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Family carers' needs for support over the life span – a population-based national survey for Switzerland

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Background

Family carers (informal carers) are increasingly recognized as **integral contributors** to healthcare delivery in Switzerland and internationally, both by **policymakers and researchers**, see, e.g.:

- *Swiss Federal Council (2014); Schweizerische Akademie der Medizinischen Wissenschaften – SAMW (2016); Kesselring (2004); Perrig-Chiello & Höpflinger (2012); World Health Organization – WHO (2012); WHO (2017)*

Several studies have analyzed the **needs of family carers (informal carers) in Switzerland**, however focusing on **specific age groups** or specific **illnesses** (e.g. caring for cancer patients):

- *Fringer et al. (2013); Riedel (2014); Rudin & Strub (2014); Bannwart & Dubach (2016); Schön-Bühlmann (2005); Fringer (2016); Höpflinger et al. (2011); Fluder et al. (2012)*

This study focused on the **entire Swiss resident population**, identifying family carers (informal carers) carers:

- **all ages** of carers (children from 9 years of age, adults, retirees) **and illnesses** of cared-for persons
- also carers who so far had not received any support (were not registered with any organizations)

Aim

The *Swiss Federal Council* issued the support program “Entlastungsangebote für betreuende Angehörige” / “offres visant à décharger les proches aidants” / “offerte di sgravio per I familiari assistenti” 2017-2020, with the aim to:

→ Promote the **reconcilability of family (/informal) care with professional activity**

In the first part of the program, the *Federal Office of Public Health (FOPH)* commissioned this specific project (<http://www.bag.admin.ch/betreuende-angehoerige-programmteil1>) in order to:

→ Conduct the **first national survey** representative of the Swiss population in this regard

→ Establish a **base of knowledge** regarding **family carers (/informal carers) and their needs**

Questions:

- **Who** are the family carers (/informal carers) in Switzerland and **how many** are there?
- Which are their **roles/tasks** and how are they **affected** by them?
- What kind of **support** do they need?

Method

Study design

- Population: **Swiss residents aged ≥ 9 years**, all language regions, all nationalities: 7.8 M in 2018 (*FSO 2021a*)
- Stratified sample (age, gender, geographical region)
 - Provided by Swiss Federal Statistical Office – “Stichprobenrahmen für Personen- und Haushaltsbefragungen” (SRPH)
 - **54'175 individuals invited** for voluntary participation by regular mail, **57% response rate** (30'885)
- Quantitative cross-sectional survey (German, French, Italian versions)
 - **Standardized questionnaire** answered online, by mail, or via telephone (free choice)
 - Conducted from **31st May until 4th September 2018** (pretests, pilot: February/March 2018)
- **Post-stratification** by interlocked weighting by age, gender, language region, degree of urbanity/agglomeration
- Analysis by descriptive statistics, inferential statistical tests of proportion (binomial), distribution (Chi-squared), central tendency (Mann-Whitney, Kruskal-Wallis), correlation (Spearman), and logistic regression

Method

Identification of target group

- “**Family carers**” / “**informal carers**”: relatives as well as unrelated persons with a caring role
- “**Caring role**”: supporting a person...
 - ...due to physical, psychological, or cognitive illness/limitation/impairment, including care at the end of life
 - ...permanently or temporarily (e.g. after an inpatient treatment)
 - ...excluding child care and volunteer work
- Given examples: everyday life, housekeeping, settling accounts, physician visits, caregiving at home
- Participants were asked to self-identify as family carers (/informal carers) given the above definitions
 - If the answer was “no”, the survey ended after this first question
 - A specific reply card for the identification of non-caring persons was provided
- An adapted version was provided to participants <16 years of age including comic strips

Method

Respondents

Table 1: Respondents by age group, gender, language, and communication compared to population

