodic health check-up. Both variables were continuous, and each additional number represented an additional visit to the doctor. The number of chronic diseases represents the conditions with which each respondent was reportedly diagnosed, with possible values ranging from 0 to 5. The diseases included hypertension, Parkinson's, diabetes, cardiovascular diseases, and respiratory conditions.

Social characteristics

Living situation was coded as 1 when the older person was the only inhabitant of the household, and as 0 when other persons were living in the household. To adjust for satisfaction with one's living arrangement, we asked, "Generally speaking, are you comfortable living alone/with the persons with whom you now live?" Answers were coded as 1 for yes and as 0 for no. Employment status was assessed with the question, "Did you work last week doing something other than house chores?" Responses were coded as 1 for yes and as 0 for no.

Discrimination was assessed with the following question: "Have you felt discriminated

against in the past 12 months?” Never was coded as 0 and used as a reference; all kinds of discrimination (socioeconomic status, being female, ethnicity, sexual preference, being a foreigner, physical appearance, health condition) were coded as one (1).

Covariates

Sociodemographic characteristics

Adjustments for gender, age, urbanization, ethnic background, education, and marital status were made.

Physical conditions

The Katz Index of Activities of Daily Living (ADLs) was used to measure the care recipient’s level of independence in this domain. The six items on this instrument were rated dichotomously, as 0 (no) and 1 (yes); higher total scores (range 0–6) indicated more independence. The Lawton Instrumental Activities of Daily Living (IADLs) Scale was used to measure independence in this domain. Items were rated dichotomously, as 0 (no) and 1 (yes); higher total scores (range 0–8) indicated more independence. Falling was measured with the following question: “In the past 12 months, have you fallen?” One or more falls was coded as 1, and no falls was coded as 0. Physical activity was measured by asking, “In the last 3 months, how many times have you participated in physical activities each week?” Response options ranged from 0 to 7. Two values over 7 were eliminated. Cognitive impairment was measured with the Mini-Mental State Examination (MMSE), the most commonly used instrument for screening cognitive functioning. This examination is not suitable for diagnostic purposes, but can be used to indicate the presence of cognitive impairment. This test has a cut-off point of 12; cognitive impairment was coded as 1, and no impairment was coded as 0.

Statistical methods

After using descriptive statistics to describe our data in the univariate stage, we identified correlations among the explanatory variables using non-parametric Spearman’s correlation analysis. According to the data, only two sets of variables were weakly correlated ($\rho < 0.3$). We used bivariate logistic regression analysis to examine the relationship, if any, between each potential explanatory variable and the outcome variable, depression. The explanatory variables entered in the binary logistic regression analysis were those frequently identified in the literature as related to depression among older persons and those with a strong relationship in the bivariate analyses within 0.20 of significance. Surveys with missing data were excluded from the multivariate analysis. Odds ratios (ORs) with 95% confidence intervals (CIs) are reported in Table 4, and we conducted an analysis of multicollinearity (the variance inflation factor was < 10). Data were analyzed using SPSS, version 18.

Written consent to analyze these secondary data were obtained from the National Agency

for Older People in Chile. Ethical approval was not required, because the agreement with the government of Chile did not include a stipulation in this regard. In addition, the data did not include personal information about the subjects. Moreover, we did not need to arrange for data storage, as they are readily accessible to any Chilean citizen

.

6.3.4 Results

Table 20. Basic characteristics of the sample.

		Total	
		n	%
Sociodemographic characteristics			
Gender			
	Male	243	38
	Female	397	62
Age			
	Number of years	Mean SD	76 8.7
Setting			
	Rural	259	40.5
	Urban	381	59.5
Ethnicity			
	No ethnic background	583	91.1
	Ethnic background	57	8.9
Education			
	Number of years of education	Mean SD	4.3 3.4
Marital status			
	Married	296	46.3
	Divorced	39	6.1
	Widow/Widower	255	39.8
	Single	50	7.8
Physical conditions			
Physical Functionality Scores			
	ADL score	Mean SD	4.2 1.1
	IADL score	Mean SD	17.9 3.8
Cognitively impaired by the Mini Mental Test			
	No	568	88.8
	Yes	71	11.1
Pain in the last weeks			
	No pain	103	16.1
	Very little	61	9.5
	A little	105	16.4
	Moderate	102	15.9
	Much	175	27.3
	Very Much	94	14.7
Admitted to a hospital in the past year			
	No	540	84.4
	Yes	99	15.5
Chronic Disease			
	Number of chronic diseases	Mean SD	1.4 1
Hypertension			
	No	190	29.7
	Yes	440	68.8
Parkinson			
	No	610	95.3
	Yes	23	3.6
Diabetes			
	No	467	73
	Yes	166	25.9
Cardiovascular condition			
	No	486	75.9
	Yes	146	22.8
Respiratory condition			
	No	493	77
	Yes	137	21.4
Polypharmacy			
	No	378	59.1
	Yes	262	40.9
Falls in the past year			
	Number of falls	Mean SD	1.2 3.2

When we see the results of the bivariate analysis for depression as the dependent variable we observe the following characteristics:

Table 21. Bivariate analysis of depression and covariates

		Not depressed		Depressed >5		Total	p-value
		n	%	n	%		
Sociodemographic characteristics							
Gender							
	Male	140	57.6	103	42.4	243	0.393
	Female	215	54.2	182	45.8	397	
Age	Number of years	mean (SD)					
		76.97	8.5	74.82	8.8	634	0.002
Setting							
	Rural	154	59.5	105	40.5	259	0.094
	Urban	201	52.8	180	47.2	381	
Ethnicity							
	No ethnic background	318	54.5	256	45.5	583	0.133
	Ethnic background	37	64.9	20	35.1	57	
Education	Number of years of education	mean (SD)					
		4.35	3.44	4.33	3.40	613	0.942
Marital status							
	Married	164	55.4	132	44.6	296	0.921
	Divorced	21	53.8	18	46.2	39	
	Widow/Widower	140	54.9	115	45.1	255	
	Single	30	55.5	285	44.5	50	
Physical conditions							
Physical Functionality Scores							
	ADL score	mean (SD)					
		4.38	0.941	3.93	1.201	640	0.000
	IADL score	mean (SD)					
		18.32	3.677	17.28	3.876	640	0.001
Cognitively impaired by the Mini Mental Test							
	No	313	55.1	255	44.9	568	0.517
	Yes	42	59.2	29	40.8	71	
Pain in the last weeks							
	No pain	76	73.8	27	26.2	103	0.000
	Very little	45	73.8	16	26.2	61	
	A little	67	63.8	38	36.2	105	
	Moderate	61	59.8	41	40.2	102	
	Much	73	41.7	102	58.3	175	
	Very Much	33	35.1	61	64.9	94	
Admitted to a hospital in the past year							
	No	311	57.6	229	42.4	540	0.016
	Yes	44	44.4	55	55.6	99	
Chronic Disease	Number of chronic diseases	mean (SD)					
		1.34	0.935	1.54	1.066	638	0.010
Hypertension							
	No	112	58.9	78	41.1	190	0.283
	Yes	239	54.3	201	45.7	440	
Parkinson							
	No	342	56.1	268	43.9	610	0.435
	Yes	11	47.8	12	52.2	23	
Diabetes							
	No	266	57	201	43	467	0.311
	Yes	87	52.4	79	47.6	166	
Cardiovascular condition							
	No	278	57.2	208	42.8	486	0.165
	Yes	74	50.7	72	49.3	146	
Respiratory condition							
	No	289	58.6	204	41.4	493	0.013
	Yes	64	46.7	73	53.3	137	
Polypharmacy							
	No	214	56.6	164	43.4	378	0.484
	Yes	141	53.8	121	46.2	262	
Falls in the past year	Number of falls	mean (SD)					
		0.87	1.747	1.5	4.412	635	0.026

chi square with phi coefficient for categorical variables

t-test for continuous variables

Nearly forty-five percent of the older persons presented some degree of depression.

Table 22. Bivariate analysis of depression and independent variables.

