

### WIRTSCHAFTSUNIVERSITÄT WIEN

## Master's Thesis

# How the Quality of Long-Term Care Services Impacts Caring Relatives' Quality of Life in Austria

Lisa Hanzl **E-Mail**: h1404087@wu.ac.at

Summer Term 2020 Supervised by Alyssa Schneebaum, PhD

#### **Abstract**

The master's thesis at hand analyzes the connection between the quality of long-term care (LTC) services and the well-being of informal caregivers in Austria. This is done by the means of a mixed methods approach. First, an ordered logistic regression model shows that medium quality of LTC services reduces the likelihood for informal carers to experience high life satisfaction and that the quality of LTC services is only of concern for caring relatives but irrelevant for non-caring individuals. However, it does not offer conclusive insight into how exactly quality of life is influenced. Therefore, a qualitative analysis is undertaken via an online questionnaire in which 20 informal caregivers participated. The survey is analyzed using the capabilities approach by Sen and thematic analysis. The main findings are that bad quality care services reduce well-being mainly due to the irregularity of said services which disrupts the daily routine. High quality LTC services on the other hand improve the quality of life through the ability to share responsibility.

# Contents

1	Intr	oduction		3	
2	Stat	e of the Art	Section   Sect		
	2.1	2.1 Well-being of Caring Relatives			
	2.2	Informal C	Caregivers' Quality of Life and LTC Services	6	
	2.3	Definitions	s	7	
		2.3.1 Wh	no are Caring Relatives in Austria?	7	
		2.3.2 Lon	g-Term Care in Austria	7	
		2.3.3 The	e Definition of <i>Quality of Life</i>	8	
3	Qua	ntitative A	nalysis Using EQLS Data	9	
	3.1	Data & Me	ethodology	9	
				9	
				10	
	3.2		_	11	
				12	
4	Qua	litative An	alysis	14	
	4.1	Methodolo	ogy	14	
		<del>-</del>			
	4.2			15	
				15	
	4.3		-	19	
		4.3.1 Ov	erview of Survey Participants	19	
			· · · · · · · · · · · · · · · · · · ·	19	
			· ·	24	
5	Dis	cussion		25	
Bi	bliog	raphy		26	
	_				
L1	st of	<b>Fables</b>		29	
Li	st of	Figures		29	
Αı	ppen	lix		29	

### 1 Introduction

This thesis is motivated by the increasing importance of care work in modern, aging societies. By the year 2030, roughly 76,000 additional formal care workers would be necessary to cover the needs of care receivers in Austria; 42,000 solely due to the retirement of care workers (Rappold & Juraszovich, 2019, p.5). This is only one of the many reasons why informal care becomes more and more important. Caring relatives are also becoming a group of increasing political importance as the government tries to shift some of the care responsibility to family members and relatives (e.g. the federal state "Burgenland" employed informal caregivers as public employees (Land Burgenland and FH Burgenland, 2018)).

Through the Covid-19 pandemic that emerged in February/March 2020, the importance of informal caregivers was especially pushed into the limelight. Elderly people were at high risk and their caregivers were put under additional strain due to the lockdown and complication to access certain care services. The measures that were taken in order to contain the spread of Covid-19 also amplified the structural problems (such as poor working conditions) around the long-term care (LTC) sector (OECD, 2020). Hence, caring relatives and their well-being are a pressing topic.

Consequently, in this thesis I aim to investigate the connection between the quality of LTC services and the quality of life of informal caregivers. Previous literature has found positive and negative links between the availability of such services and well-being of caring relatives (Di Novi et al., 2015; Eom et al., 2017; Hawranik & Strain, 2007; van den Broek & Grundy, 2018; Wagner & Brandt, 2015, 2018). To extend this field of research, this work has the objective to investigate if the quality of LTC services is an important factor in the relief of strain for informal carers.

For this, a mixed method approach is applied. The European Quality of Life Survey (EQLS) is used to conduct a regression analysis with an ordered logistic regression model. Furthermore, the insight is deepened by a qualitative analysis through an online questionnaire that was created using the capabilities approach, first coined by Sen (1985, 1993), then extended for the use of investigating gender inequalities by Robeyns (2003). Then, I use thematic analysis, developed by Braun and Clarke (2006), to evaluate the survey.

The main contribution of this master's thesis is the collection of primary data through an online survey. 20 informal caregivers from all over Austria offer an insight into the connection of their care responsibilities and well-being. The main limitation of caregiving to overall well-being is the reduced ability to allocate time the way one wants to. However, support

from other caring relatives and the simplification of administrative tasks could relieve this strain. The quality of LTC services specifically can have positive as well as negative effects. On the one hand, irregular working times of professional caregivers or changing personnel can potentially disrupt daily routines. On the other hand, high quality care services offer an ease of burden because responsibility can be shared and professional advice is available.

The remainder of this thesis is structured as follows: first, an overview of the current literature is given and the most important terms are defined. Then, an ordered logistic model estimates the influence of the subjective quality of LTC services on well-being of caring and non-caring individuals. Next, the qualitative analysis follows, describing the creation of an online survey, which was then evaluated using thematic analysis. Lastly, I conclude.

# 2 State of the Art – Literature on Caring Relatives

# 2.1 Well-being of Caring Relatives

There has been done extensive research on the well-being, quality of life (QoL) and health of informal carers since the 1980s, of which Kieninger et al. (2019) deliver a very detailed overview; including different dimensions of QoL and various methodologies. While most of the research around informal caregiving started out with a focus on "caregiver burden", more recent publications look at the QoL of caring relatives. This has two advantages: first, the experience of caregiving is not solely a negative one, which the term "burden" does not capture (Chappell & Reid, 2002). Secondly, focusing on well-being or QoL enables a comparison with non-caregivers (Stull et al., 1994).

It is known that caring relatives experience more loneliness (Wagner & Brandt, 2015), more stress and are less psychologically and physically healthy (Deeken et al., 2003). Ho et al. (2009) find that primary informal carers are at higher risk of experiencing weight loss, having anxiety and having lower QoL. This finding is affirmed for South Korean informal caregivers by Do et al. (2013). Using an instrumental variable approach, they find causal effects of caregiving on health, including experiencing daily pain and self-reporting poor or fair health. This caregiver burden could be lowered by reducing the hours of care or by proactively seeking help (van Groenou et al., 2013). van Groenou et al. (2013) also find that subjective burden is lower when the care recipient is not a close relative. The well-being of care givers is also directly connected to the amount of hours spent caring (Verbakel et al., 2018).

However, there are also positive effects associated with caregiving. These encompass for example the feeling of doing something good and a closer relationship with the care recipient (van Groenou et al., 2013). As stated by Chappell and Dujela (2008), caregivers can experience burden and still have high life satisfaction. Roth et al. (2015) find decreased mortality for informal caregivers. They also point out that media tends to portray the negative rather than the positive aspects of care.

Kieninger et al. (2019) additionally point out that most research around informal caregiving is quantitative, even though qualitative studies are more comprehensive and better able to explain caring relatives' QoL. Qualitative studies allow for more nuanced aspects of well-being. Kieninger et al. (2019, p.29) state that "[m]ixed method approaches could build upon the strength of each method and would allow both QoL and well-being to be understood as sensitizing concepts rather than concrete entities."

### 2.2 Informal Caregivers' Quality of Life and LTC Services

The literature is less comprehensive when it comes to the connection between LTC services and QoL of informal caregivers. In a study on multidimensional effects on the QoL of female informal carers, Di Novi et al. (2015) first describe a connection regarding the provision of formal care. They find a positive connection between the QoL and health of informal caregivers and the degree of formal care in their region. Using a difference-in-differences approach for Denmark and Sweden, van den Broek and Grundy (2018) show that the coverage of LTC services influences informal carers' well-being. When more LTC services are provided, the difference in happiness between carers and non-carers is significantly smaller. Finally, Wagner and Brandt (2018) explore the connection between the well-being of spousal caregivers and the availability of long-term care services across Europe. They find that the mere knowledge of available professional care services has a positive effect regarding life satisfaction, loneliness and depression, as it gives the caring relative an additional feeling of control.