| By age group (years): | [9,16)^a | [16-26)^a | [26-50)^a | [50-65)^a | ≥65 | total |
|-------------------------------------|---------------------------|----------------------------|----------------------------|----------------------------|----------------|--------------|
| Number of respondents | 4'183 | 5'652 | 8'389 | 7'026 | 5'635 | 30'885 |
| Relative frequency (RF) | 14% | 18% | 27% | 23% | 18% | 100% |
| <i>RF in population^b</i> | 8% | 12% | 37% | 23% | 20% | 100% |
| By gender: | | | female | male | other | total |
| Number of respondents | | | 15'210 | 15'675 | 0 | 30'885 |
| Relative frequency (RF) | | | 49% | 51% | - | 100% |
| <i>RF in population^b</i> | | | 49% | 51% | - | 100% |
| By language version: | | | German | French | Italian | total |
| Number of respondents | | | 21'422 | 7'001 | 2'462 | 30'885 |
| Relative frequency (RF) | | | 69% | 23% | 8% | 100% |
| <i>RF in population^c</i> | | | 67% | 24% | 9% | 100% |
| By means of communication: | | | mail | online | phone | total |
| Number of respondents | | | 23'421 | 6'026 | 1'438 | 30'885 |
| Relative frequency (RF) | | | 76% | 20% | 5% | 100% |

^aNotation: brackets indicate inclusion, parenthesis indicate exclusion

^bSource: BFS 2021a; Swiss resident population 2018 specifically from 9 years of age

^cSource: BFS 2021b; Swiss resident population 2018 from 15 years of age; other languages not considered

Method

Estimation of prevalence

- Of the 30'885 respondents, 2'425 were active carers (7.9%), and 572 formerly were carers (1.9%)
- **Logistic regression** model: being an **active carer** (“yes”/“no”)
 - Aim: accounting for correlations between **sociodemographic characteristics** when estimating their relationship with the outcome
 - Maximum-likelihood estimation (Y_i indicating a caring role, X_i the sociodemographic attributes of person i):

$$P[Y_i = \text{"yes"} | X_i] = \frac{\exp(\beta_1 X_{1,i} + \beta_2 X_{2,i} + \dots + \beta_k X_{k,i})}{1 + \exp(\beta_1 X_{1,i} + \beta_2 X_{2,i} + \dots + \beta_k X_{k,i})} \quad \forall i \in [1, \dots, N]$$

- Results:
 - **Marginal effects** (odds factors)
 - Prediction of the **prevalence** of carers for specific sociodemographic groups and for the population
- Assumption: Marginal effects within sample are externally valid

Results

Likelihood of a caring role

Table 2: Effects of demographic attributes on the likelihood of a caring role

| Predictors | Odds factor ^a | Coefficient ^b |
|--------------------|--------------------------|--------------------------|
| Age group (years): | | |
| [9, 16) | 0.68 | -0.39*** |
| [16, 26) | 0.22 | -1.51*** |
| [26, 50) | 0.44 | -0.82*** |
| [50-65) | 1.00 (ref.) | - |
| ≥65 | 0.67 | -0.40*** |
| Gender: | | |
| male | 0.84 | -0.17*** |
| female | 1.00 (ref.) | - |
| Urbanity: | | |
| urban | 0.95 | -0.05 |
| suburban | 0.98 | -0.02 |
| rural | 1.00 (ref.) | - |
| Language: | | |
| French | 0.83 | -0.19*** |
| Italian | 1.03 | 0.03 |
| German | 1.00 (ref.) | - |
| Constant | 0.16 | -1.82*** |

^aOdds factor = exp(coefficient)

^bCoefficient on the logarithmic scale

*p<.05, **p<.01, ***p<0.001

Examples:

- [50 to 65) years old Italian or German-speaking women were the most likely to have a caring role (odds = 0.162; probability = 13.9%)
- If the preferred language was Italian, the point estimate was even slightly higher, however not statistically significantly different.
- [16 to 26) years old French-speaking males were the least likely (odds = 0.025; probability = 2.4%)
- Urbanity showed no significant effect.

Note that odds factors are multiplicative (including the regression constant), and that in general:

$$\text{probability} = \frac{\text{odds}}{1 + \text{odds}}$$

Results

Prevalence in the Swiss population

Predicting the [prevalence per age group](#), taking into account the distribution of the other sociodemographic attributes in the population, yielded:

Table 3: Estimated prevalence of carers per age group (from 9 years)

| Age group: | Prevalence | Absolute number of individuals^a |
|--------------------|-------------------|---|
| Age group (years): | | |
| [9,16) | 8.6% | 49'000 |
| [16,26) | 3.0% | 28'000 |
| [26,50) | 5.8% | 166'000 |
| [50-65) | 12.2% | 215'000 |
| ≥65 | 8.6% | 134'000 |
| Aged ≥16 years | 7.6% | 543'000 |

^aRounded to 1'000 individuals; referring to the age-specific Swiss resident population according to BFS (2018)

