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Quality of life in home care

A report based on the WHOQOL-BREF questionnaire

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1. Introduction

Within an EU-funded project on home care, the Austrian Red Cross conducted a survey on the living conditions of family member carers. The survey is based on the WHOQOL-BREF questionnaire by the World Health Organisation (WHO), thus enabling comparability to previous surveys which have applied the same tools. The questionnaire involves questions on socio-demographic factors and those relating to the quality of life, and was supplemented by several questions involving the respondents' use of (supporting and special) services. As for the latter, the questions focus on both current services (i.e. which services are currently used by the respondent) and potential future services (i.e. which services would the respondent like to use in the future).

This report is prepared by the NPO & SE Competence Center, which was assigned to analyse the collected data based on the scoring syntax by the WHO[1] as well as to provide basic insights into the relationship between quality of life, socio-demographic factors and the use of services. The structure of the report corresponds to the following structure: Chapter 2 provides some basic insights into the composition of the sample, which builds the foundation for the subsequent interpretation. It discusses frequencies in socio-demographic factors (section 2.1), the use of services (section 2.2), and the quality of life (section 2.3). Subsequently, chapter 3 is dedicated to an exploratory analysis considering potential relationships between quality of life and socio-demographic factors (section 3.1), as well as between quality of life and the use of services (section 3.2). In order to analyse whether the visually observable patterns withstand statistical tests, chapter 4 applies non-parametric tests (in particular, Mann-Whitney and Kruskal-Wallis test). Finally, chapter 5 summarises the results, draws conclusions, and points out future potentials.

1.1. RESEARCH QUESTION

This report is meant to fulfil two main objectives: Firstly, it delivers a descriptive overview of the sample (and, in particular, the quality of life) based on the syntax file of the WHO in order to provide a starting point for subsequent comparisons of the results to those of other surveys. Secondly, it gains deeper insights into relationships between the constructed indices of quality of life and socio-demographic factors, as well as quality of life and the use of services. Thereby, it enables a deeper understanding of how the mentioned aspects may determine the quality of life of family member carers.

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[1] The syntax file is available at http://depts.washington.edu/seaqol/docs/Wq_bref.txt and may be reached via http://www.who.int/mental_health/publications/whoqol/en/.

2. The sample: some basic insights

Within the survey phase, 116 questionnaires were submitted of which 90 questionnaires are complete (i.e. reached page 5 of the online survey). 26 questionnaires were quit before finishing (the majority of them on page 2 or earlier) and are thus excluded from the sample. In 3 cases, missing items were imputed using the average of (I) questions f1_4 to f8_1 (for an overview of coding and shortcuts of all questions see Table A[2] in the Appendix) or (II) all remaining indicators of the respective domain (for the assignment of variables to each domain see once more Table A in the Appendix).

The WHOQOL-BREF questionnaire involves questions on various dimensions (=domains) of the quality of life. The coding procedure corresponds to the scoring syntax provided by the WHO (see chapter 1) except for transforming the domain scores into a 0 to 20 scale instead of a 0 to 100 scale. What is more, the two basic questions on the respondent's quality of life (g1) and satisfaction with his or her health status (g4) are equally transformed (i.e. such that they lie in the interval [0, 20]) in order to facilitate comparison.

Questions on the respondent's current use of supporting and special services, which are not part of the WHOQOL-BREF questionnaire, are transformed into two new variables each. The first newly constructed variable reflects the total number of (supporting or special) services (i.e. the number of services used), the second one collapses the first variable into a yes/no-scale and thus relates to whether at least one of the services has been used. At this point it should be mentioned that these variables merely consider the listed services and do not take into account whether a respondent has individually specified services that are not listed (inserted as "other" or "additional" services). A complete list of the latter may be found in Table C to Table E in the Appendix.

2.1. SOCIO-DEMOGRAPHIC FACTORS

The sub sample of complete observations that is used in the subsequent analysis consists of 90 observations and may be described as follows: The sample includes 13 male (14.4 per cent) and 77 female (85.6 per cent) respondents (see Figure 1) of which 5 respondents (5.6 per cent) do not own a school leaving certificate, 28 respondents (31.1 per cent) completed a secondary modern school (*Hauptschule*), 20 respondents (22.2 per cent) own a general qualification (GQ) for university entrance (*Matura*), 20 respondents (22.2 per cent) completed a University of Applied Sciences (*Fachhochschule*), 14 respondents (15.6 per cent) own a university degree (*Universität*), and 1 respondent (1.1 percent) has a postgraduate education (*Doktorat*). The listed figures, with 2 observations missing, are visualised in Figure 2.

As demonstrated in Figure 3, 15 respondents (16.7 per cent) are living alone, 48 respondents (53.3 per cent) are married, 12 respondents (13.3 per cent) are living in a steady relationship, 3 respondents (3.3 per cent) are separated, 10 respondents (11.1 per cent) are divorced, and 2 respondents (2.2 per cent) are widowed. As for the health status, 23 respondents (25.6 per cent) are and 67 respondents (74.4 per cent) are not currently ill (see Figure 4). A list of the specified disease and/or health problem may be found in Table B in the Appendix. With 84 respondents (93.3 per cent), the majority did not receive assistance in filling the questionnaire, whereas 6 respondents (6.7 per cent) did receive assistance (see Figure 5).

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[2] Note that all tables in the Appendix are in German in order to maintain the original wording.

Considering the respective year of birth, respondents were clustered into the following 8 age groups: {(≤25), (26-35), (36-45), (46-55), (56-65), (66-75), (76-85), (≥86)}. 1 respondent (1.1 per cent) is younger than or equal to 25 years, 2 respondents (2.2 per cent) are between 26 and 35 years, 6 respondents (6.7 per cent) are between 36 and 45 years, 31 respondents (34.8 per cent) are between 46 and 55 years), 30 respondents (33.7 per cent) are between 56 and 65 years, 12 respondents (13.5 per cent) are between 66 and 75 years, 5 respondents (5.6 per cent) are between 76 and 85 years, and 2 respondents (2.2 percent) are older than 86 years. The observation on the year of birth is missing for one respondent.

As above numbers indicate, some of the sub groups consist of a rather small sample. Considering the educational level, this particularly applies for postgraduate education (*Doktorat*). As for the family status, only few observations have been gathered for those separated or widowed, and in regards to age groups, observations for those below the age of 36 and above the age of 85 are particularly scarce. Consisting of merely 1 to 2 observations, results for these variables are expected to reflect an individual case rather than constituting a representative description of the respective group. What is more, there are several groups comprising 5 to 6 observations, which once again should be treated with caution.
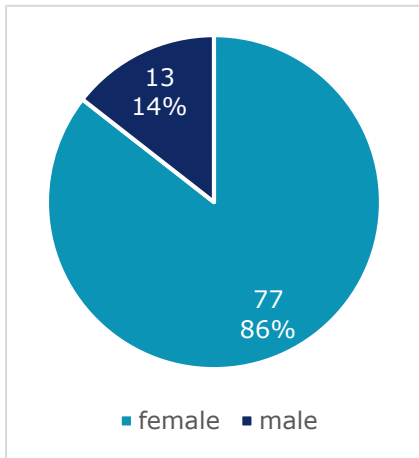
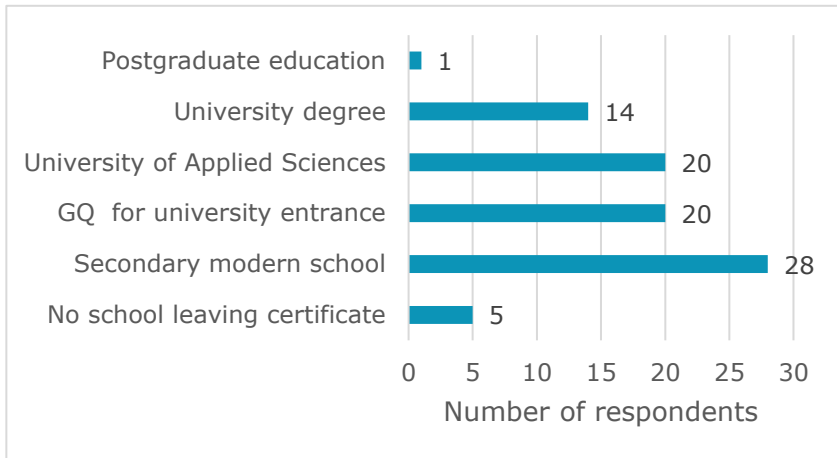FIGURE 1: GENDER (n=90)

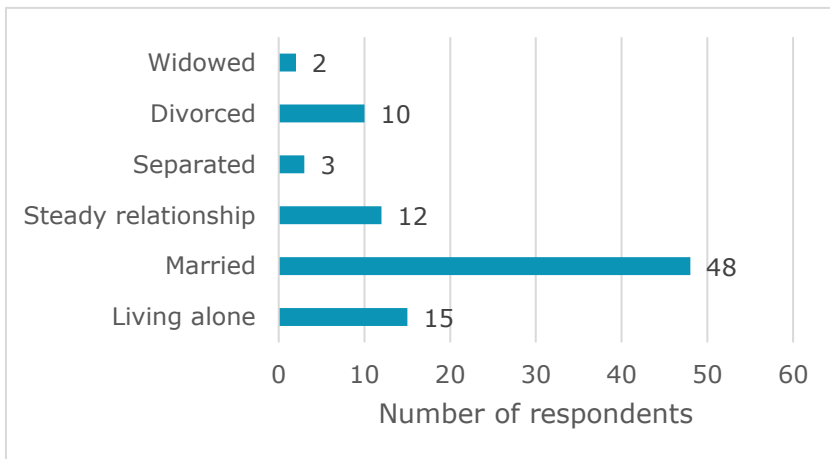FIGURE 2: EDUCATION (n=88)

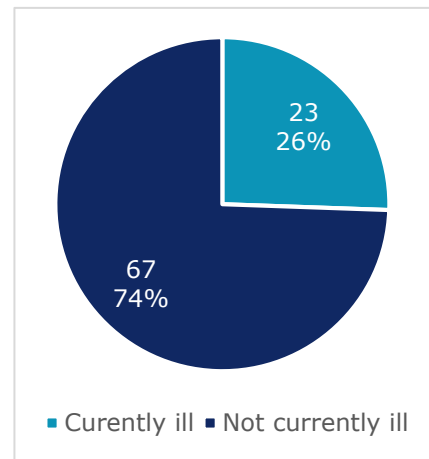FIGURE 3: FAMILY STATUS (n=90)

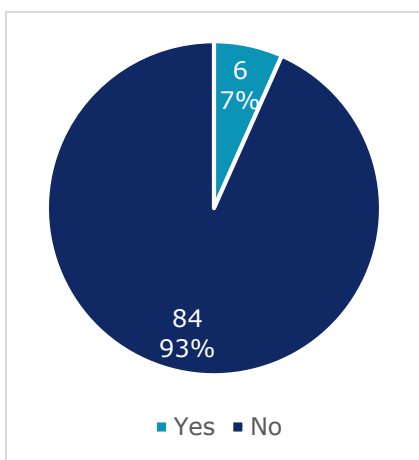FIGURE 4: CURRENT HEALTH STATUS (n=90)

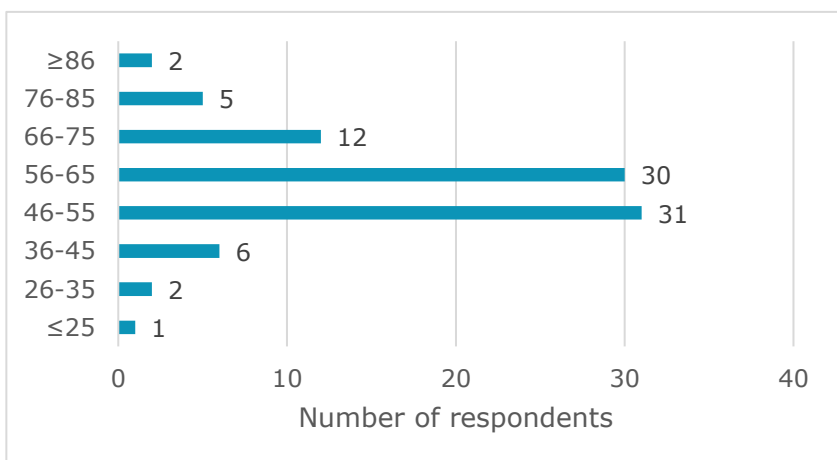FIGURE 5: ASSISTANCE IN FILLING THE QUESTIONNAIRE (n=90)

FIGURE 6: AGE GROUPS (n=89)

2.2. THE USE OF SERVICES

The use of (supporting and special services) is gathered within four additional questions (a1 to a4), and involves both current and potential future use. More precisely, future use relates to supporting services that respondents wish to use on a larger scale and special services they would like to use if possible (for ease of use, these categories are abbreviated as "current" and "future" hereinafter). Once again, German terms are maintained for all services.

As for currently used supporting services (a1 to a2), the following services were selected most frequently (in descending order): *Hauskrankenpflege*, *informelle Unterstützung*, and *Heimhilfe*. The least frequently selected service is *Besuchsdienst*, and *Essenszustellung, Besuch eines Tageszentrums, 24-Stunden-Betreuung, keine Unterstützungsleistung,* and *Sonstige* rank in the mid-range. If asked which supporting service they wish to use on a larger scale, most respondents selected *keine Unterstützungsleistung*, followed by *Sonstige, Besuch eines Tageszentrums, and Besuchsdienst.* The lowest number is observable for *Essenszustellung*, and *informelle Unterstützung, Heimhilfe, Hauskrankenpflege, and 24-Stunden-Betreuung* rank in the mid-range. The precise numbers are displayed in Figure 7 (ordered by the number of respondents for the current use of services), and a list of other (not-listed) services specified by the respondents is available in Table C and Table D in the Appendix.

