unisanté

Hes·so
Haute Ecole Spécialisée de Suisse occidentale
University of Applied Sciences Western Switzerland

La Source.
Institut et Haute Ecole de la Santé

OST
Ostschweizer Fachhochschule

Swiss **CO**hort of **H**ealthcare **P**rofessionals and **I**nformal **Ca**regivers

scohpica

SCOHPICA Informal Caregivers:
First findings from the 2025 data collection.

23.04.2026

Annie Oulevey Bachmann, Philippe Terrier, Emeric Offenstein, Jessica Hess,
Ingrid Gilles & Isabelle Peytremann Bridevaux

CHUV Centre hospitalier universitaire vaudois

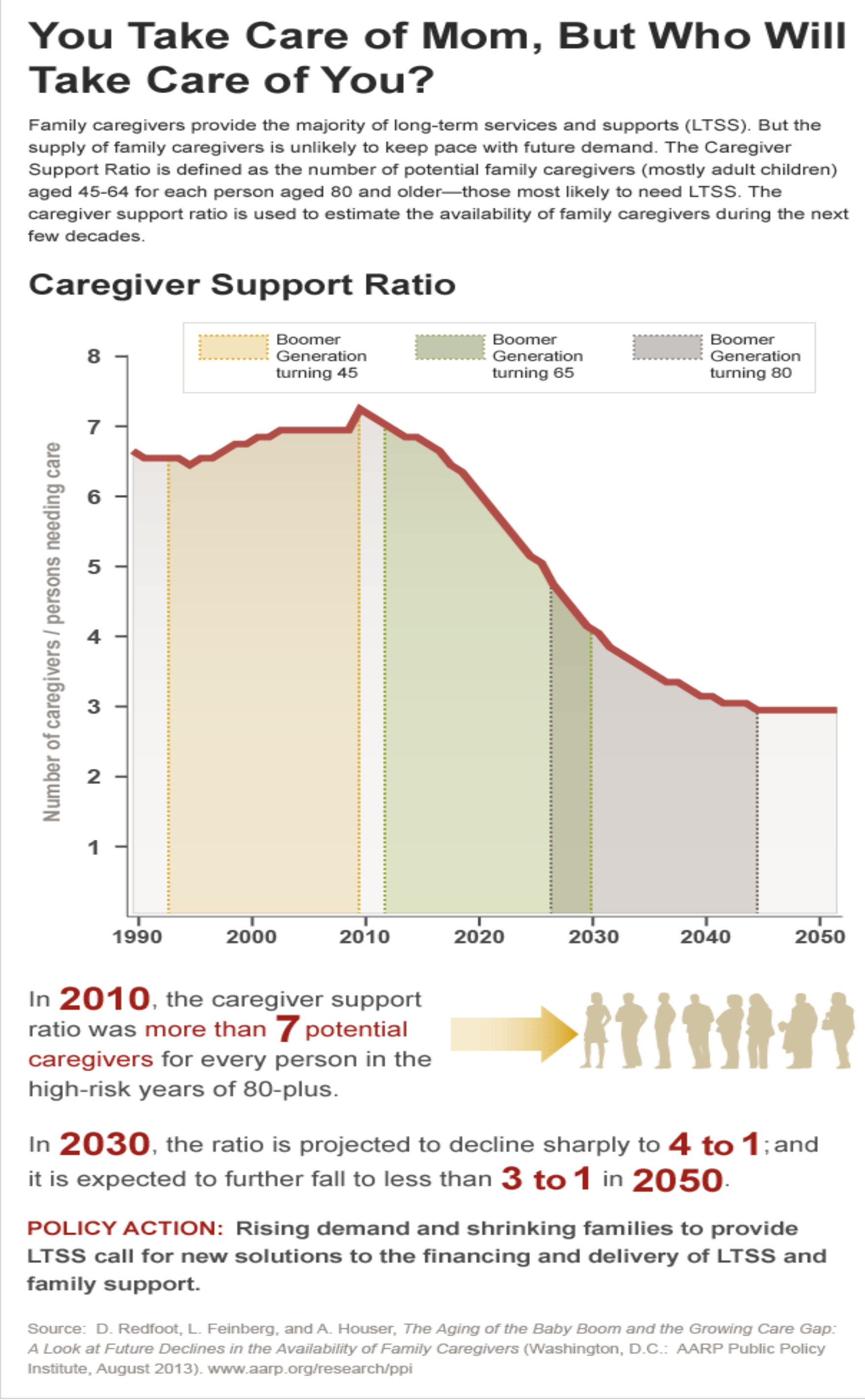
Unil.

Context of Informal Caregiving: Major Issues

Concerns and Key Issues

- Shortage of healthcare professionals (HCPs)
- Decline in the ratio of potential informal caregivers (ICs) to care recipients
- Ongoing pressures and continuous adaptations experienced by both HCPs and ICs
- Limited knowledge of the long-term experiences and needs of HCPs and ICs in Switzerland

Longitudinal data are essential for **public policy planning**, the **management and sustainablity** of HCPs and ICs in Switzerland, as well as for **ensuring high-quality care**.



You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

Caregiver Support Ratio

In **2010**, the caregiver support ratio was more than **7** potential caregivers for every person in the high-risk years of 80-plus.

In **2030**, the ratio is projected to decline sharply to **4 to 1**; and it is expected to further fall to less than **3 to 1** in **2050**.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Source: D. Redfoot, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, D.C.: AARP Public Policy Institute, August 2013). www.aarp.org/research/ppi

Overview of the SCOHPICA Project

National research project with longitudinal follow-up

Annual surveys

Two Components

1) Healthcare professionals (2022)
2) Informal caregivers (pilot study, 2024)

De-identified data

Securely stored at Unisanté

Open data

Both cohorts are funded by cantonal and national public bodies

Key Results from the analysis of data available

Dashboard

SCOHPICA project: one project ➢ Two cohorts

Health care professionals (HCP)

5-10’000 professionals over time

- 2022 – Initial baseline
- Then annually (2022–2025):
  - Baseline questionnaire
  - Annual follow-up survey (FU)
- 2022: 5,917 participants
- 2024: + 1,956 new participants and +1,214 life calendars
- 2025: + 939 new participants and +643 life calendars

2024 SNSF SCOHPICA-HCP project: sequential mixed-methods design CHF 750,000.-
Additional funding for the HCP cohort: Federal Office of Public Health (FOPH), OBSAN, and the Cantons of Valais (VS), Vaud (VD), and Neuchâtel (NE)

Aim

To provide longitudinal data on the trajectories and experiences of formal and informal caregivers in order to inform health workforce monitoring and planning.

