

The challenges and difficulties of informal caregivers

Perspectives on informal caregiver burnout

Pierre Gérard, PhD

SCOHPICA Webinar, 21 March 2024

Collaborative work

Prof. Emmanuelle Zech (UCLouvain)

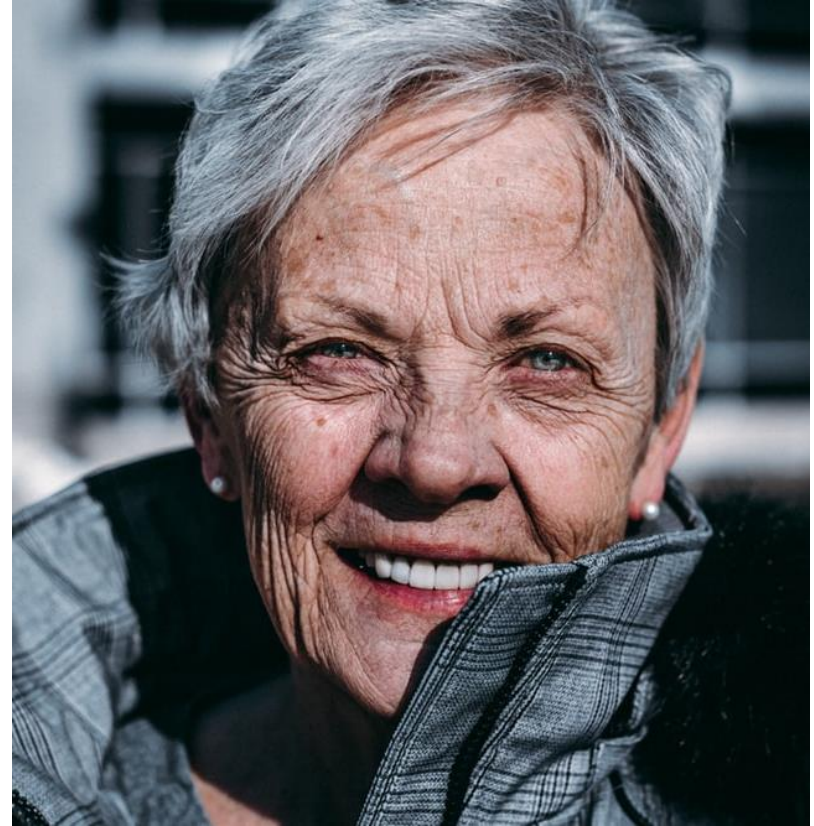


A transdiagnostic perspective

Attempting to objectify common trends

Without neglecting the specificities of each situation

Presentation of the first steps in the field (updated since)



What do they have in common?

Informal caregivers?

Assistant (mostly) for free

To a relative, friend, acquaintance

Requiring assistance due to disease, disability, or functional limitation

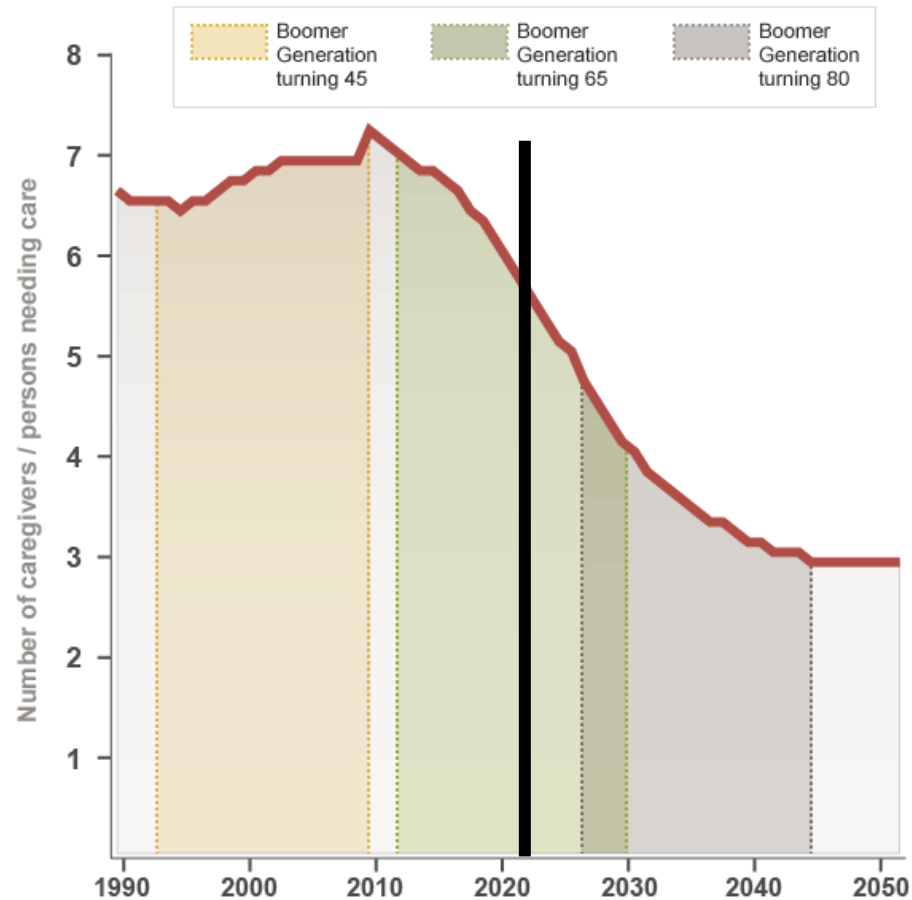
Diversity

- Causes of this restricted autonomy
- Caregiving tasks
- Individual contexts



Context of increasing needs

Caregiver Support Ratio



- The population gets older
 - Increase in chronic disease and loss of autonomy
- Increased survival for individuals with chronic diseases and disabilities
 - Increase of reduced autonomy during longer
 - Increased needs for assistance
- Reduction of the caregiver/care-recipient ratio
 - #Available caregivers
 - Per person in need of assistance

Being a caregiver is...

Filling multiple roles

Performing various tasks

Dealing with their own emotions

Supporting the care-recipient's

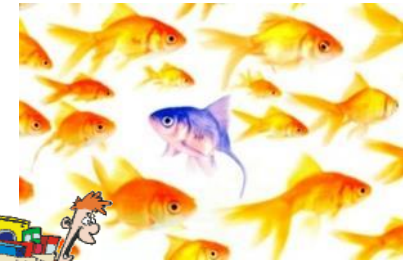
Facing social imperatives

Act like this, do that, do it that way

Being at the same time close and caring

While trying to maintain their own lives !

In short ... not always easy



A context of care-related exhaustion

Healthcare professionals (Freudenberger, 1974)

Parents (Mikolajczak et al., 2017)



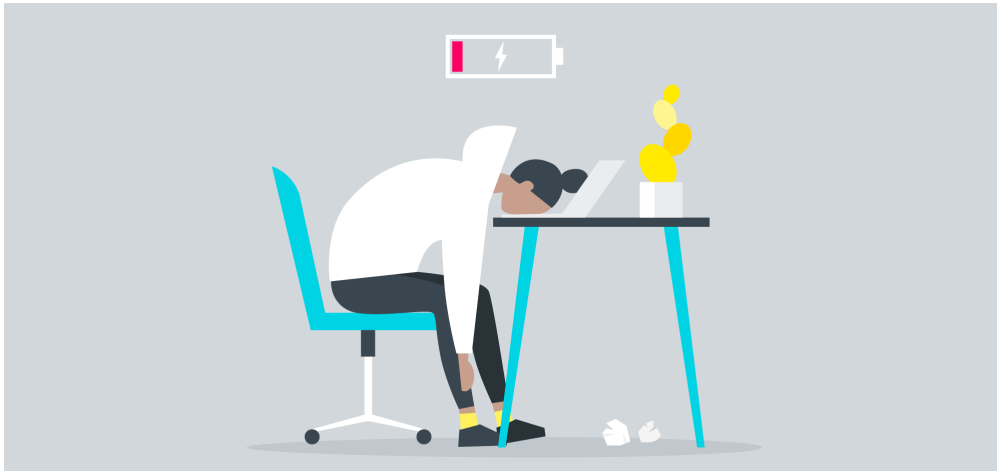
Le burnout

A condition from the professional sphere

Three dimensions

- **Emotional Exhaustion** (*being at the end of the rope*)
- Depersonalization/emotional distancing
- Loss of personal accomplishment (*loss of meaning in one's action*)

(Maslach et al., 1996)



What about the informal caregivers?

Are informal caregivers at risk of burnout?