As for special services, *Anleitung vor Ort* and *regelmäßiger Austausch* were selected most frequently, and *Kurse für pflegende Angehörige* least frequently. *Persönliche (psychosoziale) Beratung* and *mehrstündige Alltagsbegleitung* rank in the mid-range. If asked which special services the respondents would like to use if they were given the possibility to do so, *Mehrstündige Alltagsbegleitung* was chosen most frequently. Although *Anleitung vor Ort* and *Kurse für pflegende Angehörige* were selected least frequently, the number of respondents choosing this options is still non-negligible. *Regelmäßiger Austausch* und *persönliche (psychosoziale) Beratung* rank in the mid-range (see Figure 8, ordered by the number of respondents for the current use of services). An additional question has provided the possibility to specify further (not-listed) external services which the respondent would like to use. Results of this question may be found in Table E in the Appendix.

As mentioned earlier, additional variables have been created reflecting the total number of (supporting and special) services used and indicating whether the respondent currently uses none or at least one of the listed services (both of them excluding "other" services specified by the respondent). For both types of services, the majority of respondents uses at least one of the listed services, with the percentage being substantially higher for supporting services (80 per cent) than for special services (44 per cent; see Figure 9 and Figure 11). Considering the number of services used, the majority of those who are using services are using one of the listed services for both supporting and special services. The number then gradually decreases with the number of services used (see Figure 10 and Figure 12).

As visually shown, observations are particularly scarce for the highest number of used supporting and special services (2 respondents currently use 5 [4] supporting [special] services) and scarce for the second-highest number (5 respondents currently use 4 [3] supporting [special] services). These categories thus have to be treated with caution in the subsequent interpretation as they are expected to reflect individual views rather than generalizable results (which particularly holds true for the former).
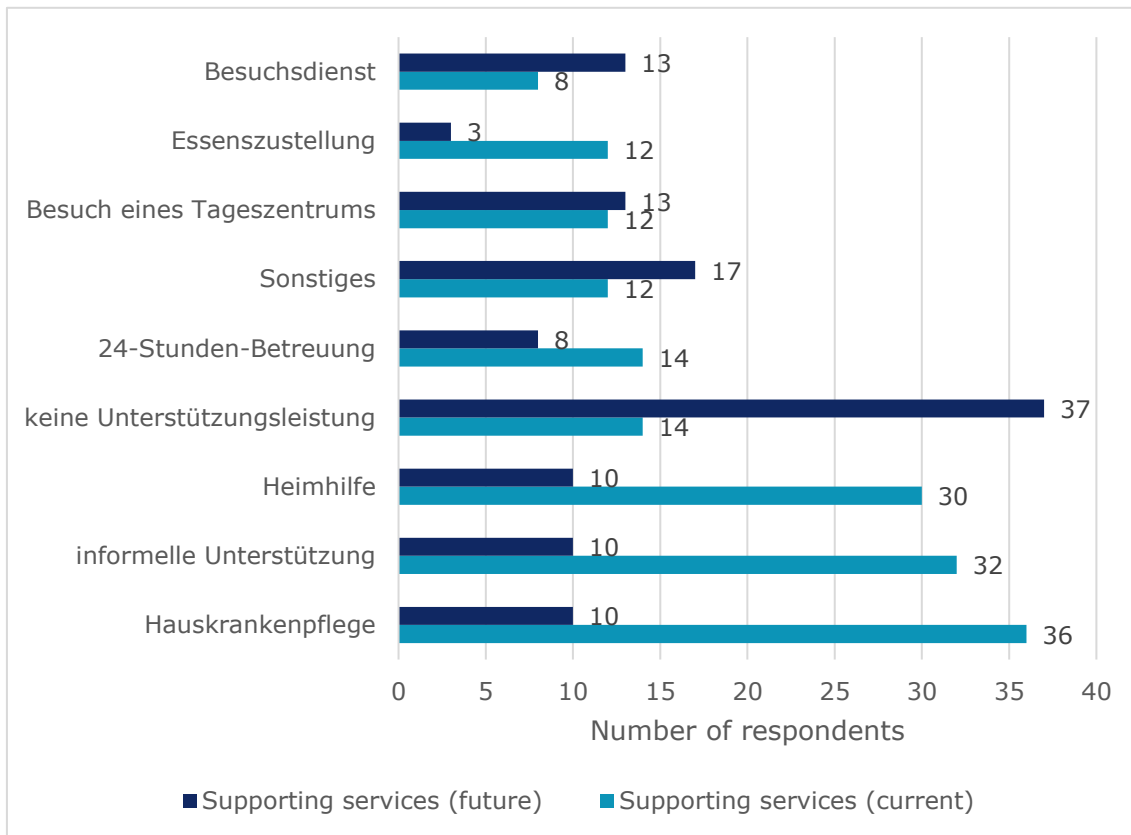
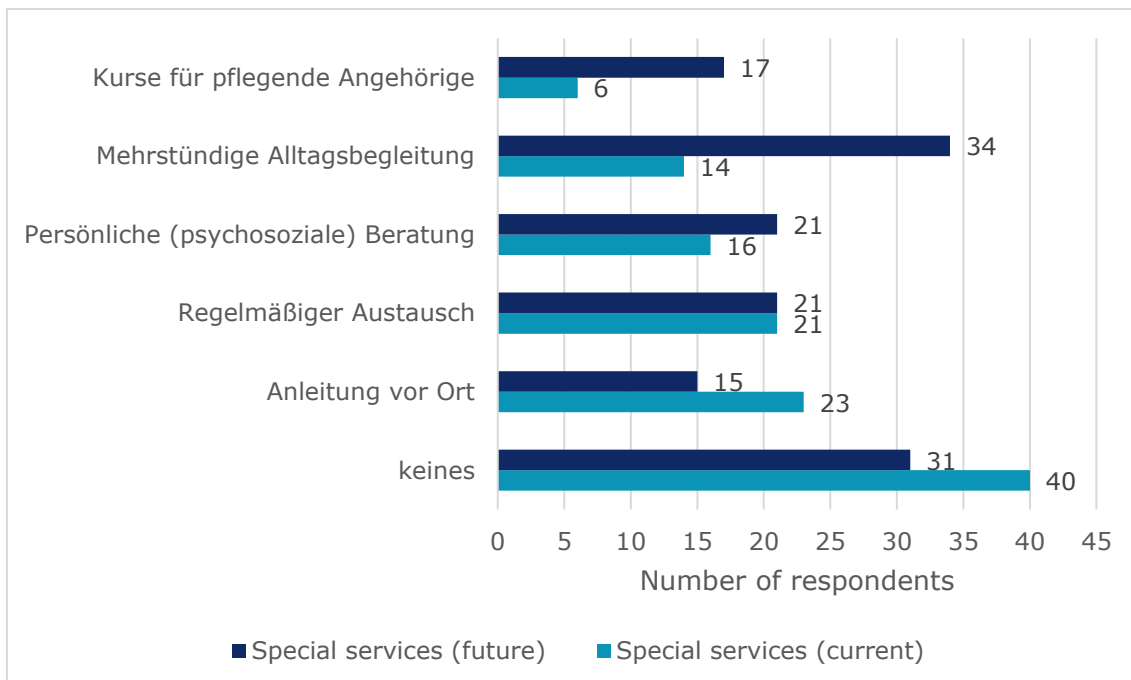FIGURE 7: CURRENT AND FUTURE USE OF SUPPORTING SERVICES

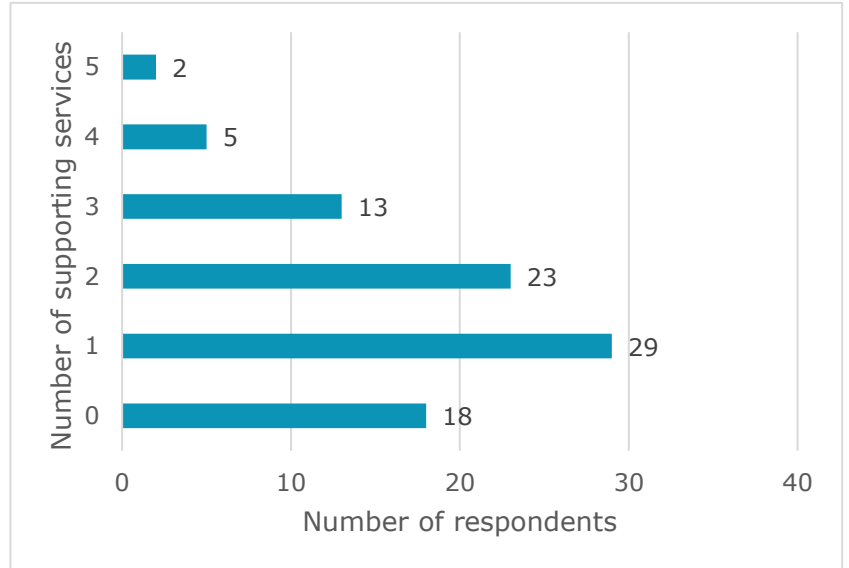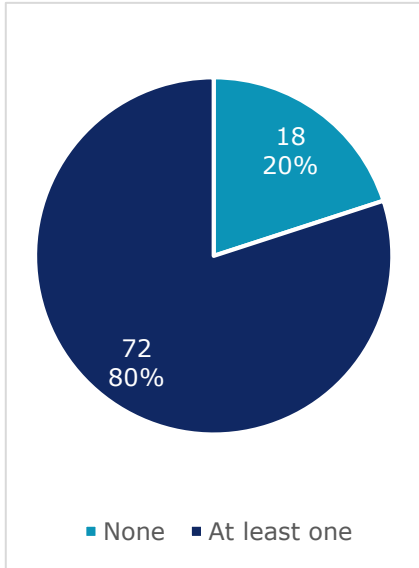FIGURE 8: CURRENT AND FUTURE USE OF SPECIAL SERVICES

FIGURE 9: USE OF SUPPORTING SERVICES (CURRENT)
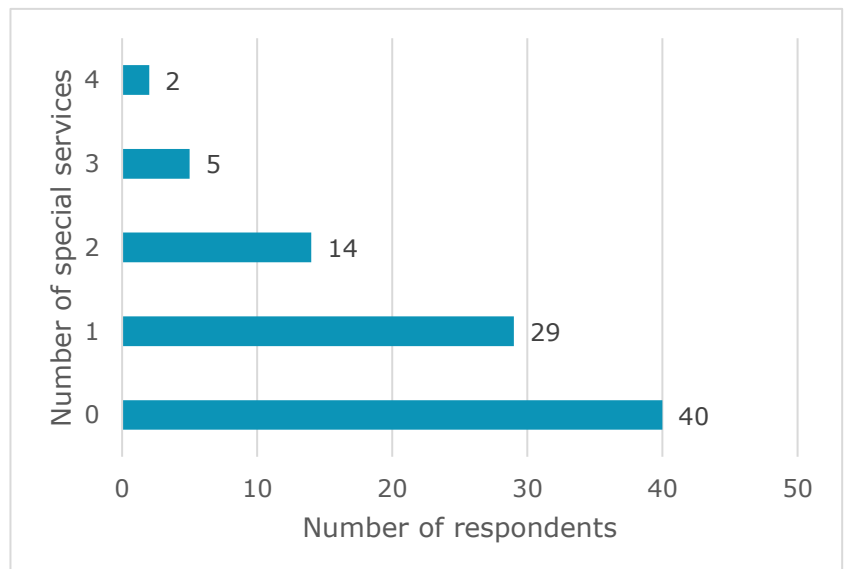

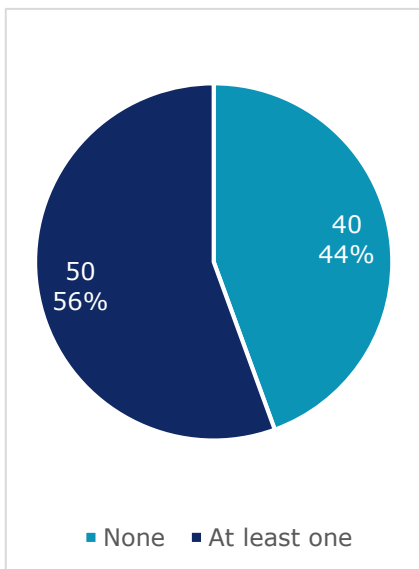FIGURE 10: NUMBER OF SUPPORTING SERVICES (CURRENT)

FIGURE 11: USE OF SPECIAL SERVICES (CURRENT)

FIGURE 12: NUMBER OF SPECIAL SERVICES (CURRENT)

2.3.   QUALITY OF LIFE

Within the WHOQOL-BREF questionnaire, two independent questions capture the overall quality of life as rated by the respondent, and the respondent's satisfaction with his or her health status. These categories do not feed into the respective domains and are thus treated separately in the subsequent analysis. In order to enable comparability to each domain, the 1 to 5 scale of both questions (g1 and g4) is transformed into a 0 to 20 scale.

As summarised in Table 1, minimum and maximum values refer to the interval boundaries, and the median amounts to 10 for both questions. On average, respondents rate their quality of life slightly higher than their health satisfaction, and both distributions are slightly skewed right (i.e. the mean lies above the median). The standard deviation amounts to 4.07 and 5.60 respectively, suggesting that in general the data points are relatively closer to the mean (i.e. the data is less scattered) for the quality of life.

Figure 13 displays frequencies (i.e. the number of respondents in each response category). It suggests that the number of respondents is more evenly distributed among response categories for health satisfaction than for the quality of life (see also the observations on standard deviations as previously discussed). As for the former, the response category selected most frequently is 15 [satisfied/*zufrieden*] (28 respondents), being closely followed by 10 [neither satisfied nor dissatisfied/*weder zufrieden noch unzufrieden*] (25 respondents) and 5 [dissatisfied/*unzufrieden*] (21 respondents). On the contrary, the gap between the leading and the second leading response is much more pronounced for the quality of life. 44 respondents rate their quality of life to be 10 [moderate/*mittelmäßig*], followed by 27 respondents in the response category 15 [good/*gut*]. At the tails of the distribution, it is observable that more respondents choose the maximum [very satisfied/*sehr zufrieden*] and minimum value [very dissatisfied/*sehr unzufrieden*] if asked for their health satisfaction than if rating their quality of life (for which maximum and minimum values correspond to very good [*sehr gut*] and very poor [*sehr schlecht*]). For example, only 1 respondent indicates that he or she has a very poor quality of life. As for health satisfaction, the number of respondents in the associated category is 5.

