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Family carers’ needs for support over the life span

– a population-based national survey for Switzerland

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Content

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 Presonen- 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-Whithey, 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

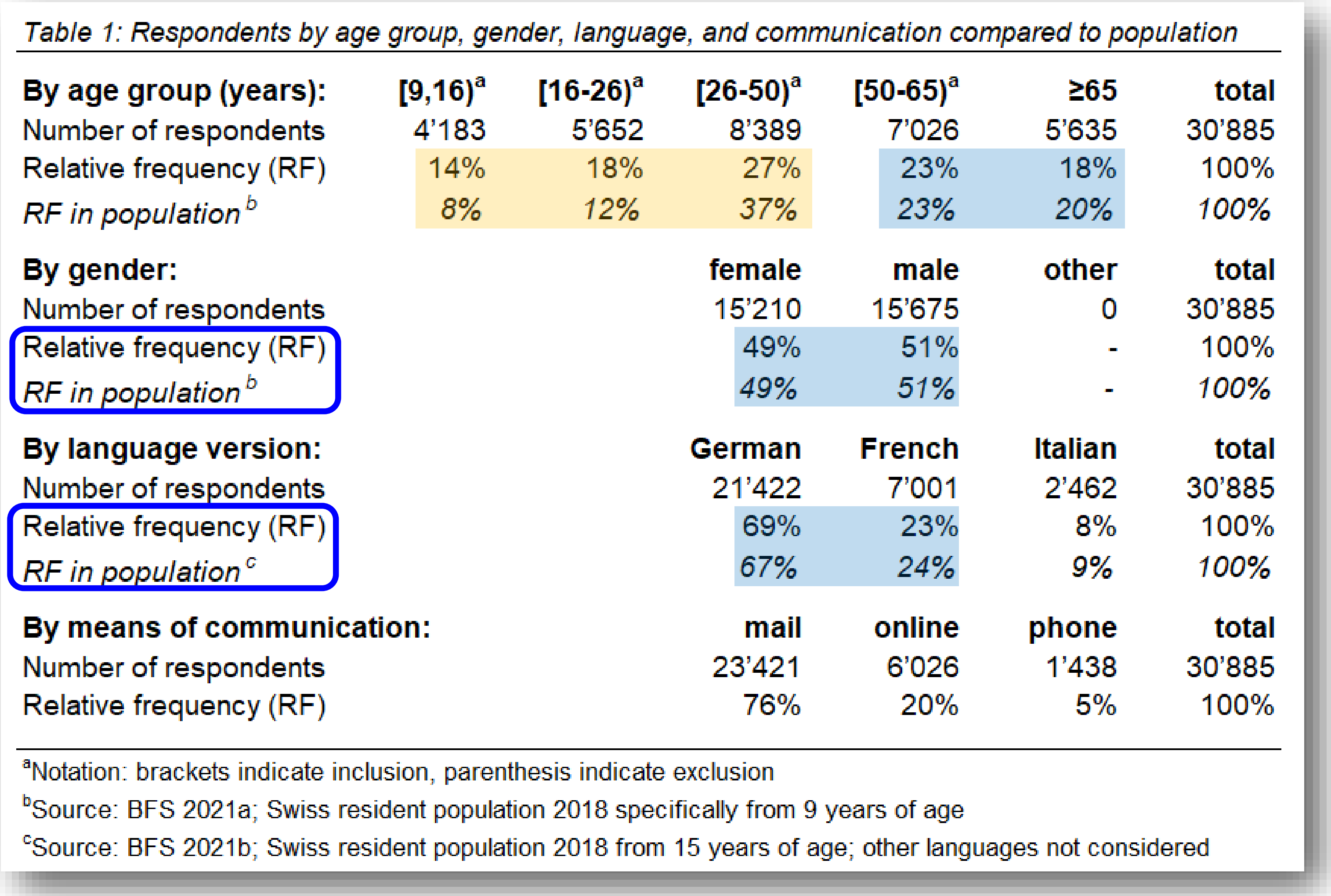


Table 1: Respondents by age group, gender, language, and communication compared to population

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%
RF in population [b]	*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%
RF in population [b]			*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%
RF in population [c]			*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%

[a] Notation: brackets indicate inclusion, parenthesis indicate exclusion

[b] Source: BFS 2021a; Swiss resident population 2018 specifically from 9 years of age