Eom et al. (2017) find that LTC services lower the overall QoL of informal caregivers in Singapore, as "caregivers' daily schedules need to be altered to accommodate healthcare providers, and caregivers might feel uncomfortable with the provider in their home" (Eom et al., 2017, p.1720). Similar results are found by Hawranik and Strain (2007) for Canadian caregivers, who express additional burden due to the frequent changes of professional care staff.

"For some caregivers, use of home-care services meant being late for work because they needed to orient each new person, while other caregivers cited increased anxiety and agitation in the care recipient. The staffing situation did not change until they persistently demanded continuity." (Hawranik & Strain, 2007, p.167)

Since these studies report ambiguous effects of the availability of LTC services on the quality of life of caring relatives, a potential question that now arises is how the quality of such services influences said well-being of informal caregivers. This issue will be the centre of this master's thesis. Formulating the problem at hand leads to the following research questions: (1) What is the link between the quality of long-term care (LTC) services in Austria and the quality of life of informal caregivers? (2) How does the quality of long-term care services influence caring relatives? Through which dimensions (i.e. capabilities) does this affect informal carers?

#### 2.3 Definitions

#### 2.3.1 Who are Caring Relatives in Austria?

The most conclusive and recent study on informal caregivers in Austria is performed by Nagl-Cupal et al. (2018). They estimate that 947.000 individuals are involved in providing care for another person – may it be a family member, a friend or a neighbor, living within or outside the own household. This care provision encompasses tasks like grocery shopping, running errands, preparing meals or simply spending time with the person one cares for. However, caring relatives might also perform heavier duties, such as personal hygiene. This greatly depends on the needs of the care recipient and can include many more chores than listed here.

In line with previous studies, Nagl-Cupal et al. (2018) show that most informal caregivers are female, with 73 percent. Children (biological, stepchildren or in-laws) are the biggest group within the different relations to care recipients with a share of 41 percent, followed by spouses or partners with 35 percent. The largest age group of informal caregivers are individuals between 51 and 60 years old with a share of 29 percent. Three quarters of caring relatives are married or in a long-term relationship.

Regarding the education of informal caregivers, people who completed an apprenticeship at most make up more than half. Only four percent have a university degree. While 53 percent are retired, one third is employed. Caregiving also affects the ability to participate in the labor market. Over a quarter of caring relatives stated that they reduced working hours or dropped out of paid employment completely due to their care responsibilities. This is especially alarming in the light of the fact that more informal caregivers are female, as it raises the risk of old-age poverty, since pension payments depend on market income. Nagl-Cupal et al. (2018) also report that individuals who care for someone in their own home, live in that same household 61 percent of the time. 40 percent of those who do not live in the same household need less than five minutes to reach the person that they tend to.

In this thesis, caring relatives, informal carers and informal caregivers will all mean individuals who in some form and intensity care for a family member, friend, relative or neighbor.

#### 2.3.2 Long-Term Care in Austria

There is no uniform definition for *long-term care* service as different countries offer different forms of LTC. In a recent publication, the OECD describes the long-term care sector as:

"a highly labour-intensive sector, which consists of a range of medical, personal care and assistance services that are provided with the primary goal of alleviating pain and reducing or managing the deterioration in health status for people with a degree of long-term dependency, assisting them with their personal care [...] and assisting them to live independently [...]." (OECD, 2020).

Concisely, social and health related forms of care of indefinite length, either at home, semi-residential or fully inpatient. In Austria, LTC services encompass mobile care services, semi-residential care, 24-hour care (24-Stunden-Betreuung), case management and inpatient care.

#### 2.3.3 The Definition of Quality of Life

Before continuing with the methodology and data that is used in this thesis, the definition of the terms *quality of life* and *well-being* will be delineated. As definitions are diverse, Kieninger et al. (2019) summarise their similarities for research on care work as follows:

"Despite a lack of consensus on the definition, most authors (of gerontological studies) agree that 'quality of life' is a multidimensional and dynamic concept that encompasses objective and subjective aspects and goes beyond the health status or functional ability of a person." (Karimi and Brazier, 2016, Vanleerberghe et al., 2017 as in Kieninger et al. (2019, p.2))

The definitions used in this thesis will be mostly based on Farquhar (1995), who distinguishes between four types of definitions of quality of life: (I) global definitions, (II) component definitions, (III) focused definitions and (IV) combination definitions. In this work, I focus and types (I) and (II), using the first for the quantitative analysis and the latter for the qualitative part. Global definitions are "all-encompassing, but because of their generality they tell us little about the possible components of quality of life or how the concept could be operationalized" (Farquhar, 1995, p.503). Since the quantitative analysis focuses on variables such as *life satisfaction* (as will be stated in the next section), it falls into this category of definition.

For the capability analysis, hence the qualitative part, research-specific component definitions are used as they focus on different dimensions of life. Kieninger et al. (2019) circumscribe three main domains of quality of life, namely physical, psychological and social. As will be explained later, the capabilities approach has multiple dimensions, which are clearly defined in section 4.2.1. The qualitative part aims to elaborate on the domains of informal carers' lives that might be affected most by the quality of LTC services. Finally, it has to be stated that the terms *quality of life* and *well-being* will be used synonymously in this work.

# 3 Quantitative Analysis Using EQLS Data

### 3.1 Data & Methodology

For the quantitative analysis the European Quality of Life Survey (EQLS) data set is used (European Foundation for the Improvement of Living and Working Conditions, 2018). This is a pan-European survey that is carried out every four years. Table 5 in the appendix gives an overview of the most important variables used. The variables given are all from the 4<sup>th</sup> wave that was conducted in 2016. For Austria, there are overall 1,181 observations in this sample, of which 232 respondents stated that they cared for "disabled or infirm family members, neighbours or friends" at least once a month, 945 stated that they did not do any care work and 4 did refuse to answer. The EQLS data set offers the best available data encompassing care responsibilities and the quality of life for individuals of all ages over 18. The Survey of Health, Ageing and Retirement in Europe (SHARE) data set might have better data on informal care work as a whole but the respondents are over 50 years old. Since I am interested in a broader effect of LTC services on informal caregivers, the EQLS data is chosen.

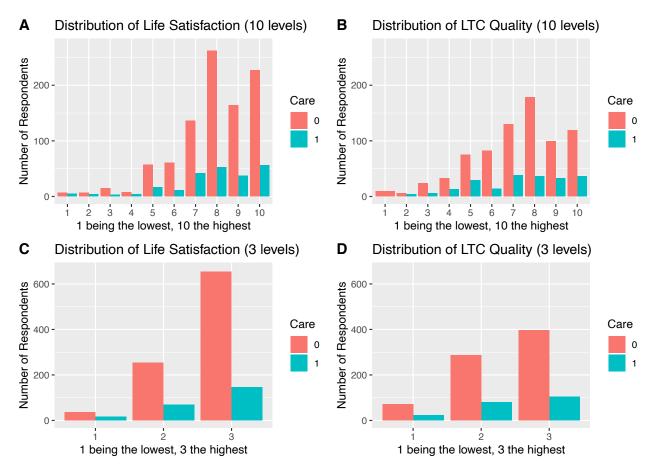
#### 3.1.1 Overview of Variables

The most important variables for the analysis at hand are "Life Satisfaction" and "Quality of Long-Term Care Services" (LTC quality). The latter is only included in the data set since 2016, therefore a longitudinal analysis cannot be done. Both of these variables range from one to ten and are subjectively chosen by each respondent. In order to facilitate the analysis, three groups are formed. Group 1 encompasses life satisfaction and LTC quality levels 1 to 4 and is the lowest category, group 2 includes levels 5 to 7 and group 3 is the highest rating, containing the levels 8, 9 and 10. Figure 1 gives an overview of the distribution of the two variables before and after grouping, divided into caring relatives (in blue) and non-caring individuals (in red).