German-, French-, and Italian-speaking regions of Switzerland

Informal caregivers (IC)

1-2’000 IC over time

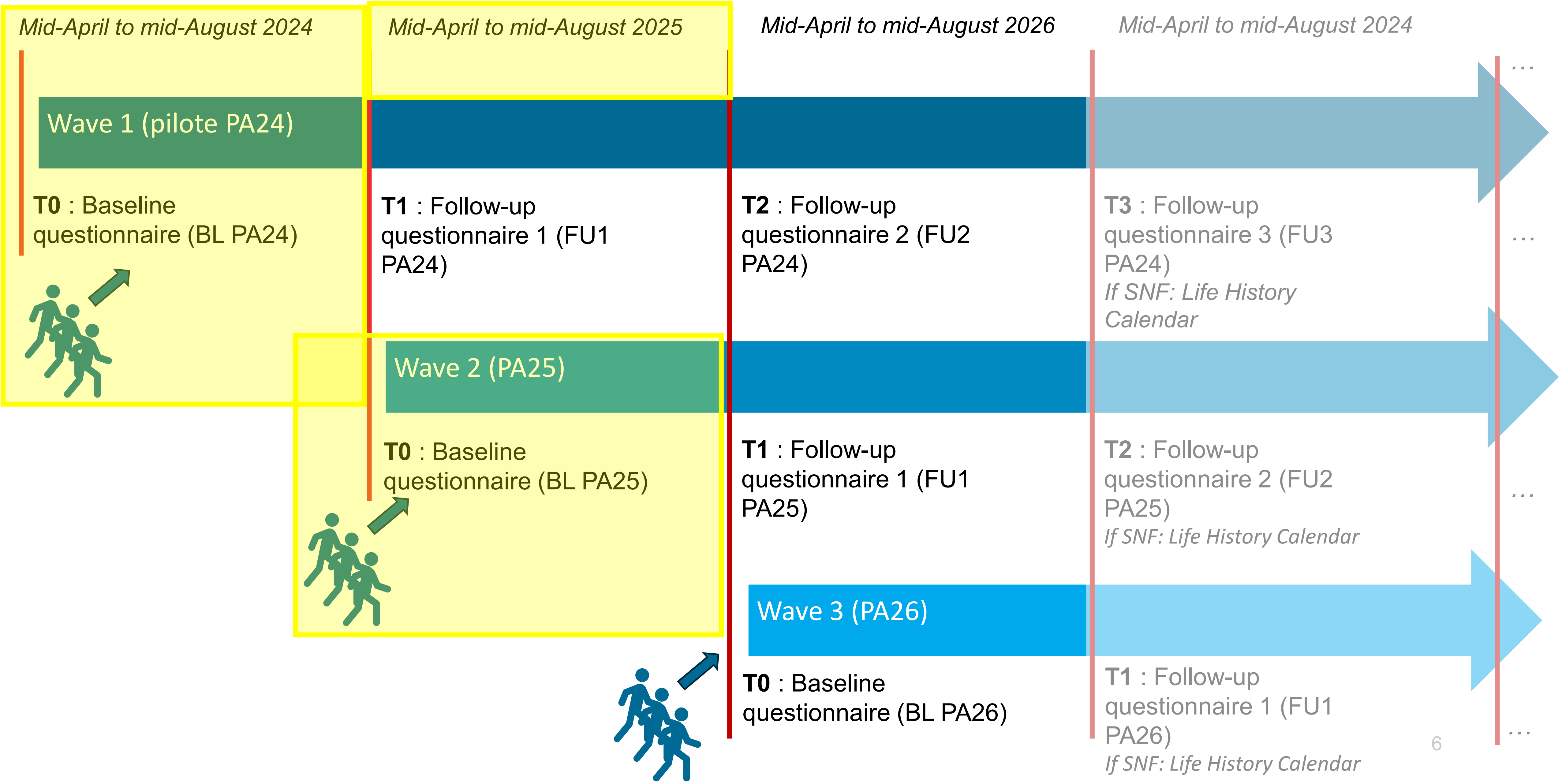
- 2024 – Inital baseline, pilot study
- Then annually:
  - Baseline questionnaire
  - Annual follow-up survey (FU)
- 2024: 305 participants (2 linguistic regions)
- 2024–2025: 658 baseline respondents (3 linguistic regions)
- 2025: 134 follow-up respondents (2 linguistic regions)
- 2026: Renewed submission of a proposal to the Swiss National Science Foundation (SNSF) on October 1

2026 funding for the ICcohort:HES-SO Health Faculty, HEdS La Source, Unisanté, OBSAN, and the Cantons of Vaud and Valais.

SCOHPICA-IC: The Informal Caregivers Cohort

- To understand the trajectories and experiences of informal caregivers.
  - To identify the factors leading individuals to become informal caregivers and to sustain this role over time.
  - To identify the formal and informal resources available to informal caregivers.
- Based on this evidence, to propose concrete pathways for improving the quality of life of informal caregivers.

Design: open prospective cohort



Mid-April to mid-August 2024

Mid-April to mid-August 2025

Mid-April to mid-August 2026

Mid-April to mid-August 2024

Wave 1 (pilote PA24)

T0 : Baseline questionnaire (BL PA24)

T1 : Follow-up questionnaire 1 (FU1 PA24)

T2 : Follow-up questionnaire 2 (FU2 PA24)

T3 : Follow-up questionnaire 3 (FU3 PA24)
If SNF: Life History Calendar

…

Wave 2 (PA25)

T0 : Baseline questionnaire (BL PA25)

T1 : Follow-up questionnaire 1 (FU1 PA25)

T2 : Follow-up questionnaire 2 (FU2 PA25)
If SNF: Life History Calendar

…

Wave 3 (PA26)

T0 : Baseline questionnaire (BL PA26)

T1 : Follow-up questionnaire 1 (FU1 PA26)
If SNF: Life History Calendar

…

Population

Professionnel·les de santé

5-10'000 à terme

Médecins, infirmiers·ères, pharmacien·nes, psychologues, physiothérapeutes, ambulanciers ·ères, diététicien ·nes, personnels d'assistance (médecins, pharmacien·nes, infirmiers·ères, etc.) et autres professionnels de santé.

... en contact direct avec les patients ...

Switzerland:
German-, French-, and Italian-speaking regions

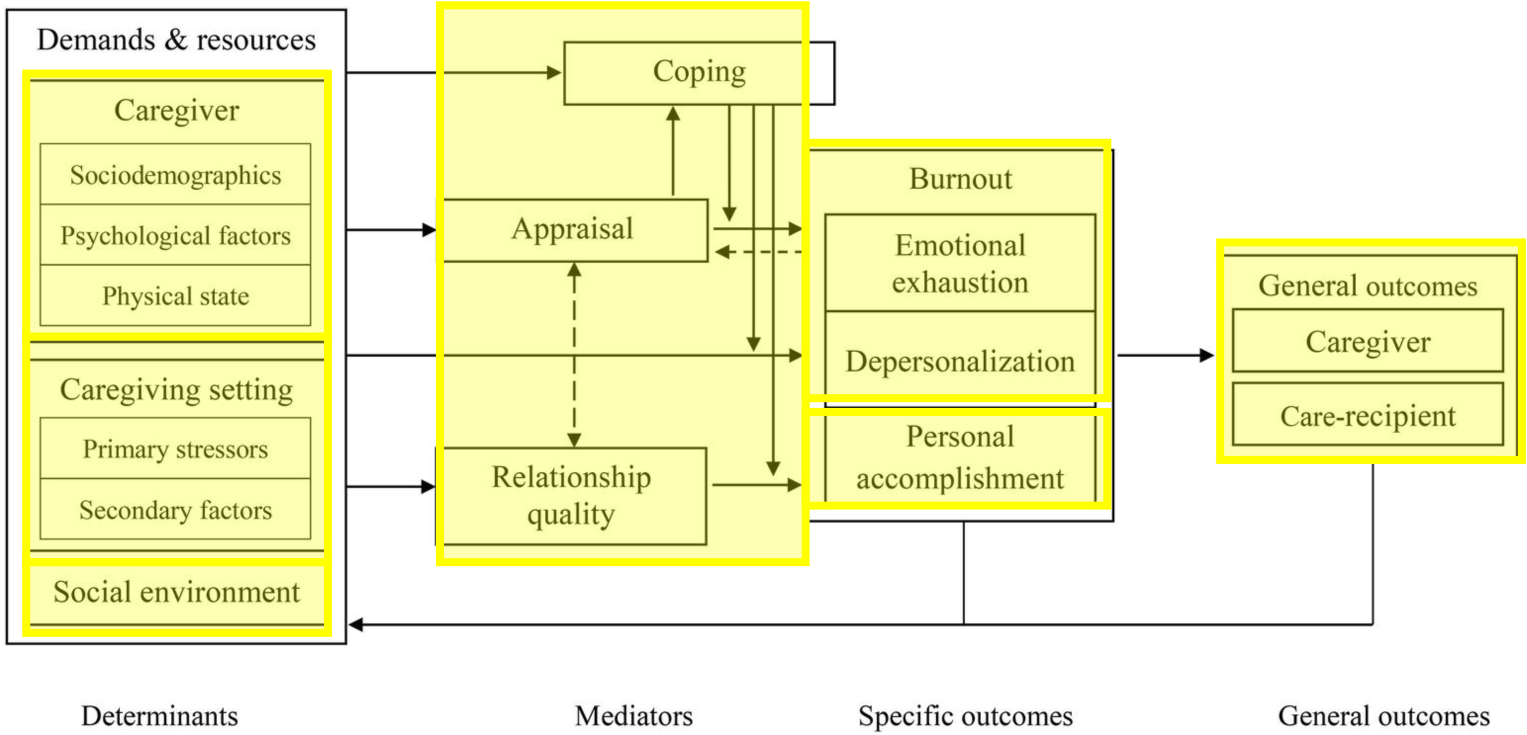
≥ 18 Y
Currently providing care to a close relative or loved one

