



EXCELC

Exploring Comparative
Effectiveness and Efficiency
in Long-term Care

**EXCELC – Exploring Comparative Effectiveness and
Efficiency in Long-term Care:**

Study Design and Descriptive Statistics for the Austrian Sample of Informal Carers

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Disclaimer



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EXCELC-project aim

To meet societal and economic challenges, health and care welfare regimes will need to become much more focused on the outcomes that matter to people and deliver these programs effectively and efficiently. Central to this goal is the need to accurately measure outcomes and reflect the value of those outcomes.

EXCELC (Exploring Comparative Effectiveness and Efficiency in Long-term Care) was a cross-country study whose core purpose was to assess the comparative effectiveness and efficiency of community and home-based long-term care (LTC) for older adults and their informal carers in Austria, England and Finland. EXCELC was using the care-related outcome tool, ASCOT, to measure the outcomes of LTC. The study has produced a German and Finnish version of the ASCOT service user and informal carer instruments.

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For the **German ASCOT instruments** for long-term care service users and for informal carers see <https://www.pssru.ac.uk/ascot/translations/> and <https://www.wu.ac.at/en/altersoekonomie/ascot> or <https://www.wu.ac.at/altersoekonomie/ascot> (information in German)

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1 INTRODUCTION

The **EXCELC project** (4/2015-8/2018) had two main analytical aims. First, it aimed to explore the effectiveness of home care service provision by comparing quality-of-life outcomes of home care service users and informal carers across three European countries: Austria, England and Finland. Second, cost-effectiveness analysis should give insights into the efficiency of service use and provision in the three countries. In order to generate the results, data on home care service users and carers had to be collected. In total, the goal was for 450 service users and 225 informal carers to be involved in the study in Austria. For more details on the study design and the sample description of Austrian *home-based care service user data*, see Trukeschitz/Litschauer et al. (2018).

The purpose of this document is to provide details on the **Austrian informal carer study design** and **data collection** and **sample characteristics** of the Austrian informal carer data for the EXCELC project.

The document consists of two parts. The first part describes the study design used for data collection of informal carers of users of home-based care services in Austria (chapter 2). The second part contains descriptive statistics of core variables of the informal carers' sample (chapter 3). The descriptive data cover regional distribution (section 3.1), socio-demographic characteristics (section 3.2), the outcome measure (section 3.3), information on service receipt (section 3.4) and factors influencing quality of life outcomes (section 3.5). Finally, we also report on survey administration and completion to give insights into data quality (section 3.6).

2 STUDY DESIGN FOR THE INFORMAL CARER SUB-SAMPLE

The aim of the data collection in Austria was to generate data on long-term care service users and informal carers in Austria that can be compared to the data of the IIASC study conducted by PSSRU, University of Kent in 2013/14 (Forder/Malley et al. 2016). The study design for the data collection in Austria drew on the English IIASC study and was developed in collaboration with the research team at the PSSRU at the University of Kent. The research approach has been adapted to the institutional setting in Austria.

The following sections give insights into the definition of the target group (section 2.1) and the data collection process (section 2.2).

2.1 TARGET GROUP OF THE AUSTRIAN INFORMAL CARER EXCELC-SURVEY

In addition to the collection of data of home-based care service users, the Austrian part of the EXCELC study also addressed informal carers of these service users. Informal carers are family members, friends, or neighbors who support or look after an older person and do not receive any wage-like remuneration.

Data collection in the EXCELC-project targeted a specific group of informal carers. Informal carers, who were eligible for this study, had to support older people using professional home-based care services. In addition, we were interested in collecting information about the main informal carer, the person who provides the bulk of informal care for the care service user.

Initially, we intended to collect data on service user–informal carer pairs only. This means the intention was to include only informal carers whose care-dependent relative, friend, or neighbor would also participate in the study. During the data collection process, it turned out that informal carers of care recipients, who were no longer able to participate (e.g. due to cognitive impairments), were interested in taking part in the study. Thus, we broadened the definition of the informal carer target group and also invited this group of informal carers (further referred to as 'solo carer interviews', i.e. informal carer interviews without a paired service-user interview) to participate.

2.2 DATA COLLECTION

This section describes the recruitment strategy (section 2.2.1), type and process of data collection (section 2.2.2) and gives an overview of the topics of the questionnaire (section 2.2.3).

2.2.1 RECRUITMENT STRATEGY FOR INFORMAL CARERS

As there are no national records of informal carers in Austria, the Austrian data collection for the EXCELC study followed two approaches. First, an invitation letter was sent to home-based care service users, also inviting informal carers to participate. Responding to the calls of prospective home care service users, researchers asked about the availability of their informal carer. In some cases, the researchers were able to arrange interviews with both home care service users and their carers. At other points, interviewers were briefed to recruit informal carers at the end of their home care service user interviews by passing on an invitation letter and information sheet about the study for the informal carer. If the researchers or interviewers did not receive any response from the informal carers after two weeks, reminders were sent out in some regions. In other areas, managers of care organizations were asked to help with the recruitment of informal carers.

The invitation letters for informal carers introduced the EXCELC study, invited the informal carers to participate, and offered a toll-free telephone number to contact the research team at the WU, the Vienna University of Economics and Business. In the phone call, the researchers explained the study aims and asked them to answer short screening questions. These questions were intended to collect information about the care setting, the contact details and whether the potential survey participant agreed to letting the researchers pass the information on to the interviewers. The details were then logged. The researchers answered any questions that the potential study participants had during and at the end of the phone call and asked for permission to pass on the contact details to the interviewer. The research team contacted one of the interviewers and passed on the contact details and core information about the potential study participant. The interviewers arranged the time and location for the interview that were convenient for the informal carer.

The **recruitment of informal carers** took place in line with the recruitment of service users and thus followed the province-by-province approach. The recruitment process started in Vienna in May 2016. Data collection in Austria took 14 months in total. It was completed in Upper Austria, Vorarlberg and Carinthia in summer 2017 and in Vienna, Salzburg, Burgenland, Lower Austria, Styria and Tyrol during autumn 2017.

2.2.2 CONDUCTING THE INFORMAL CARER INTERVIEWS

As with the home care service user data, data about informal carers were collected through computer-aided personal standardized interviews (CAPI) with tablet computers. Showcards facilitated the delivery of the survey. For further information on the general process of interviewing and training of interviewers, see the discussion paper on the study design of the service user sample Trukeschitz/Litschauer et al. (2018).

In total, 60 interviewers conducted carer interviews, with an average of 8, a minimum of 1 and a maximum of 17 informal carer interviews per interviewer. Interviewers were not restricted to do informal carer interviews only, and they also could combine service user and informal carer interviews (see 3.10.2 for details).

In addition to the computer-aided personal interviews, a total of 78 follow-up computer-aided telephone interviews were conducted with the 'solo carers' during the spring and fall of 2017. These interviews compensated for the lack of paired interviews and helped to gain more data on the corresponding LTC service user. These questions focused on the personal characteristics of the service user and on formal and informal support with (instrumental) activities of daily living (I)ADLs. Carers who did not want to be contacted again after the first interview were excluded for the follow-ups.