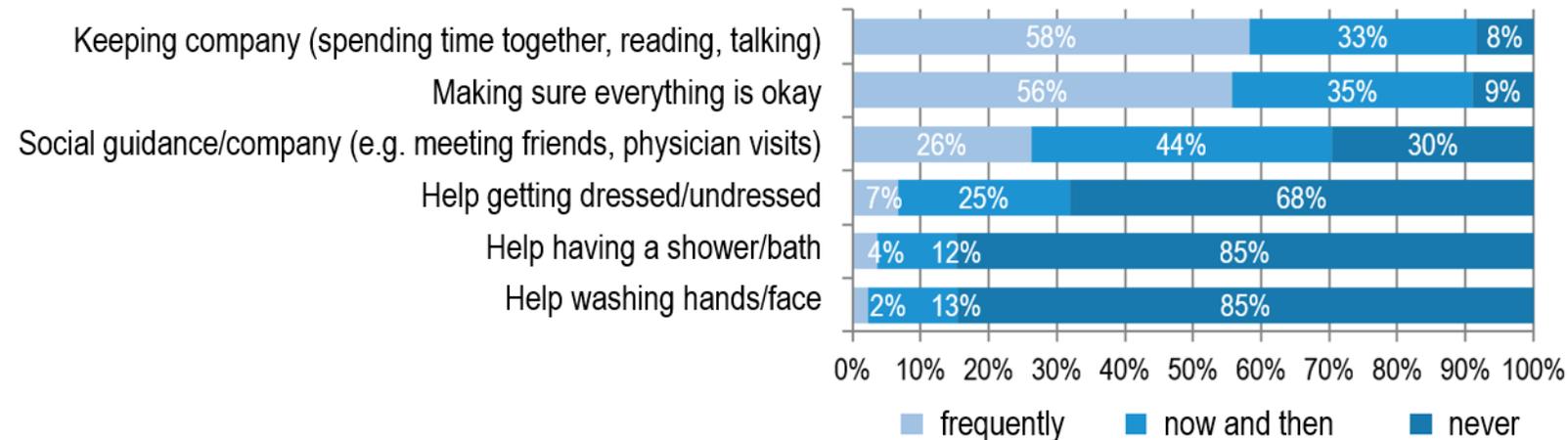
Results

Carers aged <16 years (Young Carers^a)

^aThe literature often defines “Young Carers” as carers of age <18 years

- Gender proportions (female/male) not significantly different from 50% (binomial test) or from the population (FSO 2021a)
 - Two thirds of the cared-for persons were female, one third male (p<0.001)
- Caring roles started at 10 years of age (at the mean and mode), however 11% had started at pre-school age
- 40% cared for a grandparent, 32% a parent, 14% a sibling, 14% for someone outside the closest family
 - Almost half of the Young Carers (YC, 49%) lived together with the cared-for person
- Frequent tasks:

Figure 1: Frequent tasks of Young Carers



Results

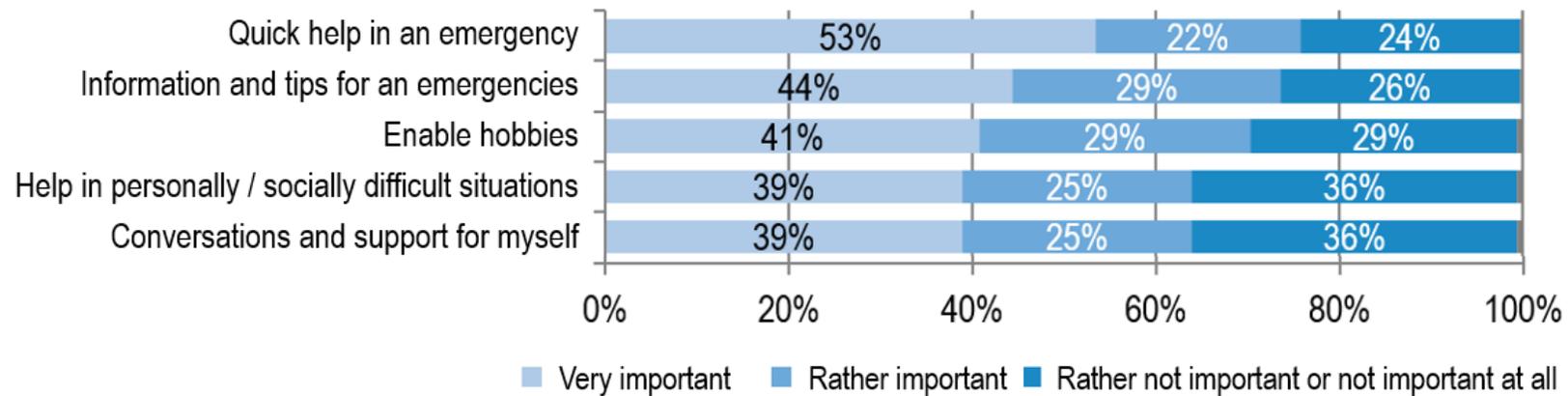
Carers aged <16 years (Young Carers^a)

