An Overview of “Quality of Life” by Elderly Receiving Care in Sweden

GOTHENBURG UNIVERSITY

Department of Social Work and Human Rights

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Author : Raiffeison Ndumea Ngoh
Supervisor : Karin Ahlberg, Anita Kihlström
ABSTRACT

The general aim of this dissertation is to examine the Quality of Life for Swedish elderly receiving care. The study will investigate how the elderly, when receiving care, conceptualize and express quality of life. The study will also show how key persons in the elders’ network understand this service and which structural factors are seemed to be important.

Qualitative study design is the highest priority throughout the research. The empirical base is comprised of literature review and interviews with elderly receiving care from both public institution and home care. Some formal and informal care providers were interviewed as well. Total seven interviews were performed in Gothenburg and its neighborhoods.

Results from the study reveal that the Swedish government has well defined policies (both social services and health care) in the care of the elderly. These formal care are supplemented by informal care and those together mediated by the elder’s network. The availability of formal care is equal to all but that of informal care differs according to the sizes and the interactions of these social networks. Also the demand for both forms of care differs according to needs by the elderly.

The elder’s view of quality of life (QOL) includes the basic needs e.g. food, shelter, safety, social contact, and other ranges of opportunities within the individual’s potential. It also includes some need for having control of their environments and possibilities to make some choices such as medical care, kind of housing and caregivers etc. Mainly the elderly expressed feelings of living ‘a good life’.

Key words: Elderly, Care, Quality and Life
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My deepest gratitude goes to my wonderful wife Olive and our two lovely daughters Beldine-Noel and Ashley. You are the joy of my life.

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CHAPTER ONE

INTRODUCTION

1.1 General Outlook

As more people become old, maintenance of quality of life for the elderly is of increasing importance. In England, for example, this was obviously when the Department of Work and Pensions recently declared that more people than ever before would be 100 years old. Of course, it would increase the ‘age-related expenditure’ such as healthcare and pensions but also, for the first time in history, give people the possibilities to enjoy a long and active life. However, this demands for a policy ensuring ‘that our prolonged old age will be worth living’ (The Week, 2011.01.08, p 18)

The Swedish policies seem to comprise this ambitions, according to official aims with care of the elderly, which is ‘to be able to live active lives and influence the conduct of social affairs and their conditions, to be able to grow old in security and with preserved independence, to be treated with respect and to have access to good health care services. Public help is intended to give the elders freedom of choice and influence, and to maintain high standards’ (www.sweden.gov.se 2010). An important statement is also that ‘all elderly persons should have equal access to these welfare services, regardless of age, sex, ethnicity, place of residence, and purchasing power’ (ibid.)

These statements with Swedish elderly care will be the focus for my study and in particular the kind of care, related to the concept ‘Quality of Life’ (QOL). My opinion is that it will be of great interest in practice, when planning elderly care in different cultures as well in theory, as a ‘sensitive concept’, when highlighting different aspects identified by research.

The concept QOL has been subjected to considerable academic lessons from many disciplines, some more related to social care than other. However, my perspective is a social
workers’ in which social political structures as well as individuals well-being will be in focus. Such a design will try to find out what kind of different, organized support the elderly receive and how they understand this support; if it is related to QOL and what kind of need it is provided for. Although there are several dynamics meanings of QOL for the elderly, this research shall look into some, selected areas, in answering the research questions.

1.2 Quality of Life (QOL)

QOL is rather a dynamic concept for many reasons. In accordance with Carr & Higginson (2001) it can change meaning dependent on what people in their actual life consider as important at any given time. The concept has some similarity with ‘well-being’ but differs in that QOL stresses on the fit of one’s expectancies and motivations with the resources and opportunities provided by the social environment. ‘Well-being’, on the other hand, often describes people’s general functioning and health (Wahrendorf & Siegrist, 2010). In spite of the possibility to give the concept many different meanings, this study defines it as a basic mood of well-being and contentment, inspire by Naess (1987). It means that a person can have a high QOL or well-being if he is active, has relation to other, has self-esteem and can be happy.

This definition comprises cognitive as well as affective aspects, which will be evident when people talk about a ‘good’ and/or a ‘bad life’. The cognitive aspect is represented by general assessments, satisfaction or dissatisfaction with life, expectation, standard and aspiration, while the affective aspect is represented by emotional, positive and negative reactions of an individual. Although there are difficulties in measurement QOL, there is a general agreement on five domains that contribute to the concept. These include physical, social, emotional, material well-being and personal growth and activity (OASIS, 2003).

There are also some disagreements regarding the relevant contribution of objective versus subjective variables in QOL. From an objective approach QOL can be defined as the level of control of resources that an individual obtains in order to consciously manage life conditions. However, this objective definition has a limitation in that the impact of culture, values and ideologies is not considered (OASIS 2003). Because of my intention to interview elderly people and their close network, I also want to listen to their subjective opinions about e.g.
satisfaction, emotion and freedom from stress. In accordance to OASIS (2003) these aspects are important because they can show in what extent people can stay optimistic and satisfied under difficult conditions.

1.3 Problem area and research question

A report from World Health Organization (WHO) predicted that the global population of those aged 60 years and above will double from 600 million in 2000, to about 1.2 billion in 2025 and around 2 billion by 2050 (www.who.int 2010). Thus opinions from elderly people will be more and more important and their problem needs to be dealt with. Particularly when elders´ health and well-being easily can be hidden from public view.

A problem connected to this is also many elders´ economic situation making them exposed to dependences, which can result in improper use of their resources. According to James et al (2003) an estimated value of 4 and 6 % also has experienced some form of abuse in the home. A study in Amsterdam (the Netherlands) showed that elder abuse was 5.6%, in which verbal aggression was 3.2%, physical aggression 1.2%, financial mistreatment 1.4%, and neglect 0.2%. Most victims reported emotional reactions immediately after the abuse (James et al 2003). In light of this it is a challenging issue for society to maximize the health and functional capacity of older people, as well as their social participation and security.

Although elderly abuse is not the core of my research, it is an important area connected to well-being of elderly. My study will focus on opinions from elderly people in Sweden and I will connect their perceptions to the concept of QOL, described above. This has lead to the broad research question ‘how is Quality of Life viewed by elderly, receiving social care’?

1.4 Purpose of the Study

The purpose of the study is to investigate QOL for Swedish elderly, receiving care. The main objectives will be to understand what kind of social support does elderly receive and how do they and their close network evaluate this? Does the support come from the society (formal support) or from other key people in the older person’s network, for example, family, friends
(informal support).

Questions to be answered are:

- What kind of support do Swedish elderly people receive?
- Is this support formal or informal?
- How does elderly conceptualize and express this support?

Definition of key words

**Elderly population:** It refers to the number of inhabitants of a given region aged 65 or older.

**Pensionaire:** It is a word often used in the Swedish discussion about elderly care but also used in e.g. Cameroon as retired workers. In this text I mostly use the word elder or elderly.

**Old age:** In Sweden, the official age of retirement is 65 years. In this study, I have therefore defined it from 65 years and above. The expressions old age, old people, elderly, elderly people, and the aged, are also used synonymously. However, old age could refer to the average life span of human, and thus the end of the human life cycle. Euphemisms for older people can be advanced adult, elderly, senior or senior citizen (www.wordiq.com 2010).

**Elderly care or eldercare:** It means here fulfillment of special needs and requirements that are unique to senior citizens. This broad term encompasses such services as assisted living, adult day care, long term care, nursing homes, hospice care and In-Home care (www.righthealth.com 2010).

**Health:** It is used here in the same meaning as WHO; a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (www.WHO.com 2003).

**Extended family:** It means here an expansion of the nuclear family (parents and dependent children), usually built around a group, in which descent through either the female or the male line is emphasized (www.britannica.com 2010). In this study, the words family, the extended family and the traditional family are used synonymously.

**Caregivers:** When the word is used here it can refer to different kinds of person, important in
the life of elderly when providing them companionship and support. Caregivers can e.g. be spouses, children, friends, neighbors, nurses, home health aides, physicians, social workers and spiritual care professionals. Some may volunteer while others get paid for their professional services (www.livestrong.com 2010)

*Family, relatives and household:* These terms have been used in the text as synonyms.

### 1.5 Motivation and Pre-understanding

The inspiration for this study started from an experience with my late grandmother Paulina Tengu. I followed her experience when she was over 90 years old until her death in 2008. She was an inspiration to both her family and the community where she lived. Besides educating her grandchildren, she served in her community called Bafia-Muyuka in Cameroon, as women magistrate in their local women’s court (customary court) on voluntary basis. She helped to settle newcomers in Bafia through counseling, housing, and sale of farm land, which could be used for subsistence farming at reduced prices. While ageing, she developed diseases like dementia, poor site, diabetes, though she still insisted on going to the farm.

When her condition deteriorated, she was moved from Bafia to her child in Mbengwi, Cameroon, for care. Before her death, Mama Paulina was being rotated between our residence in Mbengwi and my elder sister’s house in Bamenda. It was not easy to convince her to leave Bafia as she kept complaining of her food crops in the farm. At her ageing state, she always liked to follow up conversation around her, even if it did not concern her. She would ask questions. I was used to her ways and able to cope with her situation as I usually visited her wherever she was. Consequently, I noticed her situation was not too different to other elderly people as they have some common characteristics.