2.2.3 THE EXCELC-CARER QUESTIONNAIRE

As the aim of the data collection was to get data that are comparable across England, Finland and Austria, we followed the English IIASC study's approach. Either the relevant parts of the English IIASC-questionnaire were translated into German or existing German instruments (e.g. EQ5D) were included into the survey. The data collected in the interviews addressed:

- socio-demographic information
- questions related to the person supported
- any help and support the carers received
- carer's quality of life and impact of home care on carer's quality of life using the German version of ASCOT for informal carers
- experiences with home care services
- experiences with organizing care and support
- reasons for providing informal care
- health and quality of life
- social contact and support

- questions concerning interviewee behavior
- health & needs of service user (when no SU-interview was conducted)

3 THE INFORMAL CARER SAMPLE FOR THE AUSTRIAN EXCELC STUDY

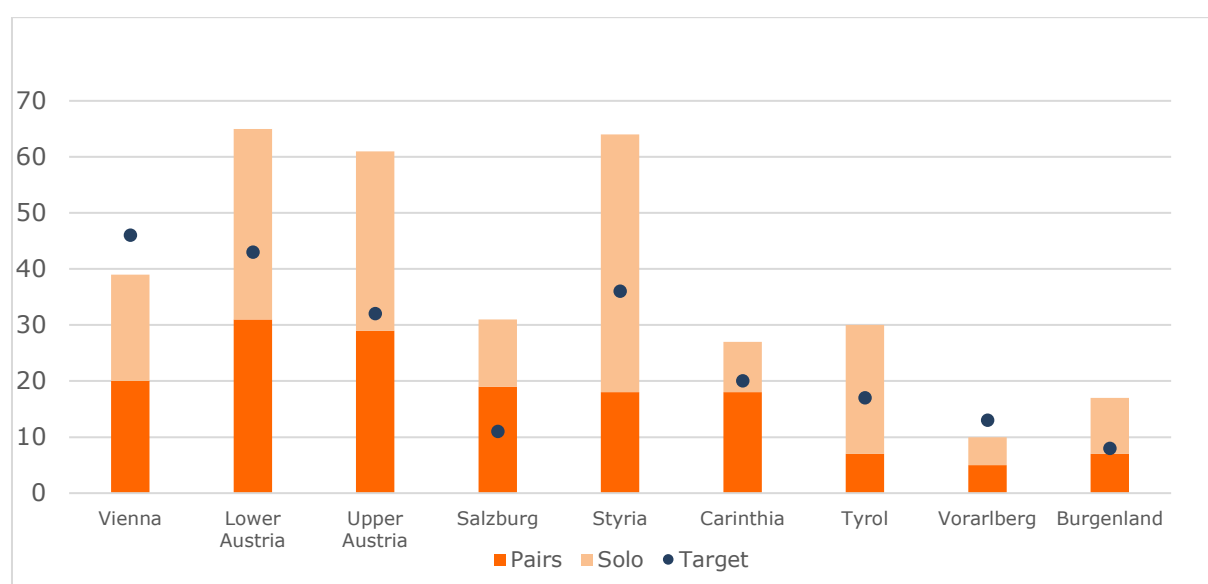
In total, 346 interviews were conducted with informal carers – 2 were excluded because of young age (<55) of the LTC service users – bringing the final number of carer interviews to 344. 154 of the informal carer interviews corresponded to a completed paired interview (SU-C pair), while the remaining 190 interviews were conducted with the carer alone and could not be matched with a service user interview (so-called 'solo carer' interviews).

The following sections contain descriptive statistics of the core variables and LTC related quality of life outcomes of the carer sample.

3.1 REGIONAL DISTRIBUTION OF INTERVIEWS

Figure 1 shows the target number of informal carer interviews for each Austrian province compared to the actual number of informal carer interviews carried out. The target numbers per province were derived from the LTC service user statistics (BMAASK 2015). With the exception of Vorarlberg and Vienna, the interview targets were reached in all provinces. In most of the provinces a considerable share of solo-carer interviews were conducted. For these interviews, we do not have paired service-user interviews.

Figure 1. Target and interviews with informal carers per region (total, pair, solo)

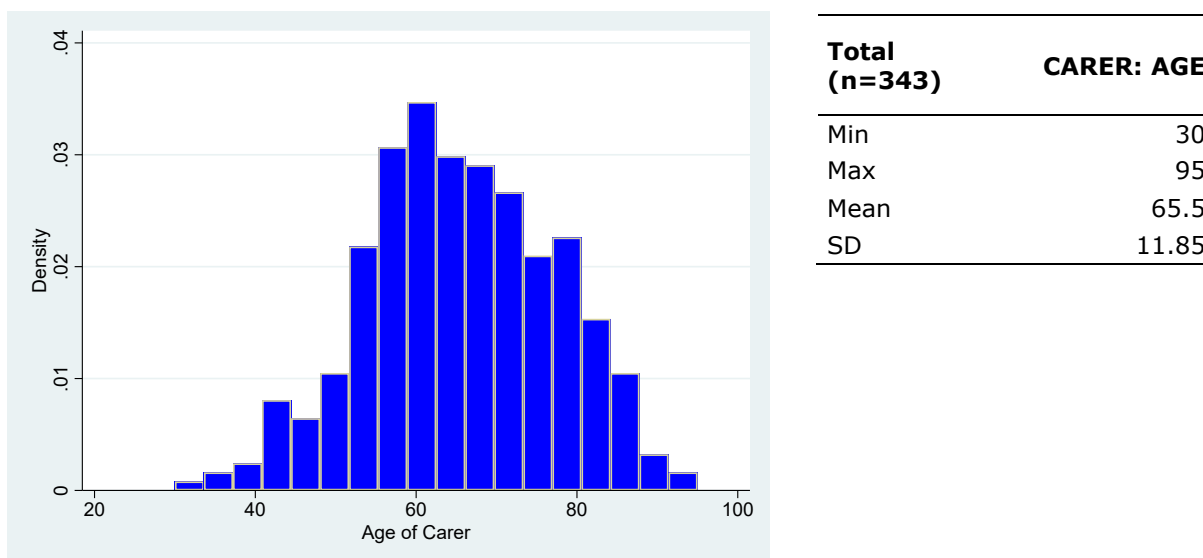


Source: WU, EXCELC INT C AUT 2016/2017 and BMAASK (2015: 101 ff.), n= 344

3.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF INFORMAL CARERS

Characteristics of the informal carer sample are shown in Table 1. In total, 344 informal carers were interviewed (one denied answering the question about age). More than half of the sample was 65 years or older. The average age of the carers was 65.5 years, with the youngest interviewee being 30 and the oldest being 95 – see Figure 2.

Figure 2. Age distribution of the informal carers in the sample



Source: EXCELC INT C AUT 2016/2017

The informal carer sample has more than twice as many women as men. This is according to the information available about informal care in Austria (e.g. Arbeiterkammer Wien 2014).

Nearly two thirds of the informal carers in the sample reported upper secondary or post-secondary education and about one fifth reported lower secondary or below as their highest level of qualification. 15% of those in the sample hold a university degree or higher.

Nearly three quarters of the total carer sample were married, around 15% were divorced or widowed and more than 10% of the sample have never married. Looking at the living arrangements of the respondents, more than three quarters stated living together with their partner (married or partnership) in one household. More than 10% reported sharing the household with someone who is not their partner, whether it is another family member or a friend.

The majority of the sample were homeowners and the remaining third was either renting or lived rent-free.

In line with the age distribution, the great majority of the sample was retired and only a fifth was in paid employment (around half of them work part-time and half full-time). Only 1% of the sample was unemployed or in education.