Informal caregivers

Informal caregivers are individuals of all age groups who provide support to a person to whom they feel close or whom they feel obliged to support. The term "informal caregiver" is used when this support is provided on a sustained basis and places significant demands on the IC.

Questionnaire

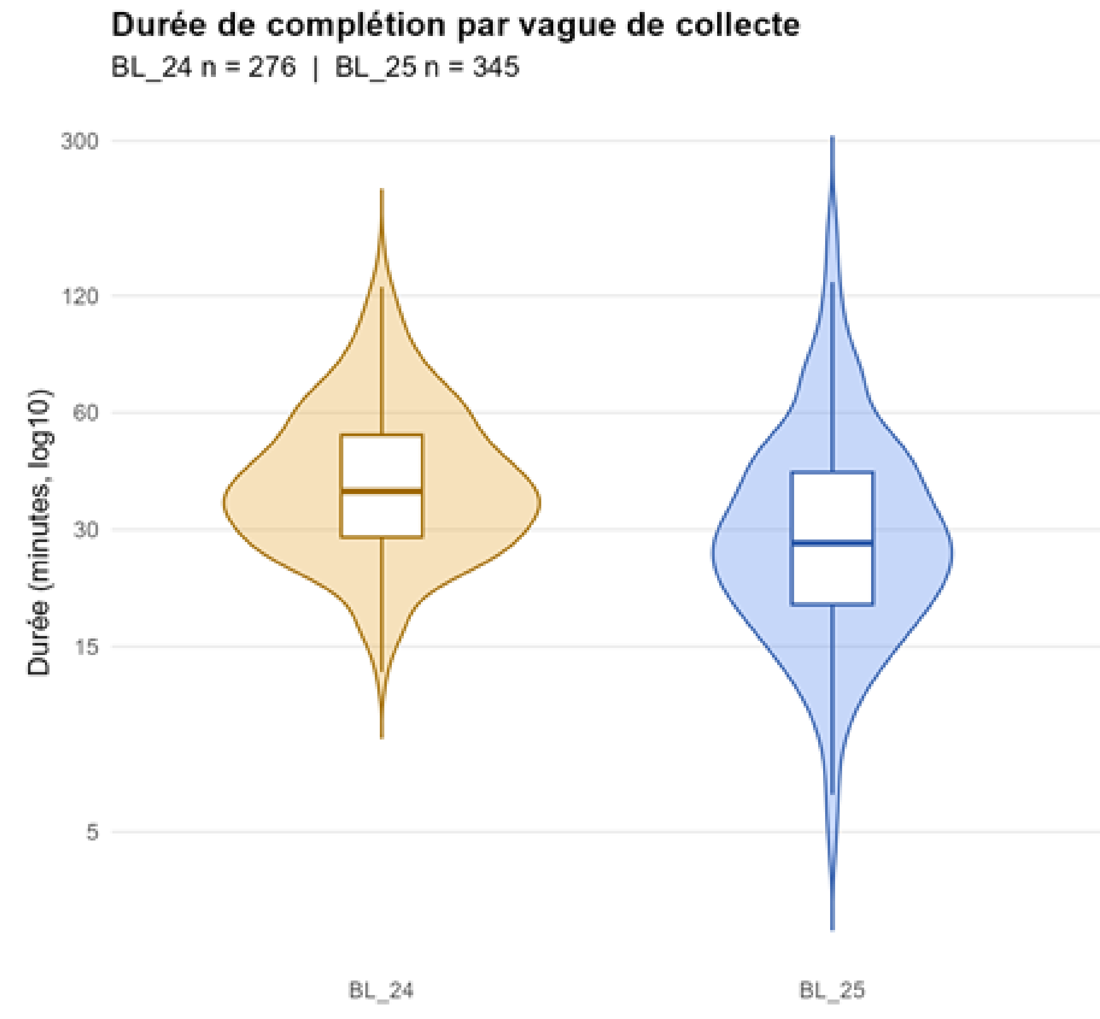
- Theoretical framework: *The Informal Caregiving Integrative Model (ICIM)* Gérain, P., & Zech, E. (2019).
- Literature Review on the determinants of well-being, quality of life, and subjective and objective burden among ICs Escasain et al, 2022
- Critical input from the Advisory Panel and Scientific Expert Group



Baseline questionnaire 2025

- Web-questionnaire: baseline 2025 168 questions
- Survey completion time: 20-45 minutes
- Languages: French, German, Italian
- One open-ended question allowing participants to provide free comments
    - “Would you like to add any further comments on the informal care you provide to your close relative and/or mention any important aspect that was not addressed in the questionnaire?”

Completion time



Data collection 2024 and 2025

- Mid-April 2024 and 2025 to mid-August 2024 and 2025
- 3 languages
- OBSAN Mandate 2025 : financial support to focus on informal caregivers aged 65 and over
- Vaud Mandate 2025 : financial support to targeted focus on Vaud-specific data and on several specific questions
- Limited financial resources: following a recommendation from the advisory panel, recruitment efforts in 2025 were concentrated on a limited number of specific cantons

Overall Participant Recruitment

- Recruitment based on a multi-pronged strategy developed in 2024 for implementation in 2025, aimed at reaching a broad and diverse group of informal caregivers (ICs)
- Mobilization of institutional and non-profit partners at both cantonal and national levels to disseminate information and the communication toolkit
- Involvement of students from the HES-SO Health Faculty to support recruitment activities
- Use of SCOHPICA webinars and dashboard to increase project visibility and announce the opening of data collection
- Outreach activities, including conferences, presence at health- and caregiving-related events, and distribution of flyers

Delivery of Two Reports in 2025

CHUV Centre hospitalier universitaire vaudois

unisanté Centre universitaire de médecine générale et santé publique · Lausanne

La Source. Institut et Haute Ecole de la Santé

SCOHPICA

Cohorte suisse des professionnel·les de la santé et des proches aidant·es

Rapport destiné à

l'Observatoire Suisse de la Santé (OBSAN)

scohpica

Swiss **CO**hort of **H**ealthcare **P**rofessionals and **I**nformal **CA**regivers