TABLE 1: QOL AND HEALTH SATISFACTION (SUMMARY)

Question	n	Minimum	Maximum	Median	Mean	Standard deviation
How would you rate your quality of life?	90	0	20	10	11.5	4.07
How satisfied are you with your health?	90	0	20	10	11.11	5.60
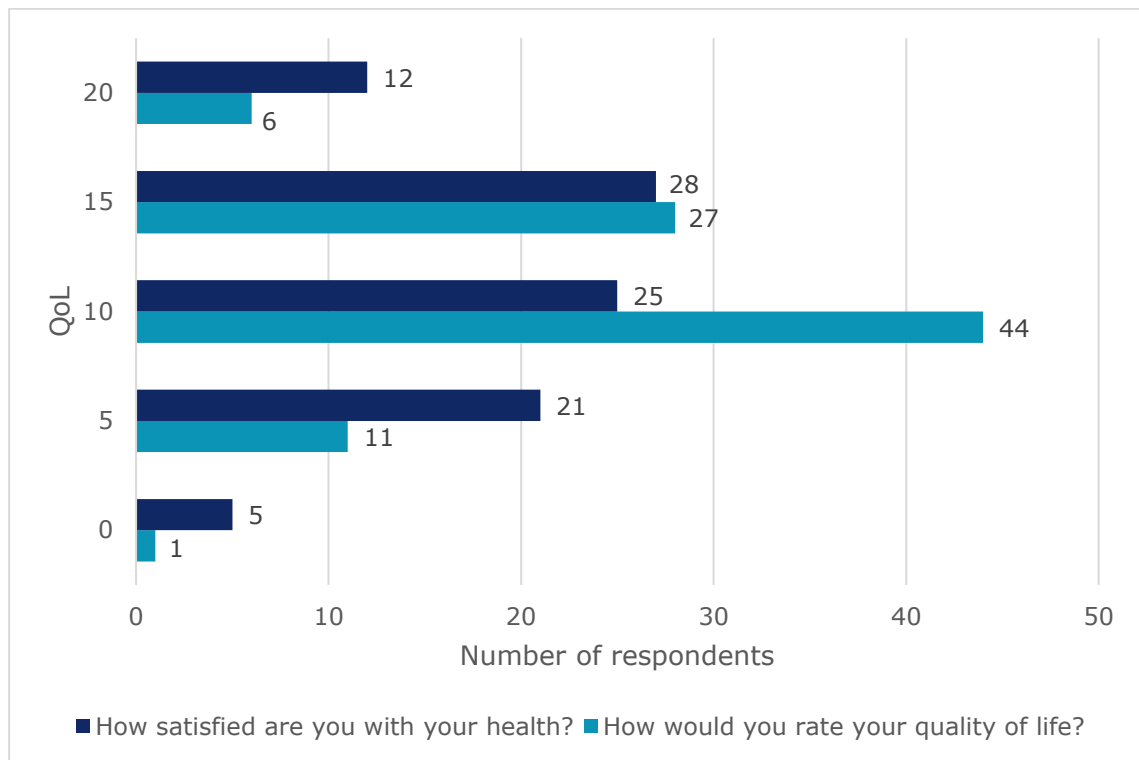
FIGURE 13: QOL AND HEALTH SATISFACTION

Beyond the above discussed questions on quality of life and health satisfaction, the WHOQOL-BREF questionnaire allows for a deeper look into different dimensions (=domains) of quality of life. More precisely, questions f1_4 to f8_1 are classified according to their underlying main focus and clustered into four domains (namely physical, psychological, social relations, and environment). The allocation of questions to the different domains, as suggested by the WHO (see chapter 1), is displayed in Table A in the Appendix.

Table 2 shows minimum and maximum value, median, mean, and standard deviation of each domain. The minimum of physical quality of life amounts to 3.57, the maximum refers to the interval boundary. With 12.52, the mean lies slightly below the median (12.86), thus indicating a negative skew (i.e. the distribution is skewed left). Psychological quality of life has a minimum value of 1.67 and a maximum value of 19.17. Mean and median both lie below the values of physical quality of life, and the distribution is slightly skewed right. As for social relations, minimum and maximum value refer to the interval boundaries (i.e. the ordinal scale is fully exhausted). The mean lies below the mean of the former two domains, and the median corresponds to the one of psychological quality of life. The distribution discloses a negative skew. The fourth dimension, which covers the environmental dimension, has a minimum value of 3.13 and a maximum value of 20. With 13.06 and 13.75, mean and median disclose the highest values of all domains. The distribution once again is skewed left. The standard deviation lies between 3.78 and 5.32 for the different domains.

What may be derived from Table 1 and Table 2 is that on average, respondents rate their overall quality of life (g1) lower than its different domains except for the one on social relations. What is more, the median of each domain exceeds the median of the overall quality of life. This finding is unexpected to some extent as in the literature, people are commonly found to rate a whole thing higher than its different parts.

Figure 14 visually shows the frequencies (=number of respondents) per domain. As the domains are composed of 3 to 8 questions each (see Table A in the Appendix), frequencies deliver a more sophisticated pattern than in the previous figure. In order to adequately visualise the respective numbers, a scatter diagram has been created indicating the quality of life per domain on the x-, and the number of respondents on the y-axis (note that, compared to the previous figure, the axes are switched). It may be read as following examples: 4 respondents rate their social relations as 0 (that is, the minimum was selected in all questions relating to the social relations domain; see left axis), the maximum (20) was reached by 4 respondents in the social relations, 2 respondents in the physical, and 1 respondent in the environmental domain (see right axis). A value of 10 was reached by 10 respondents in the psychological, 9 respondents in the social relations, 8 respondents in the physical, and 7 respondents in the environmental domain (see middle axis).

TABLE 2: DOMAINS OF QOL (SUMMARY)

Domain	n	Minimum	Maximum	Median	Mean	Standard deviation
Physical	90	3.57	20	12.86	12.52	4.15
Psychological	90	1.67	19.17	11.67	11.93	4.06
Social Relations	90	0	20	11.67	11.04	5.32
Environment	90	3.13	20	13.75	13.06	3.78
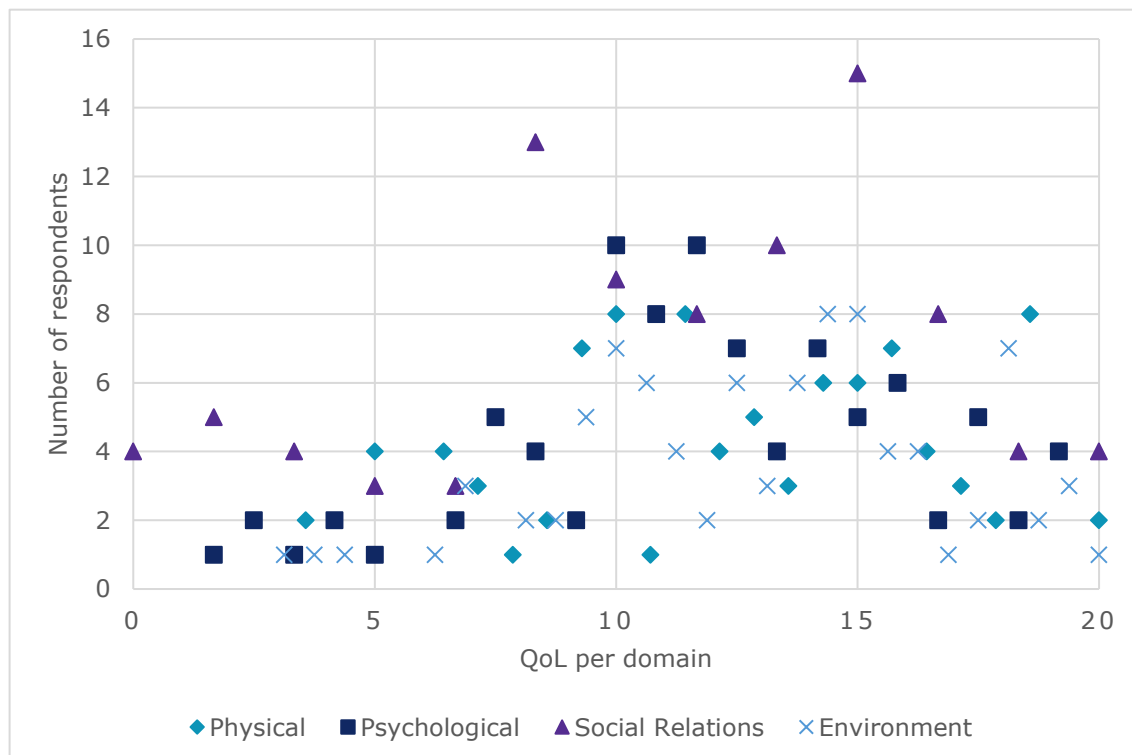
FIGURE 14: DOMAINS

At this point, it should be mentioned that the variables capturing different aspects of the quality of life are (at least to some extent) treated as cardinal data, although strictly speaking the transformed variables still refer to an ordinal scale. Doing so requires the assumption that the distance between the response catego-

ries (1 to 5 in absolute numbers in the raw sample) is equal for each consecutive category and has the advantage that mean values and selected non-parametric tests may be calculated (which once again may be crucial for comparing the results to those of other surveys). This issue will be taken up again in chapter 4.

3. Exploratory data analysis

Having provided some fundamental insights into the characteristics of the sub sample, this chapter is meant to identify potential relationships between socio-demographic factors and the quality of life, as well as the use of services and the quality of life. In doing so, more profound insights on determinants of the quality of life of family member carers may be gained. In all of the subsequent figures, the quality of life and its different domains are expressed as mean values.

3.1. QUALITY OF LIFE AND SOCIO-DEMOGRAPHIC FACTORS

Before taking a closer look at the different domains of quality of life, an examination of the two independent questions on the quality of life and health satisfaction is meant to provide first insights into the patterns between those two and socio-demographic factors.

As shown in Figure 15, men on average rate their quality of life slightly higher, and their health satisfaction slightly lower than women. Figure 16 disaggregates both variables according to the respondents' educational status. Exhibiting conspicuous results in the postgraduate category, it should be once more emphasised that the corresponding category consists of a single observation, thus impeding a generalisation of the findings. A further noteworthy result may be found for those without a school leaving certificate, who rate their health satisfaction substantially higher than their quality of life, whereas the gap between both is much less pronounced for the other categories. However, consisting of merely 5 observations, this category should once again be treated with caution. Of the remaining categories, respondents with a degree of a University of Applied Sciences disclose the highest, and those with a general qualification for university entrance the lowest mean values for both quality of life and health satisfaction. The mean values of the latter correspond closely to the ones for secondary modern schools.

As for the family status, the category *married* discloses the highest values for both quality of life and health satisfaction, which may at least partly be due to a steady emotional support received by the spouse. Mean values in the category *living alone* slightly exceed the ones in the category *steady relationship*. Whereas the quality of life does not differ for four of the six categories, the respondents' health satisfaction is slightly more variable among categories. Further details are displayed in Figure 17.

As shown in Figure 18, the differentiation according to the respondents' current health status discloses substantial differences not only for health satisfaction but also for the quality of life, with the gap being (unsurprisingly) more pronounced for the former. As for assistance in filling the questionnaire, the average quality of life is slightly, and the average health satisfaction substantially higher for those who have than for those who have not received assistance (see Figure 19). Results once more have to be treated with caution as the sample for the former is rather small.