Table 1. Socio-demographic characteristics of the informal carer sample, Austria

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Age group						
18-64 years	164	47.67	78	50.65	86	45.26
65 or over	179	52.03	75	48.70	104	54.74
Missing	1	0.29	1	0.65	0	0.00
Sex						
Female	233	67.73	103	66.88	130	68.42
Male	111	32.27	51	33.12	60	31.58
Education						
Lower secondary and below	73	21.22	31	20.13	42	22.11
Upper/post-secondary & short-cycle tertiary	208	60.47	90	58.44	118	62.11
BA/MA/PhD	60	17.44	32	20.78	28	14.74
Missing	3	0.87	1	0.65	2	1.05
Marital Status						
Never married	44	12.79	24	15.58	20	10.53
Married	251	72.97	105	68.18	146	76.84
Divorced	27	7.85	13	8.44	14	7.37
Widowed	22	6.40	12	7.79	10	5.26
Living arrangement						
Lives alone	41	11.92	19	12.34	22	11.58
Lives with partner	263	76.45	111	72.08	152	80.00
Lives only with adults who are not partner	39	11.34	24	15.58	15	7.89
Lives only with children	1	0.29	0	0.00	1	0.53
Living conditions						
Home owner	223	64.83	94	61.04	129	67.89
renting	73	21.22	44	28.57	29	15.26
Live rent-free	46	13.37	16	10.39	30	15.79
Missing	2	0.58	0	0.00	2	1.06
Employment status						
In paid employment	87	25.14	49	31.41	38	20.00
part-time	36	10.47	18	11.69	18	9.47
full-time	49	14.24	29	18.83	20	10.53
Unemployed	4	1.16	3	1.95	1	0.53
In education	2	0.58	1	0.65	1	0.53
Retired	226	65.70	94	61.04	132	69.47
Other	24	6.98	8	5.19	16	8.42
Missing	3	0.87	1	0.65	2	1.05
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

3.3 SOCIAL CARE RELATED QUALITY OF LIFE OF INFORMAL CARERS

ASCOT for informal carers aims to capture effects of LTC services for care dependent people on the carers' quality of life. It thus seeks to measure how LTC services, as for example home care, have an impact on carers' lives. We describe the results in sections 3.3.1 and 3.3.2 of this chapter.

The outcomes were measured across seven life domains that may be affected by LTC services (*Occupation, Control over daily life, Self-care, Safety, Social participation, Time and space, and Support*) collecting information on the current and the expected social care-related quality of life

(SCRQoL). For each question, respondents could rate their situation on a four-point scale (ideal state, no needs, some needs, high-level needs). The current SCRQoL measures the current situation with services in place for the care dependent person whereas the expected SCRQoL estimates what QoL would be in absence of services (Netten/Forder et al. 2011).

3.3.1 HOME CARE AND INFORMAL CARERS' QUALITY OF LIFE USING ASCOT FOR INFORMAL CARERS (ASCOT-CARER)

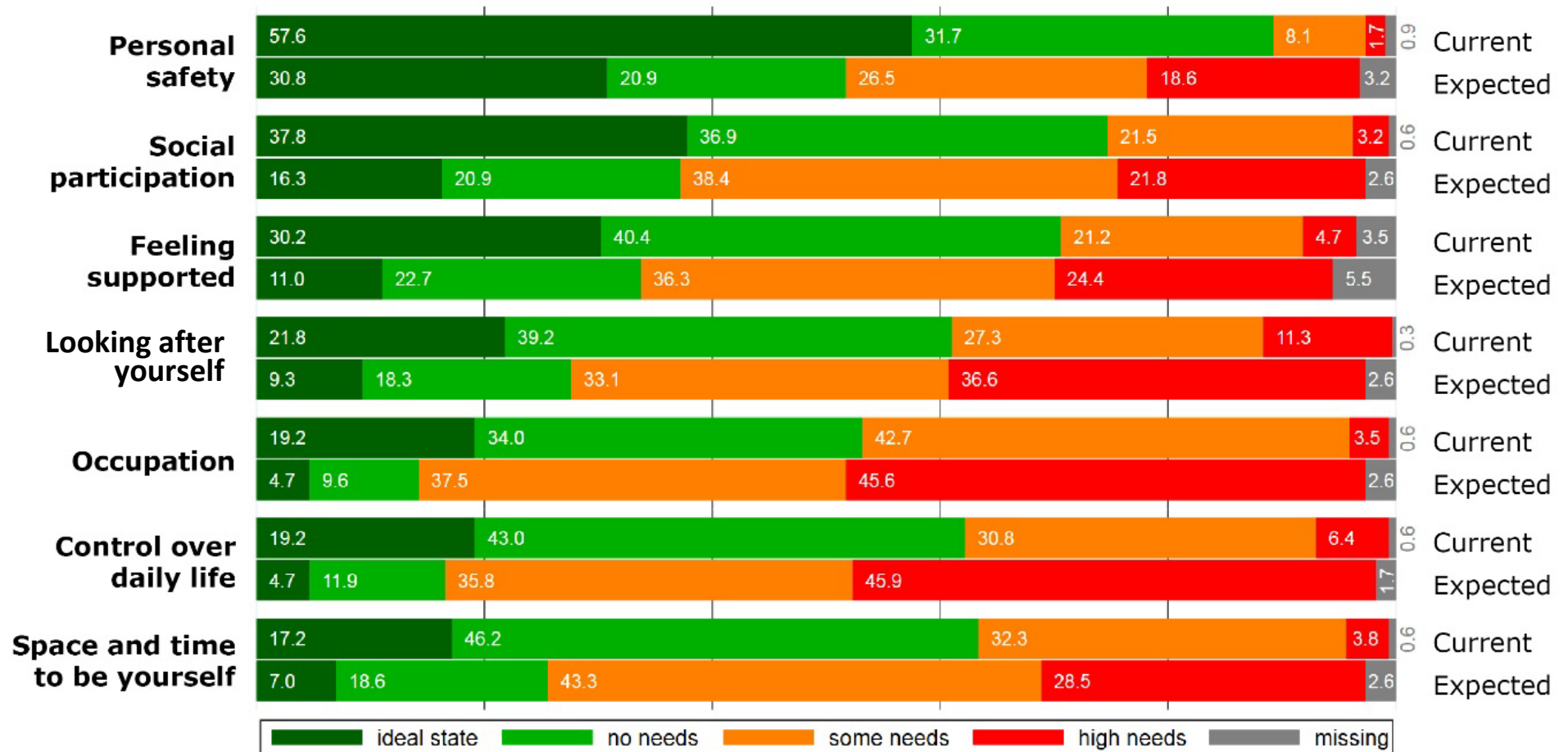
Figure 3 (on page 9) illustrates the social care-related quality of life of informal carers along seven domains comparing the current state (with home care services) and the expected states (expected well-being without the use of LTC services). For the cobweb diagram, see Trukeschitz/Hajji et al. (2018).

Considering the current state with support of home care services, the quality of life of the informal carer was rated highest for *Personal Safety*, followed by *Social Participation* and *Support* (Figure 3). Around 58% reported an ideal level of safety (meaning having no fear of abuse, being attacked or confronted with physical harm or accidents due to the caring role) and 32% reported an adequate level of safety. 38% indicated that they had as much social contact as they want with people they like (ideal state) and 37% indicated that they had adequate social contact (no needs). More than 30% felt they get the support and encouragement they needed (ideal state) and 42% reported an adequate level of support and encouragement (no needs).