	Not depressed		Depressed >5		Total	p-value
	n	%	n	%		
Health behaviour						
Number of visits to the doctor because of a health checkup						
0 times	96	54.2	81	45.8	177	0.948
1-2 times	111	55.2	90	44.8	201	
3-4 times	67	57.8	49	42.2	116	
5 or more times	81	55.5	65	44.5	146	
Number of visits to the doctor because of a disease						
0 times	256	60.1	170	39.9	426	0.002
1-2 times	66	50.0	66	50.0	132	
3-4 times	23	46.9	26	53.1	49	
5 or more times	10	30.3	23	69.7	33	
Physical activity per week in the past three months						
Number of days	mean					
(SD)	0.49	1.457	0.33	1.161	617	0.146
Tobacco smoking						
Never smoked	243	59.4	166	40.6	409	0.038
Quitted smoking	84	48.3	90	51.7	174	
Continues smoking	22	51.2	21	48.8	43	
Present alcohol drinking						
No	272	54.6	226	45.4	498	0.418
Yes	83	58.5	59	41.5	142	
Social conditions						
House Ownership						
No	33	56.9	25	43.1	58	0.955
Yes	278	56.5	214	43.5	492	
Did you work in agriculture						
Did not work in agriculture	181	54.4	152	45.6	333	0.858
Worked in agriculture	60	56.6	46	43.4	106	
Never worked	113	56.5	87	43.5	200	
White collar work						
Worked as white collar	7	63.6	4	36.4	11	0.782
Work as a blue color	234	54.7	194	45.3	428	
Never worked	113	56.5	87	43.5	200	
Living alone						
No	317	56.8	241	43.2	558	0.075
Yes	38	46.3	44	53.7	82	
Change of living place in the past 5 years						
No	30	51.7	28	48.3	58	0.547
Yes	325	55.8	257	44.2	582	
Are you comfortable with your living arrangement						
No	345	57.3	257	42.7	602	0.001
Yes	6	24	19	76	25	
Health Insured						
No	17	65.4	9	34.6	26	0.288
Yes	320	54.8	264	45.2	584	
Pensioned						
No	112	58.9	78	41.1	190	0.283
Yes	239	54.3	201	45.7	440	
Did you work last week?						
No	326	54.5	272	45.5	598	0.067
Yes	29	69	13	31	42	
Have you felt discriminated?						
No	304	62	186	38	490	0.000
Yes	51	34	99	66	150	
Do you have any recreational activity						
No	227	53.4	198	46.6	425	0.109
Yes	128	60.1	85	39.9	213	
Do you participate in an organization?						
No	267	54.5	223	45.5	490	0.276
Yes	87	59.6	59	40.4	146	
Do you volunteer?						
No	324	56.5	249	43.5	573	0.176
Yes	30	47.6	33	52.4	63	
Do you receive help from an organization?						
No	318	56	250	44	568	0.460
Yes	37	51.4	35	48.6	72	
Do you provide care to someone else?						
No	322	55.5	258	44.5	580	0.939
Yes	33	55	285	44.5	60	

chi square with phi coefficient for categorical variables
t-test for continuous variables

The logistic regression model show that there are four factors with a detrimental effect on depression “visiting the doctor because of acute diseases” and “living alone”. The same model shows eight beneficial effects on depression: age of the older person, higher ADL and IADL scores, Number of times of physical activity during the week for the past three months, feeling comfortable with their living arrangement, having worked last week in other activities than house chores.

Beneficial factors

In detail significant beneficial factors against being depressed are: every year of age (Odds Ratio-OR: 0.959, 95 percent Confidence Interval, CI: 0.935~.983); Every additional point of ADL score (OR: .796, CI: .647~.980); Every additional point of IADL score (OR: 0.928, CI: 0.873~ 0.987); every additional day of physical exercise (OR: 0.822, CI: 0.692~0.977).

Detrimental factors

Significant detrimental factors that increase the likelihood of being depressed are: being in much pain (OR: 2.605; CI: 1.372~4.945) or very much in pain (OR: 2.300; 1.086~4.868), when compared to those with no pain; visiting the doctor >4 times because of acute diseases (Odds Ratio-OR: 2.9, Confidence Interval-CI: 1.1~7.5); living alone (OR: 2.1, CI: 1.1~4.0) as opposed to living with others; feeling uncomfortable with their living arrangement (OR: 3.7, CI: 1.1~12.0) as opposed to feeling comfortable; and feeling discriminated (OR: 2.2, CI: 1.4~3.6) as opposed to not feeling discriminated.

Table 23. Logistic regression model depression and related factors. n=557.

	Odds Ratio	EXP(B)	
		Lower	Upper
Sociodemographic characteristics			
Female (ref=male)	.957	.599	1.530
Age	.959	.935	.983
Urban (ref=rural)	1.324	.874	2.005
Ethnic background (ref=no)	.568	.277	1.167
Education in years	.979	.920	1.042
Marital status (ref=married)			
Divorced	.748	.318	1.759
Widow	1.222	.751	1.989
Single	.764	.348	1.679
Physical conditions			
Falls			
How many times have you fell in the past year	1.021	.947	1.100
Functional scores			
ADL score	.796	.647	.980
IADL score	.928	.873	.987
How much pain have you felt pain during the past 4 weeks? (ref No pain)			
Very little	.538	.213	1.360
A little	1.298	.636	2.650
Moderate	1.573	.787	3.145
Much	2.605	1.372	4.945
Very much	2.300	1.086	4.868
Have you been admitted to the hospital (ref No)			
Yes	1.302	.743	2.281
Cognitively impairment			
Mini Mental Test Score	.899	.474	1.706
Health behaviour			
Number of visits to the doctors for a chechup (ref 0 times)			
1-2 times	1.120	.656	1.912
3-4 times	.824	.438	1.550
5 or more times	.728	.392	1.350
Number of visits to the doctor because of an acute disease (ref 0 times)			
1-2 times	1.365	.833	2.236
3-4 times	1.668	.788	3.527
5 or more	2.862	1.091	7.511
Chronic disease			
Number of chronic diseases	.996	.803	1.235
Smoking habit (ref Never smoked)			
Quitted Smoking	1.548	.965	2.483
Continues smoking	.993	.457	2.157
Physical exercise			
Number of days doing physical activities in the past three months	.822	.692	.977
Social conditions			
Living alone (ref=with others)	2.094	1.087	4.034
Uncom fortable with your living arrangement (ref=no)	3.671	1.120	12.039
Living alone*Uncom fortable with your living arrangement	1.113	.070	17.652
Did you work last week? (ref=no)	.516	.226	1.179
Have you felt discrim inated? (ref No)	2.240	1.384	3.628
Have you participated in volunteering activities (ref No)	1.223	.642	2.331
Constant	68.621		
Hosmer and Lemeshow Test			
Chi-square	df	Sig.	
4.039	8	.854	

6.3.5 Discussion

A total of 44.5% of the community-dwelling persons aged 60 years and older met our criteria for depression. This figure is much higher than that found in a similar study in China, which found a prevalence of 26% using the same scale and cut-off score. In Pakistan, the prevalence of depression has been reported as 22.9% among those aged 65 years and older ¹⁹⁶, which is 5 years older than our population. In the United States, the prevalence of depression among homebound, rural older persons was 35.9% ¹⁹⁷, lower than the rate found in this study, which is surprising given that it could be argued that being homebound may pose a higher risk for depression.

It should be noted that our results seem closer to those reported for Mexico ¹⁹⁸. However, as that study included psychiatric patients, it is not surprising that 51% of the sample reported depression. These data suggest that the prevalence of depression in the Republic of Chile is particularly high.

In terms of health behaviors, visiting the doctor due to an acute rather than chronic condition has been associated with depression in the literature. According to our study, those who visited the doctor on at least five occasions were almost three times as likely to meet our criteria for depression. It is possible that regular visits to the doctor and the number of chronic diseases are not significantly associated with depression, because older persons may have become used to chronic care and perceive it in a more optimistic and casual light ¹⁹².

On the other hand, visits to the doctor due to acute episodes of a condition may be related to the stress of unexpected situations. Thus, every additional visit may increase such stress and its emotional burden, especially in a population known for its frailty. This may be supported by data showing that patients with major depressive disorder visit primary care centers more frequently ¹⁹⁹ that a high percentage of those patients visiting emergency departments ²⁰⁰, suffer from major depressive disorder, and that severe mental disorders, such as bipolar disorder, are associated with an increased likelihood of receiving acute care ²⁰¹.

In terms of social conditions, living alone and feeling uncomfortable with one's living situation have been widely documented as being significantly associated with depression. Also consistent with the literature, experiencing discrimination is associated with depression. We found no difference between mild and severe depression, and the results of the GDS-15 cannot be used to diagnose clinical depression, which suggests the need for additional research regarding the type and acuity of the depression experienced by older people. In terms of the association between depression and ADLs, the SABE survey conducted in the capital city of Chile did not find a significant association between

difficulties with ADLs and depression, although it did identify this association in the other six cities examined (Buenos Aires, Bridgetown, Sao Paulo, Habana, Mexico DF, and Montevideo).