Figure 20 discloses the differences between age groups, however with the lowest {(≤25)} and the highest two groups {(76-85) and (≥86)} consisting of too few observations to draw further conclusions. Results show that the quality of life and health satisfaction decrease until the age group {(56-65)} and then increase again for the age group {(66-75)}. This may reflect the fact that during the working age, home care may be perceived as an additional (time) burden to "normal" working life, and that this burden decreases for pensioners.
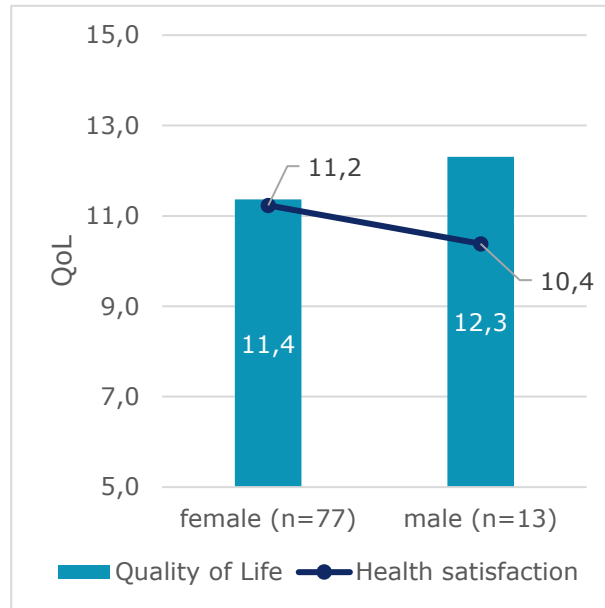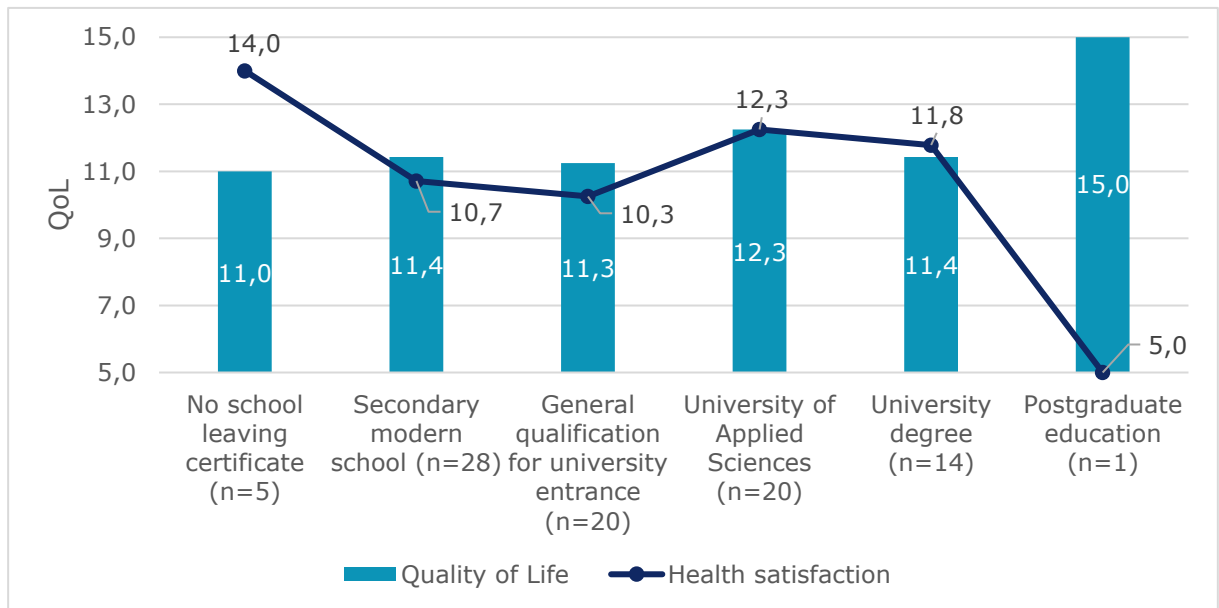
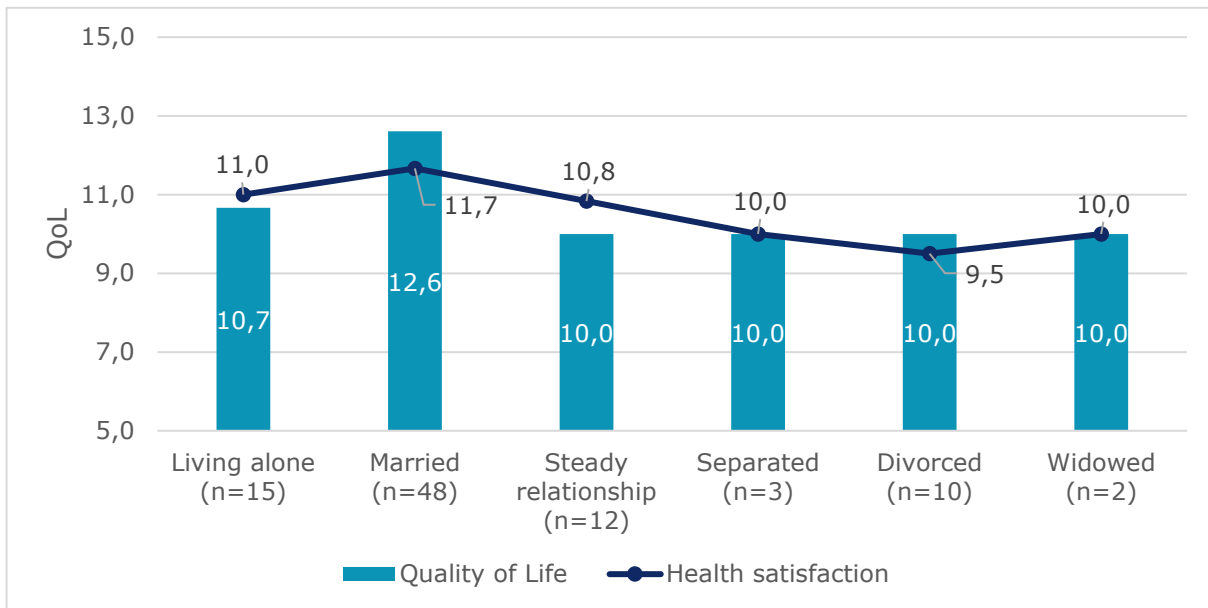FIGURE 15: QOL AND GENDER

FIGURE 16: QOL AND EDUCATION

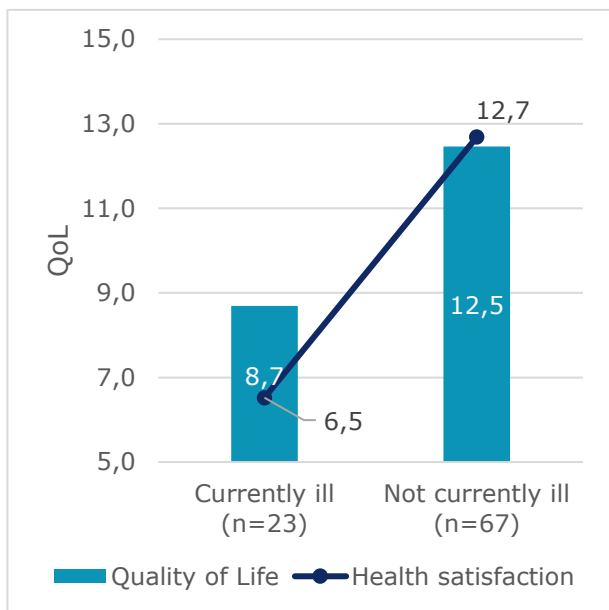FIGURE 17: QOL AND FAMILY STATUS

FIGURE 18: QOL AND CURRENT HEALTH STATUS

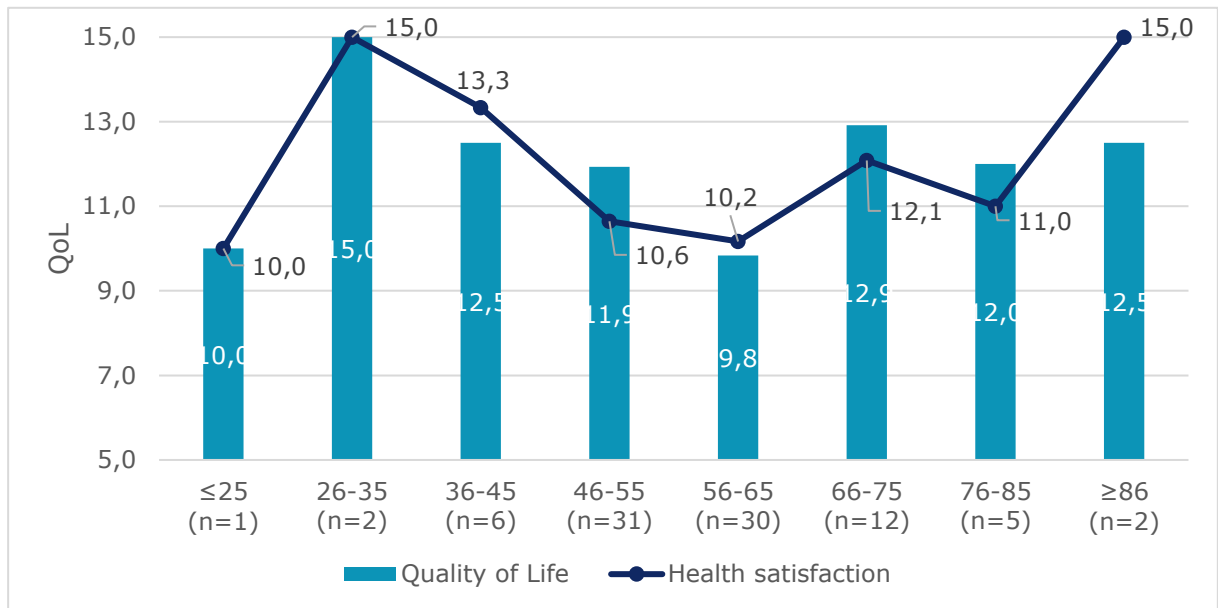FIGURE 19: QOL AND ASSISTANCE IN FILLING THE QUESTIONNAIRE

FIGURE 20: QOL AND AGE GROUPS

In the following, the quality of life as pertained to the four different domains is discussed. As Figure 21 shows, men on average rate their quality of life higher for all domains except physical quality of life, for which the mean nearly equals the one of women. The gap is particularly pronounced for psychological quality of life. Men disclose the highest mean value for psychological quality of life, and the lowest for social relations. As for women, the environmental domain displays the highest, and social relations (once again) the lowest mean value. Figure 22 differentiates the domains according to the respondents' education. The height of the bars shows the aggregated quality of life over all domains, the quality of life per domain may be drawn from the figures within the different coloured bars. In the subsequent interpretation, the category *postgraduate education* will be neglected as it consists of one single observation. On an aggregate level, the category *University of Applied Sciences* discloses the highest, and *no school leaving certificate* the lowest mean value. Among all categories, *University of Applied Sciences* shows the highest mean for all domains except physical quality, for which it shares the first place with the category *general qualification for university entrance.*