For the four remaining domains *Self-care*, *Occupation*, *Control over daily life* and *Space and Time for oneself*, there was still a majority of informal carers reporting an ideal state or no needs. About 64% reported that they had all the space or adequate space to be themselves and about the same number of informal carers reported that they had as much or enough control over their daily life as they wanted or spent their time as they wanted. Still, more than 60% reported that they looked after themselves as well as they wanted or well enough and at least 54% indicated that they were able to spend their time or enough of their time doing things they enjoy. However, for all four domains, the share of informal carers reporting an ideal state was lower than for the other three domains.

Considering the expected quality of life, Figure 3 shows that for all seven domains, quality of life of informal carers would be worse in a situation without services. With the exception of *Personal Safety*, more than half of the informal carers reported that they would have some or high needs without services. Their quality of life would be lowest for *Occupation*, *Control* and *Space*. Only about 14% would be able to do all or enough things they value or enjoy, less than 17% would be able to have control or enough control over their daily life and only around 26% would have all the space or adequate space to be themselves. A considerably high number of informal carers but still slightly less than 50% reported that they would not feel as safe as they would want or safe enough in a situation without services.

Figure 3. Current and expected quality of life using ASCOT for informal carers (ASCOT-Carer)



Source: EXCELC INT C AUT 2016/2017, n=344

Overall, ratings of carers' current QoL, with LTC service provision, were on average higher than the expected QoL in absence of services, indicating an impact on LTC on people's QoL (see Table 2). The table shows the means, describing the central tendency by using the arithmetic average of the QoL-scores and the standard deviation of the sample, measuring the amount of variation (average deviation of the QoL-scores from the mean).

Carers' current QoL seemed to be on average better for the domains *Personal safety*, *Social participation* and *Support in the caring role*. Lower current QoL levels were reported typically for the domains of *Occupation*, *Self-care*, *Control over daily life* and *Time and space for oneself*.

The impact of LTC services on informal carers' QoL was calculated by subtracting the expected QoL in absence of services from the current QoL (with LTC service receipt). Positive differences indicate a LTC-service induced gain in QoL, and for negative differences, a loss in QoL. For Austria, the domain-specific impact of LTC service provision on informal carers QoL on average turned out to be positive (see Table 3).

The impact of LTC services on QoL were highest for the *Control-over-daily-life* and for *Occupation*, which captures the time spent doing joyful and pleasant activities. In comparison, the impact of LTC service provision was lower on the carers' QoL for *Self-care* (looking after oneself including getting enough sleep and eating well) and *Time and space for oneself*.

Comparing the mean impact and the standard deviation for each domain, we found the majority of informal carers reporting a positive impact of LTC services for the care dependent person on their QoL. This is particularly the case for *Occupation* and *Control over daily living* (mean exceeds standard deviation). For all other domains, some carers may experience no or a negative impact of LTC services on their quality of life (difference between mean and standard deviation can be negative).

Table 2 also shows the distribution of the preference-weighted current and expected ASCOT score. Preference-weighted SCRQoL outcomes account for the relative importance of each domain level. The preference-weighted index uses weights are derived directly from the best-worst scaling experiment conducted in the EXCELC project with score ranges between 0 and 1.

Table 2. Distributional statistics for current and expected ASCOT-scores and ASCOT domains for informal carers

Variable	Current		Expected		Impact	
	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n
ASCOT Carers: index ^a	13.45 (4.13)	328	7.67 (4.78)	314	5.67 (4.30)	309
ASCOT Carers: preference-weighted	0.73 (0.23)	328	0.40 (0.27)	314	0.33 (0.25)	309
Personal safety ^b	2.46 (0.72)	341	1.66 (1.12)	333	0.80 (0.96)	331
Social participation	2.10 (0.85)	342	1.33 (1.00)	335	0.77 (0.90)	335
Feeling encouraged and supported	2.00 (0.85)	332	1.22 (0.96)	325	0.77 (0.95)	322
Space and time to be yourself	1.77 (0.77)	342	1.04 (0.88)	335	0.72 (0.79)	334
Control over daily life	1.75 (0.84)	342	0.75 (0.85)	338	1.01 (0.97)	337
Looking after yourself	1.72 (0.93)	343	1.00 (0.97)	335	0.71 (0.93)	335
Occupation	1.69 (0.82)	342	0.73 (0.83)	335	0.97 (0.91)	334

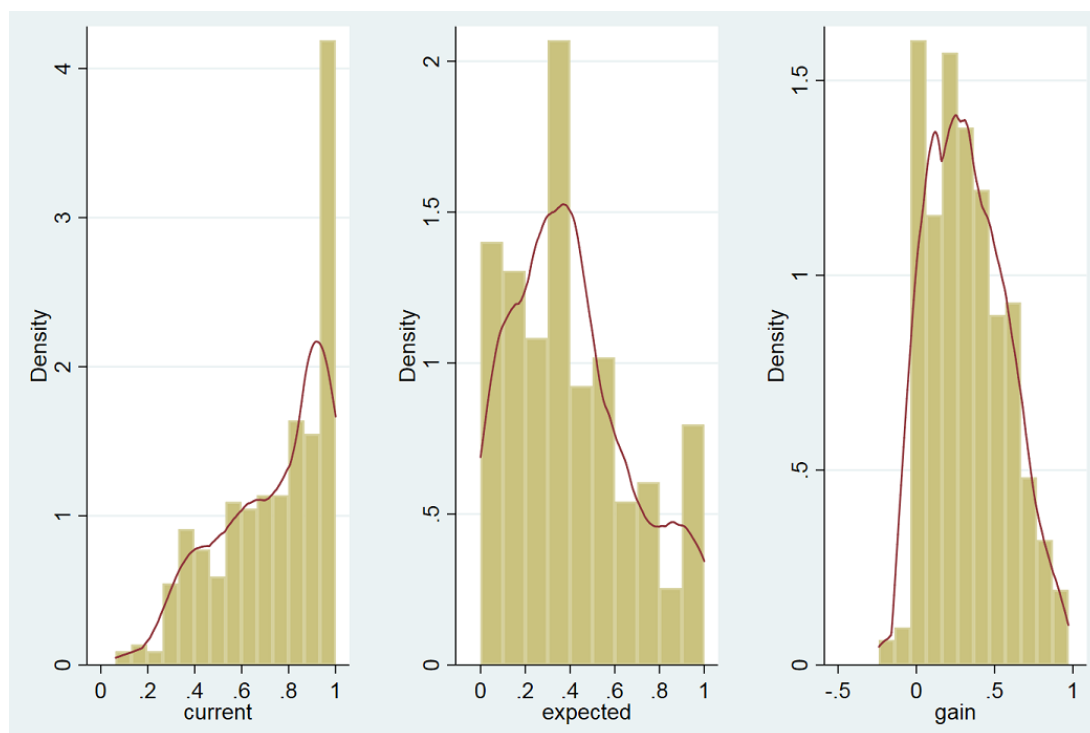
Notes: ^a overall SCRQoL-score ranges between 0 and 21

^b for single domains the value ranges between 0 and 3 for current and expected and between -3 and 3 for impact

Source: EXCELC INT C AUT 2016/2017

The density plot visualizes the distribution of informal carers' QoL (Figure 4). The density values on the x-axis account for the relative frequency of QoL states. The ASCOT current index is negatively skewed with a peak at 1, indicating a relative high share of informal carers reporting ideal states of current QoL. For the expected QoL of informal carers without LTC services the distribution of the preference-weighted SCRQoL score is positively skewed. The gain index is very close to a normal distribution with a peak around 0.3. This means that LTC services have an effect on quality of life of informal carer across all seven domains. On average informal carers' QoL had been improved by 0.3.