The same survey did not find a significant relationship between IADLs and depression in Chile, although it did find this association in the other six cities analyzed (Buenos Aires, Bridgetown, Sao Paulo, Habana, Mexico DF, and Montevideo). This lack of significance only for the Chilean sample seems counterintuitive, as the literature contains several examples of significant relationships between depressive symptoms and difficulties dealing with functional independence ²⁰². It may be argued that the present data are nationally representative, whereas the SABE survey was focused only on the mainly urban capital city.. The possibility that differences between these two settings, urban and rural, may account for the lack of significance should be explored..

Although depression has previously been associated with poor health ²⁰³ more attention should be devoted to how the ability to perform ADLs and IADLs relate to physical exercise from a longitudinal perspective. Indeed, physical exercise is an important independent protective factor against depression in that it enhances social connections and the biological markers that increase the feeling of wellbeing via the physical changes accompanying physical activities. The present study found a dose effect between physical exercise and depression, which presents the challenge of encouraging physical activity in a population that is largely sedentary.

Mental disorders, including depressive symptoms, have been linked to smoking and alcohol consumption among the general adult population ^{204,205}, but this association has not been confirmed among older persons. The present study did not find a significant association between smoking or alcohol consumption and depression. This may be due to the fact that older populations have a lower lifetime prevalence of alcohol and nicotine dependence compared to younger adult populations, although this difference has not reached statistical significance ²⁰⁴.

Discrimination has a harmful effect on the mental health of the general population in Chile²⁰⁶. Whereas no specific studies on the discrimination suffered by older persons in Chile have been conducted, our results suggest that attention should be devoted to such harmful acts.

Unemployment in Chile has been associated with poorer mental health in working-age adults ^{207,208}. However, this relationship has not been explored among older adults, apparently because of the high percentage of older adults who willingly stop working after the age of retirement, which is 65 years for men and 60 years for women in Chile. Nonetheless, it can be argued that the same mechanisms that prevent depressive symptoms in younger adults do so in older ones.

6.3.6 Conclusions

In the context of the decreasing number of marriages, reduced fertility rate, increased longevity, and absence of a long-term care system, we need to examine how to support older persons living alone to help them avoid depression. Policies that facilitate outreach to elderly individuals living alone, increase community awareness of such individuals, and encourage the social participation of those who isolate themselves later in life are of particular importance.

It is also crucial that we develop a deeper understanding of the degree to which elderly individuals are comfortable with their living arrangements. Comfort with one's living arrangement is subjective, difficult to measure, and mediated by multiple factors. Analysis of these mediating factors may help us understand how to improve the lives of those feeling uncomfortable. Finally, we need to promote approaches that prevent discrimination against older persons. We should also understand the circumstances of such discrimination and determine the extent to which it is caused by ageism. Additional evidence about this important topic is urgently needed.

6.4 Study 6:

The relation between burden of care and health-related quality of life of caregivers of community dwelling elderly people in Chile

6.4.1 Abstract

Introduction: Evidence regarding the detrimental effects of providing care for community-dwelling older persons, while extensively documented in many countries, still remains low in developing countries. In the Republic of Chile, studies focusing on quality of life or burden of care have been restricted to severe groups of care-recipients, such as older persons suffering from Schizophrenia or Parkinson's disease. Representative data of a general population of caregivers remains a challenge.

Aim: We aim to clarify the relation between health-related quality of life and the burden of care of caregivers of community dwelling older persons in the Republic of Chile, using a nationally representative survey from all over Chile.

Methods: We used logistic regression on 377 dyads of community-dwelling informal caregivers and their recipients from all over Chile. The Zarit Burden Index (ZBI) was used to measure burden of care as exposure and the Health-related quality of life (SF-36) for the quality of life of the caregivers as outcome. Gender, age, education, and urbanization were used as covariates, along the characteristics of the recipient.

Results: 43 percent of the caregivers suffers from burden of care; Among health related quality of life, from a possible score range of 0 to 100, the poorest areas are bodily pain (53.2 points) and general health (56.9 points). While our bivariate analysis shows that all roles of health related quality of life are significant within a p-value of 0.05, our multivariable binary logistic regression shows that the only significant beneficial factors against burden is: social functioning (Odds Ratio-OR: 0.98, 95 percent Confidence Interval, CI: 0.961~0.997). Other factors that decrease the likelihood of burden are every additional year of education of the caregiver (OR: 0.91, CI: 0.833~0.997); a higher independency score of the recipient in IADLs (OR: 0.91, 0.831~0.997); and a cognitively impaired recipient (OR: 0.49, 0.240~0.988).

Discussion: Our results shows that considering all aspects of health-related quality of life of the caregivers and the possibility to feel burden, the most important preventive aspect is their social functioning, or the ability to maintain their social life in quality and quantity. This may be due to the importance that Chilean caregivers give to social life. Other preventive aspects are the instrumental independency of the recipient (IADL) and a cognitive impairment status.

Conclusion: Further attention should be paid to the mechanism in which social functioning improves the burden of care, having in mind actions that may allow the caregiver to maintain their social life, such as respite care, work leaves, and labour market flexibility, among others.

6.4.2 Introduction

In an aging world where care of older persons takes an important role, the burden of caregiving has been studied extensively. This evidence shows that caregiving has a negative effect on the mental and physical health of those providing care.

Another important aspect to consider is the health-related quality of life of these caregivers that conveys how a particular disease and its treatment affect the way they perceive their wellbeing.

The Republic of Chile is among the most aged countries in South America regarding their demographic transition, along Argentina and Uruguay ¹⁷². Those aged 60 and over represented 12.95 percent by 2010 and are expected to reach 20.11 percent by 2025 and 28.2 percent of the total population by 2050 ¹⁹⁰.

6.4.3 Method

Study design

We conducted a secondary analysis of a nationwide survey data with multistage

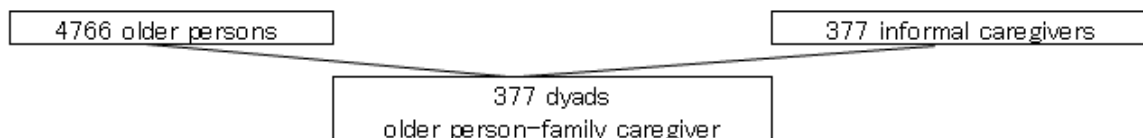
probabilistic sample entitled national survey on the dependency of older persons. The sampling framework for the survey was taken from the population and housing census of 2002, aimed at collecting epidemiological data from persons aged 60 years and over. Stratification was based on rural and urban settings (by population size) and geographical (to include subjects from all the regions in Chile). Units of analysis were, in ascending order, cities, blocks, and houses. Primary sampling units were selected proportionally to the number of houses. Houses were randomly selected. One person aged 60 years and over was selected per house, except those aged 80 years and over, who were oversampled (always selected) to account for the increased prevalence of dependency in higher age groups. More details on the survey have been published by The National Agency for Elderly People in Chile in the form of a descriptive report ¹⁷⁵.

The survey on older persons consisted of 4766 respondents aged 60. Ninety-one percent of respondents were the older persons themselves, while the remaining 9 percent were surrogates in case the older person had some degree of cognitive impairment measured using the Mini-Mental State Examination (short version) with a cut-off equal or less than 12 points. The surrogates needed to have no cognitive impairment, with a Pfeffer Functional Activities Questionnaire (PFAQ) score equal or greater than 6 points to be valid respondents. The survey was administered by 126 adults aged 18 and over, who had previous experience with complex surveys, and preferably with tertiary education. To minimize possible bias, the surveyors were trained on all the items of the survey and on how to use the PDAs to enter the responses. The PDA provides real-time validation of the entered data to avoid measurement errors. Data collection took place from November 2009 to January 2010.

Participants

We used logistic regression on 377 dyads of community-dwelling informal caregivers and their recipients from all over Chile.

Figure 16. Flowchart of older persons and informal caregivers to form the dyads



Outcome

The Zarit Burden Index (ZBI) was used to measure burden of care as exposure

Exposure

Health-related quality of life (SF-36) for the quality of life of the caregivers was used as exposure. Gender, age, education, and urbanization were used as covariates, along the characteristics of the recipient.

Covariates

Caregiver characteristics

For adjustment purposes, gender, age, urbanization, ethnic background, education and marital status of the caregivers were included.