^aThe literature often defines “Young Carers” as carers of age <18 years

Table 4: Risk factors of Young Carers not receiving enough support

| "Do you get enough help and support yourself?" | | yes | sometimes | no |
|---|------------------------|------------|------------------|-----------|
| Attachment figure within the family: | unavailable (9% of YC) | 53% | 43% | 4% |
| | available (91% of YC) | 86% | 13% | 1% |
| Cared for person has psychological problems: | yes (12% of YC) | 61% | 35% | 4% |
| | no (88% of YC) | 85% | 14% | 1% |

Figure 2: Strongest needs of Young Carers for support

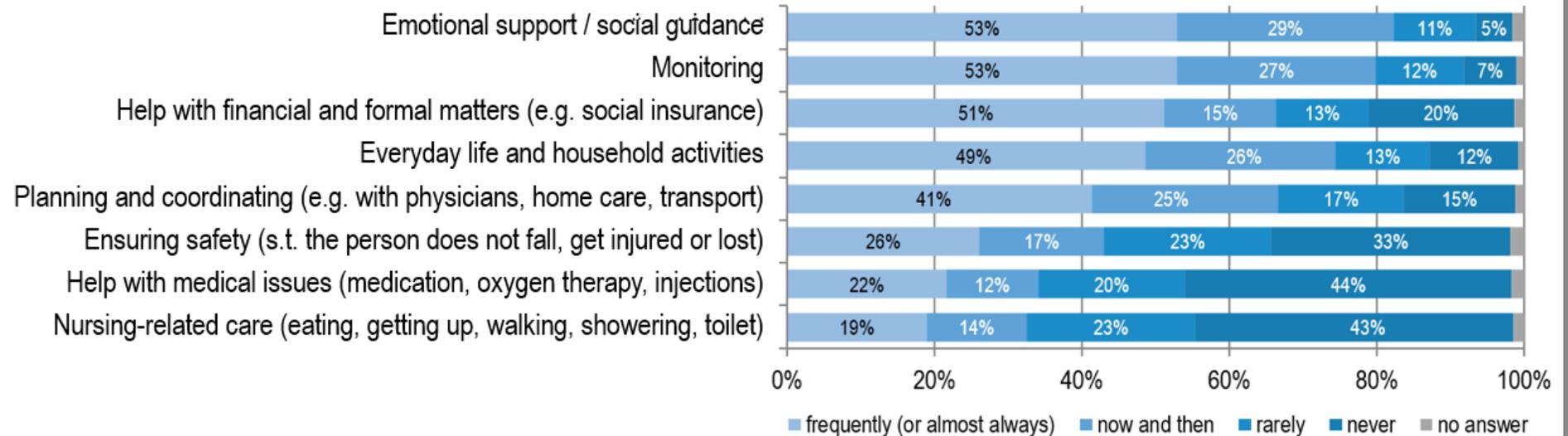


Results

Carers aged ≥ 16 years

- Slightly more than half of the carers were female (54%, $p < 0.001$), and nearly two thirds of the cared-for persons were female (65%) while one third was male ($p < 0.001$)
- 50% cared for a parent (in law), 18% for their partner, 11% for their daughter/son, 11% for other relatives
 - carers aged [50 to 65) predominantly cared for a parent (69%), older carers for their partner (44%)
- Frequent tasks:

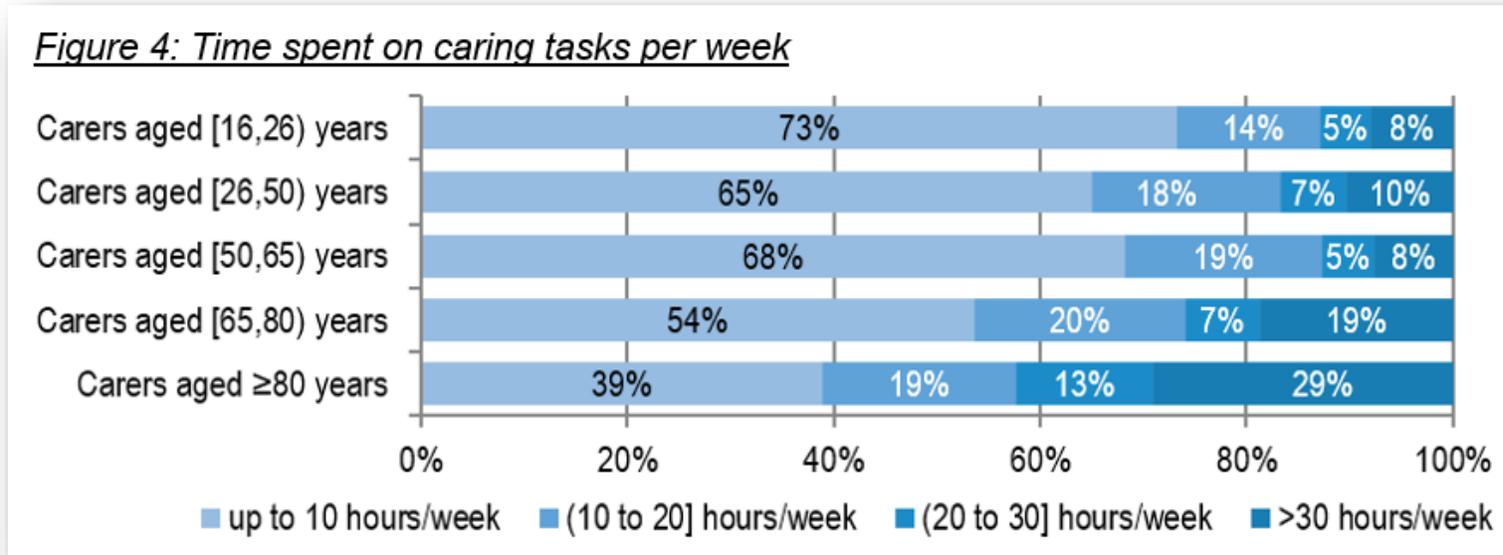
Figure 3: Frequent tasks of carers aged ≥ 16 years



Results

Carers aged ≥ 16 years

- Expenditure of time:



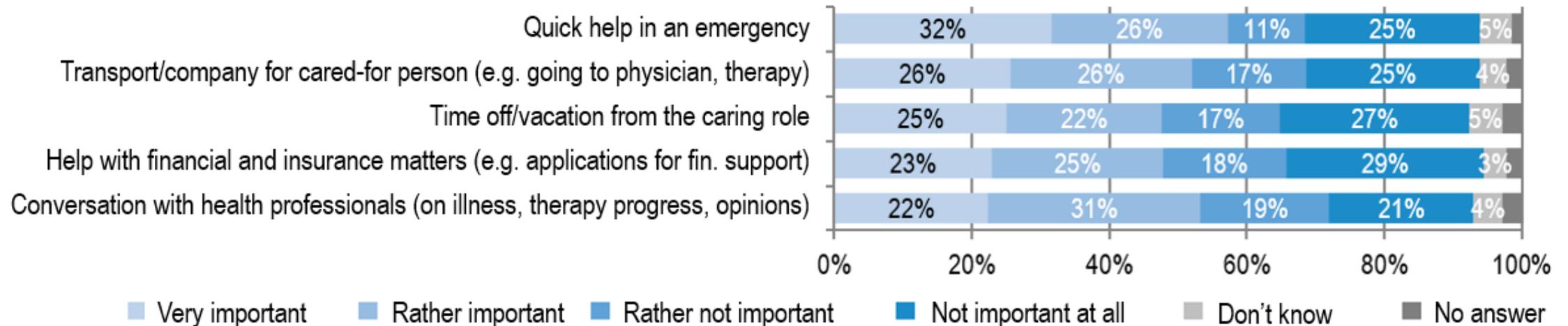
- Age group [16 to 65): 80% were economically active, vs. 79% in the population (FSO 2018a, 2018b, 2019)
 - Of the econom. active: 56% had a level of employment (LOE) of $\geq 90\%$; 26% LOE of [50% to 90%); 18% LOE $< 50\%$
- carers (aged ≥ 16 years) reported lower own health compared to the population (SGB 2019)
 - 73% of females reported “good” or “very good” health (84% in population, $p < 0.001$)
 - 72% of males reported “good” or “very good” health (86% in population, $p < 0.001$)