Care work is a highly gendered topic both in its formal as well as informal form. In the care work sector, 85% of workers in Austria are women (Rappold & Juraszovich, 2019). Figure 2, panel A shows the distribution of men and women being informal carers in the EQLS data set. Roughly two thirds of caring relatives are women in this sample, which is lower than what Nagl-Cupal et al. (2018) find, who use administrative data with a higher, more representative sample size and where the share of women is 73%. Almost half of the informal carers are between 46 and 65 years old (as seen in Figure 2, panel B). Furthermore, there is also a clear urban-rural divide, as presented in Figure 2, panel C. Informal care work is

much more common in the countryside with two thirds of the respondents stating that they live in "the open countryside" or in "a village/small town". This might also be due to higher availability of care services in urban areas (Wagner & Brandt, 2018). Panel D of Figure 2 shows the marital status of caring relatives, which is almost 50% married and unmarried. The distribution of income for caring relatives and non-carers can be seen in Figure 4 in the appendix.

**Figure 1:** Distribution of the Rating of "Life Statisfaction" and "Quality of Long-Term Care Services in the  $4^{th}$  wave of the EQLS data set



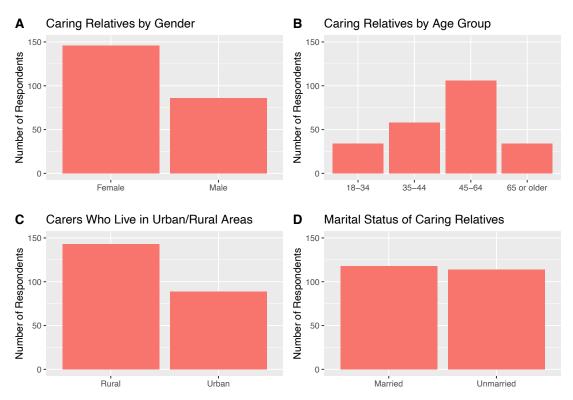
#### 3.1.2 Model Specification

As the variable in the EQLS data set on life satisfaction is not a continuous variable but a count variable that ranges between 1 and 3 after grouping, an ordered logistic model will be estimated. The following model will predict the likelihood of being in one of the three life satisfaction levels *j*:

$$Pr(y_{QoL} = j) = \beta_0 + \beta_1 x_{LTCquality} + \delta_1 S + \delta_3 M + \delta_4 U + \delta_5 R + \theta AI, \tag{1}$$

where  $y_{QoL}$  is the quality of life (measured by life satisfaction),  $x_{LTCquality}$  is the quality of LTC services, S is a dummy for sex (0 if male, 1 if female), M is dummy for the marital status (0 if unmarried, 1 if married) and U is a dummy indicating whether a person lives in an urban or rural area (0 if rural, 1 if urban). R includes regional dummies for each of the nine federal states in Austria. A controls for age, I for income. This specification will be estimated for the part of the sample who are caregivers and for non-caregivers separately.

**Figure 2:** Overview of Demographics of Caring Relatives in the EQLS data set (4<sup>th</sup> wave, 2016)



### 3.2 Results

Using the EQLS data set, the ordered logit model formulated in equation (1) is estimated with R. For this, several dummy variables are created as elaborated above. The dependent variable used to measure the quality of life is *life satisfaction*. The ordered logit model allows to investigate the effect that the level of quality of LTC services has on the likelihood of an individual to have a certain degree of life satisfaction, which both range from one to three after grouping. Table 1 shows the average marginal effects that the explanatory variables have on the probability of choosing a certain level of life satisfaction relative to some base group. Thus, valuing the quality of care services with 2 instead of 1, increases the likelihood of choosing level 2 for life satisfaction by 32.9 percentage points for caregivers and is in-

significant for non-caregivers. Choosing LTC quality 2 instead of 1 decreases the likelihood to choose the highest level for life satisfaction for informal caregivers by 41.7 percentage points. So, when LTC services are of medium quality this reduces the chance to experience the highest level of QoL. However, choosing level 3 of LTC quality instead of level 1 yields only insignificant results. For informal carers, being married decreases the likelihood of choosing the top two categories of life satisfaction, while being of higher age increases it.

The even columns of the first two rows show that the quality of LTC services has no significant impact on the likelihood of choosing levels 1 to 3 of life satisfaction for individuals who do not take care of relatives. In general, there are no significant effects found for non-carers except for the income variable. It seems that the life satisfaction of people who do not have care responsibilities is determined by different factors, which are not included in this analysis. Higher income increases the likelihood of having life satisfaction of level 3 for carers as well as non-carers and decreases the likelihood of reporting a lower category.

Even though a lot of the estimates are statistically insignificant, the main finding can be stated as the fact that while the quality of LTC services influences life satisfaction for caring relatives, it is unimportant for people who do not care for family member, friends or neighbors. Additionally, if LTC services are of medium quality, this reduces caregivers' likelihood to experience the highest level of life satisfaction.

#### 3.2.1 Limitations

There are certain limitations to this analysis. First of all, the concept of *quality of life* is one that is hard to grasp in numbers and is arguably not measurable in a holistic form. Secondly, using the available data on life satisfaction, one has to be aware that a lot of different factors influence this variable. Due to the rather small sample size, it will not be possible to include all available control variables. The sample size reduces even further due to missingness in the income variable. However, the income variable is an important control that cannot be excluded. It also has to be assumed that the quality of LTC services will generally be higher in regions that are economically better off, which will in turn be regions where the overall QoL might be higher. In order to introduce a control for this, regional dummies were included but since there might be also differences within regions, these might not capture all effects. An additional drawback is the fact that the variable on the quality of LTC services was only included in the data set since the most recent wave, therefore a longitudinal analysis is not possible. Due to these limitations but also in order to do justice to a nuanced topic such as care work, a qualitative analysis is conducted, which follows in the next chapter.

**Table 1:** How the quality of LTC services influences caregivers and non-caregivers quality of life

	Dependent Variable: Life Satisfaction					
		L	2		3	
	Care	No Care	Care	No Care	Care	No Care
LTC quality 2	0.088 (0.062)	0.010 (0.010)	0.329** (0.134)	0.092 (0.078)	-0.417** (0.182)	-0.103 (0.088)
LTC quality 3	0.031 (0.036)	0.002 (0.008)	0.157 (0.165)	0.021 (0.073)	-0.188 (0.199)	-0.024 (0.081)
Gender	-0.013 (0.020)	0.003 (0.004)	-0.068 (0.097)	0.027 (0.040)	0.082 (0.116)	-0.030 (0.044)
Age	-0.002* (0.001)	0.000 (0.000)	-0.011** (0.004)	-0.001 (0.001)	0.013** (0.005)	0.001 (0.001)
Married	0.098*** (0.044)	0.003 (0.005)	0.377*** (0.105)	0.028 (0.043)	-0.475*** (0.127)	-0.031 (0.047)
Urban	0.020 (0.030)	0.003 (0.006)	0.096 (0.133)	0.031 (0.054)	-0.116 (0.162)	-0.035 (0.060)
log Income	-0.082** (0.035)	-0.026* (0.009)	-0.439*** (0.151)	-0.245*** (0.048)	0.521*** (0.164)	0.271*** (0.051)
Regional Dummes	inclu	ıded	inclu	ıded	inclu	ded
Observations	116	505	116	505	116	505

*Note:* 

\*p<0.1; \*\*p<0.05; \*\*\*p<0.01

# 4 Qualitative Analysis

The qualitative part of this thesis is split into two major sections. First, the capabilities approach coined by Amartya Sen (Sen, 1985, 1993) is used to create a list of capabilities with specific regards to the topic of care work. The creation of this capability list is done using a framework that Robeyns (2003) outlined. Secondly, an online questionnaire is designed based on this list. A qualitative analysis is performed on the basis of these findings using thematic analysis (TA) by Braun and Clarke (2006).