Caregiver characteristics

Caregiving characteristics included the hours of care, the perceived social support, the relation of the caregiver with the recipient and co-residence.

Care-recipient characteristics

The Katz Index of activities of daily living (ADL) measured independence in the care-recipient's ADLs. The six items were rated dichotomously as zero (no) and one (yes), and we calculated a total score (range 0–6). Higher scores indicated more independence required in activities of daily living.

The Lawton Instrumental Activities of Daily Living (IADL) Scale measured independence in IADL. The items were rated dichotomously as zero (no) and one (yes), and we calculated a total score (range 0–8). Higher scores indicated more independence in instrumental activities of daily living.

Cognitive impairment was measured using the Mini Mental State Examination. The mini mental state examination (MMSE) is the most commonly used instrument for screening cognitive function. This examination is not suitable for making a clinical diagnosis but can be used to indicate the presence of cognitive impairment. This test had a cut-off point equal or less than 12. Cognitive impairment was coded as one (1) and no-impairment was coded as zero (0).

Statistical methods

After using descriptive statistics to clean and describe our data in the univariate stage, we looked for correlations among the explanatory variables by using non parametric Spearman's correlation analysis, where only two sets of variables had mild correlations ($\rho < .3$). For the bivariate relation among each one of the explanatory variables and the primary outcome of depression we used a bivariate logistic regression.

Explanatory variables to be entered in the binary logistic regression analysis were those frequently mentioned in the literature to have a relation with the depression of older

persons and those that had a strength relation in the bivariate analyses within 0.20 of significance. Observations with missing data were excluded from the multivariable analysis. Odds ratios (OR) with 95 percent confidence intervals (CI) were reported (Table 4). Finally we conducted an analysis of multicollinearity (variance inflation factor was <10). Data was analysed using SPSS version 18.

A written consent to analyse this secondary data was obtained from the National Agency for Older People in Chile. There is no need for ethical clearance since the agreement with the government of Chile did not include any ethical requirement. Additionally the data did not include any kind of personal information on the subjects. Also, no requirements are made regarding storage of the data, as it is readily accessible for any Chilean citizen.

6.4.4 Results

We present the basic characteristics for the 377 dyads in the table below.

Table 24. Univariate characteristics of the caregivers n=377

Item	n (%)
Caregiver characteristics	
Carer Age [Mean±SD]	[51.73±15.4]
Carer Gender	
Male	56 (14.9)
Female	321 (85.1)
Carer Education (in years) [Mean±SD]	[8.22±4.2]
Setting	
Rural	127 (33.7)
Urban	250 (66.3)
Carer Marital Status	
Married	212 (56.2)
Divorced	28 (7.4)
Widowed	21 (5.6)
Single	116 (30.8)
Health Insurance	
Uninsured	32 (8.5)
National	320 (84.9)
Private	9 (2.4)
Other	8 (2.1)
Caregiving characteristics	
Hours of care [Mean±SD]	[15.6±8.3]
Relation with the care recipient	
Partner	88 (23.3)
Children	165 (43.8)
Stepchildren	4 (1.1)
Parents/Parents in law	2 (0.5)
Siblings/sibling in law	16 (4.2)
Children in law	26 (6.9)
Grandchildren	27 (7.2)
Other relatives	25 (6.6)
No relatives	18 (4.8)
Private care	6 (1.6)
Co-residence	
No	54 (14.3)
Yes	320 (84.9)
Care recipient characteristics	
ADL score of the care-recipient [Mean±SD]	3.39 (1.7)
IADL score of the care-recipient [Mean±SD]	13.8 (4.9)
Cognitive impairment	179 (47.5)

Regarding our outcome and exposure measurements we can observe them in the table below:

Table 25. Caregivers` measurements of interest n=377

Item	n (%)
Outcome and exposure	
Care burden (Zarit Burden Index)	
None or light burden (<16)	287 (76.1)
Intense Burden (≥16)	90 (23.9)
Health related quality of life (SF-36)	
[mean ± SD]	
Physical Functioning	[82.98 ± 23.9]
Role Physical	[85.34 ± 23.6]
Bodily Pain	[53.19 ± 23.2]
General Health	[56.87 ± 20.8]
Vitality	[67.31 ± 21.7]
Social Functioning	[82.59 ± 22.4]
Role Emotional	[85.52 ± 22.3]
Mental Health	[70.28 ± 21.1]

It can be observed that the lowest scores are obtained for the domain bodily pain and general health.

Bivariate

An interesting point to notice is that in the bivariate analysis all dimensions of health-related quality of life are significant as shown below.

Also, the characteristics of the care recipient seem to be influential in the perception of burden of the caregiver. No characteristic of the caregiver appears to be significant. However, one caregiving characteristic appears to be significant: perceived social support.

Table 26. Bivariate analysis of sociodemographic characteristics and care burden. (ZBI \geq 46)

Item	Total n (%) 377 (100)	Depression		p-value
		None n (%) 200 (53.1)	Light to Intense burden n (%) 177 (46.9)	
Caregiver characteristics				
Carer Age [Mean \pm SD]	[51.7 \pm 15.4]	[51.72 \pm 15.54]	[51.78 \pm 15.22]	0.974
Carer Gender				0.421
Male	56 (14.9)	45 (15.7)	11 (12.2)	
Female	321 (85.1)	242 (84.3)	79 (87.8)	
Carer Education (in years) [Mean \pm SD]	[9.2 \pm 4.2]	[7.71 \pm 4.5]	[7.10 \pm 4.3]	0.254
Setting				0.270
Rural	127 (33.7)	101 (35.2)	26 (28.9)	
Urban	250 (66.3)	186 (64.8)	64 (71.1)	
Carer Marital Status				0.691
Single	116 (30.8)	90 (31.4)	26 (28.9)	
Married	212 (56.2)	157 (54.7)	55 (61.1)	
Divorced	28 (7.4)	23 (8)	5 (5.6)	
Widowed	21 (5.6)	90 (31.4)	26 (28.9)	
Health insurance				0.903
Insured	337 (91.3)	256 (91.4)	81 (91)	
Uninsured	32 (8.7)	24 (8.6)	8 (9)	
Caregiving characteristics				
Hours of care [mean \pm SD]	[15.6 \pm 8.3]	[15.35 \pm 8.4]	[16.58 \pm 7.8]	0.221
Relation with the care recipient				0.328
Partner	88 (23.3)	66 (23)	22 (24.4)	
Children	169 (44.8)	124 (43.2)	45 (50)	
Other	120 (31.8)	97 (33.8)	23 (25.6)	
Co-residence				0.303
No	54 (14.4)	44 (15.5)	10 (11.1)	
Yes	320 (85.6)	240 (84.5)	80 (88.9)	
Perceived Social Support (Duke-UNC)				0.000
Lower (<32)	87 (23.1)	53 (18.5)	34 (37.8)	
Higher (\geq 32)	290 (76.9)	234 (81.5)	56 (62.2)	
Care-recipient characteristics				
ADL score of the care-recipient [Mean \pm SD]	[3.4 \pm 1.7]	[3.6 \pm 1.6]	[2.8 \pm 1.8]	0.000
IADL score of the care-recipient [Mean \pm SD]	[13.8 \pm 4.9]	[14.4 \pm 4.9]	[12 \pm 4.3]	0.000
Cognitive impairment				0.167
No	143 (44.4)	117 (46.4)	26 (37.1)	
Yes	179 (55.6)	135 (53.6)	44 (62.4)	
Health related quality of life (SF-36)				
Scores [Mean \pm SD]				
Physical Functioning	[82.98 \pm 23.9]	[84.62 \pm 23.4]	[77.78 \pm 25.0]	0.018
Role Physical	[85.34 \pm 23.6]	[86.72 \pm 22.9]	[80.97 \pm 25.1]	0.043
Bodily Pain	[53.19 \pm 23.2]	[56.24 \pm 22.7]	[45.46 \pm 22.7]	0.001
General Health	[56.87 \pm 20.8]	[59.88 \pm 19.7]	[47.28 \pm 21.5]	0.000
Vitality	[67.31 \pm 21.7]	[71.60 \pm 19.2]	[53.61 \pm 23.3]	0.000
Social Functioning	[82.59 \pm 22.4]	[87.20 \pm 18.5]	[67.92 \pm 27.0]	0.000
Role Emotional	[85.52 \pm 22.3]	[88.97 \pm 19.9]	[74.54 \pm 26.1]	0.000
Mental Health	[70.28 \pm 21.1]	[74.30 \pm 18.9]	[57.44 \pm 22.6]	0.000

SD, standard deviation; n, number

Multivariable analysis

The results of the multivariable model show that the only significant factor regarding health-related quality of life is *social functioning*, despite the fact that in the bivariate analysis all of the domains were significant.