Besides, I got inspiration from the terrible treatment given to the elderly who are pensionaires in Cameroon. They go on retirement and stay for years without pension. Some stay for several years without retirement decisions to follow up their pension. This is common with retired civil servants in Cameroon, where the system is very bureaucratic. Even when parliamentarians take decision on decentralization, promulgated by the Head of State, it is still
Most of the elderly pensioners in Cameroon live in their villages (interior parts) upon retirement, which is quite distanced from the capital town. They are often disturbed by the fact that they need to go to the nation’s capital (Yaounde) to follow up documents, which is very frustrating as most of them return to their homes without accomplishing the tasks. At times, the pensioners are been asked by workers in the public service to give money as bribe for their file to go through. In the process, these elderly persons sleep in bars and under trees around the ministries, because they do not have houses or money to provide for where to live. During this process, some who cannot cope with the terrible situation are caught by death, in Yaounde, or on their way to and from the capital town. As the situation deteriorate with time, most elderly ended up living miserable lives, characterize with poverty and ill health until death, especially when there are no able family member to provide different forms of assistance.

Older people play crucial role in communities - in paid or volunteering work, transmitting experience and knowledge, or helping their families with caring responsibilities. These contributions can only be ensured if older persons enjoy good health and if societies address their needs. It is on this positive note that I felt motivated to join others to carry out research on the Quality of Life for the elderly. According to Fisher (1992) this kind of research, trying to understand older people themselves, can provide insight of the subjective meaning of social care for elderly as well as ways, in which life satisfaction and healthy aging are determined. So carrying out this type of research in Sweden, which is a welfare state and a developed country, will help me understand how elderly care functions in Cameroon could be as a guide, a loadstar, when advocating for support for the elderly in Cameroon.

1.6 Significance of the Study

This study will be an effective tool in understanding what kind of care older people receive care, and how they appreciate care given to them. This will provide a guide for caregivers to help the elderly adjust to the environment and show how to build a more humane society.
It can also help to inform policy makers about the promotion of autonomy and then reduce their dependency. It exposes hindrances to Quality of Life for the elderly receiving care in Sweden, and open ways for proposals. Furthermore, concerning social policy, this research can serve as a complement in guiding policy for elderly care in Sweden. Finally, it can inspire to improvement concerning the social planning for elderly in Cameroon.

1.7 Lay-out of the study

Chapter one gives a brief introduction on Quality of Life, the definition of the concept, its relevance, the purpose and use of some key definitions and how I found myself in this area of research. Chapter two shows how demographic trends and structural factors e.g. gender, class and income in Sweden may affect elderly care. Chapter three reveals the Swedish Welfare model as a background and a context for the research.

Chapter four describes earlier research and chapter five the theoretical concepts. In Chapter six I describe the methodology in which qualitative design, such as documents and interviews, were used. Chapter seven shows the results and analyses of the study. The report ends with chapter eight, in which I make a concluding discussion of my results, reflected over validity and generalization and relate briefly to a Cameroon context.
CHAPTER TWO
DEMOGRAPHIC CHARACTERISTICS

2.1 Demographic situation of Ageing in Europe

Today more infants and children are surviving into adulthood and adults are living longer and growing older. This population ‘boom’ is not only a result of an increase in birth rates, but rather a decrease in death rates fortunately. I think this development is interesting to be described for two reasons; first, my result is related to the fact that elderly people lives longer and seems to be more active and second, Cameron shares some similar characteristics.

2.1.1 Population projections 2008-2060

2008 the EU27 (it means all the 27 European countries) population is projected to increase from 495 million to 521 million in 2035, and thereafter it gradually decline to 506 million in 2060. From 2015 onwards the population growth, due to natural increase, would cease while deaths would outnumber births, from this point onwards, positive net migration would be the only population growth factor. However, from 2035 the population in EU is projected to begin to fall, as the positive net migration would no longer counterbalance the negative natural change (http://ec.europa.eu/eurostat).

The EU27 population is also projected to continue to grow older, with the share of the population aged 65 years and over rising from 17.1% in 2008 to 30.0% in 2060, and those aged 80 and over, rising from 4.4% to 12.1% over the same period. However, it will be considerable differences between the Member States. The population will rise in thirteen Member States and fall in fourteen. Among those with a strong population growth is United Kingdom (+25%) and Sweden (+18%). In 2060, Member States with a large populations would be e.g. United Kingdom (77 million), France (72 mn), Germany (71 mn), Italy (59 mn) and Spain (52 mn) (http://ec.europa.eu/eurostat). The Swedish populations will growth from around nine million to nearly eleven and will still bee the largest country in Scandinavia (Appendix 3).
2.1.2 Elderly population in EU.

As mentioned above the elderly population in EU, aged 65+, will nearly be redoubled 2060 and those aged 80+ will be threefold. Some consequences of this rapid change have already been seen e.g. there are about five people of working age for every retiree and 2050, there will be only two. This will bring to the fore some questions e.g. how can theses old people be provided for, how can they, themselves, be more productive, more active and more healthy (www.overpopulation.com 2010). The trend that the total EU population will decrease and also become much older, make it necessary to support more research about elderly people.

Table 1. Older population in EU

<table>
<thead>
<tr>
<th></th>
<th>Percentage aged 65+</th>
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<th>Old age dependency ratio (%)</th>
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<tr>
<td></td>
<td>2008</td>
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<td>EU27</td>
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<td>Belgium</td>
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<td>Bulgaria</td>
<td>17.3</td>
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<td>Czech Republic</td>
<td>14.6</td>
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<td>Denmark</td>
<td>15.6</td>
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<td>Germany</td>
<td>20.1</td>
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<td>Estonia</td>
<td>17.2</td>
<td>22.8</td>
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<td>Ireland</td>
<td>11.2</td>
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<td>Greece</td>
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<td>Spain</td>
<td>16.6</td>
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<td>France</td>
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<td>Italy</td>
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<td>Cyprus</td>
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<td>Switzerland</td>
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Source: ([www.WHO.com](https://www.WHO.com) 2010)

### 2.1.3 Impacts of the ageing population

As a large number of baby-boomers retire, there will be a fall on the *active population*. If current trends and policies remain the same, this reduction in the working-age population may likely affect the economic growth rate. The implementation of the Lisbon agenda work with this by requiring to make full use of the resources of experienced workers and at the same time making quality training available for younger people.

The ageing population will also have an impact on *social protection* and *public finances* as ageing can lead to considerable upward pressures on public spending, based on current policies. Budgetary deficits of this type could compromise the future equilibrium of pension and social protection systems in general and perhaps even the potential for economic growth or the functioning of the single currency. The EU governments have, however, already started to take action, especially in the fields of public pensions or the modernization of social protection systems. Better adapted healthcare services and a preventive approach to chronic diseases could, finally, reduce public spending on health and dependency care by half ([www.europe.eu.com](https://www.europe.eu.com) 2010).

### 2.2 The Swedish Population Trend

As can be seen the population of Sweden was little bit more than 9 million in 2008. Most of them lives in urban areas (83%). In 2001 the capital city, Stockholm, had a population of 1,6 millions and Gothenburg, in which my study take place, had a metropolitan population of 763 thousand (Th). Other cities with rather large population are Malmö (243Th), Uppsala (181Th), Norrköping (83Th), Örebro (86Th) and Västerås (98Th) ([www.nationsencyclopedia.com](https://www.nationsencyclopedia.com) 2001).
The population of Sweden is expected to grow by about 610Th people by the period 2009-2019. During the same time, those ages 65 and over, are predicted to grow with 362Th persons. At the same time the working age people (aged 20-64) will increase with 151Th persons. A slightly more than 96Th is expected to increase among the number of children and young people (aged 0-19). The trend of mortality rate reduces can results in a rise in average life expectancy. In 2060 women are expected to live 3.5 years longer or reach 86 years, compared to 83.4 years in 2010 while men are expected to live slightly more than 5 years longer, from 79.5 years now to 84.7 years then (www.scb.se 2010).

2.3 Gender, class and income

2.3.1. Gender
Although sex (or sexuality) and gender are related, they are different, and they form two distinct areas of social practice. Rubin (1975) argues, sex refers to biological differences between men and women, while gender refers to social, cultural and historical construction of femininities and masculinities. The major difference between men and women is the biological fact that fertilization occurs in women. Consequently, most societies expect women to bear children, be good mothers, be the primary care givers and see this as their fundamental role in life (Lewis, 1991?). Nagata et al (1999) found subjective well-being, health, and activities of daily living to be common among women. This is also common in the interior parts of most developing countries such as Cameroon, whereas well-being for men is related to more narrow factors like hobbies, and social opportunities.

According to Unger and Crawford (1992) gender interactions is a construction based on social expectation and social demands. Such construction seeks to give an explanation of what diverse societies are experiencing like Sweden as well as Cameroonian society, when they e.g. categorize social care as a women’s job. West and Zimmerman (1987) term such a construction and maintenance as doing gender.

Societies make codes and determine categories of certain professions like nursing, teaching, social work and social care. These are areas where most women find employment easily and concerning social care a feminist researcher maintained that female was more suitable for care work because of their deep ability to be emphatic (Noddings 1984). Even if this work has
been more and more professional, there is also a work often performed by a spouse as informal caregiver. Within the marital unit, frail elderly men are more likely to be the recipient of the informal care and women the recipient of the formal type of assistance (Larsson 2004).