Figure 4. Preference-weighted scores for ASCOT for informal carers



Source: EXCELC INT C AUT 2016/2017, n=328|314|309

3.3.2 FEASIBILITY OF THE ASCOT-SURVEY FOR INFORMAL CARERS (ASCOT-CARER)

In order to assess the feasibility of the ASCOT survey for informal carers, we assessed the understanding of the ASCOT questions, the amount of reflection taken and completion rate of the expected questions.

Table 3 illustrates that according to the interviewers' perception, the ASCOT questions were completely understood by nearly three quarters of the informal care sample (including pairs and solos), 10% understood a little and only 2% did not understand much of the task.

We assumed that the assessment of the QoL in absence of LTC services would be the most demanding task of the ASCOT survey as cognitive interviews in England showed the potential sensitivity to this

question (Rand/Malley et al. 2012). Thus, we evaluated the related degree of reflection and the self-rated feasibility (Table 3). Almost half of the sample seemed to have reflected on the expected QoL states without LTC services carefully before giving an answer and one third reported to give at least careful consideration. Less than 8% of the interviewers reported that the respondents had little or no consideration of the questions. Considering the self-ratings of the respondents, the expected questions appeared to be a bit more difficult with more than 20% reporting some or many difficulties answering the expected question. Still two thirds of the sample reported that answering was quite easy or easy.

A high majority of the sample, nearly four fifths, reported that they thought of stepping in and taking responsibility for the care tasks when they answered the expected question (see ASCOT step-in rate in Table 3). The high step-in rate is further evidence for the informal carers' understanding of the expected ASCOT question and for the value added of services for informal carers.

Table 3. Levels of understanding and reflection of informal carers on the ASCOT-questions

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Understanding of ASCOT (recorded by interviewer)						
Understood completely	254	73.84	116	75.32	138	72.63
Understood a great deal	51	14.83	23	14.94	28	14.74
Understood a little	32	9.30	13	8.44	19	10.00
Did not understand very much	5	1.45	1	0.65	4	2.11
Did not understand at all	1	0.29	1	0.65	0	0.00
Missing	1	0.29	0	0.00	1	0.53
Reflection on expected question (recorded by interviewer)						
Very careful consideration	149	43.31	60	38.96	89	46.84
Careful consideration	115	33.43	53	34.42	62	32.63
Some consideration	51	14.83	30	19.48	21	11.05
Little consideration	24	6.98	10	6.49	14	7.37
No consideration	4	1.16	1	0.65	3	1.58
Missing	1	0.29	0	0.00	1	0.53
Self-rated feasibility of answering the expected questions						
Very easy	141	40.99	69	44.81	72	37.89
Quite easy	75	21.80	28	18.18	47	24.74
Neither difficult nor easy	45	13.08	20	12.99	25	13.16
Quite difficult	48	13.95	26	16.88	22	11.58
Very difficult	31	9.01	10	6.49	21	11.05
Missing	4	1.16	1	0.65	3	1.58
ASCOT_step in						
No	60	17.44	26	16.88	34	17.89
Yes	274	79.65	125	81.17	149	78.42
Missing	10	2.91	3	1.95	7	3.69
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

3.4 INFORMAL CARER SERVICE RECEIPT

Public support for informal carers is provided at the national and regional levels and includes a variety of services such as national cash benefits, short-term care, or information and advice (Schneider/Sundström et al. 2016; Kieninger/Trukeschitz 2018). Table 4 lists the uptake rate of the different types of services available for informal carers.

Nearly three quarters of all informal carers in the sample reported no use of the carer services listed in Table 4. Only 26% reported using one or more carer services of the list. In addition, a negligible number of respondents reported the use of services other than those listed, which indicates that the list in Table 4 represents the services available. Overall, the uptake-rate of solo carers was higher (34%) than the uptake rate of carers when the care-dependent person was able to be interviewed (17%). Nevertheless, given the variety of services available for informal carers, the uptake rate was very low.

Care information services and advice were given most often as a response (11%), while about 7% reported the use of short-term care services. Short-term care services enable informal carers to take some time off while the person in need of care temporarily receives professional care at a nursing home. Nearly 6% of the carer sample indicated receiving financial support including tax deductions, social security protection for carers, or financial contribution to substitute care (such as short-term care). Only two respondents reported receipt of paid care leave or the option to work part time (for a maximum of 6 months). This service, however, was only relevant to 25% of the carer sample that reported being in paid employment.

Table 4. Utilization of informal carer services by type of service

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Use of services for informal carers ^a	91	26.45	26	16.88	65	34.21
Info & advice	39	11.34	13	8.44	26	13.68
Short-term care service	24	6.98	6	3.90	18	9.47
Financial support for carers	17	4.94	4	2.60	13	6.84
Support from a carers' group	12	3.49	4	2.60	8	4.21
Training for carers	9	2.62	4	2.60	5	2.63
Discharge service for carers = "Angehörigen-/ Pflege- Entlastungsdienst (PED)"	5	1.45	1	0.65	4	2.11
Info & advice - "carer service line" ^b	4	1.16	1	0.65	3	1.58
Financial support for carers - substitute care (financial contribution)	3	0.87	0	0.00	3	1.58
Support to stay in employment - paid care leave/part time work for carer	2	0.58	1	0.65	1	0.53
Support to stay in employment - "family hospice leave"	0	0.00	0	0.00	0	0.00
Other carers' services	3	0.87	1	0.65	2	1.05
None of these services	253	73.55	128	83.12	125	65.79
TOTAL	344	100	154	100	190	100

Notes: ^a multiple choices possible

^b A free-of-charge telephone consultation for any request care-related or not ('Bürgertelefon') replaced the former carer service line 'Pflegetelefon'

Source: EXCELC INT C AUT 2016/2017

3.5 SELF-RATED HEALTH OF INFORMAL CARERS

Health condition and health status, as measured by the self-rated health of the carer, and the long-term-illness and health-related quality of life, measured by EQ5D-instrument, have been shown to be key predictors of care-related quality of life (Rand/Malley 2017). Looking at the health condition self-assessments in Table 5, the majority of the carer sample considered their health as good or very good. A further third rated their health as fair and very few indicated bad health. Although half of the sample reported dealing with a long-term illness, this does not seem to correlate with a bad health status.

Table 5. Self-rated health condition and long-term-illness of informal carers

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Self-rated health						
Very good	56	16.28	26	16.88	30	15.79
Good	149	43.31	68	44.16	81	42.63
Fair	115	33.43	49	31.82	66	34.74
Bad	20	5.81	9	5.84	11	5.79
Very bad	3	0.87	2	1.30	1	0.53
Missing	1	0.29	0	0.00	1	0.53
Long-term-illness						
Yes	168	48.84	73	47.40	95	49.47
No	174	50.58	80	51.95	94	50.00
Missing	2	0.58	1	0.65	1	0.53
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

The EQ-5D-instrument (see EuroQol Group 1990) was used to measure health-related quality of life along five dimensions with three response levels to generate utility indices and health profiles. Overall, a substantial portion of the carer sample reported no problems in most dimensions, as illustrated in Table 6. However, still quite a few respondents experienced at least some problems in certain domains. The most prevalent problems reported were for pain and discomfort, with more than half of the respondents indicating having some problems and 5% having extreme problems. Psychological strain expressed by anxiety or depression seemed to be an issue for at least two fifths of the carer sample. Mobility was causing some problems for one quarter of the carer sample and more than one quarter indicated some problems when it comes to usual activities that are often connected with mobility. The fewest difficulties were reported regarding self-care, but still 8% indicated some problems.