PSYCHOLOGY, HEALTH & MEDICINE
<https://doi.org/10.1080/13548506.2020.1803372>



Do informal caregivers experience more burnout? A meta-analytic study

Pierre Gérain ^{a,b} and Emmanuelle Zech ^b

Systematic review & meta-analysis

Gather all studies

- Comparing informal caregivers and non-caregivers in comparable situations
- On burnout measures

Goal: having a clearer view

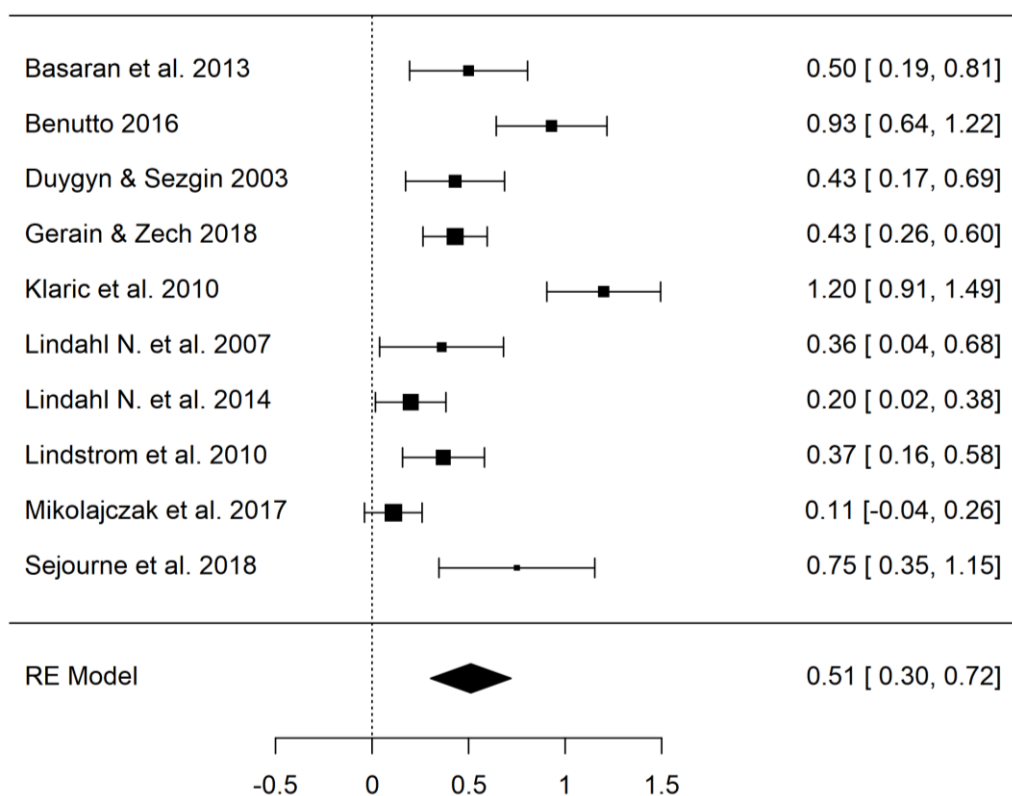
Do informal caregivers experience more burnout than non-caregivers?



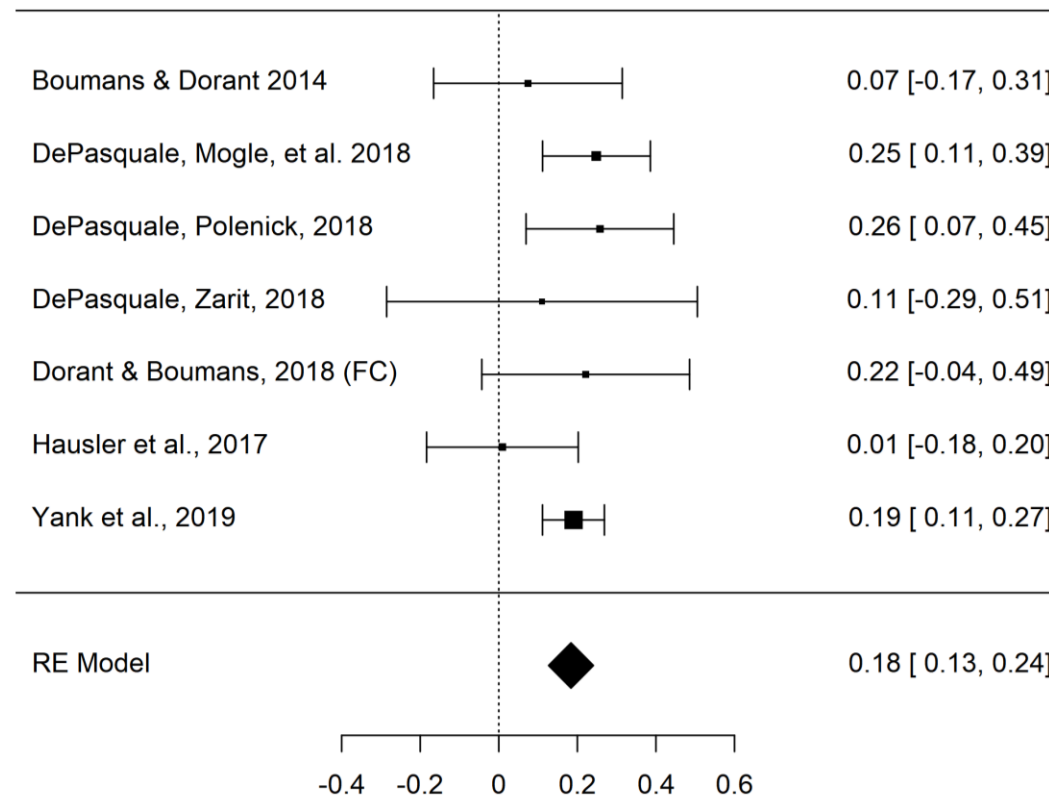
Results

More than 11 000 references → 17 studies in the end

10 Parental Burnout



7 Professional Burnout



→ More risk of burnout in informal caregivers

So, more risk of burnout in informal caregivers

... but what about informal caregiver
burnout?

A form of
burnout, but
for informal
caregivers?



Several works have pointed...

- Some caregivers report symptoms comparable to those of burned-out healthcare professionals (Angermeyer et al., 2006; Perkins and Hewitt, 2016)
- Report being at the end of the rope or "drained" by the care they provide (Thompson et al., 2014; Goodwin et al., 2017)
- Put emotional distance with the care-recipient, especially when experiencing emotional difficulties (Cross et al., 2018)
- Have the impression that they have lost sense of their role (Cross et al., 2018)

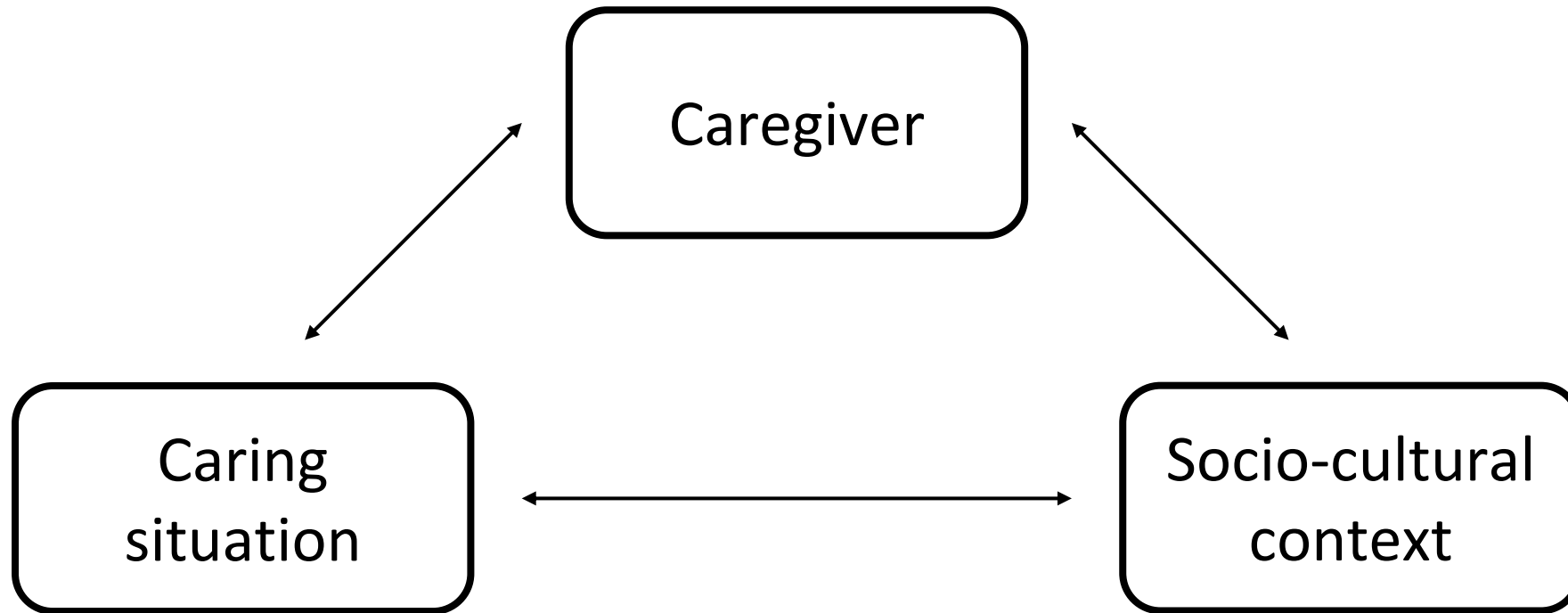
Striking parallel suggesting an investigation
of burnout in informal caregivers ...