2.3.2 Class and Income

As most countries’ resources are unevenly distributed, there is the tendency for some individuals to have the opportunity for better living condition and more advantageous life chances than others. The effect of class and income at old age is noticeable through retirement and greatly influences the life style at older age. As the socio-economic status of older persons drops, there is a high possibility that they will experience ill-health contributing to an occupational pension, owning property, accruing savings and retiring on a high income (Phillips, Ray & Marshall 2006). The old philosopher Karl Marx saw class as one of the concepts used to explain institutionalized inequalities among social groups. He related it to living conditions and life opportunities, level of skills and material resources, and relative power and privilege. He defines ‘Social Class’ as a group of people sharing common relations to labor and means of production (Marx 1867).

However, class inequality is still common in many countries in the world, whereby members of some social class are more privileged to access of material resources than others. Because of a class related authority some people can have very great influence in the society. Although there exist a movement of an individual from one social class to another, this shift or movement is insignificant as it occurs at a very low pace as the opportunity arises.

Class inequality exists among men, women and in social groups composed of men and women. Some author can see two approaches by which women’s class are measured. The first is a male-centered strategy in which the social class of a married woman is determined by their husbands’ occupations and social class whereas he unmarried or single mothers are deemed to belong to a class of their own (Liberatos & link & Kelsey 1988; Morgenstern, 1985). The other strategy is individualistic, which applies to both single and married women, regardless of their household or marital status. They are classified according to their own socio-economic position, which is mainly judged to their level of education. However, housewives turn to be grouped into one category regardless of the social class of their partner. Sweden being a welfare state, tries as much as possible to put this in balance, in order to wipe
out class inequality so its existence will be insignificant.

The level of occupational details are important for understanding class differences, since the more detailed the coding system, the more segregated men and women’s work will appear. At the level of employment within the labour market, despite the level of qualification that women have, they find it easier to do and gain access to care employment than men. While the highly educated people, especially men, gain access to better paid jobs. They constitute the high class with high status in terms of social class. They are filled with powers, often have political control and take decisions for the interest of all irrespective of class. This class differences can also be identified in social care work in Sweden, especially the one connected to domestic service, which is ‘imbued of low status’ (Johansson 2008, p 278).

2.3.4 Summary
Gender, class and income are important aspect that could be mention when looking into the wellbeing of the elderly, though in this study. I have mentioned just a few as per my desire. The nature of job positions that an individual occupy determines his/her social class, which further determine the level of income. In this effect higher paid jobs will attract higher income level and higher social class participation such that the purchasing power will be higher and vice versa. With a high purchasing power certain needs are easy obtained without passing through certain bureaucracy like the elderly with little or no income, who rely on the local authority for either complete or partial provision for their needs. Since certain low paid jobs, like caregiver, low or mid level teaching carrier and many other jobs are being classified and labelled by the society as women’s jobs, for the fact that many women are recruited in these sector than men. This implies that most men have higher purchasing power than most women which can consequently has an influence on their wellbeing as well.

Gender differences in level of wellbeing might be expected because women experience more health-related problems than men (Gold et. al 2002; Murtagh & Hubert, 2004). ‘Gender’ as oppose to ‘sex’ invoke different stages of social relationships, power, ideology, culture and an understanding that biology is potentially just socialized as other human characteristics (Levin and Lopex, 1999). Gender relations refer to power, which are socially and structurally distributed (Harmström, 2002). As one moves from Sweden to a continent like Africa, precisely Cameroon, where the culture is extremely different it is very common to witness gender practices. The culture has made it such that labour force participation for women to
occupy white collar jobs is extremely low. The men are always at the helm of power; usually the men are opportune to eat certain traditional meal and are treated with much respect in every tradition gathering than women. As the elderly in Sweden with little or no income rely on the local authority for partial or full provision for their needs, women in Cameroon most often rely on their men to provide all or part of their needs. Also the final decision whether to provide or not depends on the men. According to research, the socio economic position could be assessed by social class or income during adulthood, while in old age the socio-economic position could be assessed in terms of income, wealth or poverty (Fors, 2010).
CHAPTER THREE
BACKGROUND OF THE RESEARCH

3.1 Welfare Regimes

Welfare regimes have been classified in many different ways. Early models classified welfare on the bases from the least developed to the most developed systems. Esping-Anderson (1990) has developed a contemporary welfare model built on country differences in social policies and based on citizen rights and the organization of work. He distinguished three models of welfare regimes namely; the social democratic model, the liberal model and the conservative-corporatist.

The social democratic model e.g. Sweden and Norway is characterized by a universalistic approach to social rights, a high level of decommodification and an inclusion of the middle classes in social programs. The liberal model e.g. England, at the other extreme, provides only limited social insurance programs, which are directed mainly towards the working class. In the conservative-corporatist model e.g. Germany and Spain, social principles prevail in most areas, although they are not based on egalitarian standards but on eligibility according to social status and tradition. While country like Israel has mixed features of liberal, conservative and social democratic model thus could be categorized as ‘mixed model’. This classification is due to the way in which welfare production is allocated between state, market and households (Esping-Andersen, 1990, 1999).

The expansion of welfare states has an effect on their perception regarding the reasonable balance between public services and private, family support. This makes it also difficult to get clearer picture when comparing with other countries with a different welfare regime.

Scandinavian countries e.g. Sweden, are often described as ‘institutional welfare states’ in which the values of equity, equality and universality applies to everybody. It comprise basic rights and other benefits that can give people a reasonable standard of living. This model try to eliminate poverty and at the same time reduce inequality (Esping-Andersson & Korpi, 1997; Trydegård, 2000).
In the Swedish model units in the local government, municipalities, have a main responsibility for social care. This decentralization trend also implies decision-making but also an effort to encourage growth of an informal social sector (Trydegård, 2000). When expenses for the public welfare increased during the 1990s it was obvious that the formal social care had to be complemented by a private, family support (Government Bill, 1987/88:176; Johansson & Sundström, 2002; Larsson, 2004).

3.2 A Swedish Perspective

Sweden is a country with a large proportion of people aged over 65, which demands for a developed public service for elderly. It has resulted in higher investments than many other counties in the world. Outside the Nordic region, only a few countries around the world maintain public care services for the elderly. Sweden is on first place with investments of 2.8 percent of its Gross Domestic Product (GDP) in the elderly care sector, while Norway is in second place with 1.8 percent (www.OECD.com 2005).

In Sweden, elderly care is a social entitlement that is regulated, according to the Social Services Act (1982). Most of the care is financed by municipal taxes and government grants and only some few percents came from patients’ charges. Until recently, local authorities have a monopoly in providing elderly care but the economic and demographic developments has open up for other kind of caregivers. In the future, elderly persons will probably be more dependent on services and help from relatives or from voluntary organizations. This will result in more competition and market-like situations in elderly care. According to Swedish government website, there is a growing interest for this model in Swedish municipalities, in order to increase quality and efficiency in elderly care (www.gov.se 2010).

Social policy regarding elderly care in Sweden, are based on legislation from early 1980s – the Social Services Act and the Health Care Act – and the policy programs from 1987/88 and 1997/98. These programs used to be summarized in the ‘ÄDEL-reform’, the National plan of action for care of the elderly people (Government Bill 1987/88:176, Government Bill 1997/98:113). Emphasis has been made in these documents on Swedish elderly people’s rights and providing for them is a major challenge for the Swedish welfare state.
CHAPTER FOUR
EARLIER RESEARCH

In this chapter I will present some studies about the concept of Quality of life and research about formal and informal care. The aim has been to (1) critically access the strengths and limitations of previous research, (2) by help of them explore the theoretical conceptual frameworks of my project and (3) find out appropriate methods of data collection and analysis (Gilbert, 2008).

4.1 Research about QOL

QOL can have different meanings in different academic disciplines, which has given rise to identification of several life indicators. In an article from 2005 Wilhelmson et al. present some of them e.g. Bowker, who 1982 made researches about subjects, humanizing nursing homes in the United States. He analyzed over 300 hours of in-depth interviews and participant observations collected from residents, caregivers and care managers. He identified three categories of QOL indicators: social relationships, environmental structure, and administrative politics and programs. However, the main focus of his data was focused on the opinions of caregivers and care managers (Wilhelmson et al. 2005).

Another example is from 1991, when a working group of experts identified five general QOL indicators for nursing home residents: identity, control, intimacy, security and comfort (Wilhelmson et al. 2005). Also Loiselle et al (1997) identified quality criteria in short-term geriatric units: staff competence and interpersonal qualities such as kindness, respect, dedication and patience (Wilhelmson et al. 2005). Recently, researchers have also found that social relations, functional ability and activities may influence the QOL of older people, as
much as health status. However, Lawton (1999) has argued that the non-health-related areas of older people’s lives may well override the negative aspects of some chronic illness and poor health (Wilhelmson et al. 2005). In a Chinese nursery study about QOL indicators, the result showed that seven different aspects was important from the residents' point of view: environment, professional competence, quality assurance, basic human rights, direct care attitude, social interaction, and needs satisfaction. These indicate that system aspects as well as individual opinions can be important when studying social care for elderly.

Following a research, conducted by the Swedish Panel Study of Living Conditions of the Oldest Old (SWEOLD) in Sweden between the period 1991/1992 and 2000/2002, the result disclosed a prevalence of all specific health problems, but not poor self-rated health, between 1991/1992 and 2000/2002. Also gender and socioeconomic differences in health during both periods, were noticed e.g. women reported higher rates of impaired mobility, pain and psychological distress than men (Fors, 2010). Difference in economic wellbeing has also been evident in a study by Gustafsson & Johansson & Palmer (2009). Between 1991 and 1998 there was a deep recession in Sweden, which influenced the pension. Even if the pensioners ‘fared better than the working-age population’ their relative poverty created an increasing gap between better-off and worse-off older people. However, compared to international standard they considered that the Swedish welfare state has ‘maintained its resilience’ (ibid, p 539).