[c] Source: 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, $\boldsymbol{X}_i$ the sociodemographic attributes of person i):

$$P[Y_i = "yes" | \boldsymbol{X}_i] = \frac{\exp\left(\beta_1 X_{1,i} + \beta_2 X_{2,i} + \cdots + \beta_k X_{k,i}\right)}{1 + \exp\left(\beta_1 X_{1,i} + \beta_2 X_{2,i} + \cdots + \beta_k X_{k,i}\right)} \ \forall \ i \in [1, \ldots, N]$$

  - 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

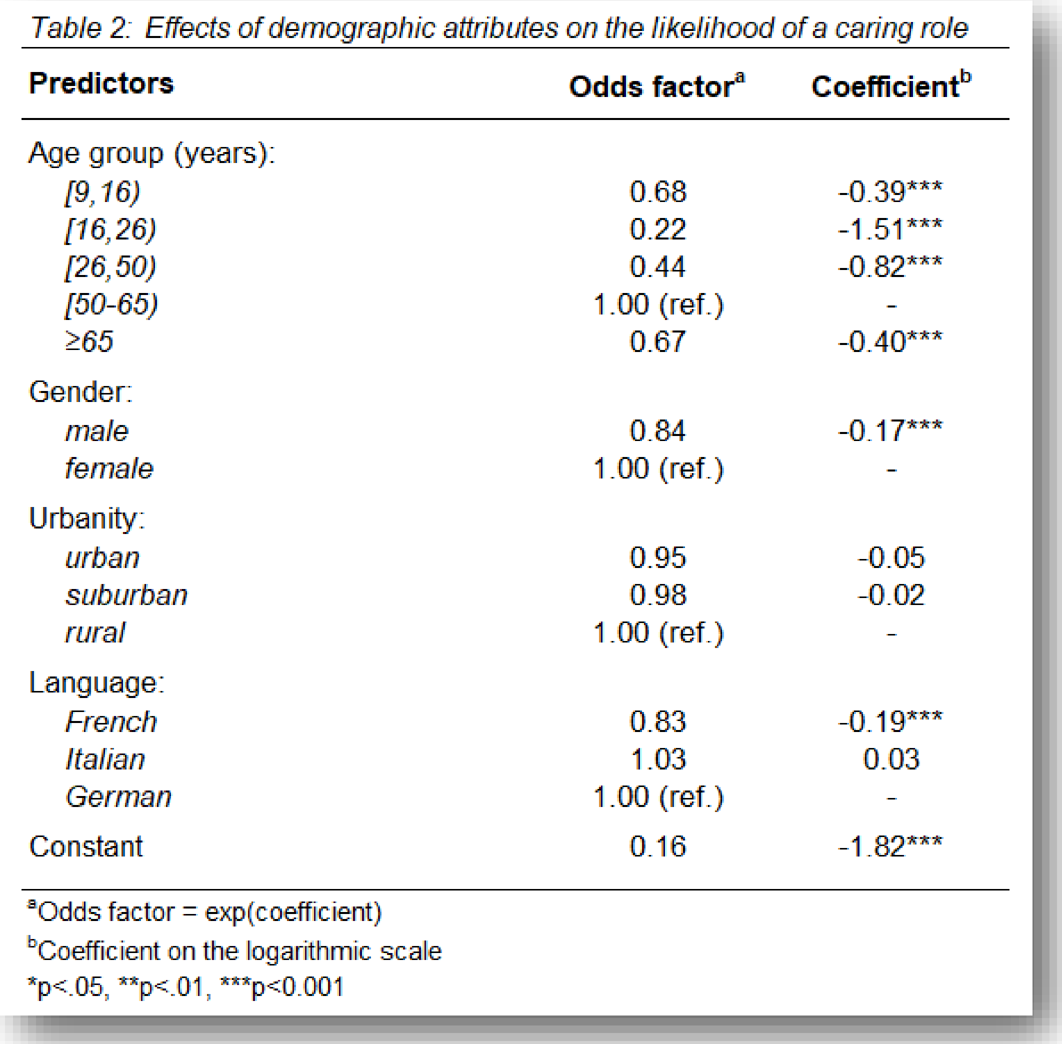


Table 2: Effects of demographic attributes on the likelihood of a caring role

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***

[a] Odds factor = exp(coefficient)

[b] Coefficient 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:

$$\text{probability} = {}^{odds}/_{1 + odds}$$

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:

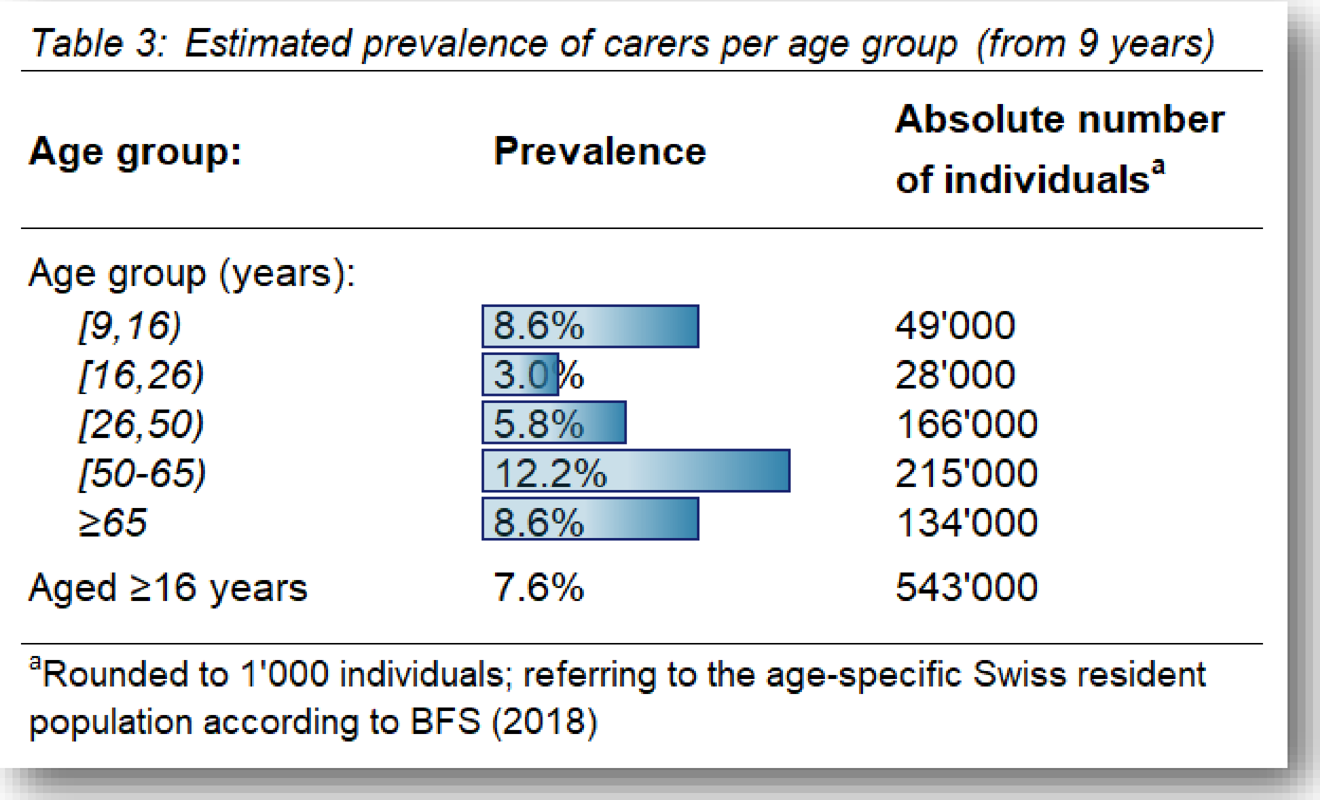


Table 3: Estimated prevalence of carers per age group (from 9 years)

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

[a] Rounded to 1'000 individuals; referring to the age-specific Swiss resident population according to BFS (2018)