Table 6. Health-related quality of life of informal carers, EQ-5D

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
EQ-5D mobility						
No problems	266	77.33	123	79.87	143	75.26
Some problems	77	22.38	31	20.13	46	24.21
Extreme problems	0	0.00	0	0.00	0	0.00
Missing	1	0.29	0	0.00	1	0.53
EQ-5D self-care						
No problems	319	92.73	146	94.81	173	91.05
Some problems	23	6.69	8	5.19	15	7.89
Extreme problems	0	0.00	0	0.00	0	0.00
Missing	2	0.58	0	0.00	2	1.05
EQ-5D usual activities						
No problems	249	71.51	117	75.97	129	67.89
Some problems	89	25.87	34	22.08	55	28.95
Extreme problems	6	1.74	2	1.30	4	2.11
Missing	3	0.87	1	0.65	2	1.05
EQ-5D pain/discomfort						
No problems	153	44.48	75	48.70	78	41.0
Some problems	171	49.71	71	46.10	100	52.63
Extreme problems	18	5.23	8	5.19	10	5.26
Missing	2	0.58	0	0.00	2	1.05
EQ-5D anxiety/depression						
No problems	216	62.79	106	68.83	110	57.89
Some problems	120	34.88	45	29.22	75	39.47
Extreme problems	7	2.03	3	1.95	4	2.11
Missing	1	0.29	0	0.00	1	0.53
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

Responses to the EQ-5D items were converted into a single index (as shown in Table 7) using weights based on the German population (see Claes/Greiner et al. 1999) because Austrian weights were not available. For more details on the approach, see the descriptive paper for the English sample (Malley 2017). The mean utility score is rather high at 0.87 (where 1 is maximum health) with values ranging from 0.18 to 1. Comparing it to the average utility index of the service user sample (0.54) (see Trukeschitz/Litschauer et al. 2018) the score is – as to be expected – much higher for the informal carers.

Table 7. Informal carers: distribution of (I)ADL indices and EQ-5D index

	mean	min	median	max	SD	skew	kurtosis	n
EQ-5D utility index	0.87	0.18	0.89	1	0.18	-2.26	8.37	339

Source: EXCELC INT C AUT 2016/2017

3.6 SELF-RATED EFFECTS OF CARING ON THE CARERS' HEALTH

Informal care provision seemed to have a considerable impact on the caregivers' health in terms of their mental and physical condition. More than three quarters reported at least one of the listed symptoms related to caring (see Table 8). Half of the sample reported fatigue and a similar number of respondents reported a general feeling of stress as a result of caring activities. Two fifths indicated that they experienced physical strain due to the caring tasks and another two fifths reported irritability. Close to two thirds of the sample reported that they had experienced depressive moods in association with caring duties and almost the same number of respondents stated sleeping problems. It has to be considered, however, that the reported health issues may reflect a short-term effect (experienced only occasionally) or also a long-term effect on health, as no information was collected on the duration of the issues.

In comparison to the paired sample, the health impairment through caring was higher for solo carers: more than four fifths of the solo carer sample reported care-related health issues and the impacts were stronger for all indicators listed (Table 8).

Table 8. Self-rated effects of caring on health of informal carers

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
No effect of caring on health	79	22.97	50	32.47	29	15.26
Yes ^a :	263	76.45	104	67.53	159	83.68
Feeling tired	171	49.71	62	40.26	109	57.37
General feeling of stress	168	48.84	63	40.91	105	55.26
Physical strain	141	40.99	54	35.06	87	45.79
Short-tempered	133	38.66	58	37.66	75	39.47
Feeling depressed	116	33.72	42	27.27	74	38.95
Disturbed sleep	113	32.85	41	26.62	72	37.89
Had to see own GP	71	20.64	28	18.18	43	22.63
Developed own condition /made existing condition worse	41	11.92	18	11.69	23	12.11
Loss of appetite	20	5.81	7	4.55	13	6.84
Other effect on health	9	2.62	4	2.60	5	2.63
Missing	2	0.58	0	0.00	2	1.05
TOTAL	344	100	154	100	190	100

Notes: ^a multiple answers possible

Source: EXCELC INT C AUT 2016/2017

3.7 CHARACTERISTICS OF THE CARE RECIPIENT AND CAREGIVING SITUATION

Other factors associated with the quality of life of informal carers may be related to the characteristics of the care recipient and characteristics of the caregiving situation, such as duration and weekly hours of caregiving.

Table 9 shows the main characteristics of the care recipient in terms of mental condition. For all items, the share of cognitive difficulties was much higher in the solo-carer sample than in the pairs-sample. This is not surprising as cognitive impairments were the main reason for carrying out an interview with the carer only. The most significant difficulties were reported for memory and orientation. Nearly three fifths of the whole sample reported short-term memory problems and half reported disorientation. A further third indicated that the care recipient had no or very low decision-making ability.

In terms of communication, the performance of the care recipients appeared to be slightly better. More than three fifths of the carer sample reported that the care recipient understands or usually understands others. Again over three fifths reported that the care recipient is comprehensible or usually comprehensible for others. 70% of the carers stated that they never or very rarely observed challenging behaviors of the care recipient. Still, more than 10% reported frequently having to deal with challenging behavior (Table 9).

Table 9. Characteristics of the care recipient

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Short-term memory problems						
Yes	202	58.72	59	38.31	143	75.26
No	139	40.41	95	61.69	44	23.16
Missing	3	0.87	0	0.00	3	1.58
Disorientation						
Yes	172	50.00	39	25.32	133	70.00
No	172	50.00	115	74.68	57	30.00
Decision making						
Rarely/never makes decisions	118	34.30	17	11.04	101	53.16
Insecure decisions	52	15.12	19	12.34	33	17.37
Some insecurities	59	17.15	30	19.48	29	15.26
Decisions logical & reasonable	111	32.27	84	54.55	27	14.21
Missing	4	1.16	4	2.60	0	0.00
Communication - comprehensibility others → SU						
Understands	97	28.20	66	42.86	31	16.32
Usually understands	69	35.47	60	38.96	62	32.63
Sometimes understands	122	20.06	25	16.23	44	23.16
Rarely/never understands	53	15.41	1	0.65	52	27.37
Missing	3	0.87	2	1.30	1	0.53
Communication comprehensibility SU → others						
Understood	124	36.05	89	57.79	35	18.42
Usually understood	98	28.49	49	31.82	49	25.79
Sometimes understood	68	19.77	12	7.79	56	29.47
Rarely/never understood	51	14.83	2	1.30	49	25.79
Missing	3	0.87	2	1.30	1	0.53
Challenging behaviors						
Never	164	47.67	86	55.84	78	41.05
Very unusual	78	22.67	35	22.73	43	22.63
Sometimes	57	16.57	19	12.34	38	20.00
Frequently	43	12.50	14	9.09	29	15.26
Missing	2	0.58	0	0.00	2	1.05
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

The intensity of caregiving in terms of duration and hours per week is shown in Table 10. The great majority of all carer respondents (87%) reported supporting one person; slightly more than 10% provided care for two people. Concerning the duration of caregiving, most of the respondents have been caring for the person between one and ten years. More specifically, a fifth reported a duration between one and three years, another fifth between three and five years and a fourth reported a duration between five and under ten years. Close to 15% have already been supporting someone for between ten and fifteen years. The duration of caregiving is slightly but not much higher for all categories comparing the solo-carer sample to the paired sample. The hours of caregiving per week paint a rather heterogeneous picture and only slightly more respondents from the solo-carer-sample appeared to spend more time per week with the care recipient.