... calling for the development of a
theoretical framework

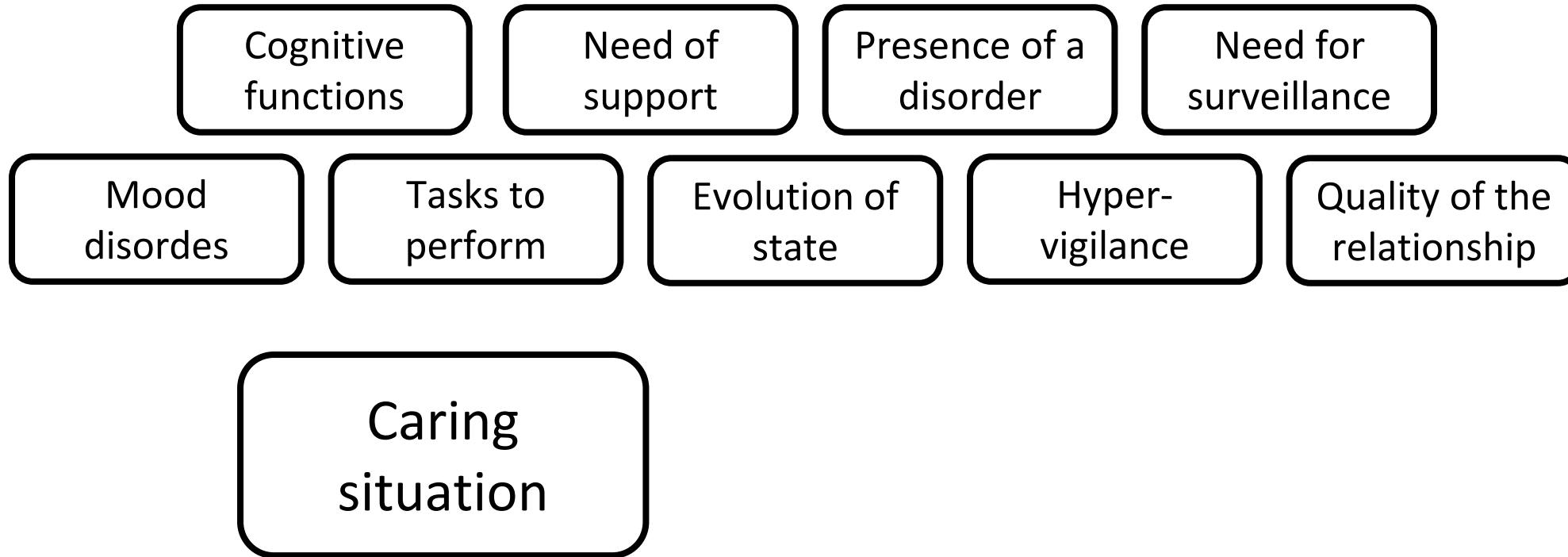
Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving

Pierre Gérain^{1,2} and Emmanuelle Zech²*

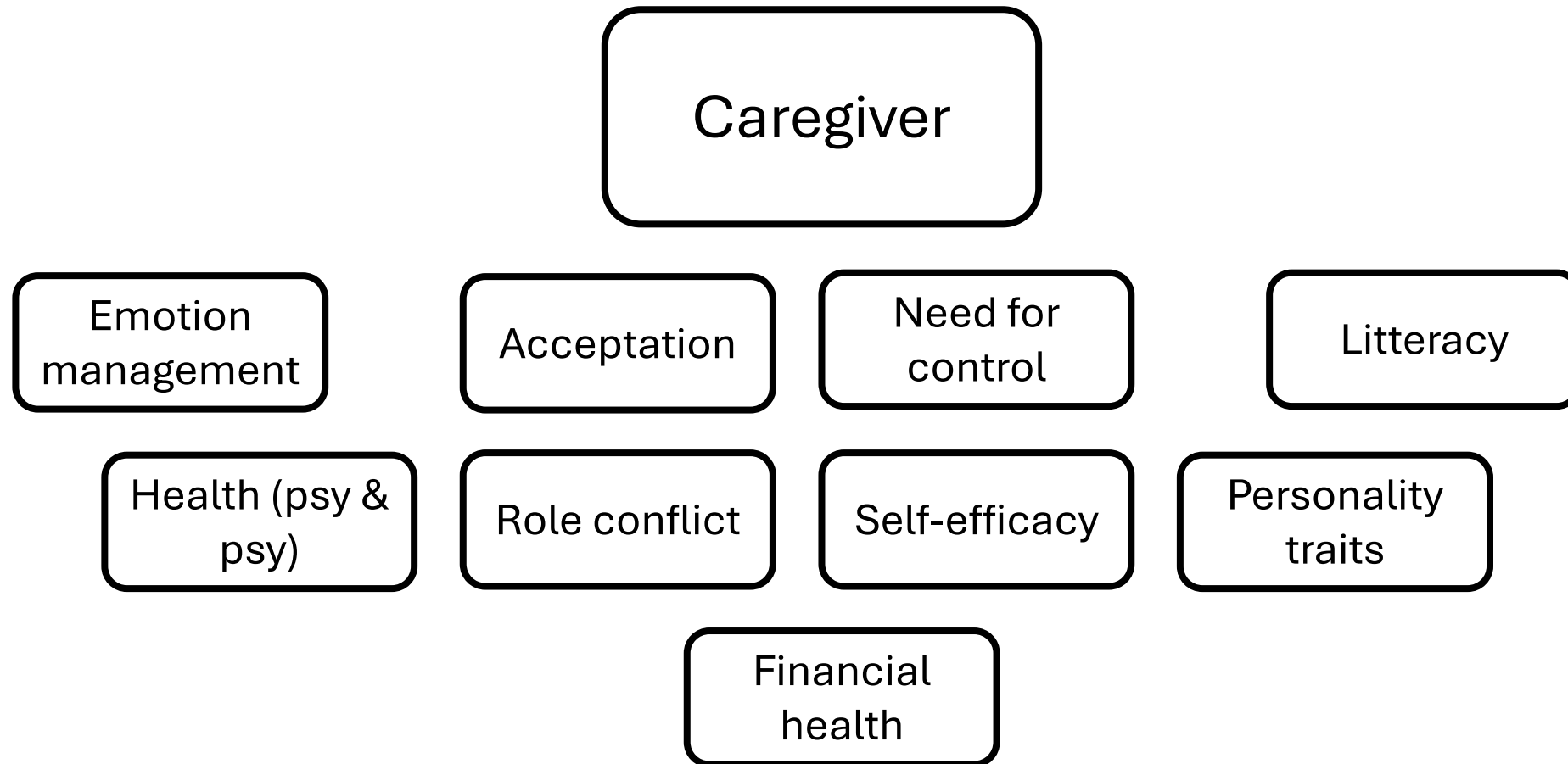
Risk and protective factors



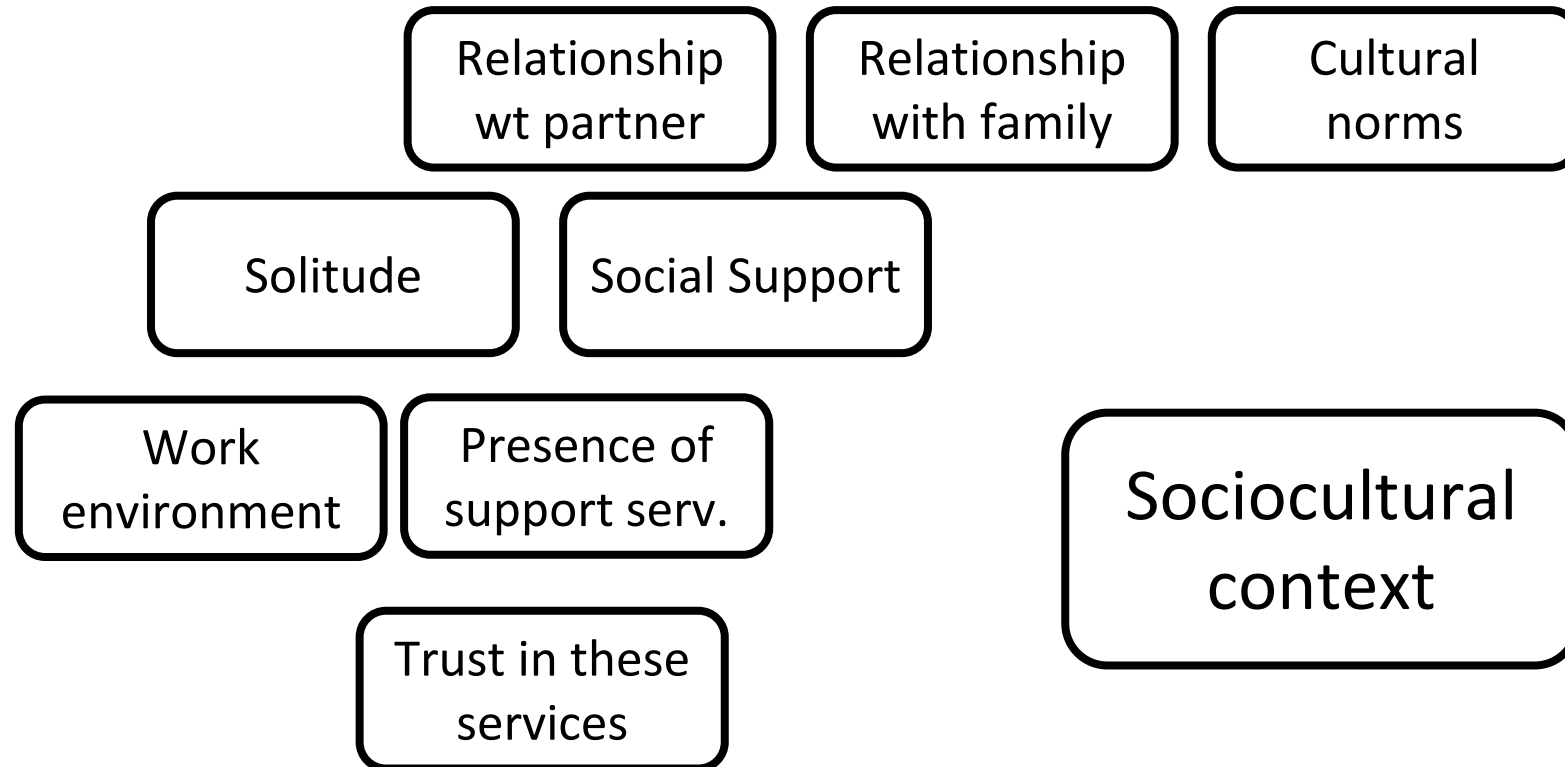
Risk and protective factors

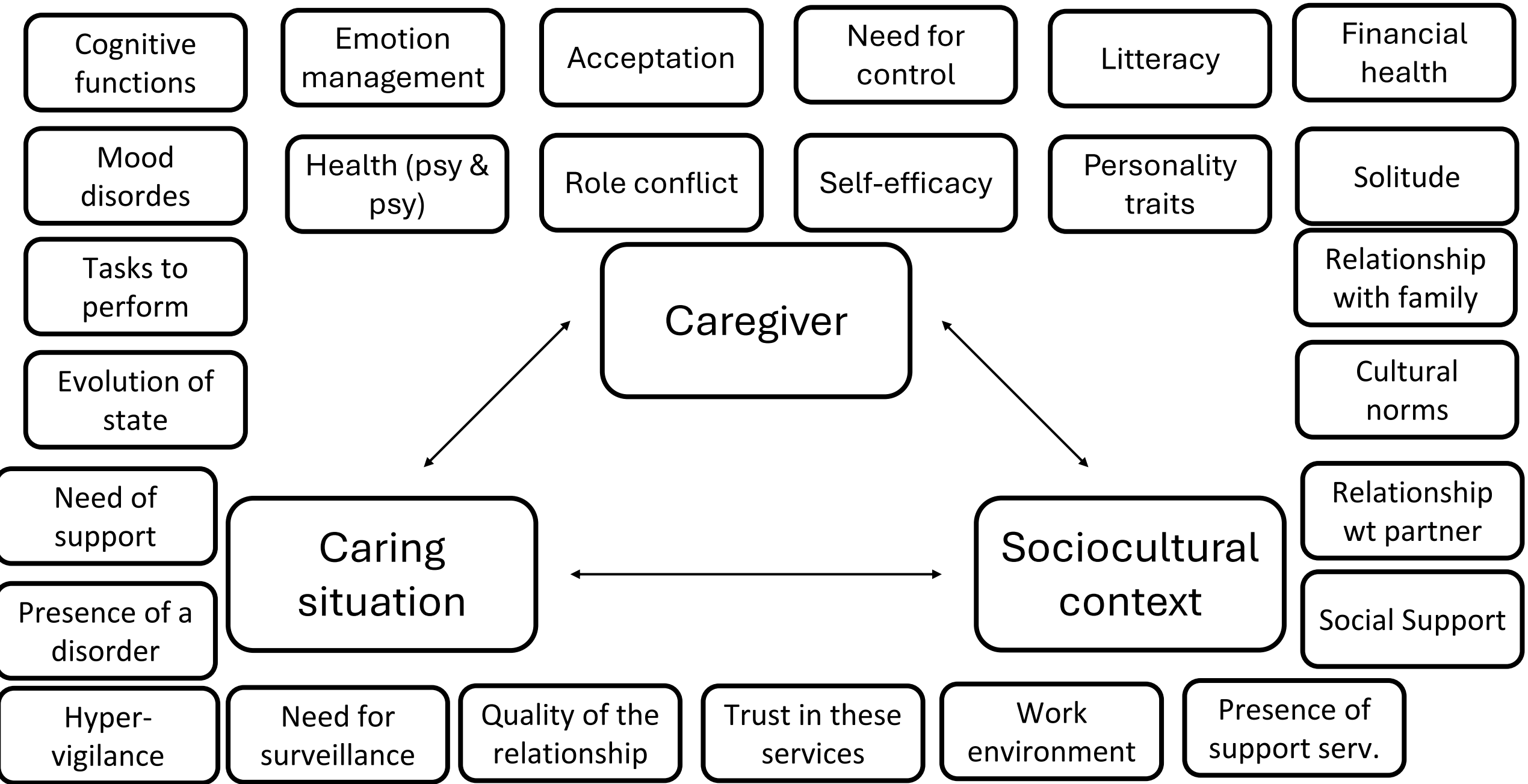


Risk and protective factors



Risk and protective factors

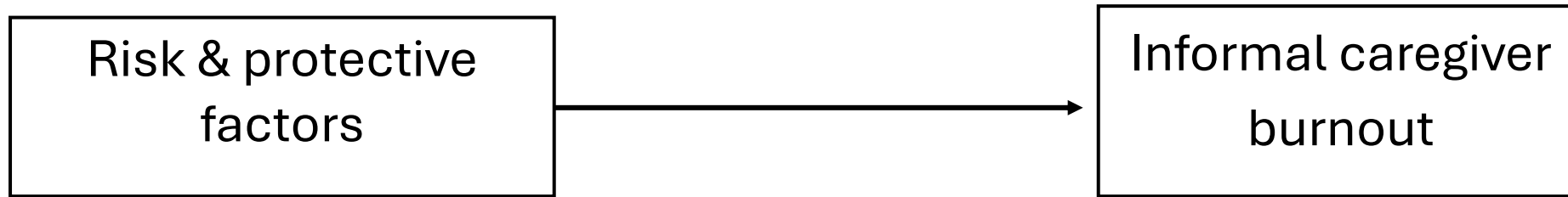




Informal Caregiving Integrative Model (ICIM)