Table 27. Logistic regression of health related quality of life (SF-36) and care burden (ZBI ≥ 46). n=207

Variables in the Equation	Odds Ratio	95% C.I. for EXP(B)		p-value
		Lower	Upper	
Caregiver characteristics				
Age of the carer	0.98	0.956	1.009	0.199
Female caregiver (ref=male)	1.15	0.466	2.847	0.760
education in years	0.91	0.833	0.997	0.043
urban_carer (ref=rural)	1.21	0.610	2.389	0.589
Caregiving characteristics				
Higher Perceived Social Support (Duke-UNC) (ref=lower)	0.57	0.261	1.229	0.150
Living with the recipient (ref=no)	1.58	0.586	4.259	0.366
Receives payment for care (ref=no)	0.39	0.102	1.505	0.172
Care-recipient characteristics				
ADL score of the care-recipient	0.91	0.694	1.181	0.465
IADL score of the care-recipient	0.91	0.831	0.997	0.043
Cognitively impaired by MM (ref=no)	0.49	0.240	0.988	0.046
Receives pension (ref=no)	0.81	0.201	3.231	0.762
Caregiver's scores on health related quality of life (SF-36)				
Physical_Functioning	1.01	0.985	1.031	0.505
Role Physical	1.00	0.974	1.020	0.779
Bodily Pain	1.00	0.987	1.021	0.656
General Health	0.99	0.970	1.010	0.317
Vitality	1.00	0.972	1.024	0.880
Social Functioning	0.98	0.961	0.997	0.022
Role Emotional	1.01	0.990	1.030	0.348
Mental Health	0.98	0.956	1.009	0.182
Constant	442.00552			0.001
Hosmer and Lemeshow Test				
Step	Chi-square	df	Sig.	
1	3.29	8	0.92	

6.4.5 Discussion

Our results show that considering all aspects of health-related quality of life of the caregivers and the possibility to feel burden, the most important preventive aspect is their social functioning, or the ability to maintain their social life in quality and quantity.

This may be due to the importance that Chilean caregivers give to social life. Other preventive aspects are the instrumental independence of the recipient (IADL) and a cognitive impairment status.

6.4.6 Conclusion

Further attention should be paid to the mechanism in which social functioning improves

the burden of care, having in mind actions that may allow the caregiver to maintain their social life, such as respite care, work leaves, and labour market flexibility, among others.

7 Overall Discussion

The number of studies contained in the doctoral thesis poses the challenge to the author of addressing the vast pieces of information that might be helpful to the objective of this research, while at the same time providing a concise, non-repetitive approach to the big key posed by this dissertation that is, providing empirical evidence for both internal and external reference. Providing internal and external reference means that the evidence could be used in the same country where it is collected and also it could be used by foreign countries that could be interested in knowing other realities.

The author would like to propose addressing the discussion and conclusion following the guiding principles stated in the introduction to this doctoral thesis, to draw the particular discussion and conclusions from each article.

The guiding principles of this doctoral research are the following:

- 1) Even where provision services are well developed, the challenge of providing high quality outcomes remains a challenge
- 2) Developed countries, have experience to share.
- 3) Developing countries, in advanced stages of the demographic transition could also help to create evidence for countries that need to strengthen their informal care settings.
- 4) Developing countries and developed countries alike need to have a thorough understanding of their present conditions regarding outcomes of care

- 1) Even where provision services are well developed, the challenge of providing high quality outcomes remains a challenge

Studies on long term care in Japan reveal very interesting pieces of information that Japan could use to share with other countries, and also to inform them. One aspect is that quality, in terms of prevalence of adverse events and clinical indicators as shown in **study 1**, is fairly high, even considering that there are no quality assurance mechanisms or quality control systems that may deter malpractice. It seems that culture of care in Japan at long-term care facilities is high without any particular incentives to control quality. It

may be argued that policies of services of excellence when serving a customer are also reflected in this aspect of provision. This reality of low prevalence of adverse events contrast dramatically with the provision of care in other long term care settings in the world, where cases of negative outcomes, ill-treatment and violence, and negligence are fairly common²⁰⁹.

In the United States of America, the Institute of Medicine (IOM) stated in its 2000 executive summary report²¹⁰, that although positive changes took place in the long-term care facilities in the past decades, particularly since a well-known IOM study from 1986⁷¹ that denounced quality problems in the long-term care and that led to the OBRA in 1987²¹¹, the quality of life for nursing home residents barely improved and serious problems still remain. Many of the reasons argued to explain poor conditions of care in the USA are the poor condition of the staff, along with a for-profit interest of the providers. In Japan, labour conditions of staff in the long term care are not particularly benevolent. It is always discussed the low payments, low expectations of career improvement for health staff at long term care facilities. The fact that service remains high in quality under these circumstances is worthy of interest and deeper attention.

The most common health problems that persist even in the long-term care settings today include pressure sores, hydration, falls, functional status, physical activity and mobility²⁰⁹. All of these outcomes were include in our studies, precisely for their relevance and difficulty to address. Actually, in the case of pressure ulcers, there has been a setback in the USA according to the final report for *healthy people 2010*²¹²: Pressure ulcers among nursing home residents (current diagnoses per 1,000 residents) went from 16 in 1997 to 20 in 2004, missing the target of 8. This means that the intended 50 percent reduction of pressure ulcer incidence in nursing homes was not only unachieved, but also worsened.

Pressure sores are one of the outcomes we set for our studies. The prevalence varies greatly by type of facility and characteristics of the users. In the case long-term care facilities in the USA, prevalence rates have been reported ranging from 3 to 30 percent for point prevalence, this means, measured once. In Japan the 6-month period prevalence rate, used in this study, is 32 percent. While the difference of a point prevalence and a period prevalence hinder the comparison, we can observe that the prevalence seems much lower in Japan. Point prevalence in long-term care hospitals has been reported to have decreased from 7.3 in 2002 to 6.4 per 100 residents in 2003²¹³. This one percent decrease took place after the introduction of the national regulation for the management of pressure ulcers in 2003. In 2007, a similar initiative took place in the *geriatric health service facilities*, where our studies took place. It was called *geriatric health facilities*

pressure ulcer prevention guidelines and aimed to provide appropriate care to prevent pressure ulcers, as one of the initiatives to provide for high-quality services for the users. The guidelines states to fundamental elements: the creation of a prevention team and the creation of a prevention committee. Through this team and committee is emphasised the important role of the staff on preventing pressure ulcers. The staff has a fundamental need to acquire knowledge on pressure ulcers, and consideration is given to the prevention of pressure ulcers occur in day-to-day care. First, the medical director of the facility needs to acquire knowledge on pressure ulcer and designate one member among the nursing staff to be the responsible person in charge of pressure ulcer prevention²¹⁴.

Subsequently, the installation of the pressure ulcer prevention team. The pressure ulcer prevention team is created in order to effectively promote the establishment of a prevention scheme. The team is composed by:

- Director shall serve as the team leader (Chair)
- A nurse should serve as the sub-leader (Deputy Chairperson)
- Doctors
- Nursing staff
- Nursing officers
- Nutritionist (nutrition division officer)
- Key persons deemed necessary by the Director

Also, the pressure ulcer prevention Committee is created. A meeting between the sub-leader and the rest of the team is held once monthly, to deliberate on the following matters:

- A facility concerning the establishment of prevention of pressure sores in complicated infections.
- Collection of information on prevention of bedsore
- On countermeasures of pressure ulcer cases reported in the facility
- The development of manuals for pressure ulcer prevention
- The implementation of pressure ulcer prevention intended for staff training

While this kind of quality improvement initiatives in Japan may partially explain the lower prevalence of pressure ulcers, these inferences are out of the scope of the present studies. However, what can be clearly appreciated is that the role played by the director of the facility and the deputy chair persons acting a sub leader of this process is very much important.

2) Developed countries, have experience to share.

One point of interest we can draw from the results is that, despite the quite homogenous provision of good quality in this type of facilities, there is still a strong effect of the staff. In the first study we see how the nursing staff has a relevant role in affecting adverse event, positively, but also negatively. This negativity is closely related to the case mix face by the staff at this particular setting. However, the lessons of the provision and outcomes is a reminder for other countries that intend to implement this kind of services to pay attention at how case mix adjustment is done when evaluating the quality of care. Additionally the configuration of the staff in term of composition, known as care-mix, is also a highly relevant piece of evidence. When dealing with care-mix setting we can observe that not only sheer number of staff are relevant, but also compositions and thresholds.