On the other hand, when older people maintain or start productive activity such as volunteer work and care for a person, a higher probability of experiencing wellbeing will happen (Wahrendorf & Siegrist, 2010). Volunteering differs from care work in that the engagement is usually based on free choice and offers opportunities of personal control and social recognition (ibid). A question is if this indicate that informal care, in which both caregivers and caretakers have a relation, built on private engagement, will improve the well-being and QOL?

Also marital history can be important for QOL because married elderly without children may be disadvantaged in their support networks compared with elderly with children (Larsson & Silverstein, 2004). However, it is unclear in the study if the never married elderly are advantaged in their support networks relative to the availability of good in-law relatives who can provide support. Earlier research says that elderly women, never married, may equally enjoy from much of informal service than the married women with children. Particularly if they have developed an informal network of non kin supports over their lifetimes, it will be
added with support from family of origin, including their sibling’s families and if they are able to develop an independent and extra-familial lifestyle (Larsson & Silverstein 2004).

Improving the QOL of nursing home residents is also a leading goal for those concerned with long-term care (Andersson & Gottfries, 1991; Kane, 2003; Kane et al., 1997). Such initiatives often represent efforts to improve the feeling of being a person, an individual (Clark & Bowling, 1990; Higgs, MacDonald, & Ward, 1992; Kane et al., 1997). Yet conceptualizing, measuring, and improving the quality of life of nursing home residents is challenging. Health, income and education have a strong impact on most dimensions of subjective QOL.

Thus health, income and wealth, age, gender and the possibility to keep ones personality intact will be important in studying well-being and QOL.

### 4.2 Research about formal and informal care.

In Sweden, elderly care involves formal and informal care. They found in their studies that formal care brings the risk of distorting family solidarity and care. This happen if the family, in that case, stay apart from providing support. In view of that informal care should not be stopped because older people in need of daily support, require the attention of both formal and informal care (Dunér & Nordström 2005). On the other hand, role and function of informal care, can be affected by the volume of support from the formal care sector (Phillips & Marshal, 2006).

Assumption has been that informal care is more preferred than formal care among elderly people in Sweden, which means they prefer to stay at home as long as possible. According to Larsson (2004) this is not the opinion among elderly people themselves because the relation between the two models is not always clear. Dunér (2008) found in her study that the quality of the informal network was depending on e.g. the geographic distance (structural dimension), the reciprocity in the symmetry of the interaction (interactional dimension) and the ability to provide social support (functional dimension). She also found that older people with support depend more on formal elder care and are less satisfied with their situation than others (Dunér 2007). According to Dunér (2007) other Swedish research and nation reports reveals that decreasing formal care of the elderly, imply increasing informal care, which is mainly
provided by spouse and offspring. One of her conclusions is that ‘the availability of formal eldercare does not seem to decrease the level of informal help’ (Dunér 2007, p 54). That rise the question whether public care for the elderly is a substitute or a complement to family care?

However, older people in-need of help on daily bases, require the attention of both formal and informal support to maintain control over their situation and to reduce feelings of dependency (Dunér & Nordström, 2005).

Among the Swedish elderly population in 2002/2003, 20% of them, aged 65 and above, where living in their own homes and received mainly formal care. 12% received only informal help, 3% received mainly formal care and 5% received both formal and informal care (www.socialstyrelsen.se 1994). Although formal care has decreased in the last few decades, the average health status of elderly has improved. This does not mean that an aspect of care has been neglected but can equally be due to the availability of modern medical equipments to care for their health related problems (Larsson, 2004).

According to Larsson (2004), it is not normal for highly dependent elderly who live alone, to receive only formal care. It states that an elderly who receive professional support will definitely require some reasonable amount of informal care. However, some evidence support the view that informal care substitute formal care of the elderly. Elderly, living in pairs as couples, are less likely to receive formal care, as they have a higher level of satisfaction than unmarried elderly (Phillips, Roy & Marshal, 2006). The research also points out that childless older Swedes receive less informal support, which is compensated with high formal care with the reverse being true for those with children (Larsson 2004).

According to Philips & Marshal (2006) there are also some negative aspects in giving and receiving informal network support e.g. if a networks will be seen as different aspects of the world, that share the characteristics of interconnectedness. If the roles and responsibilities of the network, members are not clearly defined which can make it difficult to sustain its functions. It can be lots of confusion about what and when will be done (Philips & Marshal 2006).

Research has also revealed that, the decline in public elderly care provision during the 1980s
and 1990s, coincided with the family increasing its involvement in the provision of welfare services to the elderly people (Johansson & Sundström, 2002; Larsson, 2004). This rise a question if the families were forced to fill the gap between the assisted needs by the elderly people and the level of public care the elder received?

Larsson (2004) also found that factors of importance for receipt of formal and informal care included socio-demographic data such as household compositions, gender, education, information about social network factors such as parental status, contact with relatives and friends. Finally, also psychiatric factors such as dementia, depression and functional limitations can be decisive. I will try to consider these aspects when analyzing the data in my own study.

As can bee seen my theoretical frame of reference is inspired by the discussion, earlier described, about formal and informal support. However, I will supplement it with an ecological perspective and activity theory. The reason is that opinions of the elderly depend on, not only the extern structure of social politic, bur also how they understand themselves as individuals. That implies a holistic comprehension, which also includes investigation of which possibilities of action the elderly themselves as well as persons in their close network can see.

4.3 Ecological perspective

A conceptual framework, with a kind of holistic approach, need some ecological principles. In the theory of Germain & Gitterman (1980), they present an ecological system theory for social work. They call it the ‘Life model’, which refer to the relation between a person and the environment, described as a mutual process. If individuals can take changes in a positive way by developing themselves by help of the environment, they will strengthen their life quality, QOL. This relation need to be in balance, otherwise stress symptoms will appear connected to needs, ability and surroundings (Payne 1997). For elderly people this can create feelings of loneliness and undermining feelings of dignity, self-esteem, which also can bring them into passivity (Duner 2007).

The ecological theory points out three clusters of factors important in identifying disturbances in his/her effort to find a balance. They are (1) life changes, e.g. changes of roles, status and
life room, (2) pressure from the environment, e.g. unfair treatment, non-responding organizations and (3) relation processes, e.g. inconsistent demands (Payne 1997).

The focus on dignity, self-esteem of elderly has also been discussed by McMullin & Cairney (2004). They found it related to the amount of control individuals have over their lives e.g. by gender, class and age. For older adults, changes in self –esteem was more attributed to changes in power that comes with role loss (e.g. retirement), rather than the loss of roles itself. When the elderly person no longer can perform such as playing professional football, skiing or taking up responsible positions in work place as they could in their youthful or middle age, their identity will be undermined. Thus, changes connected to roles in the family, social networks, organizations, or institutions are not always easy to handle for elderly people. Their ability depends on lot of factors e.g. cultural, social and economic capital, personal health, disposition and competence. Other aspects like changes in beauty, often constructed with youth as a reference, could also be stressing (McMullin & Cairney 2004). By processes of self-comparisons and reflected appraisals the level of self-esteem can decrease as people gets older because and their beauty fades.

The ecological theory has also been supplemented with a kind of (4) spiritually thinking, central in individuals’ existential life and feelings of meaning. It can offer religious networks for the elderly as well as more personal, inner trust. Actions in their life can also facilitate reinterpretation and reconstruction of meaning. A process similar to reconciliation! The spiritually thinking has been developed for social work by authors like Canada (1988), Joseph (1987) and Keith-Lucas (1985). The spiritually thinking has been found be important in elderly care following a study by Mac Kinlay (2006). She maintain it ‘underlie the psychosocial needs of people- they lie at the very core of what is to be human’ (ibid.,p 69).

4.4 Activity Theory

Activity as an engagement has also been recognized as an important determinant in QOL. A popular model for analyzing successful aging, as un ‘active engagement with life’, also referred to as ‘engagement in life’ or ‘productive involvement’, is based on activity theory. The theory was developed in the middle of the twenty century by Havighurst and his colleagues, who often referred to it as the ‘normal’ theory of aging (Knapp 1977). It emphasized the link between activity with health and well - being and with primary focus on
physical activities or activities that create societal value e.g. volunteer work (Havighurst, 1961). But this activity could also be blocked by social norms and ‘create crisis in self-evaluation for the individual’ (Knapp 1977, p 554).

The model shows how active engagement in life is linked with the involvement in activities like club attendance, other social group activities, voluntary work etc. It also indicates the importance of the participation rates and frequency for improving an individual’s well-being. By this perspective it is possible to estimate some aspects of QOL, related to elders’ relation to the local society and the elders’ ability to connect to human resources in the environment.

The theory associate social interaction with life satisfaction but not just per se. What is important is the ‘degree of congruence between actual and desired participation’ (Knapp 1977, p 554). That’s way quantitative testing, highlighting aspects as age, sex and socioeconomic status can be insufficient when QOL also depends on the elderly’s own preferences (Knapp 1977).