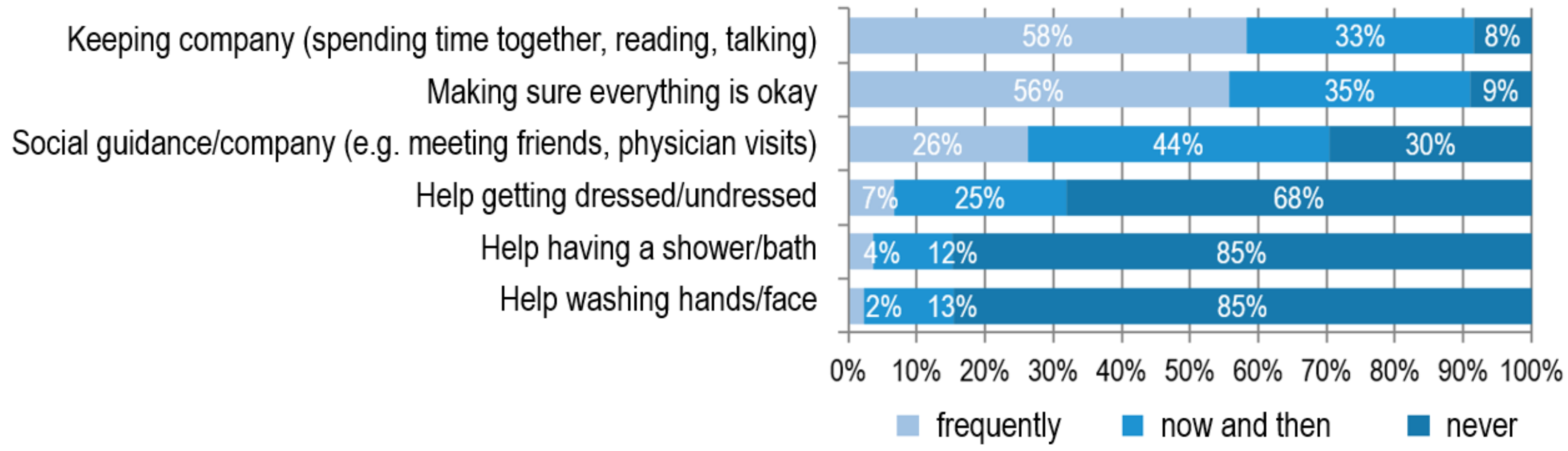
Results

Carers aged <16 years (Young Carers[a])

[a] The 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])

[a]The literature often defines “Young Carers” as carers of age <18 years

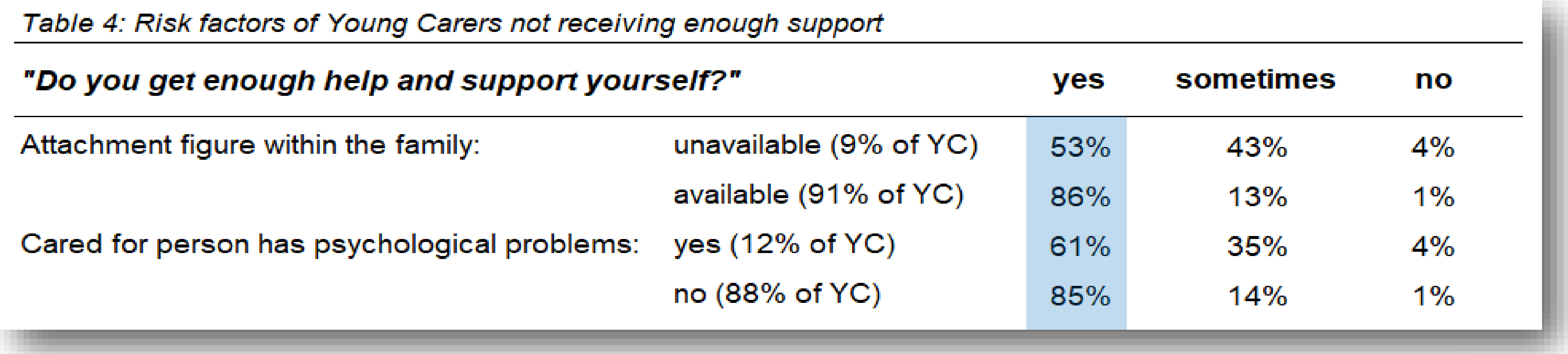
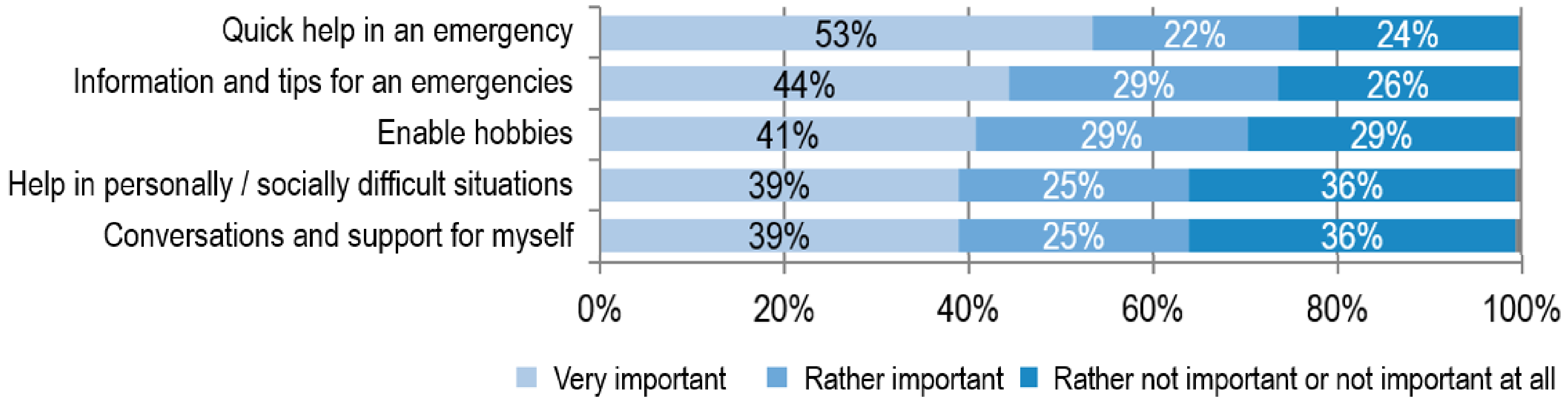