### 4.1 Methodology

#### 4.1.1 Capabilities Approach

The reason why the capabilities approach is so compelling regarding the QoL of informal carers and thus preferred over a utilitarian evaluation for the analysis, is very suitably outlined by Robeyns (2003):

"A utilitarian evaluation will only assess her satisfaction and will not differentiate between a happy, healthy, well-sheltered person, and an equally happy, but unhealthy and badly sheltered person who has mentally adapted to her situation." (Robeyns, 2003, p.63)

Moreover, the capabilities approach is not a theory that can be applied to a problem in a straight-forward fashion but it rather is a general framework. The main idea of capabilities is outlined by Sen (1985) as the amount and combinations of functionings that are available to an individual. Functionings are "the various things that he or she manages to do or be in leading a life" (Sen, 1993, p.31). Hence, the well-being is determined by the ability to achieve different, valuable functionings – Amartya Sen calls these *capabilities*. An easy example Sen gives for the differentiation between functionings and capabilities is fasting. If a person fasts, she chooses not to eat. If a person starves, she cannot eat. While both have the functioning of "not eating" the former has the capability to eat, the latter has not.

#### 4.1.2 Thematic Analysis

Outlined by Braun and Clarke (2006), thematic analysis (TA) is one of the most widely used methods in qualitative research. TA is a very flexible tool, which can be used to address a variety of problems independent of theory and epistemology, as Braun and Clarke (2006, p.78) describe: "Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data." The main goal of this method is to analyse and describe patterns within data. When

discovering themes in data, one must be aware that these patterns do not reside within the data, but are rather informed by the researchers views and internalized values. Before conducting TA, a number of decisions has to be made, which need to made explicit in order to inform a rigid analysis (Braun & Clarke, 2006). One of them is how to determine what exactly a *theme* encompasses. For this thesis, themes are chosen by the proximity in which they relate to the research question, but also by topics that are found repeatedly in the data:

"A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set." (Braun & Clarke, 2006, p.82)

Another crucial decision is the width and depth with which one wants to describe the data at hand. For this analysis, I decided to try to encompass as many themes as possible, in order to give a holistic view and capture as many effects on QoL of informal caregivers as possible. This is done by providing a rich thematic overview that aims to give a sense of the themes for the entire data set. Furthermore, I use a theoretical approach rather than an inductive one, as I code the data with a specific research question and theory in mind.

Once these fundamental issues are set, one can begin the actual analysis, which is conducted in the following way according to Braun and Clarke (2006): first, one has to familiarize oneself with the data, by either transcribing it or re-reading it multiple times. The second step is to generate initial codes, which are then collected into themes and subthemes in the next step. The fourth step is to create a "thematic map" by revisiting the themes. In a fifth step, themes are named and defined. Lastly, one finishes the analysis by "[s]election of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis" (Braun & Clarke, 2006, p.87).

# 4.2 Collection of Primary Data

One of the key contributions of this thesis is the collection of primary data via a questionnaire that is created on the basis of the capabilities list, on which I will elaborate in section 4.2.1. The objective is to collect information from informal carers in order to credibly assess their well-being by means of the capabilities approach.

#### 4.2.1 Choice of Relevant Capabilities

For the choice of relevant capabilities, Robeyns (2003) provides a framework to apply the capabilities approach to topics that regard gender inequality. Since care work in general is a

very gendered topic, as women provide most of the paid and unpaid care labor, this guideline was used to create a list of capabilities. In order to arrive at a final list of capabilities, I follow the four steps provided by Robeyns (2003, p.72):

- 1. Unconstrained brainstorming
- 2. Reading existing literature
- 3. Engaging with other lists of capabilities
- 4. Debating the list with other people

The resulting list contains ten capabilities, which are specifically designed with care work in mind. The capabilities list at hand is very close to the one that Robeyns (2003) provides for topics around gender inequality. The list is based on literature on informal care (Nagl-Cupal et al., 2018; Wagner & Brandt, 2018) and conversations with individuals who work in the care sector <sup>1</sup>. Table 2 shows a comparison between the lists of Robeyns (2003), Nussbaum (2001) and the list that will be presented here.

**Table 2:** Comparison of Capabilities Lists

Author	Nussbaum (2001)	Robeyns (2003)	Hanzl (this thesis)
Aim	Universal	Gender Equality in Western Societies	Informal Care Work in Austria
Capabilities	1. Life 2. Bodily health 3. Bodily integrity 4. Senses, imagination, and thought 5. Emotions 6. Practical reason 7. Affiliation 8. Other species 9. Play 10. Control over one's environment	1. Life and physical health 2. Mental well-being 3. Bodily integrity and safety 4. Social relations 5. Political empowerment 6. Education and knowledge 7. Domestic work and nonmarket care 8. Paid work and other projects 9. Shelter and environment 10. Mobility 11. Leisure activities 12. Time-autonomy 13. Respect 14. Religion	1. Physical & mental health 2. Shelter & possibility for retreat 3. Financial safety & independence 4. Social relations & respect 5. Paid work & other projects 6. Time autonomy 7. Engagement 8. Leisure time 9. Personal liabilities 10. Outlook on own future

As suggested by Robeyns (2003), I will now, list, describe and defend these capabilities:

*Physical & mental health*: being able to lead a physically and mentally healthy life. As mentioned in section 2.1, research has shown that informal caregivers are exposed to additional stress and at higher risk of experiencing anxiety (Deeken et al., 2003; Ho et al., 2009). Due to heavy lifting and other physical responsibilities, caregivers also experience additional physical distress.

Shelter & possibility for retreat: being able to be sheltered and to have personal space. This capability is important in the light of the fact that 61 percent of caring relatives live in the same household as the person that they care for (Nagl-Cupal et al., 2018). This might significantly reduce personal space and the possibility to have room for retreat away from the care receiver.

Financial safety & independence: being able to be financially independent and to feel financially secure. Individuals who perform intensive care work, meaning more hours and heavier tasks, tend to have lower incomes and lower educational levels (Schmidt et al., 2016). Also, in Austria Pflegegeld is paid to the care receiver, not the caregiver. However, it is likely that caring relatives take on some of the financial responsibility as well as making less market income due to their care responsibilities (which will be elaborated upon in a separate capability). Though it could be argued that this is rather a functioning than a capability, it is especially important for caring relatives as the task is not only physically and mentally strenuous but also carries additional financial risk, which reduces general well-being (Kieninger et al., 2019; Nagl-Cupal et al., 2018; Stull et al., 1994).

Social relations & respect: being able to be respected and form meaningful social relations. Informal care work can have positive as well was negative impacts on social relations. On the one hand, there is the experience of an intensified relationship between caregiver and care receiver. On the other hand, care responsibilities might limit a person's social relations apart from the care receiver (Nagl-Cupal et al., 2018).

Paid work & other projects: being able to participate in paid work and partake in projects including artistic ones. Care taking significantly reduces labor market participation – around 28 percent of caring relatives in Austria reduced their working hours or stopped working altogether (Nagl-Cupal et al., 2018). As not to limit the capabilities approach to the market economy, projects such as artistic ones are included in this capability.

Time autonomy: being able to allocate time they way one wants to. Caregiving not only severely limits the amount of time one has but also the flexibility with which it can be allocated. Social norms play a very important part in the capability of allocating one's time. Robeyns (2003, p.83) describes: "For example, women are often expected to spend more time keeping their elder parents company than their male relatives. Or they are expected to be on a constant stand-by in case a relative needs help or falls ill, or to take care of their grandchildren."

*Personal Engagement*: being able to engage in political activities or to actively participate in one's (religious) community. Political participation and engagement within the own community shapes the surroundings a person lives in. The ability to be part of this process could be reduced essentially due to care responsibilities.

Leisure time: being able to partake in leisure activities. This might be closely related to time autonomy, however, it differs in the respect that it is not only about the allocation of time but rather about the actual activities. These activities might include travelling, going out in the evening or simply being spontaneous. Care work might significantly limit the activities which the caregiver is able to engage in.