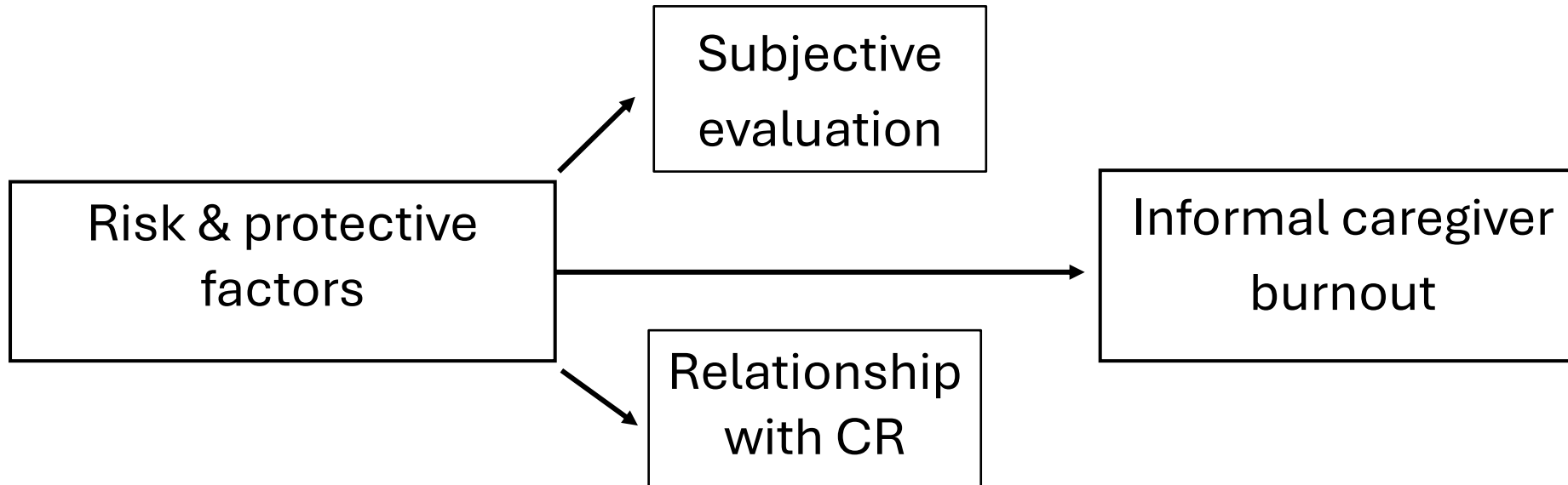
Informal caregiver
burnout

Informal Caregiving Integrative Model (ICIM)



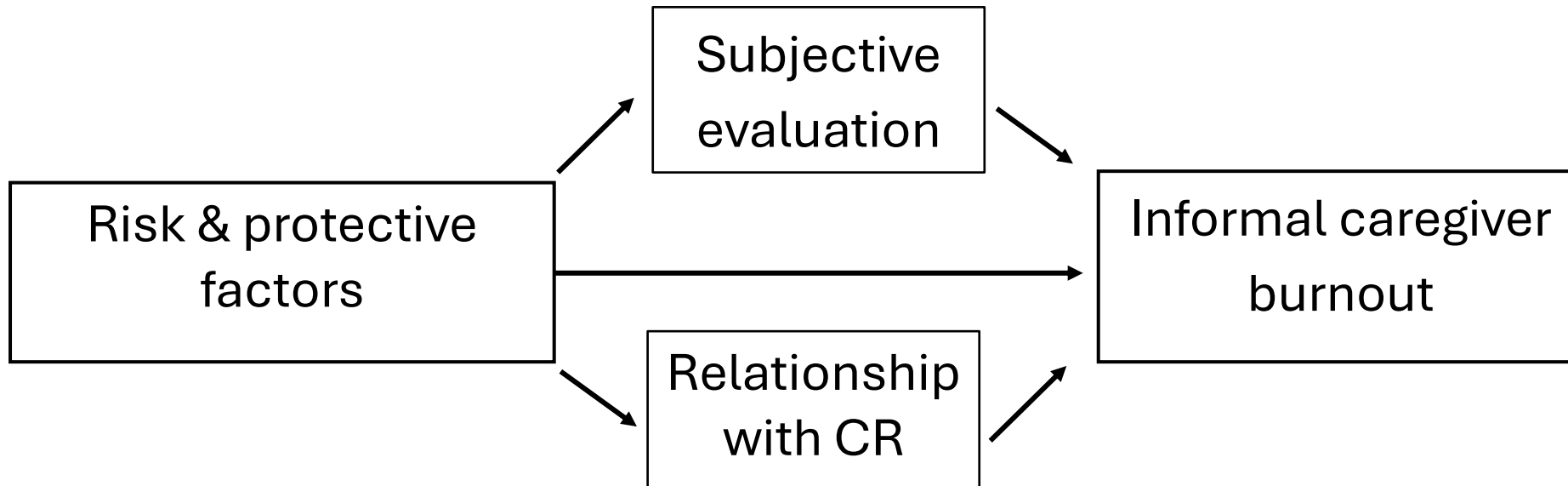
- Related to the caregiver
 - Psychological, emotional, financial, physical
- Related to the caregiving
 - Need of assistance, intensity of symptoms
- Related to sociocultural environment
 - Social support, social norms, support services

Informal Caregiving Integrative Model (ICIM)



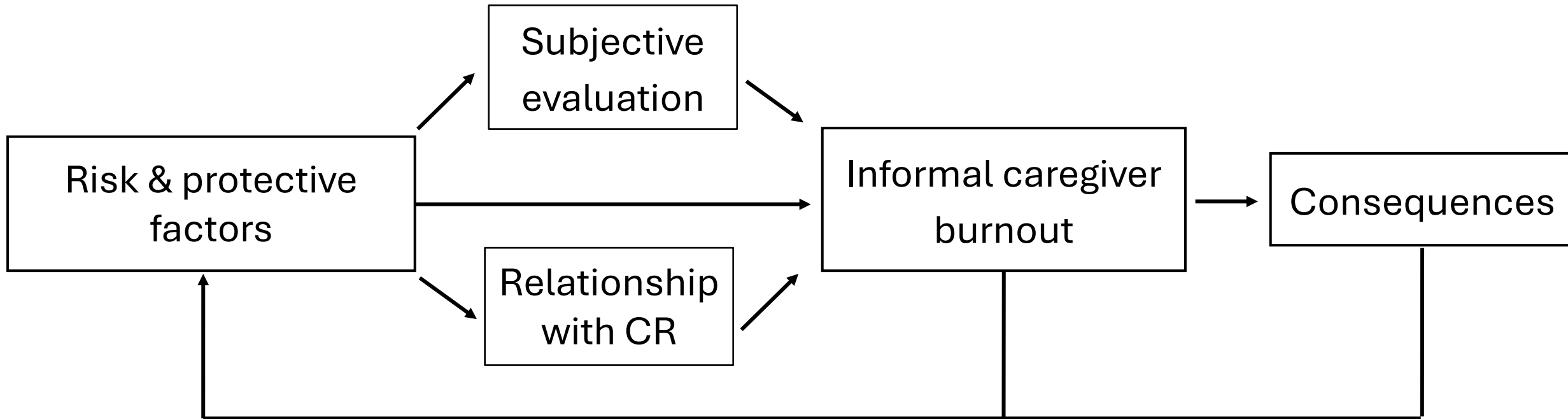
- Influence subjective perception, their "prisme"
- Influence the relationship with the CR

Informal Caregiving Integrative Model (ICIM)