As for family status, those married and those in a steady relationship rate their quality of life the highest on an aggregate level, the lowest quality of life may be observed for those separated (which is derived, however, from only three observations in the data set; see Figure 23). Considering the current health status, those who are not currently ill rate their quality of life substantially higher in all domains, with the gap being most pronounced for physical quality of life (see Figure 24). Respondents who have had assistance in filling the questionnaire on average rate their quality of life higher in the domains psychological and social relations, whereas the mean value of physical quality of life undercuts the one of those who did not receive assistance (which corresponds to the results from Figure 18). Considering age groups, a similar pattern as previously discussed (see Figure 20 and the corresponding paragraph) may be observed: Figure 26 discloses that the aggregate quality of life decreases until the age group $\{(56\text{-}65)\}$ and then increases again.
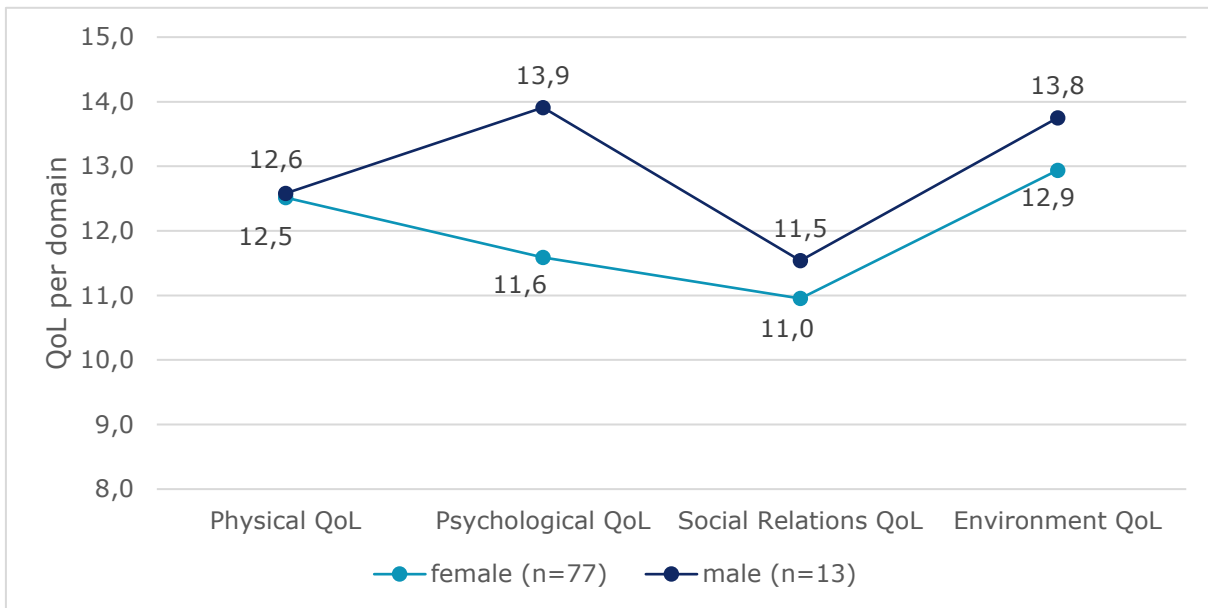
FIGURE 21: DOMAINS AND GENDER
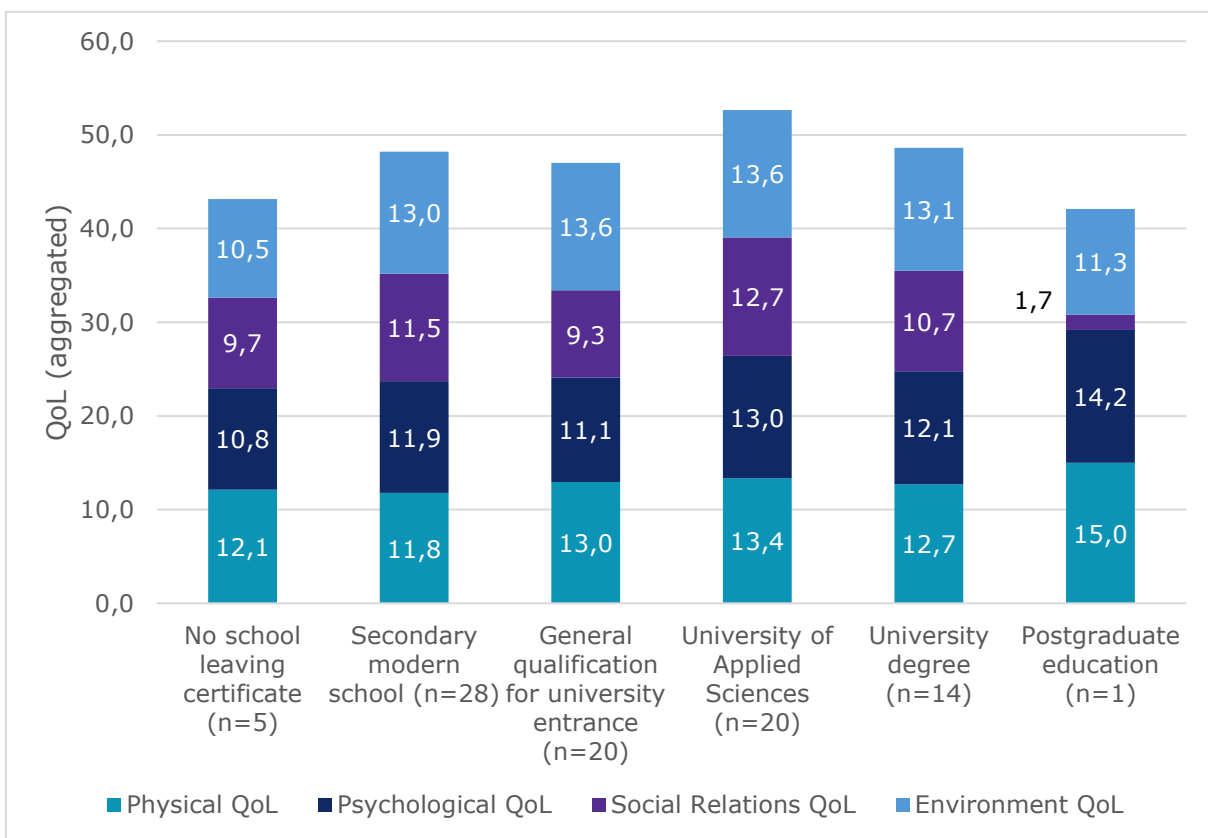
FIGURE 22: DOMAINS AND EDUCATION
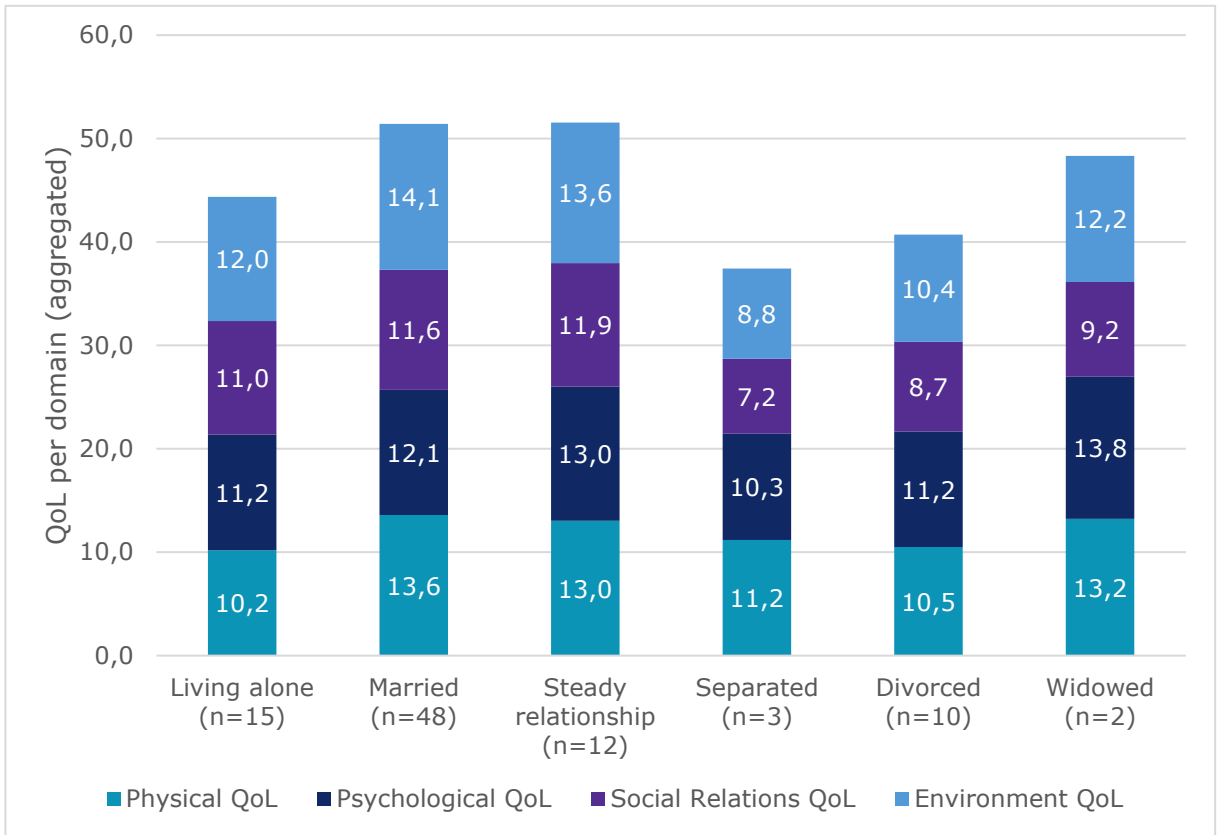
FIGURE 23: DOMAINS AND FAMILY STATUS
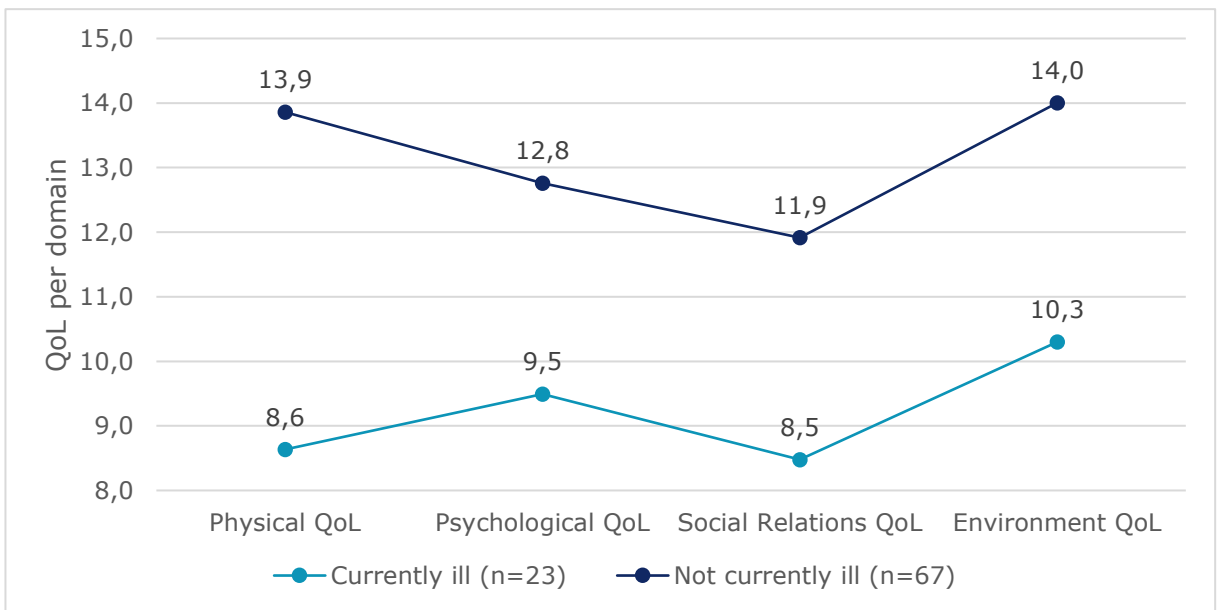
FIGURE 24: DOMAINS AND CURENT HEALTH STATUS
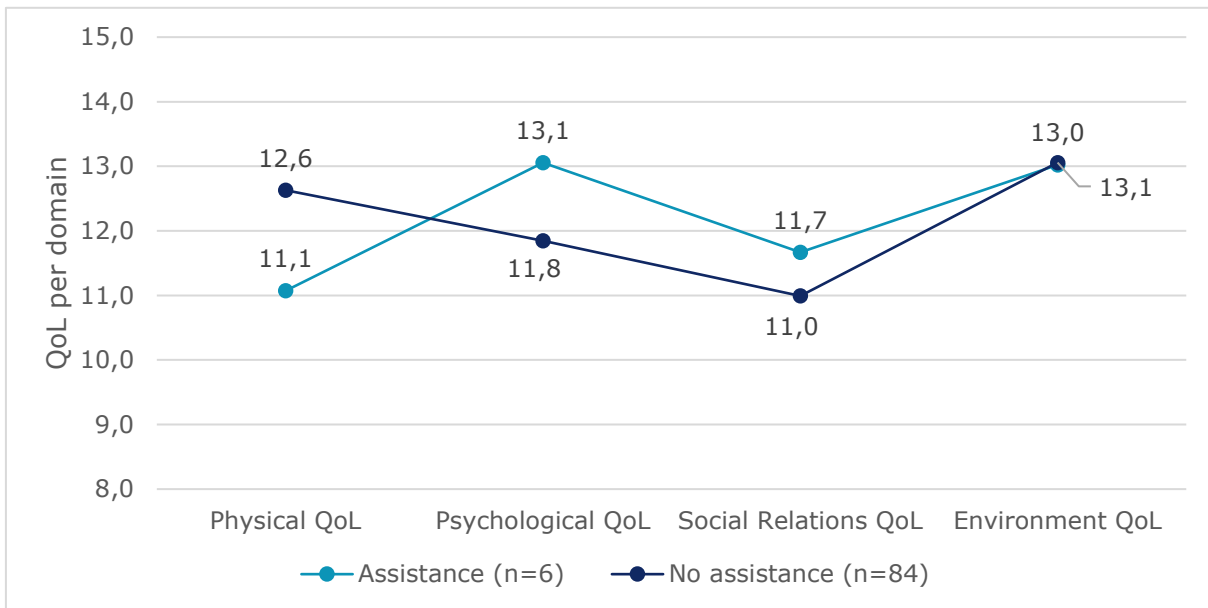
FIGURE 25: DOMAINS AND ASSISTANCE IN FILLING THE QUESTIONNAIRE
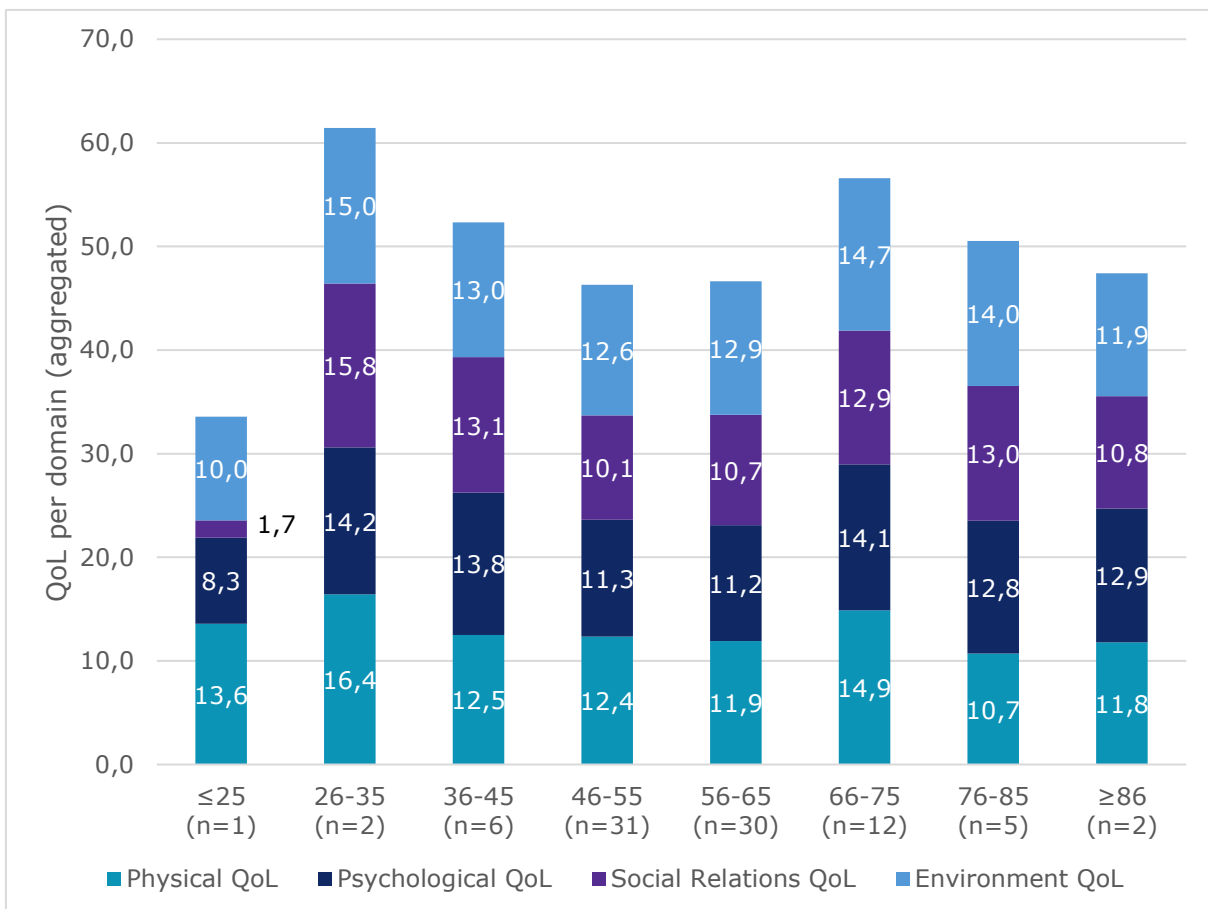
FIGURE 26: DOMAINS AND AGE GROUPS

3.2.   QUALITY OF LIFE AND THE USE OF SERVICES

Considering the use of supporting services, the quality of life and health satisfaction are rated higher if respondents have used at least one of the listed services, with the gap being more pronounced for health satisfaction (see Figure 27). As for special services, the quality of life is once again higher for those who have used at least one of the listed services, however the difference between both is less explicit. What is more, health satisfaction is rated slightly lower for those who have used one or more special services (see Figure 28). As for the latter, this may as well be a sign of people with a worse health status using more special services, which may, for example, be the case if they are more habituated to making use of (medical) services in general.