*Personal liabilities*: being able to take care of one's own household and raise children. As women perform most of the unpaid care work, it has to be said that women also exert most of the other unpaid labor within the household. However, exactly these tasks might be limited due to care responsibilities.

*Outlook on own future*: being able to freely shape one's future and to pursue own aspirations. The way a person assesses their own future significantly impacts their well-being (Gulyas, 2015), therefore the capability was included.

#### 4.2.2 Creation of the Online Survey

To collect qualitative data on the quality of life of informal caregivers in Austria, an online questionnaire was designed. Following Braun and Clarke (2013), the survey is structured as follows: It starts off with pre-participation information, including who is eligible for answering the survey and for what the data will be used. Following are around two questions for each defined capability, assessing the overall quality of life. Then, open questions regarding the quality of LTC services and mobile care services are asked. Finally, some demographic data and more detailed data on the individual's care work is collected. The survey was conducted in German, as the country of interest is Austria. The original questionnaire can be found in the appendix. Before sending out the questionnaire, it was piloted and filled out by several individuals in order to check for comprehensibility and to minimize misunder-standings of the questions.

#### Distribution of the Questionnaire & Covid-19

Originally, the intention was to either conduct interviews or to send out the survey via mail, using the help of an established organization for caring relatives. However, the survey was conducted from March to April 2020, during the lockdown in Austria due to Covid-19. That is why an online survey was created. This is limiting especially regarding the age of most informal caregivers. So, in order to reach a large enough group of relevant individuals and to guarantee credibility, the questionnaire was shared via a facebook group for caring relatives from "Hilfswerk" and via a newsletter from an organization in Vorarlberg <sup>2</sup>. Overall, the survey reached 61 individuals of which 20 answered the full questionnaire. It has to be emphasized that the lockdown did not only complicate the distribution of the survey, but these months put an additional strain onto caring relatives. Therefore, the number of respondents is rather limited and the quality of the data is restricted.

#### 4.3 Results

#### 4.3.1 Overview of Survey Participants

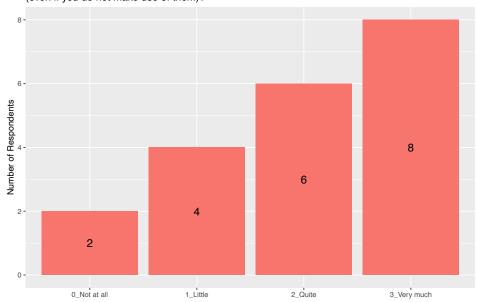
All in all, 20 individuals answered the full online survey. Out of them, 19 are female, one is male. The age ranges from 32 to 80 with an average of 50.35 years. The respondents are from seven out of the nine federal states in Austria, with Tirol and Salzburg not being represented. Five participants exclusively care themselves. More than half answered that the quality of care services influences their well-being "quite" or "very much" (see figure 3). An overview of all respondents including their ID numbers which will be indicated in the extract examples can be found in table 3. Since 61 individuals took part in the survey, but only the 20 which fully answered it are included, the ID numbers range from 1 to 61.

#### 4.3.2 Findings from the Thematic Analysis

Along the lines of TA, themes and subthemes are coded through the data which was gathered from the online survey. It is crucial to emphasize that this analysis does not display comprehensive or causal relations. However, additionally to the ordered logit regression model from section 3, the TA aims to deepen the insight into informal caregivers' well-being and its connection to the quality of care services. Not only does it add depth to the overall analysis but it also allows to include voices and opinions from affected individuals, thus presenting a valuable insight. The themes are determined in three spheres – quality of life, quality of care services and care work in general. An overview of all themes and subthemes is given in table 4.

Figure 3: Question about the Influence of the Quality of LTC Services

Would you say that the quality of care services influences your well-being (even if you do not make use of them)?



**Table 3:** Overview of Survey Respondents

ID Number	Sex	Age	Federal State	Care Receiver is the Carers	Only Carer	Employed
1	Female	60	Vienna	Parent	No	Yes
6	Female	32	Lower Austria	Parent	No	No
7	Female	56	Upper Austria	Parent	No	Yes
13	Female	44	Vienna	Parent	No	Yes
14	Female	33	Vienna	Grandparent	No	Yes
15	Female	52	Vorarlberg	Child	No	Yes
22	Female	46	Burgenland	Parent	No	Yes
25	Female	40	Vienna	Parent	No	Yes
27	Female	32	Styria	Grandparent	Yes	Yes
28	Female	62	Upper Austria	Other	Yes	Yes
29	Female	60	Carinthia	Parent	No	No
33	Female	51	Lower Austria	Parent	No	Yes
35	Female	58	Burgenland	Child	No	No
39	Female	56	Vienna	Parent	Yes	Yes
40	Female	56	Lower Austria	Parent	Yes	No
44	Female	80	Styria	Spouse	No	No
47	Female	35	Vienna	Parent	Yes	No
58	Female	54	Vorarlberg	Grandparent	No	No
59	Male	54	Vorarlberg	Parent	No	Yes
61	Female	46	Vorarlberg	Parent	No	Yes

It is important to state that I started the analysis after the quantitative part and review of the literature. It is therefore already informed by existing research around care work as well as conversations with individuals who work with caring relatives which were led during the creation of the questionnaire. While some might contend that this could limit my analytic field of vision for the TA, I would argue that this prior involvement with the topic was necessary to gain understanding as I am not directly affected by or involved in the care of a family member or friend (Braun & Clarke, 2006).

**Table 4:** Overview of Themes and Subthemes

Sphere	Themes	Subthemes
Quality of Life	Limitation of free time	Restriction of non-domestic activities
Quality of Life	Elimitation of free time	Reduced ability to be spontaneous
	Bureaucracy around care services	Wish for less bureaucracy
Care Work in	bureauctacy around care services	Lack of support doing paper work
General	Dealing with experience regarding	Duty or wish to do care work for relative
	own care work	Exchange with others & understanding
	Inconsistency in care services	Having to redo work due to bad quality
Quality of	inconsistency in care services	Bad remuneration of caregivers
Care Services	Support received from professional	Share responsibility with someone
	caregivers	Professional advice and assistance, contact person

#### Quality of Life and Care Work in General

In the sphere of overall quality of life, the theme that emerges in almost all respondents' answers is the *limitation of free time* and the inability to allocate one's time as one pleases. This arises from the requirement to always be available for the care recipient or if the care recipient needs constant help or attention.

"Vacations are only possible with a lot of planning effort around the care responsibilities. Basically, during all leisure activities, there is the thought of how it will work out together with the caregiving." (Respondent 14, 2020)

Within this theme, two subthemes are identified, namely the *restriction of non-domestic activities*, which is attributed to the *leisure time* capability, and the *reduced ability to be spontaneous*, which is connected to *time allocation*. Both capabilities are significantly restricted for most of the respondents because of the aforementioned reasons and the planning effort which is connected to care responsibilities.

[When asked which leisure activities are especially affected by caregiving] "Spontaneous and independent activities on weekends, but also evenings during the week – [just doing something] when one feels like it." (Respondent 15, 2020)

Additionally, there is the sphere of *care work in general*. This domain encompasses patterns that emerged in the data outside of the specific field of quality of life, but appear to be of significance to a number of respondents. The two main themes here are the *bureaucracy around care work* and how to *deal with the experience regarding own care work*.

"There are a lot of appointments with authorities [Amtswege] that have to be managed, a lot of administrative things that have to be handled every month, parallel to the care responsibilities." (Respondent 29, 2020)

However, according to the survey and previous literature, the experience around care work is not solely a negative one. Some respondents state that they feel that they can give something back or that it is their duty to take care of their parents. An intensified relationship toward the care receiver is also described as a positive side effect. The feeling of being understood not only arises through professional caregivers, some respondents also appreciate the exchange with people who are in the same position as caring relatives.