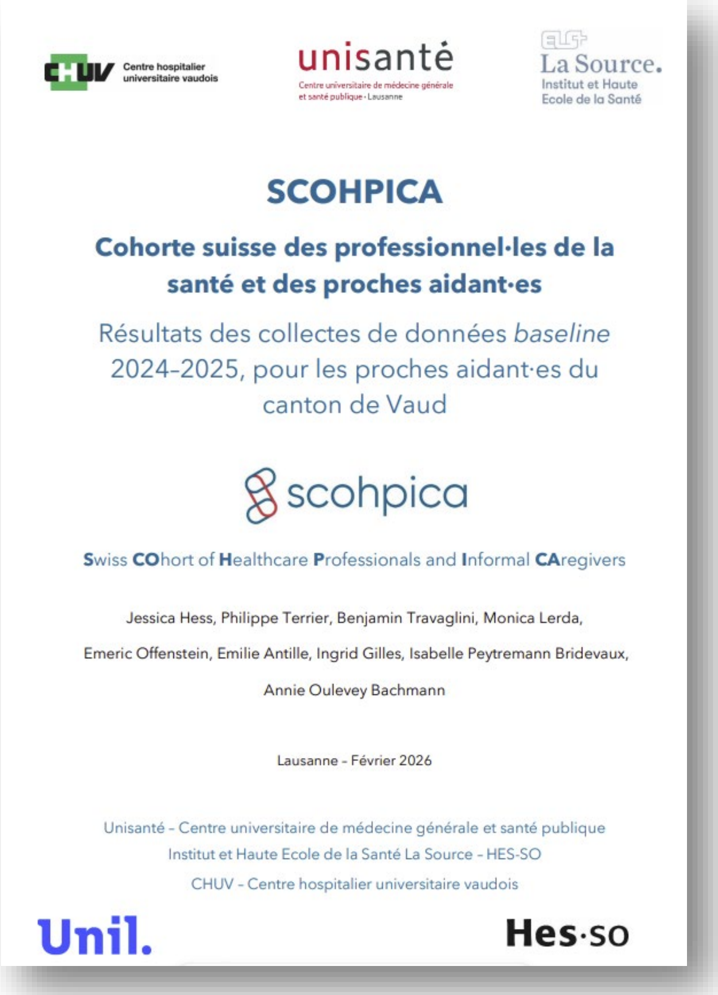
Jessica Hess, Philippe Terrier, Emeric Offenstein, Monica Lerda, Benjamin Travaglini, Emilie Antille, Ingrid Gilles, Isabelle Peytremann Bridevaux, Annie Oulevey Bachmann

Lausanne - Septembre 2025

Institut et Haute Ecole de la Santé La Source - HES-SO
Unisanté - Centre universitaire de médecine générale et santé publique
CHUV - Centre hospitalier universitaire vaudois

UNIL | Université de Lausanne

Hes·so



CHUV Centre hospitalier universitaire vaudois

unisanté Centre universitaire de médecine générale et santé publique · Lausanne

La Source. Institut et Haute Ecole de la Santé

SCOHPICA

Cohorte suisse des professionnel·les de la santé et des proches aidant·es

Résultats des collectes de données *baseline* 2024–2025, pour les proches aidant·es du canton de Vaud

scohpica

Swiss **CO**hort of **H**ealthcare **P**rofessionals and **I**nformal **CA**regivers

Jessica Hess, Philippe Terrier, Benjamin Travaglini, Monica Lerda, Emeric Offenstein, Emilie Antille, Ingrid Gilles, Isabelle Peytremann Bridevaux, Annie Oulevey Bachmann

Lausanne - Février 2026

Unisanté - Centre universitaire de médecine générale et santé publique
Institut et Haute Ecole de la Santé La Source - HES-SO
CHUV - Centre hospitalier universitaire vaudois

Unil.

Hes·so

Aims of Today’s Presentation

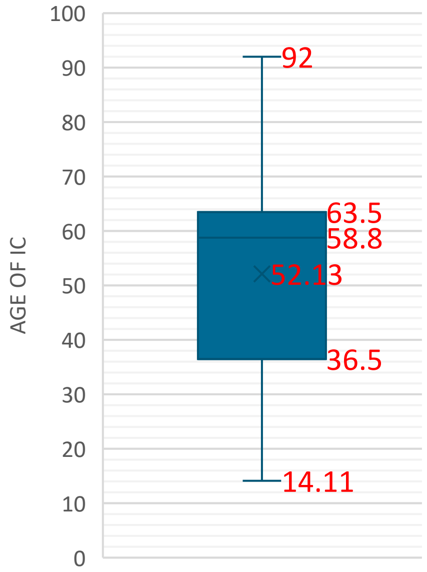
1. To describe the characteristics of the baseline (BL) 2024 and BL 2025 samples
2. To identify the determinants of ICs burnout the 24-25 sample
3. To examine whether ICs burnout acts as a mediator between caregiving-related determinants (related to the caregiver, the caregiving environment, and the social context) and the caregiver’s physical or psychological well-being
4. To present selected themes emerging from participants’ open-ended comments

Results

	n	%
Language		
French	544	82.7%
German	92	14.0%
Italian	22	3.3%
Canton		
VD	342	52.0%
FR	57	8.7%
GE	50	7.6%
NE	50	7.6%
ZH	32	4.9%
VS	28	4.3%
BE	18	2.7%
TI	17	2.6%
JU	9	1.4%
SG	9	1.4%
TG	9	1.4%
GR	7	1.1%

	n	%
Gender		
Women	505	77.3%
Relationship status		
Cohabiting / In a partnership / Married	459	70.3%
Single	91	13.9%
Separated / Partnership dissolved / Divorced	81	12.4%
Widowed	22	3.4%
[Missing]	5	0.8%
Level of education		
Low (ISCED 0-2)	53	8.2%
Middle (ISCED 3)	231	35.7%
High (ISCED 5-8)	363	56.1%
[Missing]	11	1.7%
Professional situation		
Employed	279	50.2%
Retired	143	25.7%
Other situation	42	7.6%
Informal caregiver only	33	5.9%
Homemaker	23	4.1%
Volunteer work in retirement	13	2.3%
Unemployed / Seeking employment	11	2.0%
Volunteer	9	1.6%
In education / training / apprenticeship	3	0.5%
[Missing]	102	15.5%
Reduction in working hours due to IC (valid n=332)		
Yes	82	24.7%

Figure 1. Age of IC



Results

	n	%
Number of care recipients (CR)		
1	515	78.4%
2	118	18.0%
3	17	2.6%
More	7	1.1%
[Missing]	1	0.2%
Who is the care recipient ?		
Father / Mother	218	34.2%
Spouse / Partner	213	33.4%
Son / Daughter	129	20.2%
Brother / Sister	22	3.4%
Father-in-law / Mother-in-law	14	2.2%
Friend	10	1.6%
Other	32	2.0%
[Missing]	20	3.0%

	n	%
CR Age		
80 years an more	144	39.0%
66-79 years	108	29.3%
56-65 years	22	6.0%
46-55 years	22	6.0%
36-45 years	9	2.4%
26-35 years	10	2.7%
19-25 years	16	4.3%
11-18 years	17	4.6%
0-10 years	21	5.7%
[Missing]	289	43.9%
CR health perceived by the IC		
Very poor	36	5.6%
Poor	190	29.7%
Fair	241	37.7%
Good	148	23.2%
Very good	24	3.8%
[Missing]	19	2.9%