4.5. Summery

My final theoretical frame of references will be a combination of concepts from organization theory; formal and informal care, from ecological theories; life change, environment pressures, relation pressure combined with spiritually thinking and finally from activity theory; active engagement. By help of these concepts I will try to catch the structures of care, offered to the elderly as well experiences and opinions by themselves and people in their network.
CHAPTER SIX

METHODOLOGY

6.1 Study design

In social science quantitative as well as qualitative design can be used. The choice depends on the research topic and the formulation of the research questions (Gilbert 2008). I had to reflect on questions like who my target group would be, how I could get access to this group and what kind of communication I want with them before I found out the design of my study. These questions draw my attention to a qualitative design, which means focusing on life-situations, trying to have a ‘holistic’ overview of this context. The researcher wants to capture an empathetic understanding of people’s experiences ‘from the inside’ (Miles & Huberman 1994, p 6).

When making studies on life-situation and life-world it is not enough with methodological considerations, you also had to make some ‘ontological and epistemological’ ones (Dahlberg, Dahlberg & Nyström 2008, p 23). An ontological question is e.g. what is an existence and epistemological one is e.g what is the difference between a scientific knowledge and everyday knowledge? For me it is important to understand that we exist in a cultural context influencing our mental, spiritual thinking as well as our body. As a researcher I also have to reflect over the study context as a way of being part of it and at the same time at a distance. This means also I must have my own pre-understanding under control, so I don’t interpret data just in line with my own ‘fore-meanings’ (ibid., p 138). One way to handle this has been to express my own experiences from Cameron and relate them to the study results.

Thus, for me, the qualitative design gave opportunity to describe the scenes, gather data through interviews and some documents and try to find out their meaning (Gilbert, 2008). Qualitative data often makes it easier to follow life changes, since one can tract people through their lives or ask them to tell their life histories (ibid). This is further supported by Alitolppa-Niitamo, who point out that ‘understanding of the human actions, which are based upon different interpretations, or social meanings, which are socially constructed, cannot be explained by simple casual relationships, but needs to be described in more complex and dynamic term’ (Alitolppa-Niitamo, 2004, p..).
The research question in my study is concise, answerable and draw attention to questions of ‘why’ and ‘how’ rather than only ‘what’, ’where’ and ‘when’. This is in line with Gilbert’s ideology, which states that for a social research to be reachable, the research question should have at least six properties. I considered them and they included the following characteristic; interesting, relevant, feasible, ethical, concise and answerable as a useful checklist at every stage during formulating and refining of my research question (Gilbert, 2008). I tried to stay focused on devising and refining my research question all through the research process. This involves the art and science of knowing what I wanted to know, while maintaining the relationship between the formulation of the research question, research design, the literature review, and data collection and analysis (ibid).

5.2 Study Participant

According to Miles & Huberman (1994, p 27) qualitative samples often will be small and more purposive than random. The kind of data I wanted should come from interviews and documents. It can involves two processes; the first in which you define what kind of persons you want to interview and what kind of documents you want to use and the other, in which you are describing how to find them.

Interview

I wanted to interview some representatives of elderly people themselves but also some representatives near them e.g. caregivers and social worker. The sampling strategy became a mixture of snowball and convenience sampling, which implied cases who people recommended as ‘information-rich’ as well as cases who saved time and efforts (Miles & Huberman 1994, p 28).

I accordance with this my study was conducted in Gothenburg (Sweden) and it’s neighborhood in the year 2010, where I assembled the following selection;

- Three elderly women who receives home care
- One formal care giver,
- One informal care giver,
- One social worker
- A group of three social workers
A total of 7 interviews were performed which comprised 6 face-to-face interviews and one group interview. The interviews were conducted in Furulund-Partille Municipality and Frölunda as well as Gothenburg. All my interviewees were females. I approached them with the help of the elderly care manager, who had been my fieldwork supervisor on elderly care for two months. In Frölunda, the sampling was arranged by a friend and a lecturer from department of Social Work. They were all well informed with the purpose of my research project as a master’s degree report.

Document
I also collected some data from documents. When using that kind of text you have to consider to whom the text is addressed and make your interpretation regarding to that (Denzin, & Lincoln 2000). Information from documents was obtained from several sources such as government reports, legislations and social policy literature. They were all x-ray to trace public policy on the care of the elderly. They were possible to get from goggle search as well as from the libraries. The aim was to have a good understanding of situation for elderly in Sweden and it was no special problems in connected with them. However, depending in limitation of time and that I needed documents in English, I hade to concentrate on a few, which I found most significant. These were (1) Two Policy document from the Government, Two Laws and some information documents from the Local government.

5.3 Data Collection
This process is meant to reflect a condition in the real world and should not be biased by the person who are collecting the data in any way (Grinnell, et al 2005). When qualitative interviews were my primary qualitative data collection methods I had to speak English. Sometimes it coursed me problems because that was not the respondents’ original language. However, this situation was a little bit complicated only when I made the group interview but I cooped with it by help from one of the group member. Before the interview I prepared an interview guide, which was quite sketchy in order to create the possibility of non-directive interviewing. It means the interviewee’s replies determined the course of the interview and the interview questions were open in order to allow interviewees to develop answers. I used an MP 3 recorder and my mobile phone to record each interview sessions, which I transcribed later. Each interview last for about 30 minutes. All transcribed interviews, after being examined for accuracy, was read and organize into conceptually relevant categories for the exploration of patterns and themes.
The Municipalities’ information was obtained from interviews with some staffs working in elderly care unit under the municipality. In the interview guide I included questions that could reveal to me the living conditions, health and functional ability, and the care situation of the elderly receiving social care. There were also questions, structured and open-ended, which require the respondents to assess the quality of the care that is received from a variety of sources.

From the documents I collected information of what the elderly should be offered and what kind of services this in general comprised. It was necessary to have this information when understanding what the elderly in real was offered.

5.4 Ethical consideration

Ethical dimensions of the research questions where considered from the beginning to ensure that the research project fulfils its ethical obligations, both professionally and institutionally. Like any gerontological researches, my study was obliged to follow the ethical rules and values in social sciences (www.codex.vr.se). It means that ‘security, anonymity and privacy of research subjects and informants should be respected rigourously’ (ISA, p5). The study made use of ethical principles like non-malevolence (first, do no harm), anonymity and confidentiality, informed consent and the right to privacy (Gilbert, 1993). There was no harm to the subjects as well as the researcher of this study. With the anonymity and confidentiality, I eliminated all identifying information and pseudonyms were used in cases where participants insisted that their names should be used (ibid). With relation to the requirement of informed consent, the purpose of the study was made known to each and every respondent before the start of each interview session. An email request and telephone calls were the means that I used to reach out those, concerns for the scheduling of each interview session. The correspondents’ emails also provided contact information about the researcher for the respondents to reach me easily in case of any postponement or cancellation of our interview schedule. My respondents gave their consent and approval before participating in each interview session. I also made it clear to them that participation was highly voluntary and they could decide to drop out even after the completion of the interview. I respected the right of privacy by not intruding into the area that the subjects believed to be private as well as not to ask any personal questions (Gilbert, 1993; Kvale, 1996)
5.5 Reliability, validity and generalizability

Reliability refers to ‘the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions’ (Hammersley, 1992, p 67). Good reliability can make it sure that the results will be consistent if the study were to be conducted again. This is not easy in qualitative studies but can happen ‘if things has been done with reasonable care’ (Miles & Huberman, p 278).

This study has tried to do so. The sketchy interview guide that I designed created the possibility of non-directive interviewing. In one of the session I had a disappointment with the battery of my MP 3 as it ran out. I felt frustrated not having any other recording device, thinking about how I should be forced to spend further time and money for making new arrangements. However, after a while, I recalled that even my mobile phone could do the recording. The interviewees were conducted in calm and friendly atmosphere, the interviewees listened to me attentively. At the beginning of one of the session I found my self like an interviewee instead but I realized and assume my position by help of an interviewer twinkle of an eye.

Validity is seen as ‘a question of whether the researcher sees what he or she thinks or sees” (Kirk & Miller 1986, p 21). Are the findings credible for those who know this area? Does it represent ‘an authentic portrait of what we are looking at’ (Miles & Huberman194, p 278)? In this study I used triangulation to strengthen the validity. It is a powerful technique that facilitates validation of data through cross verification from more than two sources (Altrichtel, 2006). It also gives a more detailed and balanced picture of the situation (Ibid). With this study.

Another way to strengthen the validity is to check if the findings are well linked to the categories of prior ore emerging theory (Miles & Huberman 1974). This is the case here because I was very much inspired by earlier concept and strategies.

Face validity was also performed based on the results after the piloting of the interview guide. Face validity is the very basic form of validity in which a researcher determines if a measure appears (on the face of it) to measure what it is supposed to measure (Schmitt & Landy,
With regards to how far the findings can be generalized, it is important to realize that my interviewees were not a well define sample. They were just hand picked and not properly representing all elderly people in Sweden. A reason for that was my design, but also the problem to get an elder for interview, because most of them do not speak English. Perhaps also my background contributed. Another reason was my ‘self-sponsoring research’, which implied limited financial resources at my disposal. However, generalizability as a kind of external validity was provided for by their consistent with other reported finding.

5.6 Limitation to the study

This study has a number of limitations. During the research I could not carry out findings beyond Gothenburg and its environments due to my financial constrain as self sponsored. It was also difficult to approach my target group by myself to arrange for the interviews as I could not speak Swedish. The elderly people did not like to speak English and often they were not even able, so I experienced language barrier. The maximum volume of my MP3 and my mobile phone was not appreciable though I managed with it. I had to play repeatedly to get the words well in order to obtain accurate information during the transcription process. Besides the transcription was voluminous, assembling all the data for the research was time consuming. The entire process took much time. However, I maintain these limitations not affecting the conclusions drawn in any significant manner.
CHAPTER SIX
RESULTS AND ANALYSIS

In this chapter, the results and analysis of the research are presented according to the three sub-research questions: What kind of support do Swedish elderly people receive? Is this support formal or informal? How does elderly conceptualize and express this support related to quality of life? I bring together data from interviews and documents connected to every question followed by analyses.