"I consider it my duty to take care of my parents as much as possible." (Respondent 22, 2020)

"A great help in our region is the possibility to exchange information at the Pflegestammtisch (regular informal meetings with other caregivers)." (Respondent 27, 2020)

#### The Influence of the Quality of LTC services on the quality of Life

The sphere which is related the closest to the research question of this thesis is the *quality of care services*. As figure 3 shows, 14 out of 20 respondents state that the quality of care services influences their well-being "quite" or "very much", independent of their usage of it. This is also reflected in the answers to the open questions, where two main themes connected to the quality of LTC services emerge – the *inconsistency of care services* on the one hand and the *support received from professional caregivers* on the other.

[When asked how the quality of care services influences well-being] "Rather negatively, one has to redo the work often. The care receiver is often not satisfied. The daily routine is additionally constrained as the external caregivers do not always visit at the same time." (Respondent 25, 2020)

This reflects the capabilities of *time allocation*, as the daily routine is disrupted by irregular working times, and *physical & mental health*, due to the work that has to be redone. This can be physically exhausting, but also psychologically stressful as the dissatisfaction of the care receiver most likely influences the caring relative.

"[There is] no consistent standard when it comes to long-term care services or other care services, this influences the relief of strain [such a service enables]." (Respondent 58, 2020)

This addresses the *inconsistency of care services*, which leads to additional work, as some things have to be redone due to bad quality. Some respondents connect this bad quality to the *bad remuneration of professional caregivers*, which is therefore identified as a subtheme. So, it seems that caring relatives are aware that fair wages could increase quality. However, as they themselves are under increased financial pressure due to their caregiving, this subtheme rather addresses the need for a strong public care sector.

"Highly qualified caregivers will not be willing to do the job without reasonable remuneration. When they are not healthy, they will not be able to take care of the care receiver adequately." (Respondent 47, 2020)

The theme that is represented most when it comes to the quality of LTC care services is *the support received from caregivers* – either in the form of professional advice around medication and care work in general or just by the ability to share the mental load and to worry less, as the caring relative is able to share responsibility.

[When asked how the quality of care services influences well-being] "Difficult and heavier tasks are taken over, e.g. the body hygiene. There is a safety net in case I cannot be there. There is understanding for my situation." (Respondent 44, 2020)

[When asked how the quality of care services influences well-being] "It's relieving as the care work can be shared. The know-how of professional carers is a great help. When insecurities around the care work or medication arise, an exchange of experiences is possible. [...] Responsibility can be shared." (Respondent 29, 2020)

Each respondent incorporates sharing responsibility in one way or another into their an-

swers. The fact that one has to worry less if someone competent cares for their relative poses an immense relieve for caregivers according to the findings in the TA.

#### **Overall Results**

To conclude this section, the main takeaways of the TA regarding the research questions are that engaging in care work itself limits certain capabilities and therefore the QoL. This is mainly due to limitations in the ability to allocate one's time. Another important factor is the paper work that is affiliated with care work, which informal caregivers are often responsible for as well. Simplifying these administrative tasks could significantly relieve strain of caring relatives. Facilitating the exchange between informal caregivers is also a helpful way for some carers to reduce stress.

The quality of LTC services also influences well-being – both in positive and negative ways, which is in line with the literature that is reviewed in section 2.2. It seems that high quality care services increase quality of life as they extend certain capabilities such as *physical and mental health* and as they enable the relief of worries because responsibility can be shared. Nonetheless, if these care services are of bad quality they can limit well-being, especially in the dimension of *time allocation*. This is the case because irregular times of professional caregivers disrupt daily routines. According to these findings, high quality LTC care could enable significant relief for caring relatives in Austria.

#### 4.3.3 Limitations

Additionally to the limitations due to the Covid-19 pandemic, some other restraints might bias the analysis. One mistake that complicates the capabilities analysis is that one capability (time allocation) was accidentally not listed when asked which dimensions were influenced by the quality of LTC services. Therefore, I do not take this question into account but infer the influence on capabilities solely from the open questions. The most noteworthy limitation however, is that some respondents misread or misinterpreted the question regarding the *quality* of LTC services, and answered with respect to the *availability* of LTC care services. The answers in which this misunderstanding is obvious are excluded from the analysis. Therefore, the analysis is still credible even though limited to some extend. This could have been avoided either by describing the question more clearly or by face-to-face interviews. However, due to the then prevalent situation this would not have been possible. This could be an improvement regarding future research.

### 5 Discussion

The aim of this master's thesis is to evaluate the connection between the quality of LTC services and the well-being of informal caregivers in Austria. This work provides unique results that are obtained through a mixed methods approach. The findings of the quantitative part indicate that the quality of LTC services has no influence on the well-being of non-caring individuals but is of significance to caring relatives. More specifically, rating LTC services with medium quality reduces the likelihood of caregivers choosing the highest level of life satisfaction. Due to some limitations mentioned in section 3.2.1 and in order to offer a more holistic insight into this nuanced topic, a qualitative analysis was conducted.

Using a capabilities list, which was created specifically with care work in mind, I created an online survey that contains open as well as closed questions. Informal caregivers from all over Austria offer an insight into their well-being. The thematic analysis confirms that the quality of LTC care services has an important impact of the QoL of caring relatives. While bad quality care might decrease well-being, high quality LTC services increase it. This is especially the case because of relief through shared responsibility. These results build on the existing evidence presented in section 2 and are in line with both studies that suggest positive and negative effects. So, these findings emphasize the need to widen the analysis, taking into account outcomes that enhance and limit well-being of caregivers, which can occur simultaneously.

While these findings call for a more holistic view on caregiver well-being in future research, they also have clear policy implications. One of the factors that is most limiting to the QoL of caring relatives is the inconsistency of professional caregivers with regards to quality standard but also timing. One way to offer additional relief to this often overlooked group of individuals would be a well-funded public service, that is somewhat standardized in order to provide consistency.

### References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77–101.
- Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners (Paperback ed.). Sage Publications (CA).
- Burgenland, L., & Burgenland, F. (2018). Zukunftsplan pflege: Bedarfs- und entwicklungsplanung 2018 2030. Land Burgenland.
- Chappell, N. L., & Dujela, C. (2008). Caregiving: predicting at-risk status. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 27(2), 169–179.
- Chappell, N. L., & Reid, R. C. (2002). Burden and well-being among caregivers: examining the distinction. *The Gerontologist*, 42(6), 772–780.
- Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K. R., & Ingham, J. M. (2003). Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of pain and symptom management*, 26(4), 922–953.
- Di Novi, C., Jacobs, R., & Migheli, M. (2015). The quality of life of female informal caregivers: from scandinavia to the mediterranean sea. *European journal of population*, 31(3), 309–333.
- Do, Y. K., Norton, E. C., Stearns, S., & Van Houtven, C. H. (2013). *Informal care and caregiver's health* (Tech. Rep.). National Bureau of Economic Research.
- Eom, K., Penkunas, M. J., & Chan, A. W. (2017). Effect of caregiving relationship and formal long-term care service use on caregiver well-being. *Geriatrics & Gerontology International*, 17(10), 1714–1721.
- European Foundation for the Improvement of Living and Working Conditions. (2018). *European quality of life survey integrated data file*, 2003-2016 (Vol. 3rd Edition) [dataset]. UK Data Service.
- Farquhar, M. (1995). Definitions of quality of life: a taxonomy. *Journal of advanced nursing*, 22(3), 502–508.
- Gulyas, J. (2015). Hopes and fears–future views of quality of life. In *Global handbook of quality* of life (pp. 869–894). Springer.
- Hawranik, P. G., & Strain, L. A. (2007). Giving voice to informal caregivers of older adults. *Canadian Journal of Nursing Research Archive*, 39(1).
- Ho, S. C., Chan, A., Woo, J., Chong, P., & Sham, A. (2009). Impact of caregiving on health and quality of life: a comparative population-based study of caregivers for elderly persons and noncaregivers. *Journals of Gerontology Series A: Biomedical Sciences and Medical Sciences*, 64(8), 873–879.
- Kieninger, J., Trukeschitz, B., Wosko, P., & Pleschberger, S. (2019). Mapping the domains