If disaggregating the number of (supporting and special) services used, the picture is ambiguous. For example, considering supporting services, the quality of life and health satisfaction appear to increase for the step from 0 to 1 service, but to decrease for the step from 1 to 2 services. If 4 or 5 services have been used, the mean values substantially increase (see Figure 29), but as they comprise merely 2 to 5 observations, results have to be treated with caution. This ambiguity as well pertains to special services (see Figure 30).
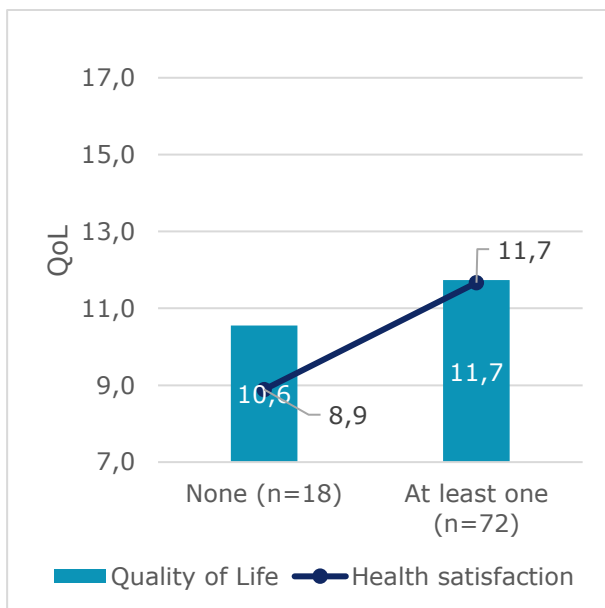
FIGURE 27: QOL AND THE USE OF SUPPORTING SERVICES
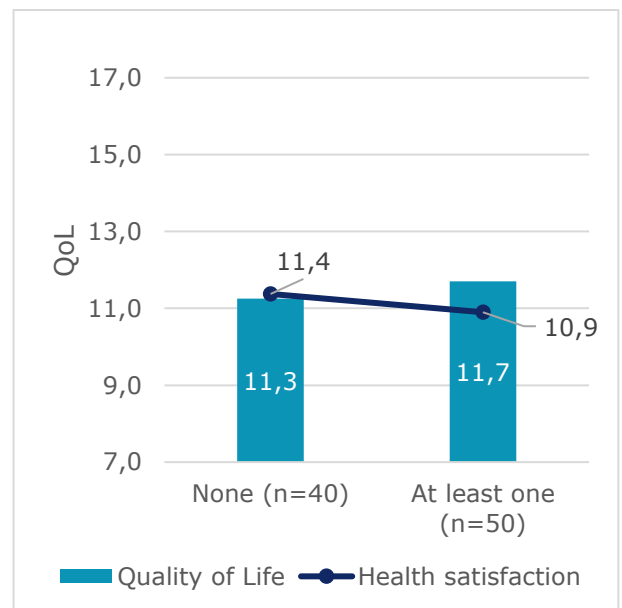
FIGURE 28: QOL AND THE USE OF SPECIAL SERVICES
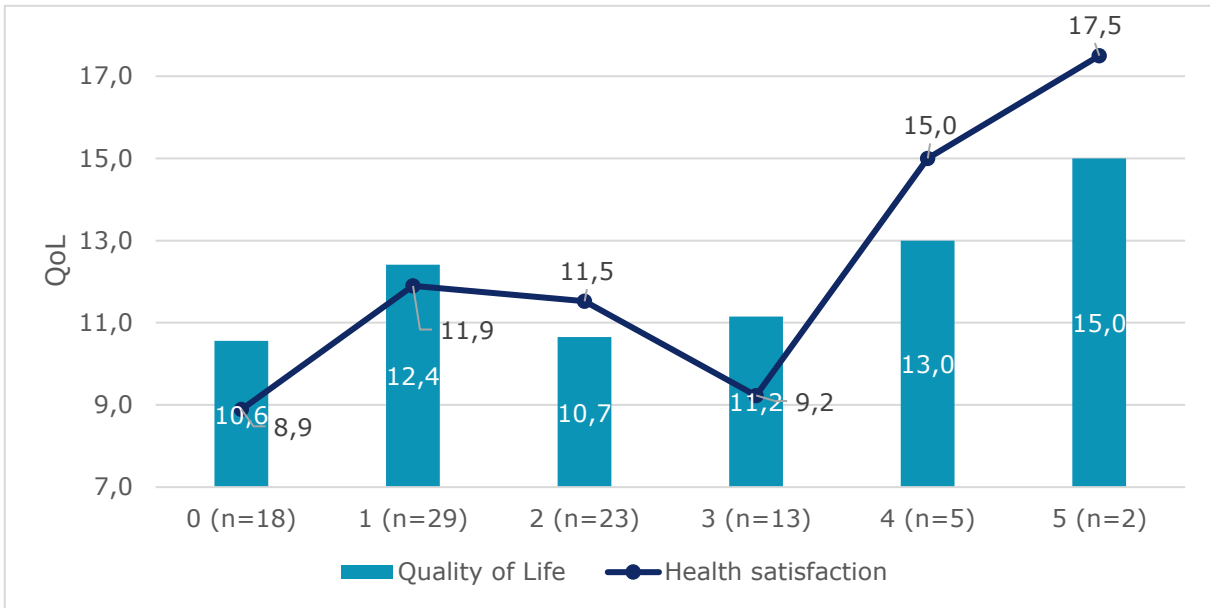
FIGURE 29: QOL ANT THE NUMBER OF SUPPORTING SERVICES
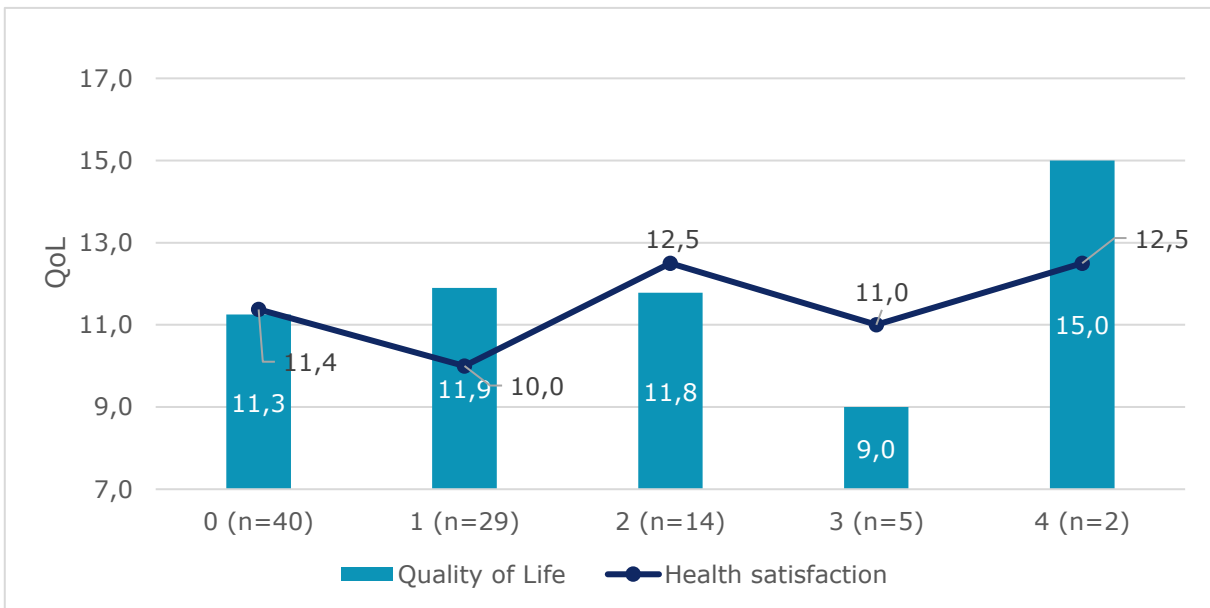
FIGURE 30: QOL AND THE NUMBER OF SPECIAL SERVICES

As for supporting services, the quality of life for those who have used at least one service is higher in all domains, with the gap being most pronounced for social relations and environment, and least pronounced for psychological quality of life (see Figure 31). The latter may speak in favour of targeting the psychological domain more explicitly.

Figure 32 considers the aggregated mean values for each domain. Once again, the different colours within each bar indicate the respective individual mean value. The pattern resembles the one in Figure 29, that is, the aggregated quality of life increases between 0 and 1 supporting services used, and delivers an ambiguous picture afterwards (keeping in mind that observations for category 4 and 5 are scarce). The increases in the respondents' quality of life between above mentioned categories are highest in the social relations and environmental dimension, and lowest in the psychological dimension.

For special services, physical quality of life does not differ between services, and quality of life of those who have used at least one service is higher in the remaining domains. The gap is most pronounced for social relations (see Figure 33).

Figure 34 once again provides a differentiation between the four domains of quality of life. It demonstrates that the aggregated quality of life slightly increases with the number of used special services until the number of 2 special services, rapidly decreases for 3 special services and then increases again (similar to supporting services, observations are scarce for the latter two categories). Between category 0 and 2, increases are highest for the social relations domain, and lowest for the physical domain.

FIGURE 31: DOMAINS AND THE USE OF SUPPORTING SERVICES

FIGURE 32: DOMAINS AND THE NUMBER OF SUPPORTING SERVICES

FIGURE 33: DOMAINS AND THE USE OF SPECIAL SERVICES

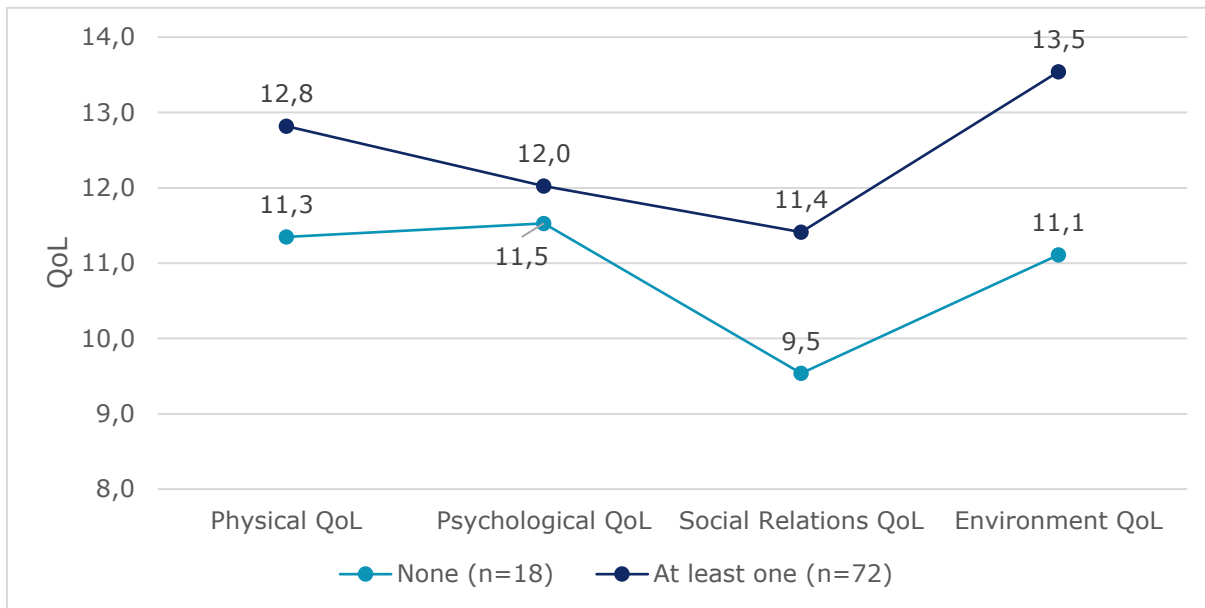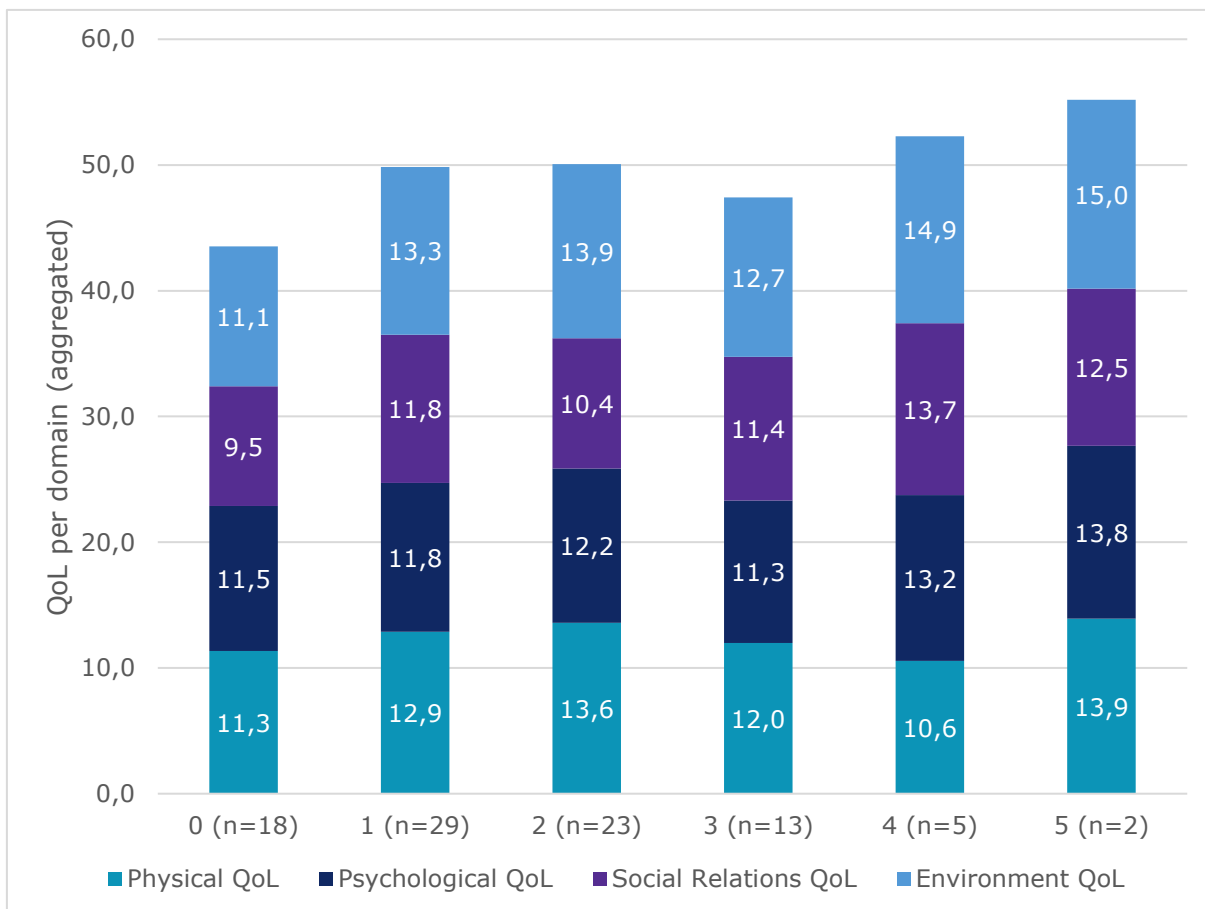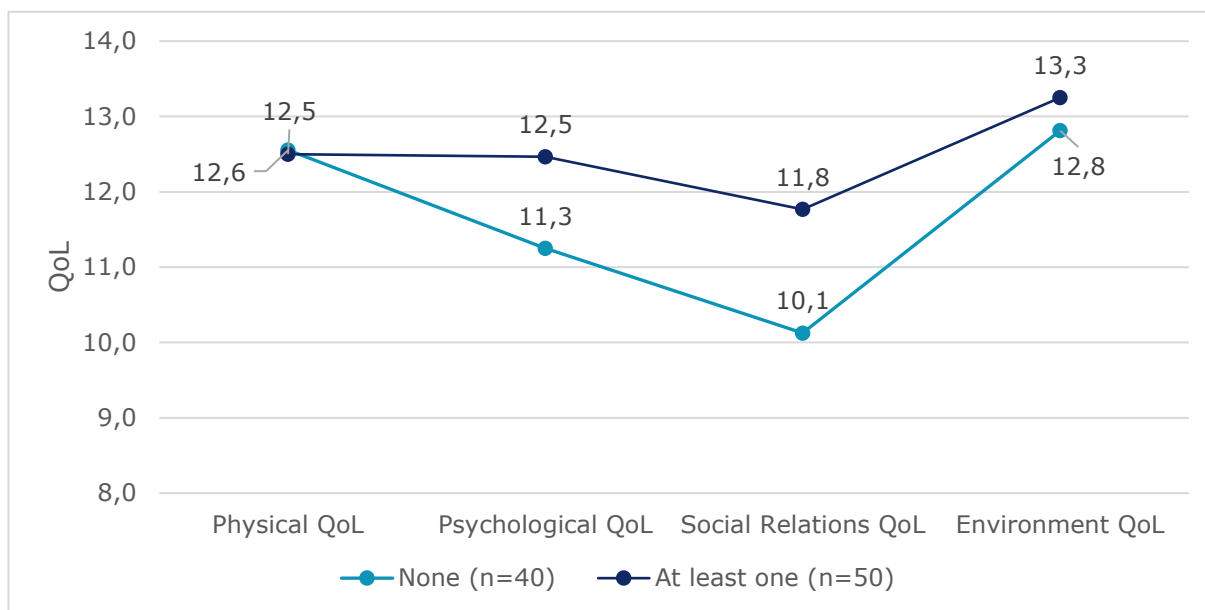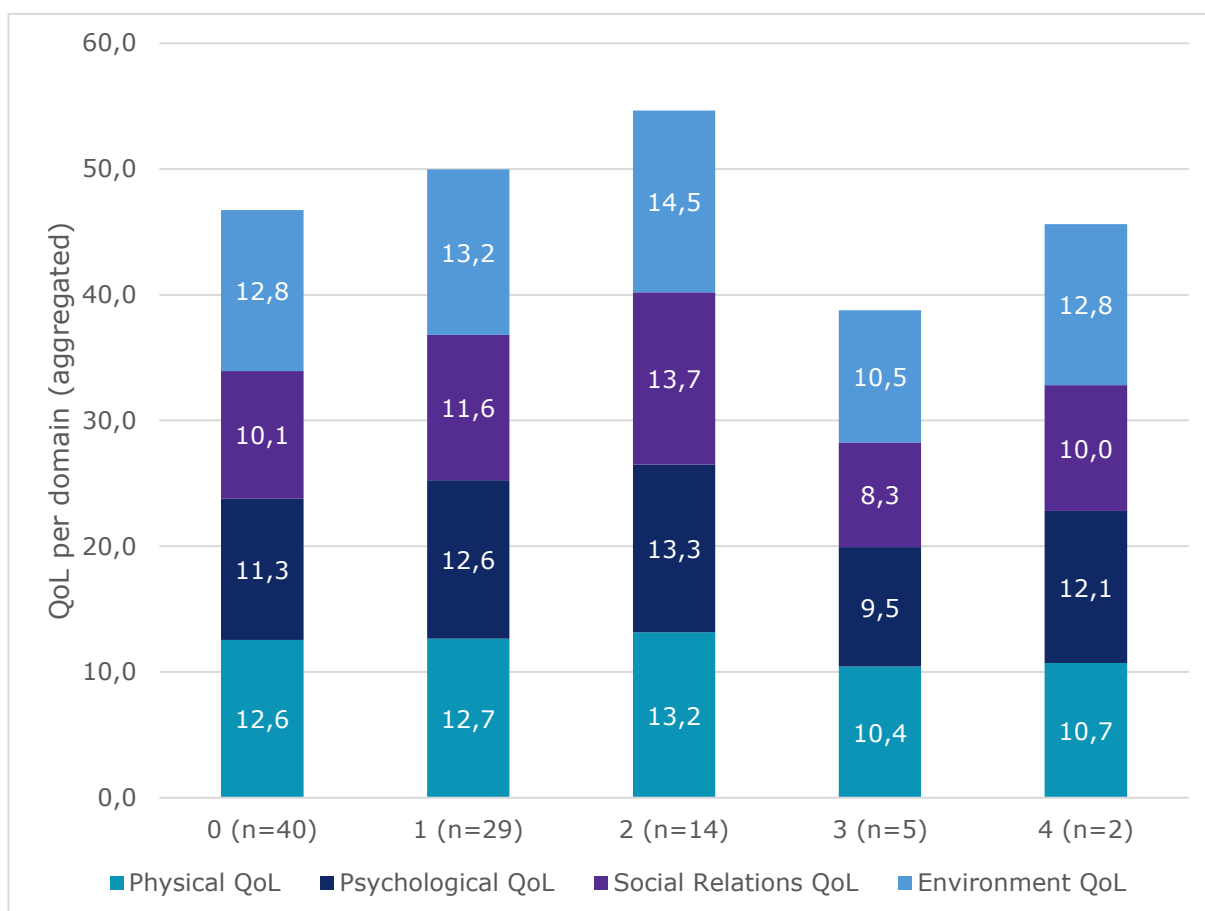FIGURE 34: DOMAINS AND THE NUMBER OF SPECIAL SERVICES