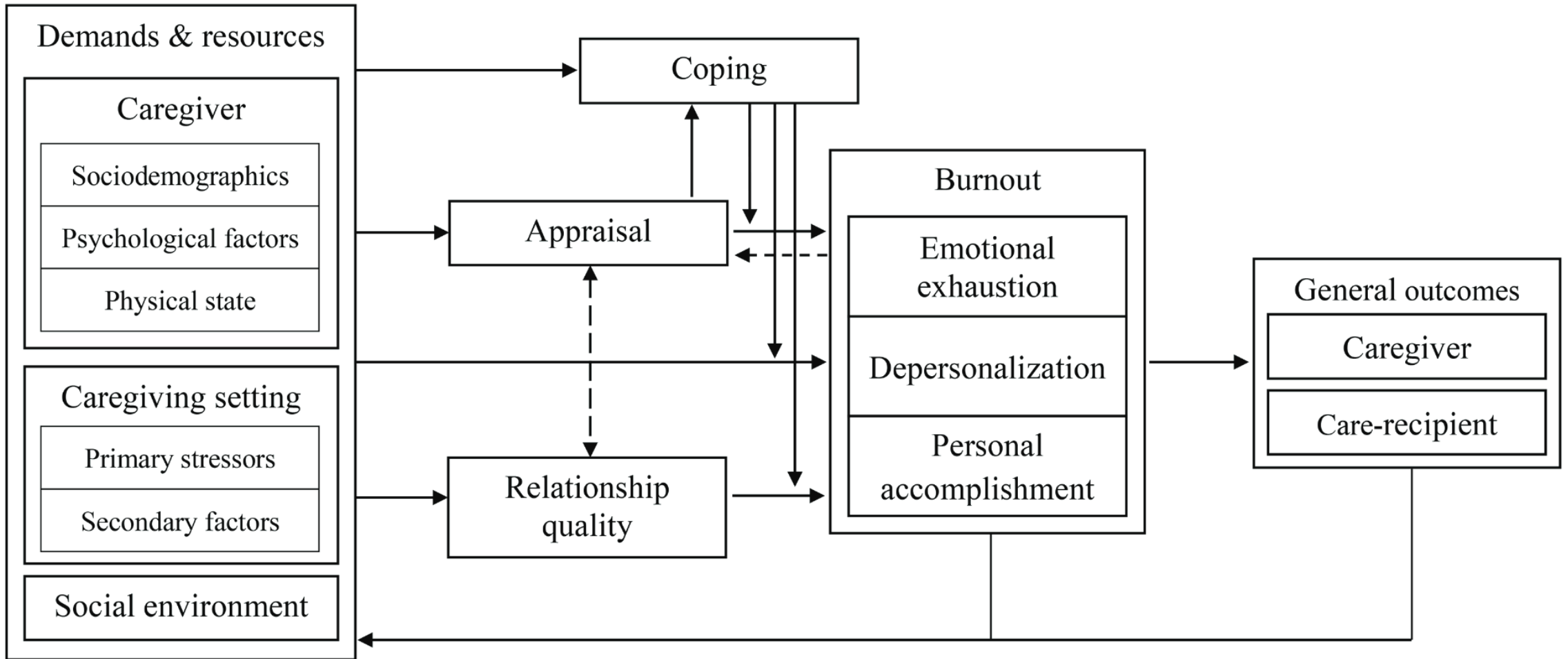
Influence **independent** and **through a mediation**

L'Informal Caregiving Integrative Model (ICIM)



Burnout having itself consequences

- On the caregiver
- On the care-recipient

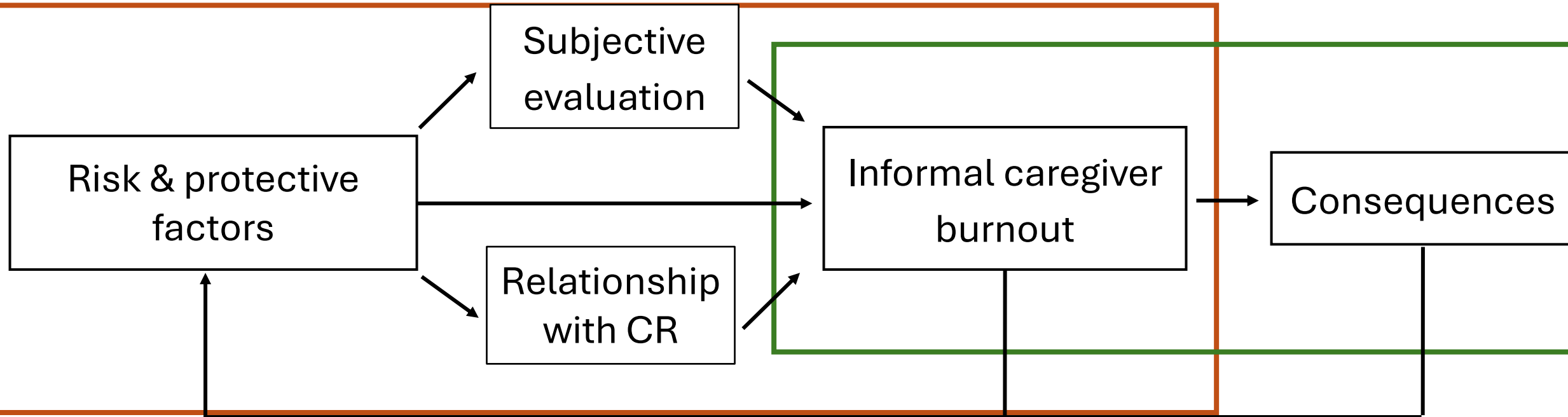


Always meant to be improved!

Examples of investigations of Informal Caregiver Burnout



Two complementary studies,



Study 1: Determinants

Study 2: Consequences

Sample

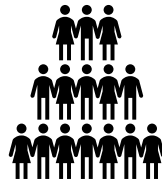
Online survey



Participants = 499



M Age = 53.08



87,78% Women



Care-recipient

A child (39.1%)



A partner (22.8%)



A parent (19.4%)



A relative (18.6%)



DOI: 10.1111/hsc.13684

ORIGINAL ARTICLE



WILEY

Are caregiving appraisal and relationship quality key mediators in informal caregiving burnout? A structural equation modelling study in Belgium and France

Pierre Gérardin PhD^{1,2}  | Emmanuelle Zech PhD² 

Study 1: Determinants

Emot. Intelligence
Low autonomy
Solitude

Caregiver: Emotional intelligence

- Better health (Mikolajczak et al., 2015)
- Protective of professional burnout (Kwon & Kim, 2015)

CGing context: Level of autonomy

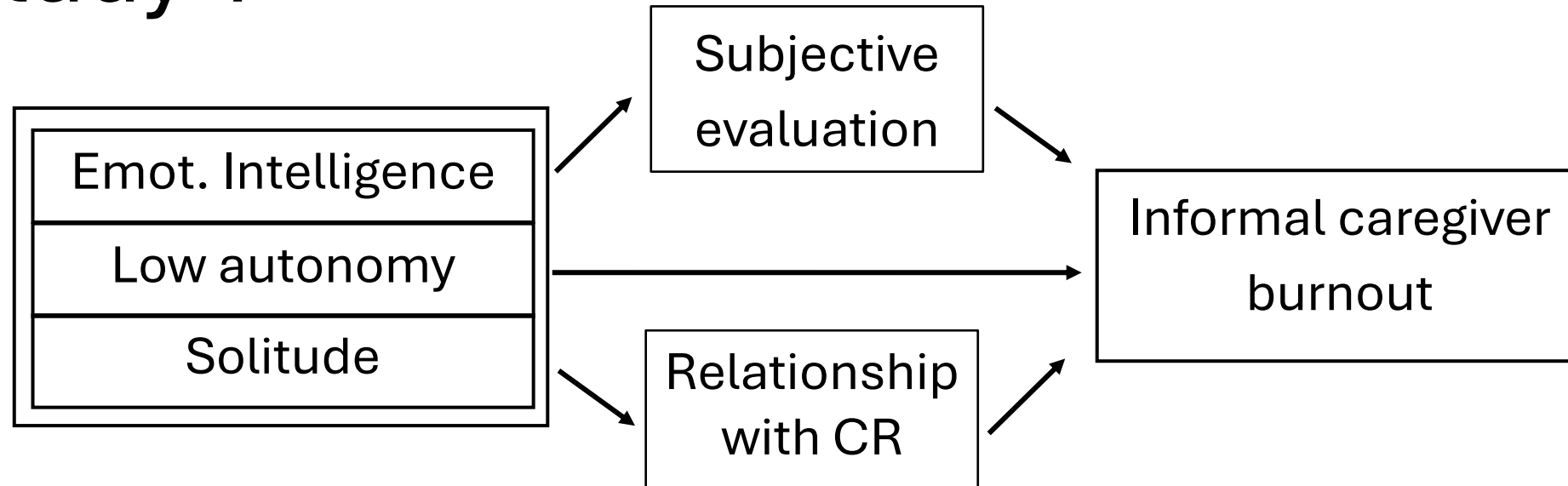
- Key element in defining the caregiving role

Social context: Solitude

- Widespread issue in caregivers (Basnyat & Chang, 2016)