6.1 What kind of support do Swedish elderly people receive?

The interviews show that the form of support available for elderly people in Sweden is a combination of family/friends and welfare state responsibility (formal and informal support). Respondents living in a care institution said:

I have been receiving help for about 13 years. I started receiving help from my children when I was at home (Woman B).

I have been receiving different forms of help from my children, and the caregivers here. I get personal care such as bathing, grooming, feeding assistance, they do some domestic chores, assisted in buying things for me and they also administer my drugs (Woman B).

For these elderly the welfare state plays a central role together with moral and practical assistance from families and friends. That is also what the defined policies, established by the Swedish government to care for the welfare of the Swedish elderly, also say. From these documents it is obvious that the general principles regarding care for the elderly are the same throughout the Swedish welfare state (www.government.se 2010). However, the Social care and the Health care have different organization, which can course some uncertainty about responsibility. Swedish municipalities and county councils have a high level of autonomy, by international standards while the health care system has a shared responsibility between the State, county councils and municipalities for health care. The county councils operate the
hospitals and out-patient clinics, while the responsibilities of municipalities include health care in special forms of housing (ibid).

To some extent, this can be balanced by a directive from 2003, which says that the elderly in Sweden also enjoy the freedom of choice in health care. When a county council decides on a course of treatment, such as hospital care, the patient is free to choose a hospital anywhere in the country (Ibid). My respondents did not express problems connected to this.

About 93 percent of the Swedish elderly live in ordinary housing (Ibid). The high standard of housing (grants for housing adaptation) makes it possible for elderly persons with disabilities to undertake the individual adaptations to their homes for comfort. Common adaptations include removing thresholds and rebuilding bathrooms.

Elderly persons living in ordinary housing, who cannot cope on their own, are being provided home care services by the municipal social services in the form of assistance with shopping, cleaning, cooking, washing and personal care. Accordance to the Government policy this makes it possible for older persons to stay in their own home (ibid.). In addition to home care services there are other forms of services that the elderly benefit from, in order for them to continue living in ordinary housing. Because home care services can be offered round the clock to the elderly, even persons with extensive need of health care, can remain at home and get meal services, safety alarms and adult day care by most municipalities. A few decades ago, there was the establishment of adult day care units for both persons with dementia and elderly persons with somatic diseases. Those with pure care needs also had the opportunity to be looked after by their families. Supervision and care is being provided for these elderly persons. The care is provided by specially selected staff and the number of elderly in these units at any one time, is limited (Ibid).

An intermediate stage between regular housing, special housing and medical care, is the Short stay housing/short-term care. It serves as a complement to home help services. Short-term housing and short-term care are used for rehabilitation, nursing after a hospital stay e.g home health care. Home health care in regular housing is run by half of Sweden’s 290 municipalities, while the other half is the responsibility of county councils. The municipalities and county councils are responsible for health care, and are required to provide assistive devices for the disabled, which is regulated by the Health and Medical Act (ibid.)
Grants for housing adaptation make it possible for elderly persons with disabilities to undertake individual adaptations to their homes. Common adaptations include removing thresholds and rebuilding bathrooms (ibid.). In order that the disabled persons use their homes efficiently, the municipalities provide grants. People can apply to the municipality for grants for home adaptations. The grants cover the entire cost, regardless of the applicant’s income and there is no upper limit for home adaptation grants.

Transportation services are also offered to elderly and disabled persons who cannot use regular public transport. The most common form of transport is a taxi, but special vehicles are sometimes available. National transportation assistance can be approved for users who have to travel outside the range of the local transport services (ibid).

The Social Services Act make alternative forms of housing for people, who are no longer able to live in their own home, possible. Since 1992 the municipalities have been responsible for all types of special housing, amongst which include, group housing for persons with dementia and nursing homes. There are also places for short-term care in special housing. Although there are alternative housing provided by the municipalities for people who are no longer able to live in their own home, the procedure to get in is not easy. One of my respondents said:

*In order to get an apartment you just apply, but there is also a cue, which means after making the application, if there is no space at the time, the elderly has to wait until another elderly dies. There is no fixed time to be in the cue. It is a matter of ‘the one who come first get first serve’ (social worker).*

The contribution by family members in health care and social care increased in the second half of the 1990s. One reason was the inclusion in the Social Services Act, which made provision that social welfare committee shall assist, through support and relief services, persons caring for elderly people close to them who are suffering from long-term illness or persons with disabilities (ibid). In addition, some municipalities provide compensation in terms of finances for family members who provide help and care. In certain cases family members, can be employed by the municipality. And in other cases, the person in need of assistance can obtain a family career grant to pay a family member for the work done (ibid.).

When a new Act came into force in 2006, municipalities were authorized to provide practical services for older people. These services include changing curtains, cleaning and washing
without any further needs assessment. Charges for the services are decided by the municipalities, but must not be higher than the municipality’s costs. Many municipalities provide these services at very little or no cost (ibid.).

Even if the elderly prefer to stay at home, some prefer to move to an institution. Here the experience of three of my respondents:

*I have been living here for four years, I moved to this center when I started having rheumatism, then I needed more help from my relatives, children, and friend and as well from the government (Woman A).*

*I was not forced to go to the institution care, my children were very busy with work and studies I also needed much attention so I asked them to take me to a care institution then I was brought here (Woman B).*

*I have been living here for about 11years. At first I never wanted to go because I was afraid that I will miss my children but they persuaded me (Women C)*

The decisions to move to an elderly institution differ among the three respondents although they are both satisfied with where they are now. This also shows that their needs can vary with time.

From the findings I am able to deduce that the Swedish elderly persons are benefiting from freedom of choice among the different elderly care systems. The act is also enabling municipalities and county councils to offer greater freedom of choice. This facilitate for the elderly to accept life changes and organize their daily life in accordance with what they really need for the moment. This ecological model gives good possibilities to strengthen the QOL for elderly.

The model is also in line with equality and human rights, when it implies that the user is more able to influence how the services granted are provided, and also to obtain services over and above those included in support decisions, either for payment or free of charge. This choice, however, presupposes the existence of several providers to choose between, which also is the case. The different Acts regulating the various care systems and their enforcement is powerful in Sweden. Just like many other nations, Sweden’s public eldercare system has played an active role in promoting residential independence in its older population.
6.2 Formal or informal support?

The findings show that formal as well as informal support in the Swedish elderly care system. The support types are provided by the public through the ‘Kommun’ (formal) and by their social network (informal). This could be either in their private homes or in a public institution. Even if there can be some differences between formal and informal care often accorded to medical standard, kind of supervision and technical utility, they both can include meals services, safety alarms, adult day care, shopping, cleaning, cooking, washing, personal care and drug administration. The caregiver can e.g. organize short walks among elderly and those who are unable to walk, can use wheelchairs or be assisted by the caregivers or another elderly person. A respondent said:

*Sometimes, I take the elderly to the cafeteria, doctor or dentist. I feel we have a nice time, good conversation and the elderly person feels safe and happy (caregiver).*

In Sweden, family and friends, along with workers in public institution, seems to form the support network for elderly and disabled persons receiving care mostly in consensus. The network can be composed of members from public, private, and non-profit organizations working together to achieve specific goals. From earlier research we noticed the importance that roles and responsibilities in the network members are clearly defined. In other case it can be confusing what and when to do certain things. However, as long as the elderly themselves and people they trust on, are supported by law and engaged professionals in reaching mutual understanding, problems can to be solved.

The families show strong commitment of care to their elderly and this seems to be like a return league whereby, when the elderly were in their independent and very active stage, they committed by expressing love and care to their families and other persons in their networks. These commitments have grown up to strengthen their relationship and it is expressed by a respondent:

*I have two children and many friends; they have been so wonderful to me. They feed me; provide my needs, especially those that I can not buy here. We discussed interestingly and
they take me for a short walk. They even bath me (woman A).

It has been a growing proportion of elderly people in Western countries living alone (Larsson & Silverstein, 2004). Certainly a vast majority of them must have to rely on support from sources outside the household in times of need. However, sometimes the elderly themselves, who are still strong enough, provide some form of support to those in needs. A respondent said:

_I have an old lady that I met who is 89 years old. She has been in this building for about 10 years, she has dementia. I tried to provide assistance to her because I am afraid that she may die. There are moments that we also share ideas from the bible (Woman B)._ 

In Sweden the education of social care has tried to provide the formal care by trained and qualified staff (www.government.se 2010). Nowadays e.g. the care manager have education from university, but often they are not involved in the daily care. The voice of a care giver and a socialworker in an institution told me about competence:

_Regarding the competence of the formal and the informal caregivers I can say it is very high both formally and informally, though lacking in reoccurring education through the workplace. Before I was recruited I did not have any formal training as a caregiver, I am working out of experience. I have been working now for about eight years. I establish a professional and friendly relationship with my client. I listen to them slowly; building up a trusting relationship by listening and noticing unique characteristics (Caregiver)._ 

_Looking at the Partille community, this organization has the lowest percentage of schooling compared to Partille as a whole. 67% of the caretakers have the right education, but here the percentage is much lower with about 25% but that is the formal competence. In the informal, the nurses and other personnel stated that caregivers are very caring and they feel very strongly for the elderly people (Social worker A)._ 

Sweden, like many other nations, has a good public eldercare system, that has played an active role in promoting residential independence in its older population. Only a few percents lives ‘in between’ parents, adult children or other relatives (Sundström, 1994). This implies that the offspring has higher preference for living independently. Around 20% of Swedish
elderly people do not have any children which has resulted in the fact that the oldest old population of Sweden is living alone (82 % of women live alone compared to 44 % of older men (Statistics Sweden, 1999a). In urban areas, such as Stockholm, the proportion of elderly persons living alone is even higher.