Table 10. Characteristics of the caregiving situation

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Number of people supported by the informal carer						
One	299	86.92	130	84.42	168	88.95
Two	38	11.05	18	11.69	20	10.53
Three	3	0.87	3	1.95	0	0.00
Four or more	4	1.16	3	1.95	1	0.53
Duration of care giving						
Less than 6 months	5	1.45	2	1.30	3	1.58
Six months, less than 1 year	9	2.62	4	2.60	5	2.63
1 year - less than 3 years	74	21.51	40	25.97	34	17.89
3 years - less than 5 years	77	22.38	34	22.08	43	22.63
5 years - less than 10 years	90	26.16	32	20.78	58	30.53
10 years - less than 15 years	47	13.66	19	12.34	28	14.74
15 years - less than 20 years	15	4.36	3	1.95	12	6.32
More than 20 years	23	6.69	17	11.04	6	3.16
Missing	4	1.16	3	1.95	1	0.53
Hours of care giving per week						
0-4 hours	25	7.27	15	9.74	10	5.26
5-9 hours	42	12.21	24	15.58	18	9.47
10-19 hours	68	19.77	34	22.08	34	17.89
20-34 hours	47	13.66	18	11.69	29	15.26
35-49 hours	25	7.27	13	8.44	12	6.32
50-99 hours	55	15.99	18	11.69	37	19.47
100 hours or more	69	20.06	28	18.18	41	21.58
Missing	13	3.77	4	2.60	9	4.74
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

A majority of the informal carers stated carrying out a high number of different care tasks including a high share of social and emotional support (see Table 11). From a list of eleven different care activities, three fifths of the informal carers reported carrying out between nine and eleven of these tasks. Another fourth reported between seven and eight tasks. Over 95% of the sample reported offering emotional support and an even higher share saw their role in keeping service users' company. Concerning the more specific tasks, close to 90% of the respondents indicated help with arranging LTC care services, with more than 90% reported help with paperwork and again over 90% reported other practical help. Respondents are, to a lesser extent (but still with 67% of the sample), carrying out personal care tasks and around the same proportion of respondents reported supplying physical help.

Table 11. Type and number of tasks carried out by the informal carer

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Carer tasks						
Keeping an eye on	338	98.26	149	96.75	189	99.47
Keeping company	332	96.51	148	96.10	184	96.84
Emotional support	330	95.93	147	95.45	183	96.32
Other practical help	316	91.86	143	92.86	173	91.05
Help with paperwork	311	90.41	129	83.77	182	95.79
Help with services/benefits	301	87.50	119	77.27	182	95.79
Taking him/her out	271	78.78	128	83.12	143	75.26
Physical help	234	68.02	98	63.64	136	71.58
Personal care	232	67.44	87	56.49	145	76.32
Giving medicines	223	64.83	81	52.60	142	74.74
Other help	110	29.07	42	27.27	58	30.53
Number of care tasks						
1-2	3	0.87	3	1.95	0	0.00
3-4	5	1.45	3	1.95	2	1.05
5-6	42	12.21	26	16.88	16	8.42
7-8	85	24.71	46	29.87	39	20.53
9-10	162	47.09	58	37.66	104	54.74
11	47	13.66	18	11.69	29	15.26
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

For more information on informal support of home care service users by tasks see discussion paper on the Austrian service user sample (Trukeschitz/Litschauer et al. 2018).

3.8 IMMEDIATE ENVIRONMENT – SUITABILITY FOR CARING

Around 70% of the informal carers seemed content with the immediate environment in which the care was delivered and reported that the design of the home was (for the most part) appropriate for caring (see Table 12). A further 20% of the respondents reported that the design of the home met only some of their needs and 10% rated the home as inappropriate for caring.

Nearly two thirds of the informal carers resided with the care recipient with a higher share in the solo-carer sample (over 70%).

Considering other responsibilities of the carer towards their own children, only 7% of respondents reported living with one or two children in the household. Therefore, it seems that the majority of the carers did not have to meet additional parental responsibilities at home.

Table 12. Characteristics of the immediate environment of the care setting

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Design of own / SU's home for caring						
Very well	141	40.99	72	46.75	69	36.32
To most needs	102	29.65	41	26.62	61	32.11
To some needs	68	19.77	28	18.18	40	21.05
Inappropriate	31	9.01	12	7.79	19	10.00
Missing	2	0.58	1	0.65	1	0.53
Co-residing with Service User						
Yes	218	63.37	83	53.90	135	71.05
No	125	36.34	71	46.10	54	28.42
Missing	1	0.29	0	0.00	1	1.00
Children in Household						
None	318	92.44	140	90.91	178	93.68
1	16	4.65	10	6.49	6	3.16
2	9	2.62	3	1.95	6	3.16
3	1	0.29	1	0.65	0	0.00
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

3.9 FINANCIAL AND SOCIAL RESOURCES OF INFORMAL CARERS

3.9.1 FINANCIAL RESOURCES OF INFORMAL CARERS

The financial situation of the carer may be a proxy indicator for the capacity of the household to purchase private support (Malley 2017). The income distribution in Table 13 reflects a rather heterogeneous picture of high-income and low-income households. The first, second and ninth, tenth percentile has each below 7% of informal carers. Around 50% of informal carers are in the middle of the income distribution between the third and sixth percentile. (Considering the living arrangement of the household in section 3.2, it is assumed that the reported household income mainly refers to a two-person household).

Fewer than 10% of the informal carers in the sample reported some or severe financial difficulties, with the majority reporting that they manage quite well or very well (65%) and a further 25% considering their financial situation as alright. However, nearly a quarter of the respondents reported a negative effect of care on their financial situation.

Table 13. Income distribution and self-reported financial situation of the household of informal carers

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Income distribution per household (percentiles)						
less than 13,677 €/pa	15	4.36	10	6.49	5	2.63
13,677 – less than 18,831 €/pa	22	6.40	13	8.44	9	4.74
18,831 – less than 23,554 €/pa	43	12.50	16	10.39	27	14.21
23,554 – less than 28,741 €/pa	44	12.79	18	11.69	26	13.68
28,741 – less than 34,638 €/pa	40	11.63	16	10.39	24	12.63
34,638 – less than 40,965 €/pa	43	12.50	20	12.99	23	12.11
40,965 – less than 48,067 €/pa	33	9.59	12	7.79	21	11.05
48,067 – less than 57,910 €/pa	31	9.01	14	9.09	17	8.95
57,910 – less than 73,881 €/pa	14	4.07	6	3.90	8	4.21
73,881 €/pa or more	10	2.91	8	5.19	2	1.05
Missing	49	14.24	21	13.64	28	14.74
Self-reported financial situation						
I/we manage very well	69	20.06	33	21.43	36	18.95
I/we manage quite well	156	45.35	68	44.16	88	46.32
I/we get by alright	84	24.42	33	21.43	51	26.84
I/we have some financial difficulties	23	6.69	12	7.79	11	5.79
I/we have severe financial difficulties	9	2.62	6	3.90	3	1.58
Missing	3	0.87	2	1.30	1	0.53
Financial difficulties as a consequence of caring						
Yes	79	22.97	28	18.18	51	26.84
No	262	76.16	124	80.52	138	72.63
Missing	3	0.87	2	1.30	1	0.53
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