Results

	n	%
Care recipient's place of residence		
Living with me	325	51.3%
In their own home	235	37.1%
In an institution (e.g. nursing home, residential care facility, day care centre)	66	10.4%
Other	4	0.6%
Abroad	3	0.5%
[Missing]	25	3.8%
Travel time to the care recipient		
Less than 15 minutes	69	39.7%
15 to 29 minutes	56	32.2%
30 to 44 minutes	26	14.9%
45 to 59 minutes	2	1.1%
More than one hour	21	12.1%

	n	%
Degree of choice in providing care		
1 = I had no choice at all	57	10.7%
2	94	17.6%
3	46	8.6%
4	29	5.4%
5	58	10.9%
6	38	7.1%
7	36	6.8%
8	47	8.8%
9	36	6.8%
10 = I was completely free to choose	92	17.3%
[Missing]	125	19.0%
Caregiving perceived as a moral duty		
1 = Not at all	7	1.2%
2	2	0.3%
3	5	0.8%
4	7	1.2%
5	38	6.3%
6	21	3.5%
7	47	7.8%
8	89	14.8%
9	104	17.3%
10 = Completely	281	46.8%
[Missing]	57	8.7%

Results

Continuous variables	**Mean**	**SD**	**Median**	**Min**	**Max**
Length of time providing care [years]	9.2	9.98	6	0	100
Weekly hours of informal caregiving [hours]	32.75	42.06	15	0	168

	n	**%**
Professional and/or volunteer support		
Yes, professional services only	204	56.7%
No	121	33.6%
Yes, both	32	8.9%
Yes, volunteer services only	3	0.8%
[Missing]	298	45.3%
Subjective assessment of caregiving amount		
Satisfactory	210	61.8%
Too high	98	28.8%
Could be increased	32	9.4%
[Missing]	318	48.3%

RESEARCH PRESENTATION — APRIL 2026

Predictors of burnout in *informal caregivers*

A mediation model of quality of life.
SCOHPICA study — Switzerland, 2024–2025.

SPEAKER
Philippe Terrier
HE-ARC Santé, Neuchâtel

SAMPLE
n = 573
Informal caregivers, 18–100 y

METHOD
VIM + Regression + path analysis

COHORT
2024 & 2025
Pooled baseline waves

We asked:

Among collected candidate factors, which ones actually drive the burnout of informal caregivers, and through what path does that burnout shape their quality of life?

SCOHPICA · Swiss study of informal caregivers

OFS Statistics 2023 · Bastawrous (2013), Pinquart & Sörensen (2003)

WHAT WE SET OUT TO UNDERSTAND — AND IN WHOM

Three questions, one Swiss caregiver cohort.

QUESTION 01

Who is most at risk of burnout?

Identify the *socio-demographic and care-context* characteristics associated with higher burnout among informal caregivers.

QUESTION 02

Which factors drive burnout?

Among *candidate predictors* — psychosocial, behavioural and contextual — isolate those that explain burnout variance.

QUESTION 03

How does burnout shape quality of life?

Test whether burnout *mediates* the link between its upstream drivers and caregivers' physical and psychological quality of life.

DATASET

Who the analyses are run on.

SAMPLE

n = 573

Informal caregivers, aged 18 to 92 years.

WAVES

2024 + 2025

Pooled baseline waves of the SCOHPICA caregiver questionnaire.

SCOPE

Switzerland

Nationwide · French, German and Italian language versions.

OUTCOME

Burnout

BAT-12 — Burnout Assessment Tool (Schaufeli et al., 2020).

SCOHPICA informal-caregiver questionnaire · Baseline waves 2024–2025

WHAT THE SCORES MEASURE

Eight validated instruments feed the models.

OUTCOME

BAT-12

Burnout Assessment Tool

12 items, mean 1–5 (higher = more burnout). **Exhaustion, mental distance, cognitive and emotional impairment.**

→ Schaufeli et al. (2020),

RISK

ERI-OC

Effort-Reward Imbalance — Overcommitment

6 items, sum 6–24. Tendency to **overextend oneself** in the caring role.

→ Siegrist (1996)

PROTECTIVE

SOC-13

Sense of Coherence

13 items, sum 13–91. Ability to find meaning, comprehend and manage difficult situations.

→ Antonovsky (1987)

APPRAISAL

Lawton CAS

Caregiving Appraisal — Personal accomplishment

6 items, sum 6–30 (reverse coded). Frequency of positive appraisal of caring.

→ Lawton et al. (2000)

OUTCOME (ICIM)

WHOQOL-BREF

Quality of life — physical & psychological

Domain scores rescaled 0–100 (higher = better). Two domains used downstream.

→ WHOQOL Group (1998)

BEHAVIOUR

Brief COPE

Active-coping subscale (8 items)

Sum 8–32. Frequency of use of active coping strategies.

→ Carver (1997); Muller & Spitz (2003)

CONTEXT

VAS 1–10

Visual analogue scales

Relationship quality, freedom to care, time and financial satisfaction (10 = best / most free).

→ Self-report, single items

SOCIO-DEMOGRAPHIC

ISCED & Others

Educational attainment, 3 levels

Recoded into Low / Middle / High ISCED bands. Plus age, sex, income, care hours.

→ Eurostat / UNESCO (2011)

ROADMAP

From 47 candidate variables to a mediation model.

A data-driven screen narrows the predictor space; regression quantifies unique associations; path analysis tests how burnout channels these effects onto quality of life.

Step 01

Variable importance

A **conditional random forest** screens **47 candidate predictors** and ranks them by unique (non-redundant) contribution to burnout variance.

cforest + permimp · Boruta

→

Step 02

Multiple regression

Retained predictors enter a **multiple linear regression** on the BAT-12, with **MICE multiple imputation** (m = 40) and Rubin pooling of coefficients.

OLS + MICE (m = 40)

→

Step 03

Path analysis

For each robust predictor we fit an **X → Burnout → Quality of life** mediation triad, with bootstrap confidence intervals.

lavaan · bootstrap 5 000

cforest (Strobl et al., 2008) · permimp (Debeer & Strobl, 2020) · lavaan (Rosseel, 2012)

STEP 01 — METHOD

Ranking predictors without double-counting.

With 47 candidate variables — many of them psychological scales that overlap — a naïve importance ranking inflates correlated predictors and hides weaker but unique ones.

Conditional Permutation Importance (CPI) measures the drop in prediction accuracy when a variable is permuted *while holding correlated predictors fixed* . It returns each variable's **unique contribution**.

IN PLAIN TERMS

CPI asks: “if I scramble this variable but keep its neighbours intact, **how much worse does the model get?** ” Large drop → non-redundant signal. Small drop → variance shared with a correlated neighbour.