Results

Carers aged ≥ 16 years

- Most carers (86%) had at least one other person (private or professional) to help them with their tasks
- In a quarter of the cases (27%) professional home care (Spitex) was present
- Needs for support:

Figure 5: Strongest needs of carers aged ≥ 16 years for support



Discussion

Representativeness

- While unprovable in general, this study satisfies the criteria for a **strong case for representativeness**
- **Potential limitations**: non-mandatory participation (however post-stratification), self-reported data

Prevalence

- **Age <16**: This study provides the **first population-based estimation** of the prevalence for Switzerland (**8.6%**). Lux & Eggert (2017) estimated a prevalence of **5% for Germany** among children aged 12 to 17 years. Nagl-Cupal et al. (2014) estimated **4.5% for Austria**, and Lloyd (2011) found **12% for Northern Ireland** (children aged 10-11 years).
- **Age [16-65]**: Bannwart & Dubach (2016) estimated **300'000 individuals for Switzerland (vs. 409'000** in the present study), these authors however used a more **narrow definition** (“Pflege von Erwachsenen”)
- **All adults**: Wetzstein et al. (2015) estimated a prevalence of **6.9% for Germany** (for persons aged ≥ 18) (vs. **7.6%** for Switzerland in the present study, age ≥ 16)

Discussion

Needs for support

- The most prominent need for support is [help in emergencies](#)
- This is followed by transport services/company, care-related and personal conversation, personal relief/time off, and help with financial and insurance matters
- [Establishment and accessibility](#) of according [structures and services](#) are therefore key
- In several cases, reports of [unawareness of the carer of certain services being offered](#) imply that information plays an important role in utilizing services. Wetzstein et al. (2015) made similar observations in Germany.

De Roos et al. (2017) further identified growing up with a chronically ill family member to be a [risk factor for psychological problems in adolescents](#).

- [Early interventions](#) regarding health, social issues and education can prevent the development of inadequate caring roles (see, e.g., Frank 2002; Frank & Slatcher 2009)

Liechti et al. (2020) identified [risk factors](#) that correlate with [emotional stress/problems of carers](#): mental illness of the cared-for person, multimorbidity, volatile health of the cared-for person (among others)

Conclusion

This study likely shows representative results for [Switzerland](#) and thereby provides a key [base of knowledge](#)

- Family carers (informal carers) (approx. 600'000) are [important contributors](#) to healthcare delivery and society
- People [aged around 50 to 65](#) have a particularly high probability of assuming a caring role of ([up to 1 in 8](#))
- But [also minors](#) frequently are carers ([1 in 12](#)), often already starting around the age of 10
- Several of the carers' important needs for support have not been met exhaustively

As stated by the [synthesis report](#) by the FOPH (2020), which links the different projects of the program:

- Family carers (informal carers) will remain key [contributors](#) to and [subjects](#) of [healthcare and social policy](#)
- [Increasing awareness](#) for their role, as well as periodic [data collection](#), are vital to this process
- Subject needs to be [permanently integrated](#) into cantonal and municipal [policy](#), as well as [education](#) of health professionals and involved government officials

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Appendix

Questionnaire

- Information collected on:
 1. **Who** are the **carers?** (age, gender, nationality, education, employment, health, household composition)
 2. **Who** are the **cared-for persons?** (age, gender, household composition, illness/limitation/impairment)
 3. Which **tasks** do the carers perform? (nursing-related care, medication, personal hygiene, monitoring, household activities, financial matters, coordination with health professionals, emotional/social support)
 4. What are the **carers' personal capabilities** and to what extent do they perceive their role as **a burden?**
 5. Which kind of **support** do the carers need/welcome?
- Types of questions:
 - Mainly **multiple choice and multiple answer** (partly with option “**other**” for free text input)
 - **Likert** scales (e.g., frequency of support: “never”, “rarely”, “now and then”, “frequently”, “almost always”)
 - **Few open** question for explorative answers (other areas of support), durations (/age) inserted as numbers