- and influencing factors of quality of life in informal carers of community-dwelling older adults. *Discussion Paper 1/2019 of the WU Research Institute for Economics of Aging*.
- Nagl-Cupal, M., Kolland, F., Zartler, U., Mayer, H., Bittner, M., Koller, M., ... Stöhr, D. (2018). *Angehörigenpflege in Österreich. Einsicht in die situation pflegender angehöriger und in die entwicklung informeller pflegenetzwerke*. Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz.
- Nussbaum, M. C. (2001). Women and human development: The capabilities approach (Vol. 3). Cambridge University Press.
- OECD. (2020). Who cares? attracting and retaining care workers for the elderly. Retrieved from https://www.oecd-ilibrary.org/content/publication/92c0ef68-en doi: https://doi.org/https://doi.org/10.1787/92c0ef68-en
- Rappold, E., & Juraszovich, B. (2019). *Pflegepersonal-Bedarfsprognose für Österreich*. Wien: Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz.
- Robeyns, I. (2003). Sen's capability approach and gender inequality: selecting relevant capabilities. *Feminist economics*, 9(2-3), 61–92.
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309–319.
- Schmidt, A. E., Ilinca, S., Schulmann, K., Rodrigues, R., Principi, A., Barbabella, F., ... Galenkamp, H. (2016). Fit for caring: factors associated with informal care provision by older caregivers with and without multimorbidity. *European journal of ageing*, 13(2), 103–113.
- Sen, A. (1985). Commodities and capabilities. Amsterdam: North-Holland Publ. Co. Retrieved from https://permalink.obvsg.at/wuw/AC02159099
- Sen, A. (1993). Capability and well-being. In *The quality of life* (p. 30-53). Sen, Amartya and Nussbaum, Martha.
- Stull, D. E., Kosloski, K., & Kercher, K. (1994, 02). Caregiver Burden and Generic Well-Being: Opposite Sides of the Same Coin?1. *The Gerontologist*, 34(1), 88-94. Retrieved from https://doi.org/10.1093/geront/34.1.88 doi: 10.1093/geront/34.1.88
- van den Broek, T., & Grundy, E. (2018). Does long-term care coverage shape the impact of informal care-giving on quality of life? a difference-in-difference approach. *Ageing & Society*, 1–18.
- van Groenou, M. I. B., de Boer, A., & Iedema, J. (2013). Positive and negative evaluation of caregiving among three different types of informal care relationships. *European Journal of Ageing*, 10(4), 301–311.
- Verbakel, E., Metzelthin, S. F., & Kempen, G. I. (2018). Caregiving to older adults: Determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. *The Journals of Gerontology: Series B*, 73(6), 1099–1111.

- Wagner, M., & Brandt, M. (2015). Loneliness among informal caregivers aged 50+ in europe. *Ageing in Europe: Supporting policies for an inclusive society*, 179.
- Wagner, M., & Brandt, M. (2018). Long-term care provision and the well-being of spousal caregivers: an analysis of 138 european regions. *The Journals of Gerontology: Series B*, 73(4), e24–e34.

# Notes

# **List of Tables**

1	How the quality of LTC services influences caregivers and non-caregivers	
	quality of life	13
2	Comparison of Capabilities Lists	16
3	Overview of Survey Respondents	20
4	Overview of Themes and Subthemes	21
5	Overview of Variables from the EQLS Dataset ( $4^{th}$ Wave, 2016)	30
<b>L1St</b> 1	<b>of Figures</b> Distribution of the Rating of "Life Statisfaction" and "Quality of Long-Term	
List	of Figures	
2	Care Services in the $4^{th}$ wave of the EQLS data set	10
		10
	Care Services in the $4^{th}$ wave of the EQLS data set	10
3	Care Services in the $4^{th}$ wave of the EQLS data set	11

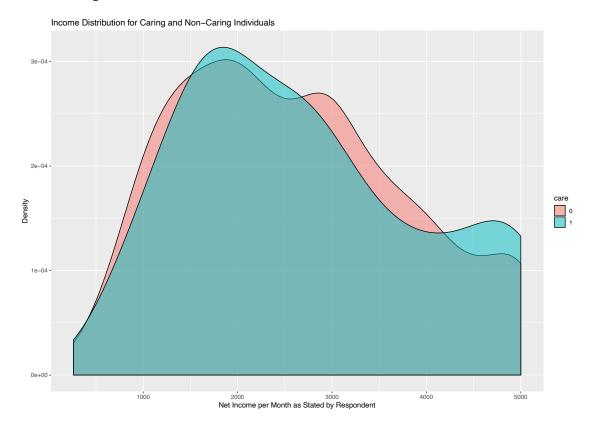
<sup>&</sup>lt;sup>1</sup>Special thanks to Reingard Fessler and Karin Hecht <sup>2</sup>Thanks to Angela Jäger and Andrea Plut-Sauer

# Appendix

**Table 5:** Overview of Variables from the EQLS Dataset (4<sup>th</sup> Wave, 2016)

Overview of Imporant Variables				
Quality of Life	Quality of Life			
Q4	Life satisfaction			
Caring for Relatives				
Q42d, Q42e	Caring for disabled or infirm family members, neighbours or friends			
Q43d, Q43e	Average hours of care per week (outside of paid work)			
<b>Quality of LTC services</b>	•			
Q58e	Overall quality of LTC services			
Demographic Variables				
HH2a	Sex			
HH2b	Age			
HH2d	Employment status			
Q53	Residential area			
Q87	Level of education			
Q96, Q97	Income level of household			

**Figure 4:** Distribution of Income in the EQLS dataset (4<sup>th</sup> wave, 2016)





### Sehr geehrte Damen und Herren,

Mein Name ist Lisa Hanzl und ich studiere derzeit Volkswirtschaft im Master an der Wirtschaftsuniversität Wien. Im Rahmen meiner Diplomarbeit beschäftige ich mich mit dem Einfluss der Qualität von Pflegeeinrichtungen (24-Stunden-Betreuung und mobile Betreuungs- und Pflegedienste) auf das Wohlbefinden von pflegenden Angehörigen, also Menschen, die unbezahlte Pflegearbeit leisten.

Um ein umfangreicheres und diesem komplexen Thema gerechteres Bild zu bekommen, würde ich mich freuen, wenn Sie diesen Fragebogen ausfüllen. Dabei bitte ich Sie, alle Fragen nach eigenem Ermessen zu beantworten – Wohlbefinden ist schließlich für jeden und jede etwas Anderes. Das Ausfüllen des Fragebogens dauert circa 15 bis 20 Minuten.

Die Begriffe Wohlbefinden und Lebensqualität werden hierbei an zehn Bereichen fest gemacht zu denen ich Ihnen je 2 Fragen stelle. Anschließend finden Sie einige offene Fragen zum Thema Qualität von Langzeitpflegeeinrichtungen und Fragen zu Ihrer Person.