3.9.2 SOCIAL RESOURCES OF INFORMAL CARERS

The majority of the carers reported the support of at least one other person who is also regularly (but usually to a lesser extent) taking care of the care recipient. Still, 40% of the sample did not receive extra help from other informal carers. The number of main carers receiving informal support is only slightly higher for the solo carer sample compared to the paired sample (+ 2.5 % points)

Table 14 Informal support of main carer

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Other informal carers						
Yes	206	59.88	90	58.44	116	61.05
No	138	40.12	64	41.56	74	38.95
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

3.10 DETAILS OF SURVEY DELIVERY

Responses given to survey questions may be influenced by different external factors, such as the presence of someone else during the interview or the gender of the interviewer. In addition, the number of interviews per interviewer may also affect the accuracy of the conduct and the response rates in terms of routine and motivation of the interviewer.

3.10.1 ADMINISTRATION MODE AND SURVEY DELIVERY

The research team preferred interviews to be conducted privately as having someone else present in the room during the survey may have an influence on the answers given. However, as Table 15 shows, it was not always possible for the interviewers to insist on complete privacy and close to half of the interviews (45%) were conducted with the presence of someone else during the interview, often the care recipient. Given a high share of co-residency with the care recipient (over 60%, see section 3.5.4), some carers did not want to or could not leave the care recipients alone for 2 hours. In other cases, the premises of the apartments were not suitable for separation.

The presence of the care recipient in particular may influence responses to sensitive questions, such as the cognitive characteristics of the care recipient. However, in the majority of the cases the interviewers reported that the presence of the LTC service user did not seem to affect the responses of the interviewee (interviewer reports).

Table 15. Presence of others during the interview with the informal carer

	ALL		PAIRS		SOLO	
	n	%	n	%	n	%
Someone else present at interview						
Yes	156	45.35	72	46.75	84	44.21
No	188	54.65	82	53.25	106	55.79
TOTAL	344	100	154	100	190	100

Source: EXCELC INT C AUT 2016/2017

3.10.2 NUMBER OF INTERVIEWERS

A total of 60 interviewers conducted interviews with informal carers. Two thirds of the interviewers were women (Table 16). On average, interviewers conducted 8 interviews with a maximum of 17 by one interviewer (Table 17). As the motivation of the interviewer is important to increase response rates and maintain the motivation of the respondent (Bowling 2005), conducting 5 to 10 interviews per interviewer seemed reasonable.

Table 16. Number of informal carer interviewers

	n	%
Number of Interviewers		
Male	20	33.33
Female	40	66.67
TOTAL	60	100

Source: EXCELC INT C AUT 2016/2017, own calculations

Table 17. Informal carer interviews per interviewer

	Mean	Min	Max	Median
Interviews per Interviewer	8.29	1	17	8

Source: EXCELC INT C AUT 2016/2017

4 SUMMARY & CONCLUSIONS

344 informal carers were interviewed on their care situation and their care-related quality of life in Austria during a period of 14 months in the years 2016/17. The study addressed informal carers (family members, friends, neighbors) who have provided support to an older person and focused on the impact of home care services (directed toward the carer and to the care recipient) on the carers' quality of life (QoL). Fewer than half of the interviews (154) corresponded to a service user interview and the remaining 190 interviews were conducted with the carer alone for various reasons (e.g. the service user was unable or did not want to).

Informal carers of home care service users in Austria were difficult to approach. As there is no national data base on informal carers in Austria, informal carers of home care service users had to be contracted after the service user agreed to contribute to the interview. Informal carer-service user pairs were hard to approach. Some informal carers refused to take part in the study, other informal carers expressed their interest in taking part but their relative was no longer able to conduct a service user interview. Thus, the number of pairs was lower than expected although we completed more interviews with informal carers than planned.

Home-based care services had on average a positive impact on the quality of life of informal carers in each domain, with the highest score for *Control-over-daily-life* and the lowest score for *Looking-after-yourself*. The Adult Social Care Outcomes Toolkit (ASCOT Carer) for informal carers was used to measure social care-related QoL of informal carers across seven life domains. Overall, results show a positive impact of LTC service provision on carers' QoL, improving the QoL by 0.3 –points on the ASCOT-scale on average. Impact of home-based care service provision were highest for the *Control-over-daily-life* and for *Occupation* domains and lowest for *Looking-after-yourself* and *Time-and-space-to-be-yourself*.

Only a minority of informal carers used services explicitly directed to support informal carers. Despite the availability of a variety of services directed at the carer (such as national cash benefits, short-term care, information and advice), just a quarter of the informal carers in the sample reported the use of one or more services for informal caregivers.

The majority of informal carers in the sample reported good or fair health; however, a great majority experienced care-related impact on health. Other factors affecting LTC-related carers' quality of life production, such as their health condition (measured by EQ5D), burden of caring, characteristics of the care-recipient and caregiving situation and contextual factors were also taken into account. The general evaluation of the informal carers' health in the sample is quite good, with an average EQ-5D-score of 0.87 (where 1 is maximum health). More than 75% of the carers in the sample, however, reported to experience care-related impact on health, such as fatigue, a general feeling of stress, physical strain or irritability.

The large majority of informal carers reported to support the home care service user with a variety of different tasks, whereby emotional and social support, supervision and practical help were indicated the most. Concerning the different tasks carried out by the informal carers, there is a high share of informal carers keeping company with the care dependent person, keeping an eye on him/her and supporting with paperwork, help with services, and accompaniment when leaving the house. The weekly hours for caregiving and the duration of caregiving are rather evenly distributed in the sample.

The majority of informal carers co-resided with the care recipient and was happy with the environment in which the care was delivered. For 70% of the informal carers of the sample, the immediate environment in which the care was delivered was appropriate and more than three fifths of the carers co-resided with the care recipient.

Most of the informal carers reported a good or very good financial situation. Only very few carers of the sample seemed to have financial difficulties (fewer than 10%) and close to one fourth reported a negative effect of care on their financial situation.

Strengths and limitations of the data on informal carers in Austria

The data has several strengths, particularly due to the sample, which was large and evenly distributed across all Austrian regions, enabling a deep analysis and providing representative results. A variety of informal carers - not only family carers but also neighbors and friends who provided care - were included in the sample. The collection of data through personal standardized interviews provides methodological strength, as high response rates were achieved and good data quality was ensured. However, data limitations may lie in the sample characteristics, as middle-class respondents comprised the majority of the study. More socio-economic diversity would therefore strengthen the findings. Concerning the process of data collection, a potential risk of interview bias (such as social desirability bias) has to be acknowledged. Due to the EXCELC projects' aims, we collected data on informal carers of home care service users, thus the data cannot be used for an overall assessment of informal care in Austria. Nonetheless, the data make quite an important contribution to the data

base for evaluations of the impact of interventions on the quality of life of informal carers using the ASCOT informal carer measure. A major focus of future work will be the assessment of ASCOT for informal carers, testing the validity of the instrument. Further, factors associated with LTC service-induced changes in quality of life of informal carers should be examined.

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