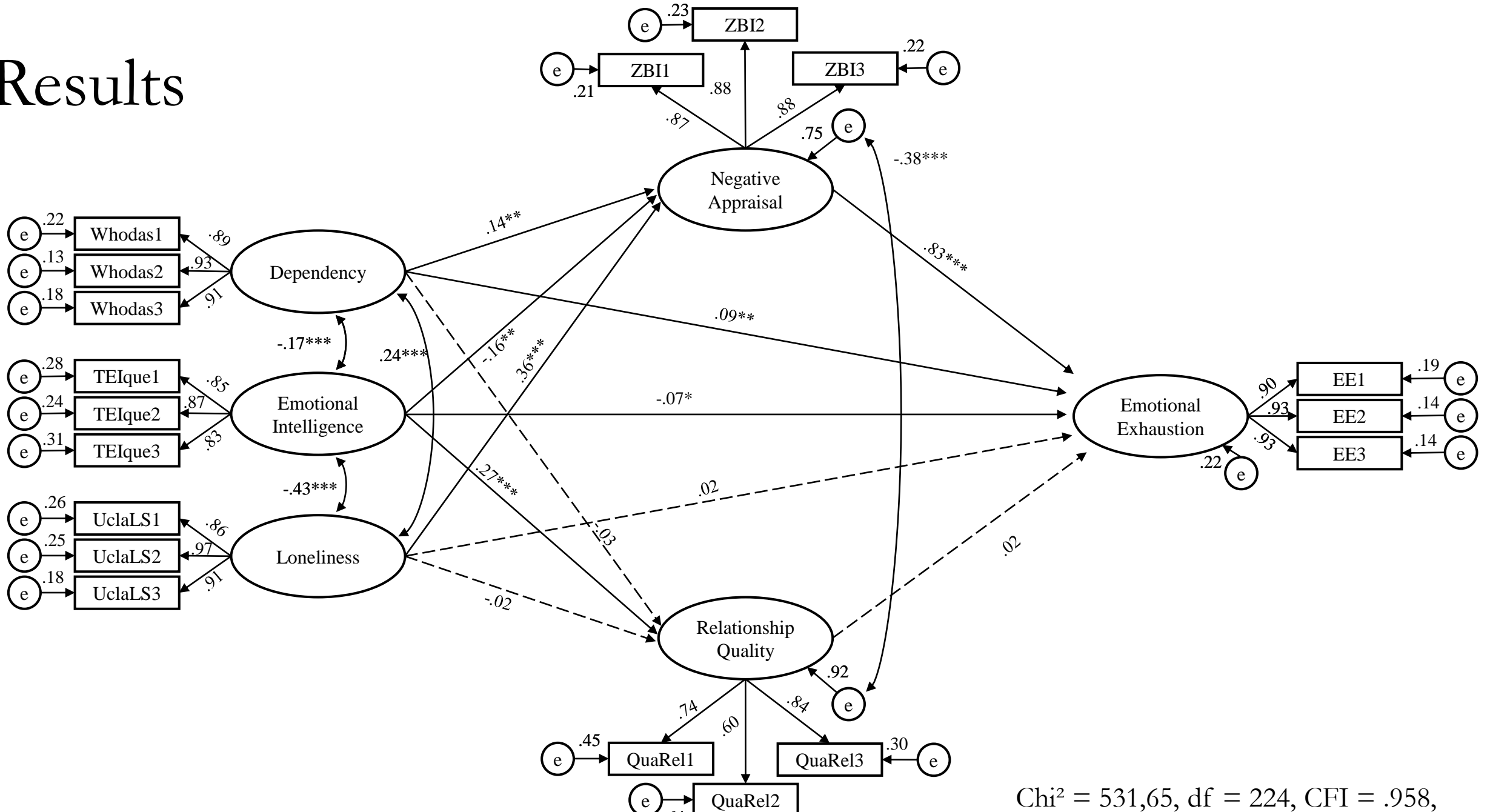
Study 1



Goal:

- Verify the role of risk and protective factors in the model
- Explore the mediation role of subjective evaluation & relationship quality

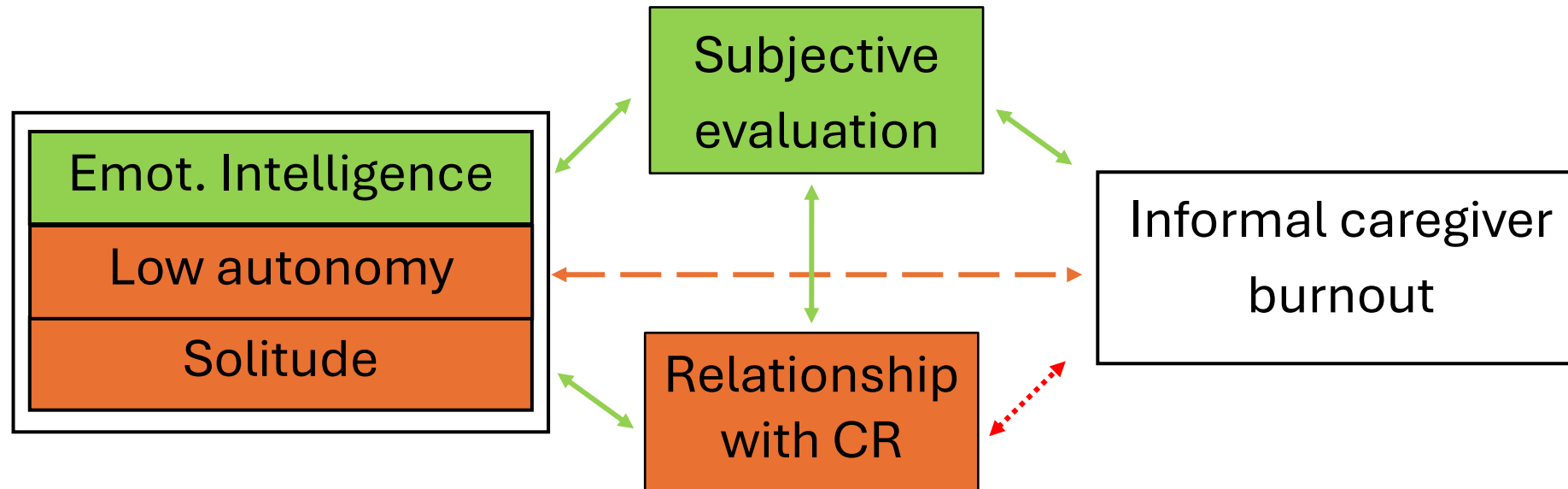
Results



Note: † = $p < .10$. * = $p < .05$. ** = $p < .01$. *** = $p < .001$.

Chi² = 531,65, df = 224, CFI = .958,
RMSEA = .055, TLI = .949, SRMR = .046.

Study 1: Results



- Subjective evaluation as a central component
- Quality of the relationship loosely associated with ICB
 - Strong association with subjective evaluation
- Emotional intelligence as a protective factor
- Solitude influences ICB *via* the subjective evaluation

A Harmful Care: The Association of Informal Caregiver Burnout With Depression, Subjective Health, and Violence

Journal of Interpersonal Violence

1–25

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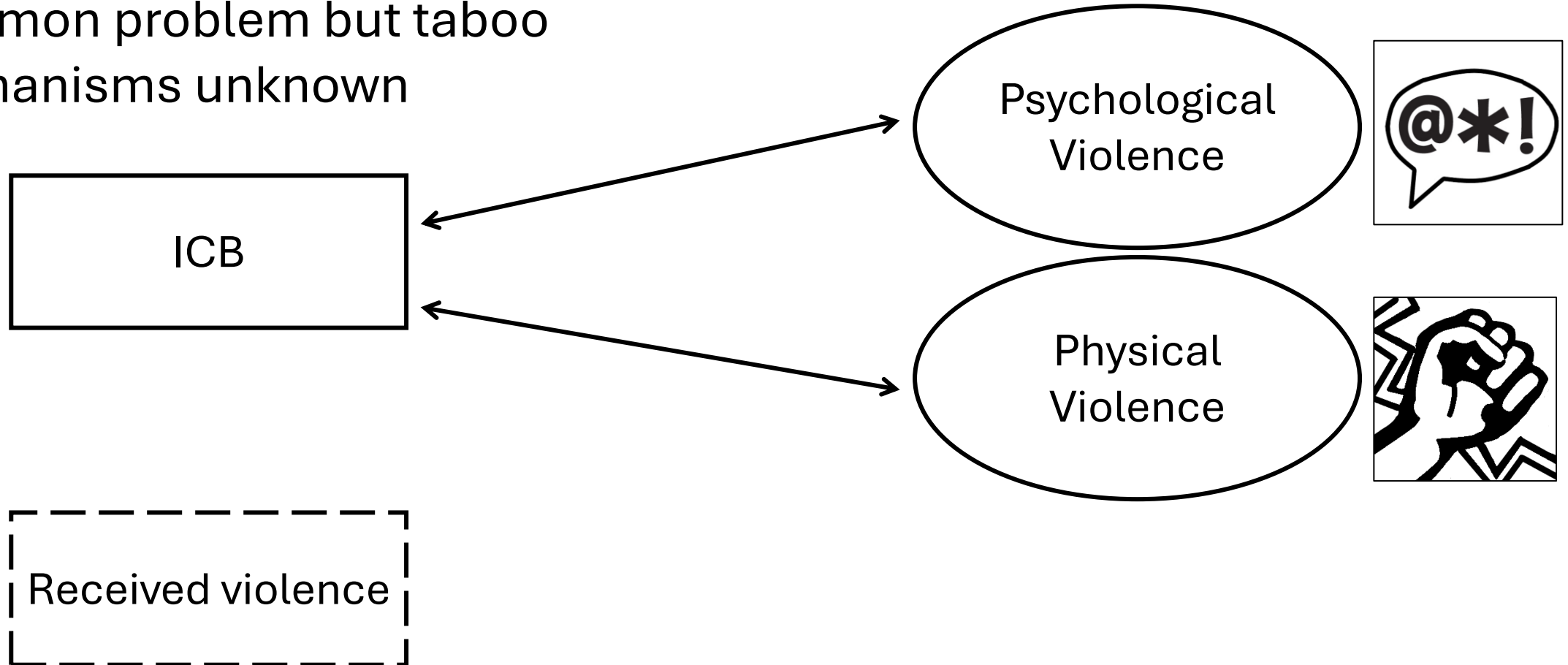
Pierre Gérain,^{1,2}  and Emmanuelle Zech¹ 