Vielen Dank für Ihre Hilfe! Beste Grüße,

#### Lisa Hanzl

Teil	${f A}$ : Unterkunft und persönl	iche Rückzugsmöglichkeit	
A1.	Leben Sie im selben Haushalt v		
A2.	Verfügen Sie über ausreichend persönliche Freiräume?	Rückzugsmöglichkeiten und  Ja  Nein	
Teil	B: Soziale Beziehungen und	d Respekt	
B1.	Wirkt sich Ihre Pflegetätigkeit anderen Menschen aus?	auf Ihre persönlichen Beziehungen zu  Ja  Nein	
B2.	Falls ja, inwiefern?	Positiv (z.B. mehr oder intensivere soziale Kontakte)  Negativ (z.B. einschränkend)	



В3.	Fühlen Sie sich in Bezug auf Ihre Pflegetätigkeit respektiert und wertgeschätzt?	
	Gar nicht	
	Wenig	
	Ziemlich	
	Sehr	
	C: Finanzielle Sicherheit	
C1.	Fühlen Sie sich generell finanziell abgesichert? (z.B. falls Ihr Kühlschrank heute kaputt wird, können Sie sich problemlos einen neuen leisten?)	
	Gar nicht	
	Wenig	
	Ausreichend	
	Sehr	
	keine Antwort	
Teil !	D: Bezahlte Arbeit und andere Projekte	
D1.	Üben Sie neben der Pflege bezahlte Arbeit aus?	
	Ja	
	Nein	
D2.	Falls ja, in welchem Stundenausmaß?	
	Vollzeit (mehr als 35 Stunden/Woche)	
	Teilzeit (mehr als 10 Stunden/Woche)	
D.2	Geringfügig (bis zu 10 Stunden/Woche)	
D3.	Wenn nicht, hätten Sie die Kapazität neben Ihrer Pflegetätigkeit zu arbeiten?	
	Ja	
	Nein	
<b>D4.</b>	Falls ja, in welchem Stundenausmaß?	
	Vollzeit (mehr als 35 Stunden/Woche)	
	Teilzeit (mehr als 10 Stunden/Woche)	
	Geringfügig (bis zu 10 Stunden/Woche)	
<b>Teil</b>	E: Freizeitgestaltung	
E1.	Haben Sie ausreichend freie Zeit, die Sie selbst gestalten können?	
	Gar nicht	
	Wenig	
	Ausreichend	
	Sehr	



E2.	Welche Bereiche Ihrer Freizeitgestaltung sind durch Ihre Pflegearbeit besonders beeinflusst?	
	Sie können in ganzen Sätzen oder in Stichwörter	n antworten.
Teil :	F: Engagement	
F1.	Ist Engagement (politisch, in der Gemeinschaft, in der Kirche, etc.) für Sie ein wichtiger Bestandteil Ihres Lebens? (Egal, ob Sie sich gerade engagieren oder nicht)  Ja Nein	
F2.	Haben Sie neben Ihrer Pflegetätigkeit genügend Ressourcen (Zeit, Energie, Geld, etc.), um Engagement nach Ihrem Belieben nachzugehen?	
	Ja Nein	
	G: Eigene Verpflichtungen Ilen Kinder, Haushalt, etc.	
G1.	Haben Sie neben Ihrer Pflegetätigkeit genügend Ressourcen (Zeit & Energie), um eigenen Verpflichtungen nachzukommen?  Gar nicht Wenig Ausreichend Sehr	
G2.	Welche Bereiche sind durch Ihre Pflegearbeit besonders beeinflusst?  Sie können in ganzen Sätzen oder in Stichwörter	n antworten.
Teil !	H: Freie Verfügung über Einteilung der eigenen Zeit	
H1.	Können Sie sich Ihre Zeit (außerhalb von bezahlter Arbeit) frei einteilen?  Ja Nein	



H2.	Wie sehr fühlen Sie sich durch Ihre Pflegetätigkeit in Ihrer freien	
	Zeiteinteilung eingeschränkt?  Gar nicht	
	Wenig	
	Ziemlich	
	Sehr	
Teil	I: Körperliche und psychische Gesundheit	
I1.	Verstärkt Ihre Pflegetätigkeit vorhandene körperliche Beschwerden? (durch schweres Heben, etc.)	
	Gar nicht	
	Wenig	
	Ziemlich	
	Sehr	
12.	Was verbinden Sie mit Ihrer Pflegearbeit? (Mehrfachauswahl möglich)	
	Stress	
	Bereicherung	
	Überforderung	
	Sich gebraucht fühlen Einsamkeit	
	Etwas zurückgeben	
	Sich Sorgen machen	
	Intensive Beziehung zur gepflegten Person	
	Sonstiges	
	Sonstiges	<b>Y</b>
Teil	J: Bestrebung eigener Vorhaben und Ziele	
J1.	Wie sehen Sie Ihrer (nahen oder fernen) Zukunft entgegen?	
	Positiv Neutral	
	Negativ	
J2.	Haben Sie das Gefühl, Sie können Ihre Zukunft selbst gestalten?	
J4.	Gar nicht	
	Wenig	
	Ziemlich	Ţ
	Sehr	



	K: Fragen zum Thema Qualität von Pflegeeinrichtungen untworten Sie die folgenden Fragen, auch wenn Sie diese Dienste nicht in Anpruch nehmen.					
K1.	Würden Sie sagen, die <u>Qualität</u> von 24-Stunden-Pflege und mobilen Pflegedienstleistungen beeinflusst Ihr Wohlbefinden ( <u>selbst wenn Sie</u>					
	diese nicht in Anspruch nehmen)?					
	Gar nicht					
	Wenig					
	Ziemlich					
	Sehr					
K2.	Falls ja, inwiefern? (Führen Sie hier gerne aus)					
Beispiele	: Sie müssen sich weniger Sorgen machen, falls Sie selbst nicht mehr pflegen können, oder Entlastung da Sie die gepflegte Pers	son in guten den wissen?				
	Hand	ien wissen:				
K3.	Welchen der folgenden Bereiche beeinflusst die Qualität von					
110.	Pflegedienstleistungen (24-Stunden-Pflege und mobile					
	Pflegedienste) am meisten? (Mehrfachauswahl möglich)					
	Dies sind die 10 Bereiche, zu denen Sie vorhin eben schon Fragen beantwe	ortet haben.				
	Unterkunft und persönliche Rückzugsmöglichkeit					
	Soziale Beziehungen und Respekt					
	Finanzielle Sicherheit					
	Bezahlte Arbeit und andere Projekte					
	Freizeitgestaltung					
	Engagement					
	Eigene Verpflichtungen (Kinder, Haushalt, etc.)					
	Körperliche und psychische Gesundheit					
	Bestrebung eigener Vorhaben und Ziele					



K4.	Warum genau? In welchem Ausmaß? Führen Sie hier gerne detaillierter aus.			
	Sie können in ganzen Sätzen oder in Stichwörtern antworten.			
Teil L: Demographische Fragen Zum Schluss möchte ich Ihnen ein paar Fragen zu Ihrer Person stellen.				
L1.	Ihr Geschlecht			
		weiblich		
		männlich		
L2.	Ihr Alter (in Jahren)			
112.	in their (in Junion)			
L3.	In welchem Bundesland leben Sie?			
		Burgenland		
		Kärnten		
		Niederösterreich		
		Oberösterreich		
		Salzburg		
		Steiermark		
		Tirol		
		Vorarlberg		
		Wien		
		Nicht in Österreich		
L4.	Pflegen Sie ausschließlich selbst?	Trient in Obterior		
L4.	r negen sie ausschnedich seibst:	Ja		
T -		Nein		
L5.	Falls nein, welche Pflegeservices nehmen Sie in	n Anspruch?		



L6.	In welcher Beziehung stehen Sie zur gepflegten Person? Die gepflegte			
	Person ist Ihr_e			
	Ehepartner_in			
	Elternteil			
	Kind			
	Sonstiges			
	Sonstiges			
L7.	Wie intensiv pflegen Sie? Wie viele Stunden ca. pro Woche?			
L8.	Haben Sie Gedanken zu diesem Thema? Gibt es etwas, dass Sie noch			
	sagen möchten?  Sie können in ganzen Sätzen oder in Stichwörtern antworten.			
L9.	Als letzte Frage, was könnte Ihre persönliche Situation verbessern,			
	was würde Ihnen helfen? Was würden Sie für Ihr Wohlbefinden			
	brauchen?			
	Sie können in ganzen Sätzen oder in Stichwörtern antworten.			
	Vielen Dank für Ihre Zeit und Ihre Antworten!			
	VIOLOTI SULLITO SOLO UNIU LILLO I LILLO VIOLOTO			
S	ollten Sie weitere Fragen haben, stehe ich Ihnen sehr gerne zur Verfügung.			
S	weitere Fragen haben, stehe ich innen sem gerne zur verragung.			
Moine Kentektdeten: Lice Henri E Meil: lice henri@island.com Tel.: 0470 1275 720				
Meine Kontaktdaten: Lisa Hanzl E-Mail: lisa.hanzl@icloud.com Tel.: 0678 1275 739				