TECHNICAL SPECS

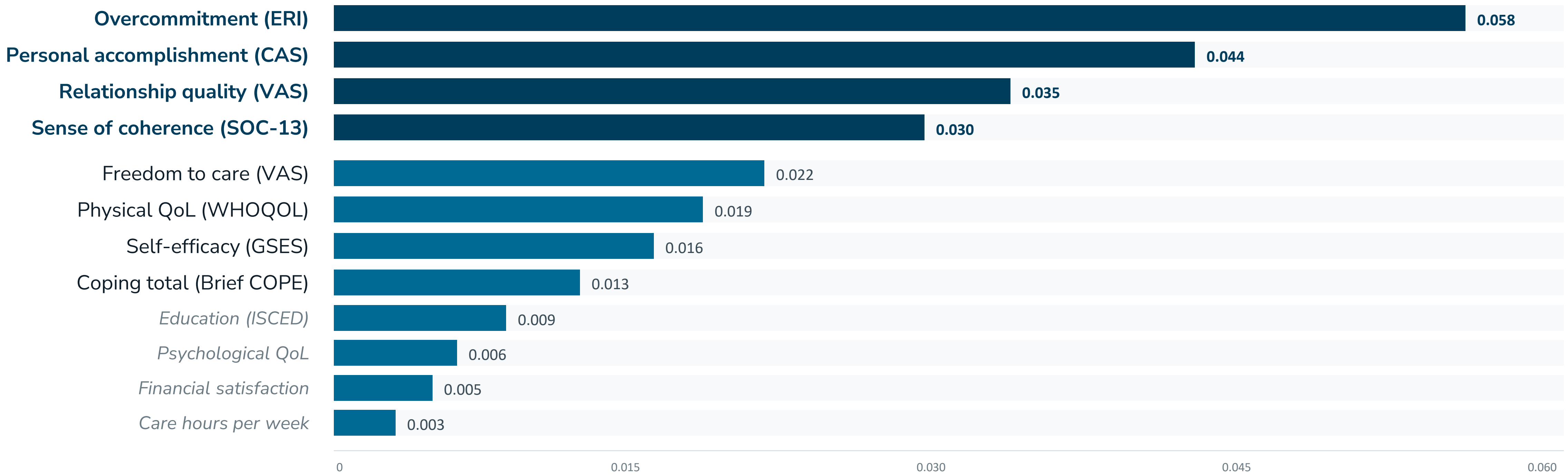
Engine	**cforest** — party package · Conditional Inference Forest
Importance	**Conditional Permutation Importance** (permimp), threshold ρ = 0.95
Tuning	ntree = 500 · mtry = 7 · **5 random seeds** averaged
Robustness	Boruta confirmation test applied on the same forests
Output	Top variables feed Step 02 (regression) and Step 03 (path analysis)

Strobl et al. (2008, 2009) · Debeer & Strobl (2020) · Kursa & Rudnicki (2010)

STEP 01 — RESULTS

Top 4 predictors stand out cleanly above the rest.

Conditional permutation importance (CPI) — higher is better..



cforest + permimp · threshold ρ = 0.95 · 5 seeds · Boruta-confirmed

STEP 02 — RESULTS

Eight predictors are associated with burnout.

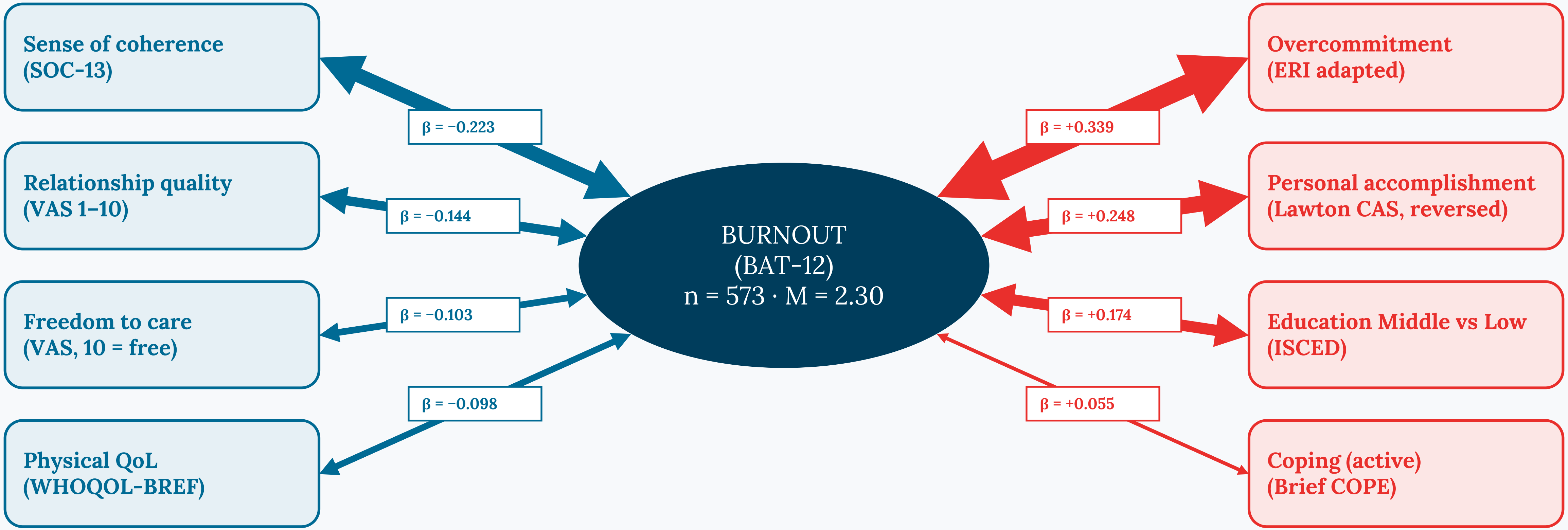
Protective factors

negative association with burnout

BURNOUT
(BAT-12)

Risk factors

positive association with burnout



Sense of coherence (SOC-13) — β = −0.223

Relationship quality (VAS 1–10) — β = −0.144

Freedom to care (VAS, 10 = free) — β = −0.103

Physical QoL (WHOQOL-BREF) — β = −0.098

BURNOUT
(BAT-12)
n = 573 · M = 2.30

Overcommitment (ERI adapted) — β = +0.339

Personal accomplishment (Lawton CAS, reversed) — β = +0.248

Education Middle vs Low (ISCED) — β = +0.174

Coping (active) (Brief COPE) — β = +0.055

Multiple OLS regression + MICE (m = 40) · standardised β · thickness ∝ |β| · only p < .05 shown

STEP 03 — METHOD

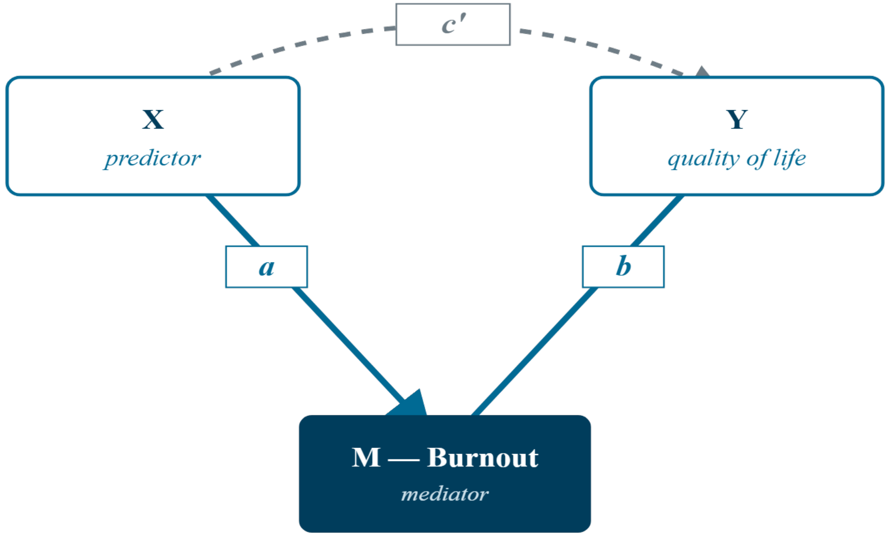
Is burnout the channel between determinants and QoL?

Regression tells us what *covaries* with burnout. But it cannot tell us *how those determinants reach quality of life* : directly, or via the caregiver's burnout.