4. Non-parametric tests

In order to analyse whether the visually observable patterns withstand statistical tests, a Mann-Whitney test has been applied for all two-layered variables (e.g. gender), and a Kruskal-Wallis test has been utilised for variables with 3 or more layers (e.g. age groups). These tests are applicable for ordinal (and cardinal) data and do not require the data to be distributed in a particular way (e.g. normally distributed). Both tests relate to central tendencies between groups.

As Table 3 shows, only few of the discussed grouping variables (gender, education, family and current health status, assistance in filling the questionnaire, age groups, and the use and number of supporting and special services) disclose statistical significance. On the 10-percent level, the central tendency of men and women if considering psychological quality of life significantly differ from each other. As discussed previously (see Figure 21 and the corresponding paragraph), male respondents rate their psychological quality of life substantially higher than female respondents. Compared to other domains, the gap between female and male respondents is particularly large in this domain.

Statistically significant results (on the 5-percent level) may as well be observed for family status in both the physical and the environmental domain. Results from a post-hoc test[3] show that within the physical domain, significance at the 10-percent level (p=0.098) is observable between the categories married and single. Some noticeable differences as well prevail between married and divorced (however without statistical significance, p=0.251). Within the environmental domain, noticeable yet not significant results are observed between married and divorced (p=0.142) and married and separated (p=0.433). As previously discussed, those married rate their physical and environmental quality of life substantially higher than those single, divorced, and separated.

The current health status discloses significant (p<0.05) to highly significant (p<0.001) results for both the independent questions on the quality of life and health satisfaction, and each of the four domains. As shown in Figure 18 and Figure 24, respondents who indicate to be currently ill rate all of the different aspects substantially lower than those who are not currently ill.

The use of supporting services reveals significance at the 10-percent level for health satisfaction and the environmental domain (those who have used at least one service rate both aspects substantially higher than those who have used none of the listed services; see Figure 27 and Figure 31), of which the former as well delivers statistically significant results if considering the exact number of supporting services. A post-hoc test reveals that none of the groups significantly differs from another group, however the strongest differences appear to prevail between the groups {0 and 4}, {0 and 5}, {3 and 4}, and {3 and 5}. In particular, the health satisfaction of those who have used 4 or 5 supporting services is substantially higher than the health satisfaction of those who have used 0 or 3 supporting services. The fact that results are conspicuous yet not significant may be traced back to the limited number of observations in category 4 and 5.

As previously mentioned, if assuming that the distance between the response categories is equal for each consecutive category, one may additionally apply tests that require a cardinal scale. For example, the t-

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[3] In order to test for which groups statistical significance prevails, a Dunn-Bonferroni test has been applied.

test may be used to test whether central tendencies of two defined groups significantly differ from each other. This test, however, additionally requires the data to be normally distributed. Applying a Kolmogorov-Smirnov test on each dimension suggests that this assumption merely holds true for the physical (p=0.091) and the environmental (p=0.154) domain, whereas data on the independent questions on the quality of life and health satisfaction (p=0.000 in each case), as well as on the psychological (p=0.042) and social relations (p=0.002) domain are not normally distributed. Nevertheless, a t-test has been applied to test the sensitivity of results for supporting services. Results are robust to applying the t-test, that is, statistical significance prevails for both the use and number of services if considering health satisfaction, and for the use of services within the environmental domain.

TABLE 3: RESULTS OF NON-PARAMETRIC TESTS (MANN-WHITNEY-U AND KRUSKAL-WALLIS)

		QoL	Health Satis-faction	Physical	Psycho-logical	Social Rela-tions	Environ-ment
Gender	Mann-Whitney-U	418,5	466,5	488,0	346,5	489,5	457,5
	Wilcoxon-W	3421,5	557,5	3491,0	3349,5	3492,5	3460,5
	Z	-1,0202	-0,4033	-0,1438	-1,7724	-0,1270	-0,4945
	Asympt. Signifikanz[a]	0,3076	0,6868	0,8857	**0,0763**[*]	0,8989	0,6210
Education	Chi-Quadrat	2,6924	4,6489	1,9775	3,3001	7,0110	2,6851
	df	5,0	5,0	5,0	5,0	5,0	5,0
	Asympt. Signifikanz	0,7473	0,4602	0,8522	0,6538	0,2198	0,7484
Family status	Chi-Quadrat	7,9384	1,6514	11,6396	2,5468	6,1433	12,1423
	df	5,0	5,0	5,0	5,0	5,0	5,0
	Asympt. Signifikanz	0,1597	0,8950	**0,0401**[*]	0,7694	0,2925	**0,0329**[*]
Current health status	Mann-Whitney-U	399,5	302,0	221,0	448,5	504,5	370,0
	Wilcoxon-W	675,5	578,0	497,0	724,5	780,5	646,0
	Z	-3,7203	-4,4786	-5,0939	-2,9868	-2,4754	-3,7118
	Asympt. Signifikanz[a]	**0,0002**[***]	**0,0000**[***]	**0,0000**[***]	**0,0028**[**]	**0,0133**[*]	**0,0002**[***]
Assistance in fill-ing the question-naire	Mann-Whitney-U	246,0	190,5	201,0	204,5	249,5	234,5
	Wilcoxon-W	3816,0	3760,5	222,0	3774,5	3819,5	255,5
	Z	-0,1052	-1,0280	-0,8267	-0,7704	-0,0407	-0,2836
	Asympt. Signifikanz[a]	0,9162	0,3040	0,4084	0,4411	0,9676	0,7767
Age groups	Chi-Quadrat	8,2880	8,9730	7,9550	4,8080	8,7000	4,3090
	df	7,0	7,0	7,0	7,0	7,0	7,0
	Asympt. Signifikanz	0,3080	0,2550	0,3370	0,6830	0,2750	0,7440

Use of supporting services	Mann-Whitney-U	586,0	487,0	518,0	644,5	502,0	460,0
	Wilcoxon-W	757,0	658,0	689,0	815,5	673,0	631,0
	Z	-0,6779	-1,6782	-1,3141	-0,0354	-1,4816	-1,8999
	Asympt. Signifikanz[a]	0,4978	**0,0933** `·`	0,1888	0,9718	0,1385	**0,0574** `·`
Use of special services	Mann-Whitney-U	933,5	947,0	978,5	860,5	829,5	978,0
	Wilcoxon-W	1753,5	2222,0	2253,5	1680,5	1649,5	1798,0
	Z	-0,5853	-0,4447	-0,1749	-1,1358	-1,3928	-0,1790
	Asympt. Signifikanz[a]	0,5583	0,6565	0,8611	0,2560	0,1637	0,8580
Number of supporting services	Chi-Quadrat	3,9690	9,9645	4,6724	1,7744	3,8350	5,1487
	df	5,0	5,0	5,0	5,0	5,0	5,0
	Asympt. Signifikanz	0,5539	**0,0762** `·`	0,4571	0,8794	0,5734	0,3980
Number of special services	Chi-Quadrat	3,9226	2,0591	1,7267	4,1637	7,1535	4,6044
	df	4,0	4,0	4,0	4,0	4,0	4,0
		0,4166	0,7249	0,7859	0,3843	0,1280	0,3303

[a] (2-sided)   `·`<0.1, `*`<0.05, `**`<0.01, `***`<0.001

5. Conclusion

5.1.   IN BRIEF

- On a 0 to 20 scale, respondents on average rate their overall **quality of life** to be 11.5, and their **health satisfaction** to be 11.11
- On a 0 to 20 scale, respondents on average rate their **physical** quality of life to be 12.52, their **psychological** quality of life to be 11.93, their **social relations** quality of life to be 11.04, and their **environmental** quality of life to be 13.06
- Considering the **gender**, men rate their psychological quality of life significantly higher than women
- Considering the **family status**, those married rate their physical and environmental quality of life higher than those single, divorced, and separated
- Considering the **current health status**, those currently ill rate their overall quality of life, their health satisfaction, and each of the differentiated indicators (physical, psychological, social relations, and environment) significantly lower than those not currently ill
- Considering the **use of supporting services**, those who use at least one of the listed services rate their health satisfaction and their environmental quality of life significantly higher than those who use none
- Results have to be treated with caution as the **sample is relatively small** (some groups consist of too few observations to generalise the findings)

5.2.   IN DETAIL

This report was prepared by the NPO & SE Competence Center in order to (I) deliver a descriptive overview of the sample (and, in particular, the quality of life) based on the syntax file of the WHO, and (II) gain a deeper understanding of relationships between the constructed indices of quality of life and socio-demographic factors, as well as quality of life and the use of services. The underlying survey was conducted by the Austrian Red Cross and builds on the WHOQOL-BREF questionnaire. The results feed into an EU-funded project on home care, and are meant to provide a baseline for comparisons to other surveys as well as to enable a deeper understanding of how socio-economic factors and the use of services may determine the quality of life of family member carers.