Regarding staff composition, in Japan, the rules for staffing at long term care facilities were defined by the Ministry of Health in a document called *personnel of a long-term care health facility, the criteria for the operation, as well as facilities and equipment* (issue 40 by Ministry of Health and Welfare, March 31, 1999) ²¹⁵. The requirements for the geriatric health services facilities per 100 users are as follow:

- Physician (regular employee): 1
- Nurses: 9
- Care staff (Care worker): 25
- Physical therapist, occupational therapist, speech therapist: 1
- Care manager: 1

Note: (Overall, nursing staff should account for about 2/7 of total staff, while care staff should account for the remaining 5/7)

Results from study one suggest that every additional nurse per 100 users reduces the likelihood of falls by 23 percent. However, when these nurses are registered nurses the likelihood to have pressure ulcer increase by 23 percent. These seemingly contradictory effects lead us to think that attempts to infer conclusions from these results should strongly consider other factors in play, such as care mix, or how the characteristics of the users affects the demand and characteristics of care staff, and the necessity to have a longitudinal view of care needs and ensuing changes.

Despite the aforementioned words of caution, we should also discuss how the allocation of staff is made. In the Japanese case only consideration to the numbers of users is made

and not to the characteristics of these users. In the case of Chile there is a consideration per characteristics of the users. The requirements for the long-term care facilities are as follow:

- Medical Director (facilities with less than 21 users): 1 at least 4 hours per week.
- Medical Director (facilities with more than 20 users): 1 at least 1 hour per day.

Facility with bedridden users:

- Certified Nursing Assistant: 1 at least 12 hours daily and 1 for emergency night calls.
- Care staff (Care worker): 1 per every 7 users at least 12 hours per day and 1 per every 10 users at night.

Facility with physically or cognitively impaired users:

- Certified Nursing Assistant: 1 at least 2 hours daily and 1 for emergency night calls.
- Care staff (Care worker): 1 per every 12 users at least 12 hours per day and 1 per every 20 users at night.

Facility with independent users:

- Care staff (Care worker): 1 per every 20 users, 24 hours a day.

When considering this apparent difference in the criteria for the allocation between Japan and Chile, we must note that in the case of Japan, long term care facilities are divided into three types: Facility covered by public aid providing long-term care to the elderly, geriatric health service facilities (the one we study on this thesis) and sanatorium type medical care facilities for the elderly requiring care. Each one of them aims to different profile of users by their. Thus, users at *facility covered by public aid providing long-term care to the elderly* only need help with daily life activities, while users on the other extreme at *sanatorium type medical care facilities* require medical care for extended period of time. In the middle of this spectrum we find *geriatric health service facilities*, where users present an intermediate condition and who require rehabilitation to return home.

Study two points towards a topic that could be worth mentioning and shared and that has begun to be discussed in the USA recently. It is the role the medical director's leadership in the quality improvement initiatives with the introduction of the MDS 3.0 in 2010¹⁵⁴. The idea of the importance of the medical doctors or medical directors is a rather innovative approach in this context, although it has been show that the presence of certified medical directors is an independent predictor of quality in US nursing homes²¹⁶.

In the long term care facilities, the concept of leadership has been usually attributed and expected from nurses, considered as the vital professional component and central element of the services provided at LTCFs and their ensuing success¹⁴⁷. However to the knowledge of the authors in Japan there is no particular quality assessment measure aimed at the doctors beyond the certification requirement and quantity allocation. In our study, the leadership of the physician shows an increase in the likelihood to belong to the best 25percent performer with the lowest prevalence of pressure ulcers. This kind of successful experiences has been reported before¹⁵² by means of multidisciplinary interventions. This is particularly reflected on the MDS 3.0 section M, related to skin conditions that calls for the leadership of the medical doctors in education and collaboration in clinical matters ¹⁵⁴. In Japan, the participation of the director plays an important role in the creation and administration of the committee for the prevention of pressure ulcers²¹⁴. The medical director in Japan selects the nurse responsible for the supervision of the pressure ulcer program. In the case of Japanese Geriatric Health Facilities the directors are required to be a medical doctor, as it is in the USA regarding nursing homes. However, it must be noted that in the case of special nursing homes in Japan, the director not necessarily needs to be a medical doctor.

In the case of Chile, the medical director does not necessarily needs to be a doctor, but a professional related to the health sector. It is recommended that the director had some degree of specialization in geriatrics, but this is only a recommendation. Also, in Chile there is no certification process for the position of medical director. This results particularly important as it has been shown before to have independent beneficial effects on quality²¹⁶.

Additionally in this study a beneficial effect of leadership of the management on the likelihood to belong to the best performing group regarding dehydration is shown. This kind of positive effect of the management has been shown before ¹⁵⁵ as the management may supervise the staff on the hydration strategies in the facility. However, no study on the direct effect of the management's leadership has been found through the literature review. A more detailed approach would be necessary to explore the effects of management on dehydration.

Certainly Chile could benefit from a more rigorous certification process for medical directors of long term care facilities, however, the training and capacity building in Chile regarding human resources to face the ageing of the population remains extremely low, and has been mentioned as a critical component of the necessary preparation plans⁶⁹. Ways in which more incentives could be given to medical doctors to go to the long term

care system seems relatively far, while there is no dedicated funding scheme for this kind of service. Private initiative could drive the change process, however, the demand remains relatively low. Although, human resources tend to cope with care in the community decreases it might be expected a more important role of a formal care provision. In this context a more professional approach to care could benefit from these experiences on management positions and the results of this study points to the eventual benefits of this participation both in Japan and Chile.

Study three shows that in *geriatric health service facilities*, falls are a particularly important challenge. One important point of its significance is the fact that Japanese geriatric health service facilities are aimed at rehabilitating people, so any adverse event that would go in the opposite direction (physical decline) should be considered one of the least desirable outcomes. Additionally falls represent a great burden on long term care services and its users as they are an important factor for mortality and disability all over the world. Even the fear of falling poses a threat as it increases the likelihood of loss of function, depression, feelings of helplessness, and social isolation²¹⁷. Unfortunately, in Chile, a way to approach the risk of falling has been physical restraint. Physical restraint has been shown to be a wrong approach to fall prevention and should be discouraged as it increases the likelihood of falls instead of decreasing it²¹⁸. Moreover, physical restraint is not only harmful regarding falls, but other health outcomes, such as behaviour issues, cognitive performance, walking dependence, activities of daily living, pressure ulcers and contractures when compared to users who are not restrained²¹⁹. However, this approach to physical restraint is not exclusive of Chile. It has also been widely used in Spain²²⁰ and backed up by the *Catalan Association of Directors of Centers and Geriatric Services Care Units*, who argue that physical restraint decreases the likelihood of injuries for their nearly 20 percent of physically restrained users²²⁰. We must note that Spain and its quality assurance scheme has been used as a reference for future government approaches to care⁶⁵. While it must be noted that physical restraint is a valid medical procedure, it should not be considered a common and utilitarian way to approach care, for health and human rights reasons.

3) Developing countries, in advanced stages of the demographic transition could also help to create evidence for countries that need to strengthen their informal care settings.

While in countries like Japan there has been a strong institutionalization of care through the implementation of the long term care system, in developing countries with no long

term care systems the role of the community in the provision of care is a fundamental part. After an intense demand achieved after the introduction of the long term care, Japan now intends to promote family care as a way to deinstitutionalize, to face the ever increasing costs and threats to the sustainability of the system. **Study four** and **Study six** suggest that an important element to consider when setting or encouraging informal care in the community is social support and social functioning, respectively. The results of **Study four** shows that caregivers who perceived they are supported by the community have a lower likelihood to present depression symptoms, a very sensitive condition that affects mental health. On the other hand, **Study six** shows that the most important aspect of health related-quality of life is social functioning or the possibility to maintain the quality and quantity of their social life. Countries considering strengthening their provision of informal care should consider initiatives to expand and make stronger social networks that in turn will be perceived by the caregivers of older adults as support. Theoretically, perceived social support is a stronger predictor of wellbeing than received social support. However, perceived social support can only be achieved after received social support has been granted. Assuming that not all the support provided is perceived it would require focalized efforts on those areas that are more likely to be perceived and easier to provide. Looking for ways to alleviate the burden of caregivers is especially important when we see in our study that nearly half of the population present depression. Societal changes must also be taking into account. Chile presents higher numbers of possible informal caregivers in the community compared with countries like Japan. The question that this situation poses is how to encourage family care without lessening the economic potential than Japan intend by promoting the labour participation of women. The caregiving task is characterized all around the world as a task to be performed by women. This feminization of care have brought undesired effects on the quality of life of many women and ensuing costs for the society as well. The challenge for Japan would be to increase the number of family caregivers while at the same time increasing the number of female workers. The possible solution would be the inclusion of care flexibility laws in to the working places in Japan. This care flexibility could be in the form of respite care and care leaves that would allow caregivers to have both a caregiver role and a worker role.