Path analysis fits the full chain *X → Burnout → Y* in one model, and decomposes every total effect into a direct and an indirect component. We test the **ICIM framework** (Gerain & Zech, 2019) on each top predictor.

c'	**Direct effect.** X → Y residual after controlling for the mediator.
$a \cdot b$	**Indirect effect.** Share of the total effect that travels through burnout. Tested with **bootstrap CIs (5 000 resamples)**.
PM	**Proportion mediated** = ab / total. What fraction of the effect is carried by burnout.

THE MEDIATION TRIANGLE

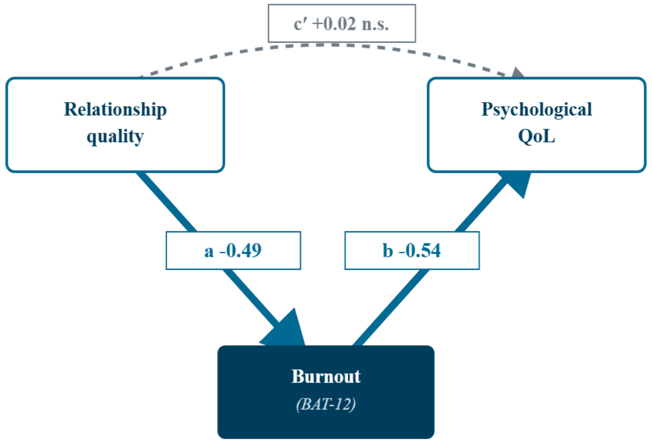


Solid arrow = significant path · Dashed arrow = not significant · Arrow thickness ∝ |β|

STEP 03 — RESULTS (I) (I)

Burnout carries most of the effect of upstream determinants onto QoL.

Relationship quality → Psychological QoL

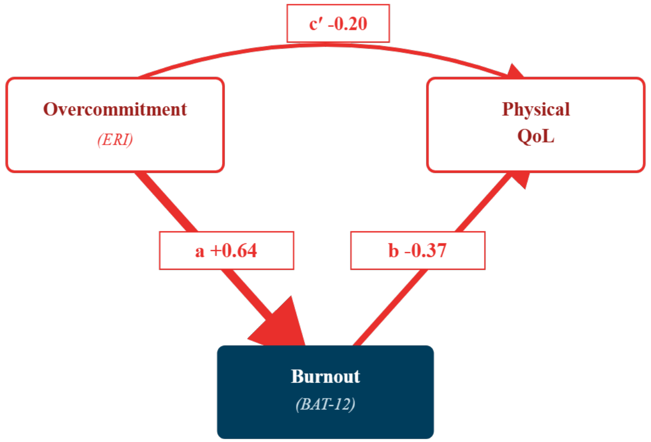


INDIRECT EFFECT · 95 % CI

ab = +2.61 [+2.11, +3.28]

94%

Overcommitment → Physical QoL

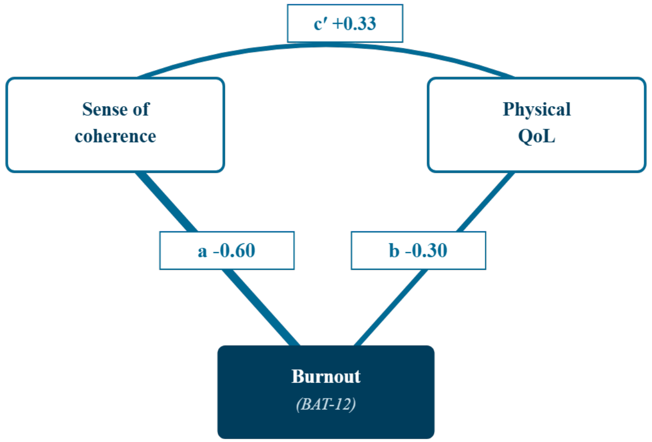


INDIRECT EFFECT · 95 % CI

ab = -1.07 [-1.42, -0.80]

54%

Sense of coherence → Physical QoL



INDIRECT EFFECT · 95 % CI

ab = +0.24 [+0.17, +0.33]

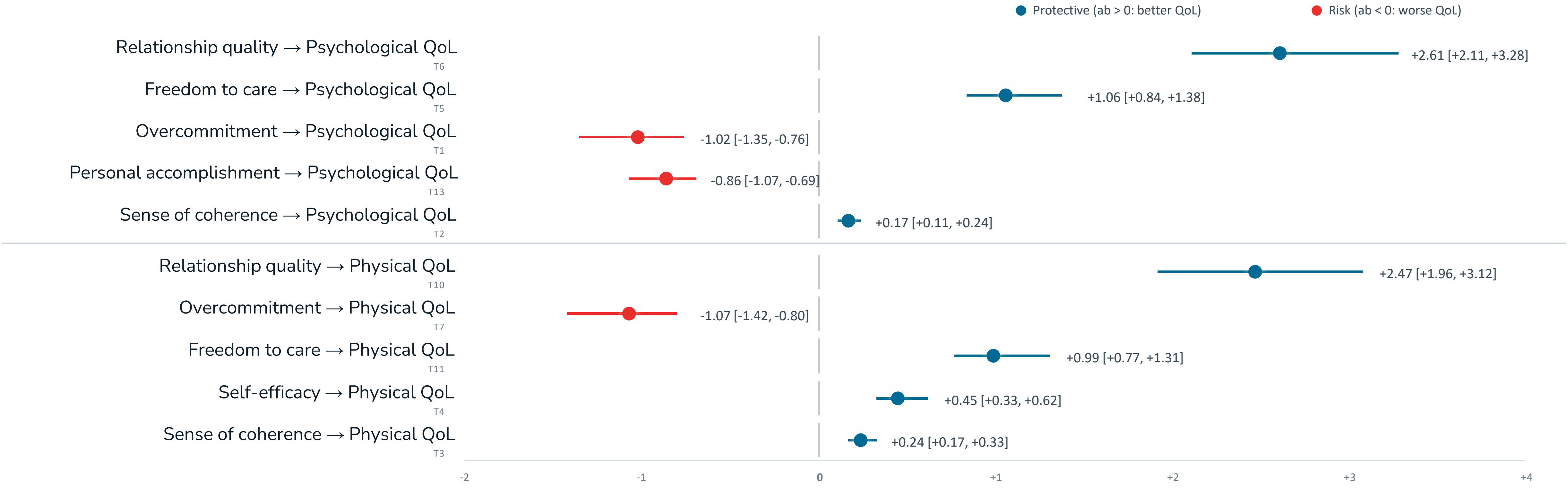
35%

lavaan · MLR + FIML · bootstrap 5 000 · all three indirect effects significant after Bonferroni (α = 0.0038)

STEP 03 — RESULTS (II)

All significant indirect effects at a glance.

Every X → Burnout → QoL triad passing Bonferroni correction — sorted by effect size.



Path analysis (lavaan) with shared MICE (m = 40) · bootstrap 5 000 · all 10 triads significant after Bonferroni (α = 0.0038)

Indirect effect ab (unstandardised, with 95 % bootstrap CI)

KEY TAKEAWAYS

Four levers for the burnout of informal caregivers.

Psychological factors dominate. Alone, they explain 64 % of burnout variance — adding 11 quality-of-life, context and demographic variables adds only +2.8 pp of R^2 adj.

Relationship quality is the strongest lever on psychological QoL — and **94 % of that effect** is mediated by burnout, making burnout the near-complete channel between the couple-caregiver bond and psychological well-being.