Table 4: Risk factors of Young Carers not receiving enough support

"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%

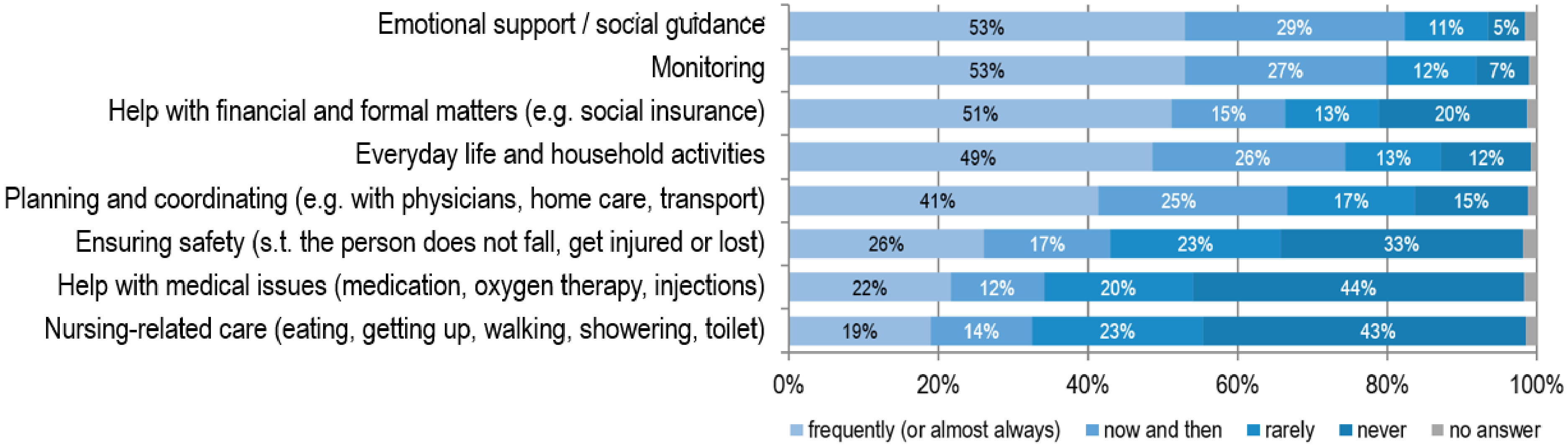
Figure 2: Strongest needs of Young Carers for support



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:

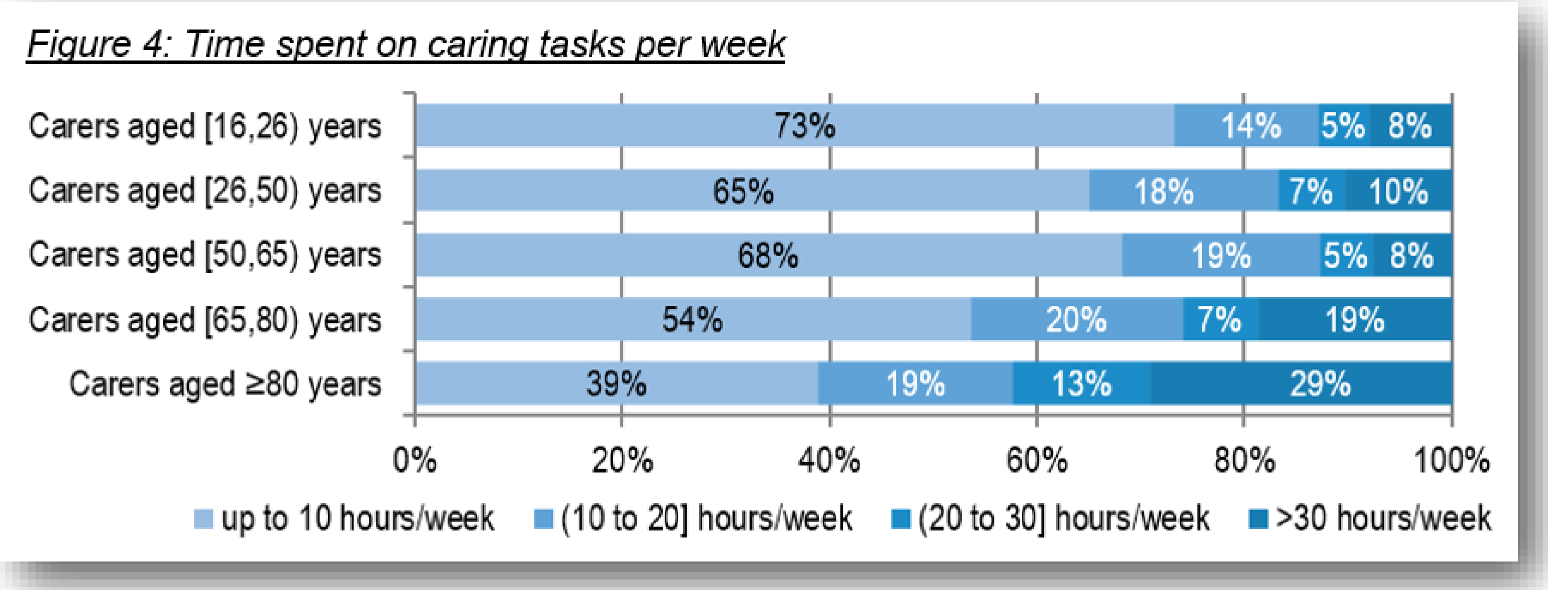


Figure 4: Time spent on caring tasks per week

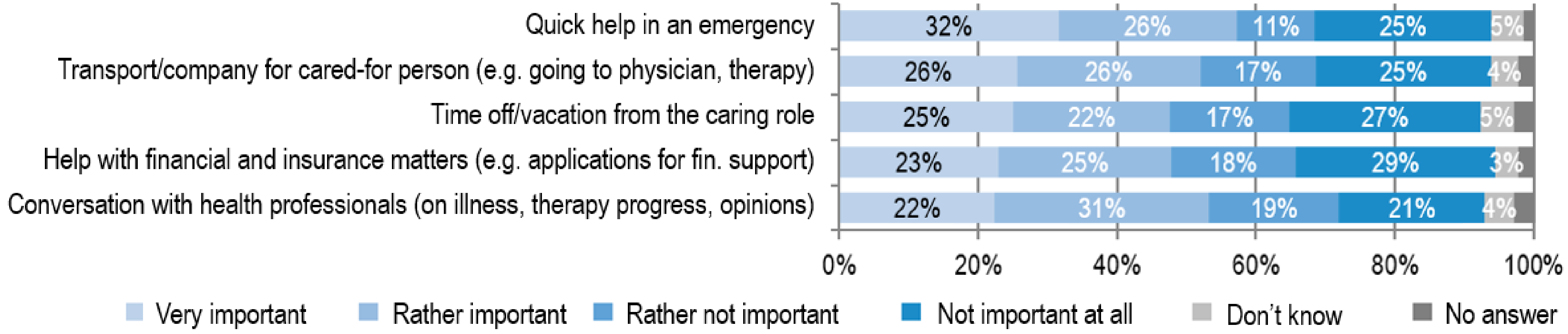
- Age group [16 to 65): 80% were economically active, vs. 79% in the population (*FSO 2018a, 2018b, 2019*)
  - Of the econom. active: 56% had a level of employment (LOE) of ≥90%; 26% LOE of [50% to 90%); 18% LOE <50%
- carers (aged ≥16 years) reported lower own health compared to the population (*SGB 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