Findings show that the quality of life lies between 11.11 and 11.5 for the individual questions (health satisfaction and the quality of life respectively), and between 11.04 and 13.06 for each domain. As for the latter, the highest value corresponds to the environmental domain, and the lowest relates to the domain of social relations. Considering dependencies within the sample, results show significance ($p < 0.10$) for the following aspects: gender in the psychological domain, family status in the physical and the environmental domains, current health status in both individual questions and in each of the four domains, the use of supporting services in health satisfaction and the environmental domain, and the number of supporting services in health satisfaction.

In particular, men rate their psychological quality of life higher[4] than women, those married rate their physical and environmental quality of life higher than those single, divorced, and separated, and those currently ill rate all of the different aspects (i.e. quality of life, health satisfaction, and each of the four domains) lower than those not currently ill. As for the use of services, those who use at least one of the listed supporting services rate their health satisfaction and their environmental quality of life higher than those who use none of them, and those who use 4 or 5 supporting services rate the environmental domain higher than those who use 0 or 3 supporting services (which, however, has to be treated with caution as observations are scarce for category 4 and 5). Although the number of used supporting services delivers an ambiguous picture, it is noteworthy that the gap is least pronounced for psychological quality of life, which may speak in favour of targeting this domain more explicitly.

The remaining grouping variables, despite some visually observable tendencies, do not reveal statistically significant results. Beyond other reasons, this may be traced back to one of the following aspects (or a combination of all of them): (I) the sample is relatively small, and although the distribution of observations (for example, among age groups) appears reasonable, there are too few observations in the less-populated groups, (II) the standard deviation of both the independent questions and the different domains of quality of life is relatively high (see Table 2), (III) differences may be determined and/or driven by non-captured factors (e.g. the severity of care dependency). In order to address these issues, enlarging the sample as well as including questions covering the level of care dependency may deliver more conclusive (and robust) results.

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[4] Note that here and in the following, discussed findings refer to central tendencies between groups.

Appendix

Coding	Shortcut	Domain	Question
s1	Gender		Was ist Ihr Geschlecht?
s2_1			Wann sind Sie geboren?
s2_3	Education		Was ist Ihr höchster Schulabschluss?
s4	Family status		Wie ist Ihr Familienstand?
s5_1	Current health status		Sind Sie gegenwärtig krank?
s5_2			Wenn etwas mit Ihrer Gesundheit nicht in Ordnung ist, was glauben Sie, was es ist?
g1[5]	QoL		Wie würden Sie Ihre Lebensqualität beurteilen?
g4	Health satisfaction		Wie zufrieden sind Sie mit Ihrer Gesundheit?
f1_4		Physical	Wie stark werden Sie durch Schmerzen daran gehindert, notwendige Dinge zu tun?
f11_3		Physical	Wie sehr sind Sie auf medizinische Behandlung angewiesen, um das tägliche Leben zu meistern?
f4_1		Psychological	Wie gut können Sie Ihr Leben genießen?
f24_2		Psychological	Betrachten Sie Ihr Leben als sinnvoll?
f5_3		Psycholoical	Wie gut können Sie sich konzentrieren?
f16_1		Environment	Wie sicher fühlen Sie sich in Ihrem täglichen Leben?
f22_1		Environment	Wie gesund sind die Umweltbedingungen in Ihrem Wohngebiet?
f2_1		Physical	Haben Sie genug Energie für das tägliche Leben?
f7_1		Psychological	Können Sie Ihr Aussehen akzeptieren?
f18_1		Environment	Haben Sie genug Geld, um Ihre Bedürfnisse erfüllen zu können?
f20_1		Environment	Haben Sie Zugang zu den Informationen,

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[5] The coding of questions relating to the quality of life as well as their assignment to the respective domain is based on the syntax file by the WHO (see chapter 1).

			die Sie für das tägliche Leben brauchen?
f21_1		Environment	Haben Sie ausreichend Möglichkeiten zu Freizeitaktivitäten?
f9_1		Physical	Wie gut können Sie sich fortbewegen?
f3_3		Physical	Wie zufrieden sind Sie mit Ihrem Schlaf?
f10_3		Physical	Wie zufrieden sind Sie mit Ihrer Fähigkeit, alltägliche Dinge erledigen zu können?
f12_4		Physical	Wie zufrieden sind Sie mit Ihrer Arbeitsfähigkeit?
f6_3		Psychological	Wie zufrieden sind Sie mit sich selbst?
f13_3		Social Relations	Wie zufrieden sind Sie mit Ihren persönlichen Beziehungen?
f15_3		Social Relations	Wie zufrieden sind Sie mit Ihrem Sexualleben?
f14_4		Social Relations	Wie zufrieden sind Sie mit der Unterstützung durch Ihre Freunde?
f17_3		Environment	Wie zufrieden sind Sie mit Ihren Wohnbedingungen?
f19_3		Environment	Wie zufrieden sind Sie mit Ihren Möglichkeiten, Gesundheitsdienste in Anspruch nehmen zu können?
f23_3		Environment	Wie zufrieden sind Sie mit den Beförderungsmitteln, die Ihnen zur Verfügung stehen?
f8_1		Psychological	Wie häufig haben Sie negative Gefühle wie Traurigkeit, Verzweiflung, Angst oder Depression?
a1	Supporting services (current)		Welche der folgenden Unterstützungsleistungen nehmen Sie in Anspruch?
a2	Supporting services (future)		Welche dieser Leistungen würden Sie gerne in größerem Umfang als derzeit möglich in Anspruch nehmen?
a3	Special services (current)		Welche der folgenden speziellen Angebote für pflegende Angehörige nehmen Sie derzeit in Anspruch?
a4	Special services (future)		Welche der folgenden speziellen Angebote für pflegende Angehörige würden Sie gerne in Anspruch nehmen, wenn Sie die Möglichkeit dazu hätten?
a4_7			Welche zusätzlichen externen Unterstützungsleistungen würden Sie sich wünschen?
s6			Hat Ihnen jemand beim Ausfüllen des Fragebogens geholfen?
s7			Wie lange hat es gedauert, diesen Fragebogen auszufüllen?

TABLE B: CURRENT HEALTH STATUS (DETAIL)

[s5_2] Wenn etwas mit Ihrer Gesundheit nicht in Ordnung ist, was glauben Sie, was es ist? [Krankheit/Gesundheitsproblem]
Beides. Durch Überlastung u Stress wird eigene chronische Erkrankung aktiv.
Berufskrankheit
Bewegungsapparat, Lymphe, Gewicht
BluthochdruckGichtDiabetes Typ 2
Burn out
Burnout, Überlastung, beruflich, Familie und Pflegesituation
D. M.
Diabetes hashimoto Depression hypertonie rls
Diverse durch Schlafmangel verursachte neurologische Störungen.
Epilebsie
Knieschmerzen (Oberschenkelhalsbruch)
Kompliziert gebrochene Füße, die dauerhaft anders geblieben sind.
Magenschmerzen
mehrere schwerwiegende Probleme da lange Zeit unbehandelt
Parkinson, Kreuzprobleme
Psychische Erkrankung
Rücken
Schilddrüse Bandscheibenvorfall
Schlaflosigkeit,Depressionen
Skoliose, Migräne, Schädelhirntrauma, Borderlinesyndrom, Depressionen
Stress, Sorgen
Wirbelsäule/Schmerzen, Beine
Wirbelsäulenerkrankung, Kreislaufprobleme

TABLE C: OTHER SUPPORTING SERVICES (CURRENT)

[a1_9] Welche der folgenden Unterstützungsleistungen nehmen Sie in Anspruch? [Sonstiges]
alles selbst gemacht
Au-pair
Beartung durch diverse Institute
Beratung, Fahrdienst
Erweiterte Familie
Familienmitglieder von auswärts
Freizeitassistenz für die Tochter
Heimhilfe durch Freund
Physiotherapeut kommt 3x wöchentlich nach Hause. Haushilfe regelmäßig
privat gelegentlich
Reinigung
Tagesstätte

TABLE D: OTHER SUPPORTING SERVICES (FUTURE)

[a2_9] Welche dieser Leistungen würden Sie gerne in größerem Umfang als derzeit möglich in Anspruch nehmen? [Sonstiges]
1xige Spaziergehhil
Abend-Wochenendbetreuung
Besuche durch Seelsorge
Fahrdienst, psychologische Supervision
Freizeitassistenz
Freizeitassistenz, Urlaub mit Assistenz
Internat
Kinder und Geschwister
kurzfristige Unterbringung für 1 bis 2 Wochen
Physiotherapeut 3x wöchentlich nach Hause, Haushaltshilfe regelmäßig

Psychologische Beratung
punktuelle Unterstützung
Reinigungskraft
Tages- und Abendbetreuung des binderten Kindes um privat Dinge machen zu können
teilweise Betreuung
unbürokratische, stundenweise Unterstützung zu Hause
Urlaub

TABLE E: OTHER EXTERNAL SERVICES (FUTURE)

[a4_7] Welche zusätzlichen externen Unterstützungsleistungen würden Sie sich wünschen?
1x ausprobieren, ob 5 Stufen im Haus bewältigbar sind... Unterstützung durch kräftigen, geschulten Mann.
Abend und Wochenendbetreuung
begleitung bei terminen
bessere medizinische Betreuung, ab und zu Hausbesuche durch unsere Hausärztin
Betreuung abends, damit man selber weggehen kann.
Dass ich nicht dafür, dass ich meinen demenzkranken Mann pflege, finanziell noch bestraft werde, weil ich selbst auch eine Pension habe. Deshalb kosten nämlich Betreuungsstunden doppelt soviel!
eine Ansprechsstelle, die Probleme mit 24h unbürokratisch entgegennimmt, die Themen bündelt und politisch etwas verändert.eine Ansprechstelle für die 24h Helferinnen, wenn Sie ein Problem am Arbeitsplatz habenThema Transport bei 24h Pflege wie un-menschlich ist er(Rauch, Handy am Steuer, stundenlanges Kurven von Haushalt zu Haushalt - über 20 Stunden im Auto für eine 14 Stundenstrecke, nur ein Fahrer,)Thema "Wir haben Helferinnen bestellt und Menschen sind gekommen"Was ich nicht verstehe ist, dass für Menschen mit geistiger Beeinträchtigung nur Personal mit Ausbildung arbeiten darf, jedoch für Menschen im hohen Alter, die sich teilweise genauso nicht mehr "wehren" können, weil sie schlichtweg vergessen, was sie erlebt haben, IRGENDJEMAND arbeiten darf, der weder über eine Ausbildung NOCH ausreichende Sprachkenntnisse für komplexere Gespräche verfügt.Ich hätte mir gewünscht, als ich merkte, dass 3x täglich Sozialsprengel nicht mehr genügt, dass ich eine Entlastung in der Zeit von 6 - 20 Uhr zur Verfügung habe, eine Person, die sich ums Frühstück kümmert, ums Lüften, Blumen gießen, Saubermachen und Bewegung, eine ums Mittagessen und den Abwasch und eine ab 17 Uhr fürs Abendessen. Dann hätten wir vielleicht nicht gleich 24h Hilfe gebraucht.
einfachere Abläufe bei Verordnungen(Rollstühle, Schienen, Schuhe,....)kein Kämpfen für die Bewilligung von Medikamenten und oben Genanntemfachübergreifenden Austausch mit Betreuungspersonal und Erarbeiten eines gemeinsamen Entwicklungszieles (Lehrer, Erzieher, Krankenschwestern, Therapeuten,..)stundenweise oder tageweise Unterstützung bei der Betreuungeinfacheren Zugang zu Therapien
fähige verantwortungsvolle 24h Pflegerin

finanzielle Unterstützung für Pflege zu Hause durch Angehörige - bessere Abgeltung oder Zuzahlung zu zugekauften Leistungen, teils nicht leistbar....

Höheres Pflegegeld

Ich würde mir mehr Unterstützung de Angehörigen wünschen!

Ich würde mir wünschen, dass Mitarbeiter von Behörden geschult werden im Umgang mit pflegenden Angehörigen respektvoller und sensibler zu sein. Ich würde mich außerdem einen Urlaub nur für mich wünschen, um einmal auszuschlagen und Energie zu tanken.

Krankentransporte

mehr ANNERKENNUNG für die Pflege durch die Öffentlichkeit

mehr finanzielle Unterstützung

mehr geförderte Betreuungsstunden für meine Mutter

Mehr Stunden bzw. Zwischeneinsätze

Mehr Stunden zur Betreuung

Mehrstündige Heimhilfe

mobile Physiotherapie und Psychotherapie auf Krankenschein

Punktuelle Unterstützung, um 1x 5 Stufen zu bewältigen, um aus dem Haus zu kommen mit Rollstuhl und dann weitersehen.

Spontane Rundumbetreuung , wenn der Angehörige weg muss oder spontane Unterbringungsmöglichkeit, und dafür die finanzielle Unterstützung

Stundenweise Betreuung in einer Einrichtung

teilweise 24-Stunden-Betreuung

Therapien: Logo, Physio, Bewegung

unbürokratische, stundenweise Unterstützung (ohne 5 Anträge stellen zu müssen und alles 5x erklären müssen) und vor allem leistbare Hilfe

Urlaub

Urlaub mit Assistenz

Wie es derzeit organisiert ist, passt es gut. Die Flexibilität der Betreuungszeiten ist sehr gut! Kurzfristige Hilfe ist meinst möglich, das ist eine wunderbare Erleichterung!

wie oben angegeben - Tags- und Abenbetreuung des behinderten Kindes fallweise; Erweiterte Kostenübernahme für Psychotherapie für Geschwisterkinder und Eltern

Würde mir sehr wünschen von den Behörden mehr Verständnis und Wertschätzung gegenüber den pflegenden Angehörigen und den Patienten!!!

zuständig fühlende Ärzte, Ärzte die Probleme ernst nehmen. Bessere Unterstützungsmöglichkeiten, um selber Kraft zu tanken. Bessere Unterstützung um angemessenen wohnraum zu schaffen.