Overcommitment is the single strongest risk driver (β = +0.34). It also transmits over half of its effect on physical QoL *through burnout* (PM = 54 %).

Sense of coherence is the strongest protective factor (β = −0.22). Interventions that strengthen meaning, comprehensibility and manageability are likely the highest-value psychological target.

Thank you — questions welcome.

Qualitative analysis: free comments

Question : Would you like to add any further comments on the informal care you provide to your close relative and/or mention any important aspect that was not addressed in the questionnaire?

Reponses 2004-2025 = 204

Ideas expressed (occurrences) : 674

Analysis realized in collaboration with BSC in Nursing students (Legay et al., 2026) and Master student in Psychology (Selmani and Travaglini)

- Main Themes :
  - Lived experiences and practical knowledge gained from caregiving
  - Finances, recognition, and public policies
  - Caregiver-care recipient relationship and family dynamics
  - Health, vulnerability, and caregiver burden
  - Professionals, systems, and service organizations

Quality of IC-CR relationship

- Relationship complexity and nature

  "…accepting what she wants me to do, the criticisms, the negative remarks she makes toward me…» *…accepter ce qu'elle veut que je fasse, les critiques, les remarques négatives qu'elle fait à mon encontre...*

  « Our relationship is financial » Notre relation est financière

  « She is afraid that I will abandon her » Elle a peur que je l'abandonne

  « …sometimes I feel manipulated…» *Je me sens parfois manipulée*

- Ambivalence of the bond (affection, duty, also tensions) Pillemer, K. and Suitor, J.J. (2002)

  « The difficulty is that the person being helped does not appreciate the assistance, which is often a source of conflict » *La difficulté est que la personne aidée n'apprécie pas l'aide qui est souvent source de conflits*

  « I sometimes have to put up with their bad temper... on a daily basis » *Je dois supporter parfois son mauvais caractère… au quotidien.*

  « ...I will do what is necessary... despite... frustration… » *Je ferais ce qu'il faut… malgré… frustration*

Sens of coherence

- Transformation of roles and identity Skaff, M. and Pearlin, L. (1992)

  « I have become their informal caregiver at the expense of being a spouse » Je suis devenu son très proche aidant au détriment de conjoint

  « I am losing myself » Je m'oublie

- Soial recognition

  « lack of consideration... of respect... The caregiver is disdained...» Absence de considération… de respect… Le proche aidant est dédaigné…

  « I felt used » Je me suis sentie utilisée

  « No place in society... without a salary or recognition » Aucune place dans la société… sans salaire ni reconnaissance

Overcommitment

Burden

« Caregiver for both of my parents... » Proche aidante de mes 2 parents

« Personally, it’s really too much to handle if I also had to work » Personnellement, c'est vraiment trop à gérer si en plus je devais travailler

Increased vulnerability and fragility

« For me, it is difficult as a chronically ill person to cope with our situation » Pour moi c’est difficile en tant que malade chronique de faire face à notre situation

« I am still recovering from my stroke » Je suis encore en convalescence après mon AVC

« I am getting psychological help so that I can stay on track » Je me fais aider psychologiquement pour pouvoir garder le cap

Discussion

- Quality of IC-CR relationship
  - Result: Quality of IC-CR relationship is negatively related to ICs score of burnout
  - High-quality perceived relationships are a key protective determinant of caregiver health, both directly (well-being, vitality) and indirectly (via reduced burden and distress)

Tough, H., Brinkhof, M. W. G., & Fekete, C. (2022)
Sun, R., & Francis, L. E. (2024)
Bagheriamiri, Z., Mirsepassi, Z., & Sayadi, L. (2024)

  - Clinical relevance: assessing the perceived quality of the informal caregiver–care recipient relationship is relatively easy.
    - Interventions aimed at supporting this relationship are feasible and have been shown to produce positive effects for both informal caregivers (ICs) and care recipients (CRs)

Birkenhäger-Gillesse, E. G et al. (2021)
Zhou, J., Chen, X., Wang, Z., & Li, Q. (2023)
Zhao, Y., Zhang, S., Lu, M., Qiao, Z., & Shi, X. (2025)
Wang, X., et al. (2025)

Discussion

- Sens of coherence
  - Result: Sens of coherence is directly and indirectly related to ICs well-being
    - A meta-analysis (35 studies) showed that higher SOC is consistently associated with lower caregiver burden and better mental health outcomes. SOC emerges as a robust determinant of caregiver well-being, indirectly supporting better quality of life through reduced distress del-Pino-Casado, R., et al. (2019)
    - In a latent profile analysis among caregivers of breast cancer patients, higher SOC groups exhibited significantly better subjective well-being, highlighting SOC as a differentiating factor in caregiver quality of life and psychological adaptation
      Wang, H., Wu, Y., Huang, X., & Yan, H. (2025)
    - Peer-reviewed evidence consistently shows that:
      - SOC is modifiable in ICs through targeted interventions Li, R et al. (2020)
      - The most effective interventions are multicomponent and theory-driven Yu, D. S. F et al. (2023)
      - Meaning-making and resource activation are critical levers del-Pino-Casado, R., et al. (2019)

Discussion

- Overcommitment (ERI)
  - Result: OC reflects the difficulty of determining whether efforts are adequately rewarded. High score of OC is strongly positively related to ICs score of burnout
    - High overcommitment (intrinsic ERI component) is a strong predictor of burnout, especially in caregiving professions Diekmann, K. et al. (2020); Shoman, Y. et al. (2023); Liang, H. Y. et al. (2023
    - A recent study has examined the links between effort and reward (including overcommitment), as conceptualized in the present research, among grandparent informal caregivers providing care to their grandchildren Zhou, Z., Li, J., & Wang, P. (2025)
    - Deepen the analyses in this direction
  - To examine whether interventions aimed at improving informal caregivers’ ability to assess their effort–reward **balance** could reduce their burnout risk

Limits and strenghs

- An ongoing challenge: participant recruitment and funding.
  - Recruitment is based on a multi-pronged strategy aimed at reaching a broad and diverse group of informal caregivers. However, it is constrained by limited resources to fund the informal caregivers (ICs) cohort.
  - Self-identification as an ICs and willingness/capacity to complete the questionnaire are prerequisites for participation in the survey.

- Free annual provision of comprehensive data for other researchers and for public authorities.
- Gradual increase in the number of participants will enhance data quality year after year.
- Anticipation of the growing need for data on ICs considering forecasted healthcare workforce shortages.

In sum

- SCOHPICA-IC provides annual results to the public and policymakers through an open-access dashboard.
- SCOHPICA-IC can deliver tailored data or specific analytical results to policymakers to support evidence-based public policy development in favor of ICs.
- The project is carried out by a small, highly committed team and strongly supportive field partners; substantial progress has been achieved with limited resources.
- The initial findings are promising, they are consistent with existing evidence while also opening up new avenues for further investigation.

Get involved: participate or share!

The results of the 2025 data collection will be made available online in the coming weeks.

SCOHPICA donne la parole aux professionnel·les de la santé et aux proches aidant·es

Cohorte suisse des proches aidant·es

scohpica

Cohorte suisse des professionnel·le·s de santé
et des proches aidant·e·s

- Cette plateforme propose un accès libre aux principaux résultats des proches aidant·es.

Facilitating access to analytical results for the public and policymakers

Link for the Dashboard

L'équipe SCOHPICA PA vous remercie !

Annie Oulevey Bachmann

Co-responsable SCOHPICA

Emeric Offenstein

Responsable du volet proches aidant·es

Philippe Terrier

Statisticien

Jessica Hess

Chargée de recherche