The demographic patterns of fertility, living arrangements, and migration of the Swedish elderly are also salient factors in the use of formal and informal care. The married elderly with children receive more of informal support and enjoy a better quality of life than the unmarried elderly without children, who rely more on the formal support. Although the married women without children may be disadvantaged in their support networks compared with those with children, it is hard to conclude how it influence the QOL. This extensive support network can have positive as well as negative influence in decision making process that concerns an elderly. One of my respondents says:

*Well having children or more of informal support network can be both positive or negative, because sometimes when children are involved, they want to decide so much for the elderly people (mother and father), and most of the time, their decision is not the person’s choice. Of course, if they don’t have children, the support cannot be compared when they have children and also you don’t have any one to speak for you. So it is both positive and negative (Social Worker).*

On the other hand it is doubtful if the never married elderly are advantaged in their support networks, depending on the availability of good in-law relatives can provide support. Nevertheless, the never-married elderly may possibly develop an informal network of supports over their lifetimes that may be added support from their family of origin, including their sibling’s families. This can be explained by the fact that many never-married elderly and child-less, especially women, can develop an independent and extra-familiar lifestyle. So the pressure of environment can differ from person to person, no matter how the network looks like.

The study reveals that Swedish elderly people prefer to live in their private homes and receive care for as long as they could. This support the conclusion that a majority of Swedish elderly under care receive more of informal care than formal care. The type of informal care services and the frequency can varies from one individual to another and depends on the need,
intimacy with the social network and the size of their social network.

6.3 Elder’s conceptualization and expression of Quality of Life?

An evaluation of QOL must be able to identify the cognitive as well as the affective aspect of an individual. When determine if he or she is living a ‘good’ or a ‘bad’ life one of the respondents expressed their opinions in this way:

*In the past when I was younger my dream was to be educated in order to get a good job. Now that I am old, quality of life is to have a good place to live, to have enough money so as to be able to eat good, living in a neutral country with no war, living with friends and helping others is part of my life. I do not need lots of money because I do not know what to do with it. Money is not so important. (Woman A).*

*My children and friends visit me and they buy me things that are not sold here, they take me for light walk, they converse with me. The caregivers come to me from time to time and we converse a little, they make sure that I don’t forget to take my drugs at the appropriate time. With that I am feeling fine (Women B).*

*I can say that I enjoy Quality Life when I am eating good food, when I am visited by my friends and children, when I am living in a comfortable place and when I am meeting up with my appointments with the doctor (Woman C).*

Although some of the elderly share similar perceptions as to what QOL is, still there are some differences as well. This is supported by Hughes & Hwang (1996) who saw that the perception to QOL could be at a variance from person to person over time and higher QOL can be attained as people’s needs are met. Some of the needs can be used for food, to adapt to a stressful environment, for entertainment and for companion sake, just to name a few. From my findings I realized that one’s needs over time can be influenced by many factors, some of which may include environment, peers, state of health, age, etc.

The informal support received by the elderly in Sweden can also depend on the type of
relationship they had when they were strong. If the relation was bad between the elderly and their children or other relatives when they were still strong, can result in less informal care. On the other hand, strong bonds will result in greater informal care. A situation may occur when strong bonds will be broken by death or other reasons, which can make the elderly depressed. Such situation can only be handled by an experience care giver, like one of my respondent, who said:

*I establish a professional and friendly relationship with my client. I listen to them slowly; building up a trusting relationship by listening and noticing unique characteristics* (Care giver).

In one institutional care home there was an elderly association, in which the elderly comes together once a month to share coffee and into which also elderly, living in their private homes was invited. During this time they play certain games and other forms of sports to keep the body active. They also perform stage dance and group singing. They air out their problems among themselves and tride to come out with different possibilities how their problems could be dealt with. This aspect of active engagement can be referred to as ‘engagement in life’ or ‘productive involvement’ based on activity theory. According to Havighurst (1961), this theory emphasizes the link between physical activity, health and well-being, which could create societal value such as volunteer work.

Elderly can have different age and marital status differences e.g. single mothers (never married), some single mothers due to divorce or widows. Some have children while others don’t have and some are living in different places and have different networks. In my research it was interesting to see how differences were accepted and did not created pressure to adaption. On the contrary they shared similar perceptions about QOL.

Feelings of being old are seen as a continuous process influenced by life engagements and other interactions. However, changes can include new or conflicting role demands, and crisis events, all with reciprocal tasks for the individual, family, group or community, as well as the environment. A respondent said:

*I was very active in the group of rheumatism and I was a board member. I held the post of the vice secretary, and I did that for about 7-8 years, it entails lot of work that I could no longer*
support it, I later resigned ....When I was younger, I was a teacher at a pre-school in America, I also taught English here in Gothenburg but now I could not because of age..... I use to make traveling tours to some of my friends who are far away when I was young but now I am unable but we talk only on phone (Woman A).

When I was young I use to go on a bike ride but now I cannot (Woman B).

When I was young I use to do skiing but now I can’t (Woman C).

In order to handle these situations intervention is required and needs to be directed toward reinterpretation of relationship. That can improve the potentialities for growth, health, and social functioning. If the environments are made more responsive to new kind of needs, rights, goals and capacities elderly experiences, this can strengthen QOL. Even among the elderly themselves some play a leading role as the stronger elderly, who are at the forefront when organizing their own group activities. A respondent said:

Well I can tell you in the next big room, I have two groups of older women /.../ and we have a movement that comes from China they call it chi gong/.../I was taught this when I was in a hospital suffering from rheumatism, and I learned it there and the teacher thought I could do it very well and to have my own group. When I started it I had to show them what care is. Most of the women are widows and nobody has touched them, but I had to take sometime to hug them, sometimes, I do some massage on them and they said this is a very good thing that they have had since they lost their husbands and that I am a kind person. (Woman A)

Peoples’ needs and problems can also depend on stressful person-environment relationship, which need to be changed. Most of the elderly have these possibilities to create an environment that could accommodate them in a more conducive way. The elderly in institutional placement can e.g. create different interest groups, in which some of the topics for discussion include religion, where they share some light on the gospel and sometimes sing songs of praise. A respondent said:

The elderly don’t quarrel amongst themselves but there are small groupings amongst them. Like the elders who like to talk about religion, some talk about educational issues and there are others who, just like talking, whereas there are some who keep away from these groups because they don’t like talking (Caregiver).
During a short visit to a public care institution I found some other interesting activities that the elderly in Sweden do. For instance, they form groups among themselves according to their interests. At times they organize group conversations about the past, some did light cleaning on flower beds, others learned how to do embroidery, while some took part in learning how to play guitar. Some also enjoyed singing old time music. A respondent said:

*I belong to a social group at Frolunda where we meet once a month to discuss our problems, drink coffee, play games, sing and plan for a short visit (Woman C).*

When conducting this kind of productive activities a high degree of autonomy and control, and a high degree of esteem or recognition can be achieved. The interaction among elders is of vital importance to their health and well-being. Some prefer to spend time on the phone, conversing with friends or relatives who may be far or near. This can be a way to cope with loneliness and other forms of stress and increase self-esteem. A respondent said:

*I think about my worries but I keep it in my stomach. The doctor tells me to shout it out, beat the pillow, but I don’t, and that makes me to have ulcer (Woman A).*

*When I am worried I make phone calls to my children and some friends, at times I try to sing, while I also explain to the care givers who usually help to look for solutions (Woman B)*

Attempting to know from the elderly what makes them happy and how they feel about life I let the respondents sum it up.

*One of the things that make me feel happy is when I am maintaining contacts with friends. I have five close friends, some are in Sweden others are in the US. Those in Sweden do visit me but those very far in the US don’t. We communicate through telephone since I no longer travel. I am also very close to my daughter and two close relatives, they often visit me. I am happy if my children are fine. (Women A)*

*I am happy to be here, I love Partille and the building is a big one. I like my apartment, I live in the 9th floor with enough space, I have a parlor and a bedroom with a good balcony and a good view that I sometimes stand and see every where in Partille. I have a small car just
parked outside I am very grateful, having food every day (Woman B).

I am satisfied. I have every thing, doctors, nurses, social workers, dentists, the post office and the bank (Woman C)

The findings show that the elderly have many different ideas of what QOL can be. However, such as being in a family context without tensions, having friends and good medical care seems to be highlighted. That’s in line with the ecological perspective in which a good balance between different aspects in the life is important. In next chapter I will summing up and discuss the findings.
CHAPTER SEVEN

CONCLUDING DISCUSSION

The aging population in Sweden is increasing as the years go by, which indicating that support to the elderly is of vital importance to enable them a sustainable life. The present study investigated how ‘Quality of Life’ is viewed by elderly and receiving care in Sweden. The findings shows that the model for elderly care is a combination of family and welfare state responsibility (informal and formal support respectively), with the welfare state playing a central role together with moral and practical assistance from family. This combination has started a debate whether one is either seen as a substitute or a complement to the other. Nevertheless Sweden, as a welfare state, has a lot of investment in the domain of elderly care.