The same arguments hold true for results of **Study six**. If we expect to keep the social life of the caregivers and thus alleviating their burden of care, we should consider respite care, the possibility for the caregivers to rest and cope with this demanding task of care. Other aspects of social life are related to their labour participation. Work and employability has been shown to allow workers to cope with caregiving duties.

Having said that, while the actual levels of perceived of social support are high at the moment of the survey in Chile (three fourths) we might expect them to decrease as time passes, because the number of persons with whom informal caregivers share their caregiving role decreases. Also, the number of family members is low and co-residence of parents and children is also decreasing. If we add the participation of women in the labour force we might only expect the amount of available family care to be lower.

A point that can be made is the fact that nor informal care, nor formal care can function independently, assuming the whole burden of care by themselves. If all the need of care were to be provided by the formal sector, sustainability would not be achieved. The scale of resources needed to provide 100 percent of care is unattainable if intended for a long run. On the other hand, leaving the responsibility of care only to informal caregivers is a moral problem because of the tremendous toll that caregiving takes on the lives of the caregivers. Additionally we must consider the increasing number of people that in old age have nobody to take care of them, as the number of older persons living alone increases.

Another important aspect to sustain the care provision in the community is the capacity to maintain and improve the wellbeing of the recipients themselves. **Study five** shows results that point to facts that may affect the mental health of the recipients, specifically their depressive status. In this study we confirm evidence that had been found in the literature, but not explored in Chile in the context of old age. In **Study five** *physical exercise* appears to have a protective effect on depressive symptoms. However, we must carefully interpret these results because of the cross-sectional characteristics of study we cannot fully assert if the depressive condition decreases physical activity or if physical activity decreases depression. Nonetheless, this result is coincident with previous studies that show the beneficial mental health effects of physical exercise. This leads us to think that we should explore further ways on which physical exercise could be encouraged among older persons, as a way to improve not only their functional conditions, but their mental health as well.

Regarding social conditions, living alone is documented as associated to depression, along with feeling uncomfortable with their living arrangement are mentioned in the literature. As stated before, societies age as they develop, and one aspect of this development is the change of the composition and characteristics of the families. In the case of Chile, as in the case of most developing countries we can expect a decrease of the number of family members, decrease in the number of children, and decrease in the number of married couples. These conditions will make harder for the older persons to find care opportunities in the community and will increase the number of older persons living alone or in environment that are not under their decision power. Policies aimed at

supporting those elderly must be further studied, like in the case of volunteer activities that take case in Japan, where volunteers work as home helpers. Community empowerment is also important, for the neighbours could have a better understanding of their communities, older persons and their needs.

4) Developing countries and developed countries alike need to have a thorough understanding of their present conditions regarding outcomes of care

The challenge of low evidence regarding outcomes of care remains valid both in the Japanese Geriatric health facility care and the informal care in Chile. Neither in Chile, nor in Japan there is a systemic quality assessment approach to quality assurance. Quality assurance has been limited to disclosure of structural characteristics both in Japan⁵ and Chile⁶⁵. Evidence-based policy-making, is not a novel ideal, however is has gained renown momentum in ageing due to the necessity of making tight decision when resources are scarce. In the last years it has become a more important concept in public debate in the developing world. We would expect policy making to be driven by analysis of the reality, and not by ideology. No doubt this is an important moment to promote evidence as a driven force of change. However, creating evidence seems a rather neglected are of the discussion.

In the case of aging, a policy has been developed in an environment subject to compete with political interests, where old age does not have a strong force in the political agenda in Chile⁶⁹ or the developing world¹¹. We require systems that are informed by evidence at every step of a policy making process, starting with problem identification, to the development of the most adequate countermeasure, and subsequent evaluation of its effectiveness. This becomes essential when we deal with a complex problem as ageing, because of the implications it has in all spheres of society.

This evidence should also be open to rigorous public and academic debate. In Japan, while the effort to make structural characteristics public can be praised, it is still far away from allowing us to draw causal assertions on what factors are involved in the quality of care provided in geriatric health service facilities. In Chile, the same descriptive nature of the information provided is also far away from allowing us to know the causal mechanisms leading to burden and depressive symptoms. Validating evidence and transparency can help governments to obtain grass-root support to ideas. We need an evidence-based approach to public policy to create effective policies.

7.1 Implications

The comparison between these two different settings may prove difficult, due to the fact

that factors affecting family care are very different from those affecting facility care. However, as described above, there is space where lessons can be inferred from the finding of this doctoral research.

7.1.1 On staffing levels

First, study one suggests the importance of setting the staffing levels for facilities. In Chile, the requirement is made according to the characteristics of the patient, as there is only one kind of facility, called nursing home:

For long bed ridden users a minimum of:

One paramedic for the 12 hours of daylight, and one available to be called at night if required if there is a bedridden patient.

One care worker per every 7 users 12 hours a day, and one every 10 users at night.

For dependent users, physically or mentally:

One paramedic for 2 hours every day, but available to be called 24 hours.

One care worker per every 12 users for the 12 hours of daylight, and one per every 20 users at night.

For independent users:

One care worker per every 20 users, for 24 hours

In Chile, nurses, nutritionists, physical therapists, and occupational therapists are only recommended but not enforced by law.

In the case of Japan the staffing requirements per 100 users are related to the kind of facility:

Intermediate facility:

One physician (regular employee)

Nine nurses

Twenty-five care staff (Care workers)

One physical therapist, occupational therapist, or speech therapist

One care manager

Welfare Facility for the Elderly Requiring Long-term care:

One physician (either visiting or regular employee)

Three nurses

Thirty-one care staff (Care workers)

One care manager

Sanatorium Type Medical Care Facility for the Elderly Requiring Care

Three physicians

Seventeen nurses

Seventeen care staff

One care manager

This lack of professionals in the long term care setting poses serious questions on the kind of outcomes these facilities may be able to obtain. As shown in the results of study one, care outcomes are particularly sensitive to staffing levels, and the influence of the staff varies by outcome. In the case of the Chilean facilities, the high clinical awareness we argue in **studies one and two** might take place when detecting pressure ulcers is non-existent. This may presume a higher than established presence of pressure ulcers in the incipient and growing number of Chilean facilities. However, in reality, what happens is that facilities in Chile avoid having users with dependency. There is a systematic effort of facilities to avoid admitting users with cognitive impairment or bedridden status in higher needs of care. Admission is restricted to those users who demand less care. The characteristics of the users that we argue may explain the detrimental effect on pressure ulcers in Japan, in Chile does not take place because facilities are simply not prepared, nor willing to deal with a more complex case mix. The ethical challenge posed then, it is that these persons, in high need of care have to remain at home, where care is not professional and constrained by family, and environmental characteristics.

Assuming that more dependent users were willingly admitted into Chilean long term care facilities, the lack of more professional and specialized staff may pose serious doubts on the quality of care provided. The fact that the law of long term care facilities only suggest the presence of nurses, physicians and other professionals, may suggest that the clinical awareness is poor in this kind of facilities. It is argued throughout this doctoral research that the role of nurses is important, along the role of physicians and managers. In a facility with no registered nurses to deal with pressure ulcers at early stages as suggested in **study one**, and without the leadership of physicians as suggested in study two to prevent pressure ulcers, we can only wonder the real conditions of pressure ulcers for those users with dependency or bedridden.

The results of **study one and study two** in this doctoral research call for a higher type of professionals to be present at long term care facilities. Especially, nurses, registered nurses and physicians, in order to address the needs of those who require a highly more

specialized type of care. Additionally, while not a direct implication of this study it seems clear the necessity to provide a more diversified range of facilities, which could address different users in need. Having just one kind of specified facility only leads to perpetuate the idea that only independent users can be accepted. Having a wider broad of facilities, allows them to become specialized in the care of care they provide and therefore adjust more easily to staffing levels required by law. For example, in the Chilean facilities, the existence of one bedridden user immediately require one paramedic, independently of the number of users. A facility specialized in more complex cases would use this requirement more efficiently. Nonetheless, it remains the challenge of facilities that are not funded by the state, and that may bear the costs of care through charity and payments made by the users they serve.