Following the results obtained during the present study, I found that the elderly in Sweden live longer than those in most countries in the world. They prefer to stay and receive support as long as possible in their homes. The elderly get personal care such as bathing, grooming, meals services, shelter, safety alarms, adult day care, shopping, cleaning, cooking, personal care, social contact, drug administration and other range of opportunities within the individual's potential and to have certain degree of control and choice within their environment. They may also be offered help with chores such as housekeeping and lawn maintenance. Home care also includes hospice care for terminally ill patients or rehabilitative care for those recovering from surgery or illness, nursing home care, assisted living and acute in-patient hospital care.

The various supports helps the elderly in stress coping, to adapt to their environment, boast their self esteem and enjoy some degree of freedom, to chose whether to live in a private home or a public institution. Despite the fact that there is freedom for the elderly to choose among home care or institutional care, I would say that the freedom is at times limited, because the decision to either move to an institution or to stay at home in some cases is taken by the relatives instead of by the elders themselves and most often the decision is against the will of the elders. There are times where it is either the relatives’ or the elders’ wish to move to an institution. However, it is not possible because of the cue system in Sweden, which can develop when all the apartments are occupied. Then the elder has to wait until another elder dies.
The form of elder care provided, varies greatly among other countries and is changing rapidly. The case of Cameroon, where the elderly have no option to choose rather than staying at home and receive help from relatives, have other challenges. In the Cameroonian society, the cultural values and the traditional practices stress the need for elderly members of the family being treated with honor and respect. Families are expected to provide the needed care and support for their elderly member. However, recent changes in the size and structure of families have caused the re-arrangement of the roles and functions of the members in the families.

Apart from family members, there are some non-governmental organizations (NGOs) like Help Age International, which provide some form of assistance to the elderly. It is still the family that plays the major role in Cameroon. The Non-Governmental Organizations (NGO) sector constitutes a very important institutional mechanism to provide user friendly, affordable services to take care of the elderly persons. However, this sector in Cameroon is playing only a minor role, catering only for a smaller segment of the old age population. For an aged person to be considered as the head of the household to a greater extent, it serves as guarantee of availability of better care and support from the family members. In the Cameroonian society, because of the general prevalence of patriarchal family system, a male member of the family, more often the eldest male member, is considered as the head of the household. A female member becomes the head only when she is living alone or when there are only female members in the family.

The present study reveals that a vast majority of Swedish elders under care prefer to live in their private homes as long as they could, and receive more informal care than formal care. The type of informal care services and the frequency varies from one individual to another and depends on the need, intimacy with the social network and the size of their social network. There is no doubt that the elderly express feelings of living a good life as they also appreciate the care being provided for them by their social networks as well as by the formal sector. The result support previous research by Dunér (2007) and by Duner & Nordström (2005) about well-beings among the elderly, receiving care. One interesting conclusion I draw from my study is that the larger the social network, the greater the informal support and the higher the quality of life could be, which indicates that relations is of great importance.
However, elderly people not having that can be compensated with good care from the formal support.

The results of the present study will be a tool in understanding the way older people in Sweden will receive care, and how they perceive care given to them. This will provide a guide for caregivers to help the elderly adjust to the environment and show, more general, how to build a humane society. Finally, it can also help inspire to improvement of social planning for elderly in Cameroon.
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Appendix 1: RECOMMENDATION

Elderly care in Sweden has been on a positive footing. Looking at the demographic studies of the aging population of Sweden and in order to meet up with future challenges in elderly care as there will be increase demand for care givers, I will therefore make the following recommendations:

That incentives or remuneration for social workers and care givers should be increased. This profession is widely known to belong to women popularly called women’s job characterized by low pay. With the millennium gold of increasing women’s participation in labour force more women will be empower to pick up lucrative jobs, this might cause shortage of care givers.

Secondly, Sweden harbors immigrants, among the elderly home there are immigrant who do not speak Swedish either because there are unable to learn it or it disappears due to dementia as such there is communication barrier between the elderly immigrant and the care givers. To help solve problems like these immigrants need to be encouraged to take up positions in care profession so as to handle problems of this nature in the future.

Thirdly many more seminars need to be organize with the aim of given informal care givers updates in elderly care.
Appendix 2: INTERVIEW GUIDE

A) Interview guide for the elderly

Name: ------------------------------------ Age: --------- Sex: --------------
Nationality: ------------------------- Mother tongue: -------------------------
Marital status: ------------------------ Do you have children? If yes, what is the age of the
eldest and the youngest -------------------------------
Profession/Occupation---------------- What position did you occupy? ------------
Number of years of service------------ Why did you stop working? ------------
Apart from Swedish, how many other languages do you speak? ------------------
For how long have you been receiving care? ----------------

Describe a “normal day” in your life the latest week?

What does quality of life mean to you?
What does quality of care mean to you?
Are those providing care able to understand you? ? ---------------------
Have you got relatives? ---------------------
If yes, are they also in Sweden? ---------------------
Are you in contact with them? ---------------------
If yes, do they some times visit you? ---------------------
How do you feel talking with them? ------------
-----------------------------------------------

Have you got friends? ---------------------
If yes, are they also in Sweden? ---------------------
Are you in contact with them? ---------------------
If yes, do they some times visit
you? -----------------------------------
How do you feel talking with them?  -----------------------------------
 Are there some things from earlier time in your culture that you think you are really missing?
If yes, what are they? -----------------------------------
 Are there some things that you really like to have or to do more often?  -----------------------------------
If yes, what are they? -----------------------------------

Who provide these things to you? -----------------------------------
How often do you get them? -----------------------------------

ORGANIZED LEISURE
Do you belong to a social group?  ----------------------------------- What are some of the things you do in the group?  -----------------------------------
Do you find them interesting, If yes, how?  -----------------------------------
How often do you meet?  -----------------------------------

FREE LEISURE
Are there some activities that you do during your leisure time?  When you have no group activity what do you do when you are alone?  -----------------------------------
If yes, what kind of activities-----------------------------------
Do you do it alone, or with friends or with some body who direct you? 

Is there any other activity which you usually do that you can not do now? 

If yes, which activities? 

Do you some times feel worried (anxiety)? If yes, what are your worries about? 

When you are worried what do you do? 

Have you ever had the feelings that you where once treated poorly or have you ever had a poor treatment? 

Is your presence felt in your group? 

Are you recognized in your family, social group as any other member? 

Are you able to take decisions by your self? 

Are you allow to express your opinion? 

Do you feel loved by your relatives and friends, If yes how? 

How would you describe your relatives, friends and formal care givers do they treat you with some love and respect? 

Do they at times play with you? 

Are they always available when you need them? 

What do you think about where you are living; is it ok with you, if yes why? 

Is there enough space? 

Are you satisfied with the care they provide for you, do you think that they actually know the work? Can you confine trust in them? 

What do you think about the care which is been provided to the male inmates, Do you receive equal care? 

Do you some times have fun with your inmates? If yes what kind? 

B) Interview guide for the Care givers 

To you what is the meaning of quality of life of the elderly to? 

What kind of relation ship do you establish with your client and how do you do to establish the relation ship?
What kind of relationship do you establish with family members who provide care to an elderly?

What do you think about the competency of the formal and informal care givers?

Do you sometimes have a common activity with the elders and how are their reactions?

Do you sometimes receive complaints about worries from your client?

If yes, what are the worries about and how do you react towards the worries? What are some of the difficulties/challenges you face with the elders and how do you handle them?

C. Interview guide for the Social Worker

To you what is the meaning of quality of life of the elderly to?

What kind of relationship do you establish with your client and how do you do to establish the relationship?

What kind of relationship do you establish with family members who provide care to an elderly?

What do you think about the competency of the formal and informal care givers?

What opinion do you have about the balance between formal an informal care systems when looking into the future?

Differences if the caretakers are childless? Are there any classification in elderly care and how is it organize?

Who decides for them where to leave and why?

Does the Commune provide to them all what they want? If not or if part who provide the rest? (Landsting??)

What happen if they don’t have any other source?

Is the decision as to where the elderly has to live and receive care decided by them selves or by some other person?

What is the procedure for elderly who receive care at home to obtain help from the Commune?
What do you find challenging in performing your job? What are some of the difficulties/challenges you face with the elders and how do you handle them

D) Interview guide for other professionals

1) When drawing out laws and policies for the elders in Sweden, does the politicians request for expatriate advice from social work professionals?

2) In Sweden, does the state provide subsidies for elderly care to the kommun? If yes does all the Kommun receive equal support from the state? If not what does the state consider before given out subsidies to various kommun?

3) What do you think about the competency in elderly care with regards to formal care givers in Sweden, is there any special training that they under go before been recruited in to provide care for the elders?

4) Is it proper for us to conclude that the model of elderly care in Sweden is a combination of family and welfare state responsibility?

5) What opinion do you think about the balance between formal and informal care systems when looking into the future?

6) What do you think about the filial obligation norms to help and support elderly parents: Is it strong in Sweden?

7) Is it possible to determine the size of the informal support network in Swedish elderly care?

Social work is considered a “woman” profession and less paid in Sweden. Don’t you think that in the future many people will turn to receive training in lucrative professions like doctors lawyers, engineers etc than social work which may result to shortage of social work force to cater for the growing elderly population and may consequently result to a fallen standard of care in Sweden?

Appendix 3: POPULATION IN EU

Table 1. Total population

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<tr>
<th>EU27</th>
<th>2008</th>
<th>2035</th>
<th>2060</th>
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