Finally, following the beneficial effects found for the leadership of physicians in study two, the widely discussed idea that medical staff should be more involved takes more relevance if needed to be applied in Chile. With the implementation of Minimum Data Set (MDS) v3, the role of the medical staff have been recognized as important to manage skin conditions. One of those conditions is pressure ulcers. This is in addition to the role played by the staff in Japan when dealing with the pressure ulcer prevention team. Thus, study two calls for not only the presence of medical staff in the prevention of pressure ulcers, but to their active involvement in the function of care.

7.1.2 On fall prevention

Long term care facilities in Chile, as mentioned earlier, are defined as a single kind of institution that serve, in theory, a wide set of persons in need. In practice, the only users that are admitted are independent users who do not require much care. As stated before, this requirements is made based on the scarce resources facilities have to deal with more complex cases. This leads to a situation where facilities in Chile could be more closely compared to facilities aimed at assisted living or those who are aimed at short stays and rehabilitation. One important factor for the user and the management in this kind of facility is to avoid physical decline and the subsequent loss of independency. As shown in **study three** the only factor associated to physical decline we found were falls. Thus, **study three** calls for the necessity to prevent falls in facilities if we want to avoid, expensive, painful and grave situations that may arise from them. Additionally, as pointed in **study one**, the only significant factor associated to falls we found was the number of nurses per 100 users. In the Chilean setting however, there is no requirement for nurses, but only paramedics. As described in **study one**, other staff were not significant (care workers,

physicians). Thus, it seems necessary to explore the effect that nurses have on falls in the Chilean setting, and the possibility, as stated earlier of increasing the qualifications of the care staff in Chile.

7.1.3 On the promotion of social capital

In a country like Japan following the implementation of a very pervasive long term care system, which aims at recovering their capabilities to provide family care, it seems very important the reassuring notion we found in Chile that to keep the mental health of caregivers is very important to make them feel supported. **Study four** shows how important their perception of social support is when dealing with effects of burden of care such as depressive symptoms. The same notion is used in study four when explaining why taking vacations seems to have a beneficial relationship. We argue it is explained also as a token of the support they receive. Being able to take vacations is a sign of a network that enables respite, either by the support of surrogates in their social circle or the possibility to afford that respite on a personal account. As mentioned before, in Chile there is formal system, as the long term care insurance system, to provide some kind of respite. Therefore, this kind of respite is fully provided by their social network. In countries like Japan, with the possibility to provide this kind of service, it is suggested to be important to allow and protect this kind of benefits. Although it is not found in the results of this study if the same appreciation and value of social support is given by Japanese caregivers as it is given by Chilean caregivers in a similar way, we may argue that social support, as measured in this study may be generalized to caregivers in other settings.

On a related point, **study four** points to the detrimental effect of having a close relationship with the recipient. This is a reality that affects the main caregivers of the older persons, both in Japan and Chile. As most caregivers are female, and so it is a great number of partners, we should consider with special care to this caregivers and think of ways to support them. In Japan, the main type of caregiver seems to be the daughter-in-law, maybe following the same kind of argument we give for this association: proximity affects the mental health of the caregivers. While the proximity of the relationship cannot be changed, we can suggest ways in which that proximity could be alleviated along with the hours of care.

Additionally, **study six** shows that the caregivers in Chile give a significant importance to the role of social functioning, that is, the possibility to maintain, in a qualitative and quantitative way, their social connections. In connection with the points made in study

four, countries with a functional provision of family and community care, should make an utmost effort to protect, promote and support activities aimed at social functioning, where respite care seems to be among the options presented in this discussion of implications.

7.1.4 On the role of health insurance

In the case of Japan and Chile, citizens enjoy a universal health care insurance system. Unfortunately in the case of Chile, despite being entitled to access to health care, an important number of caregivers are not insured, probably to avoid paying the monthly premiums required by law in case they have a steady income and eventual co-payment on the services received. The challenge therefore is to keep the enrolment under the universal system, avoiding the fact that co-payment and payment of premiums may actually hinder the coverage. Mental disorders such as depression tend to be underdiagnosed, not treated, stigmatized, overlooked or misclassified in many cases, especially in settings where the availability and affordability of the services is not optimum. A further search for causes for not enrolment and ways to ameliorate it should be conducted. While coverage in Japan is very high, attention should always be paid to depressive symptoms, which attack silently and are usually kept secret.

Finally, the experience of having a universal health insurance has proven to be essential for a healthy life course, including mental aspects, as shown in **study four** and should be encouraged to those countries that still do not have it.

7.1.5 On the role of physical activity

As shown in **study 4**, a lesson shared with Japan is the importance of physical activity, not only for the physical health, but also for the mental health of the older persons. On this point, following the discussion on the benefits of physical activity, it is the challenge of protecting and encouraging physical activity. Japan, but particularly Chile, are undergoing an increasing process of sedentarism (sedentary lifestyle) and unhealthy eating habits. While eating habits in Japan have started to change rather recently, in Chile the consumption of junk food and hyper-caloric food has gained a rather extensive effect on the population, and obesity become a problem for over half of the population. The implications of physical activity should be considered, encouraged and protected both in Chile and Japan.

7.1.6 On the role of living arrangements

Study five on the depression of the older persons shows consistently the importance of living arrangement in the mental health of older persons. First, the detrimental effects of living alone. It has been widely documented the detrimental effects of living alone. This effect is of particular importance to countries like Japan that are in an advanced stage of population ageing. This is because their low fertility, low rate of marriage and extended life expectancy predispose them to end up living alone. The results of **study five** prompt to the necessity of supporting those older persons living alone, but also keeping in mind their opinion on how comfortable they feel with their living arrangement. As shown in this study, when the older persons do not feel comfortable, they will be more likely to be in the group of depressive symptoms. Therefore, this study calls for the necessity of approaching the concept of living arrangement from a perspective that value their reality and also their wishes and feelings.

7.1.7 On the role of discrimination

Discrimination has been pointed as a social construct to affect gravely the health of older persons. Discrimination against the elderly, known as ageism, is a highly relevant factor that is difficult to observe in many cultures where negative viewpoints on the process of ageing are deeply rooted in the beliefs of the people. Furthermore, ageism comes to add other negative connotations to the process of social inclusion already suffered by older persons. As UNFPA documents³¹, in six countries (Kazakhstan, Macedonia, Moldova, Serbia, Tajikistan and Ukraine), those aged 65 and older experience the highest levels of social exclusion at 45 percent, compared with the 31 percent average for all age groups. The highest levels were found in Moldova and Tajikistan³¹. To measure social exclusion they use a Multidimensional Social Exclusion Index, which captures the complex nature of social exclusion along three dimensions: economic (income), social services (affordability and accessibility of health and education) and participation (political participation and in social networks)³¹. As mentioned earlier in the discussion of implications, many of these elements are contained in the studies that compose this doctoral research, such as social services (health access) and participation (social network). Therefore, the social exclusion and discrimination against old persons should be of utmost importance, both in Chile and Japan and should be addressed following the guidelines given by the Macao Declaration. The Macao declaration³² has seven areas of concern, the first one is social position of older persons. This point of concern states the negative image of ageing and the aged population, where the elderly appears frail, disabled and dependent, while actual research shows a different situation. Policies and program aimed at fighting discrimination and promoting social inclusion should consider

this aspects based on actual, empirical evidence. For that a legal framework should be in place to protect citizens from discrimination. In 2014, it was approved for the first time a law in Chile to punish any kind of discrimination based on appearance, beliefs or prejudices. This was an important milestone to protect older persons from ageism. However, the process to understand discriminatory practices against the elderly may take more time to assimilate. Prejudice against older persons seem to be deeply rooted in the Chilean society, and as long as ageism is identified and point out as a type of discrimination little can be done to enforce the law. Much can be learned in Chile about the laws on violence against the elderly, where psychological violence is properly addressed.

Finally, despite the scarcity of data, it seems necessary to continue the efforts to provide evidence of the situations of the elderly, both in developed countries, as in developing countries. There is much to be learn on both sides and the challenges of ageing, while similar around the world, also present peculiarities that ought to be fully understood.

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*To my mother,
never ending source of inspiration.*