Study 2: consequences of ICB

Violence in the caring relationship

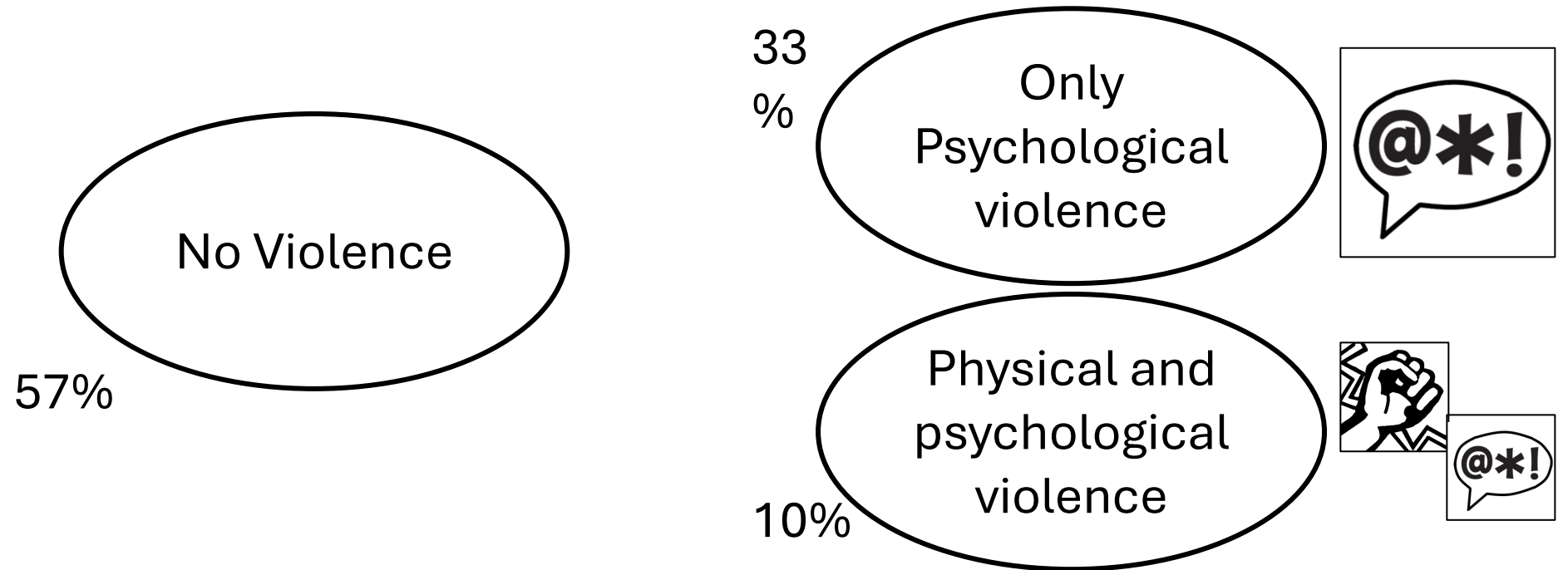
Common problem but taboo

Mechanisms unknown

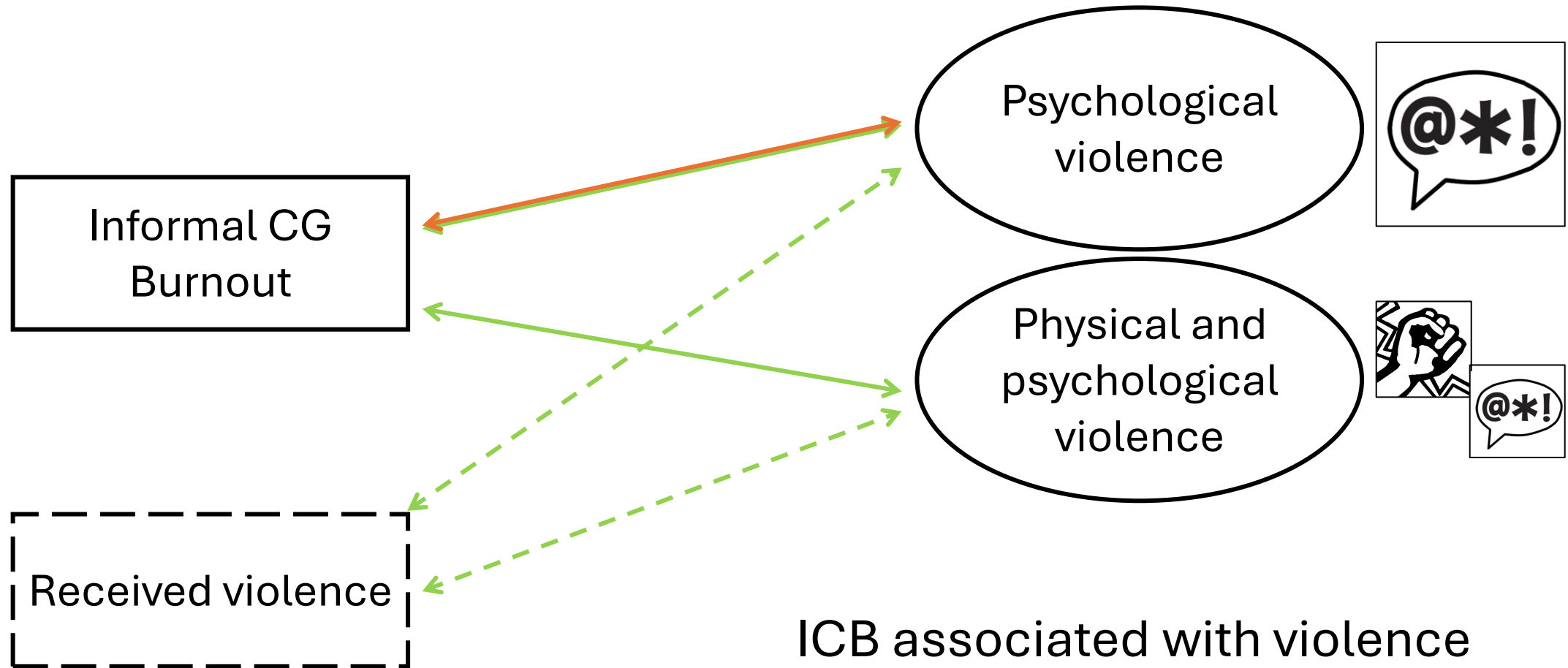


(Acierno et al., 2010; Lafferty, Fealy, Downes, & Drennan, 2016)

Study 2: Perpetrated violence



Study 2: Perpetrated violence & ICB



ICB associated with violence

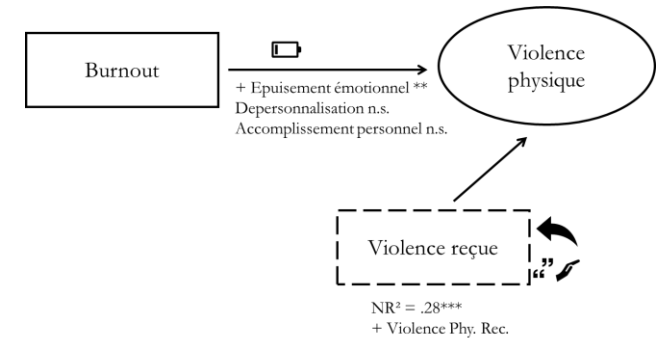
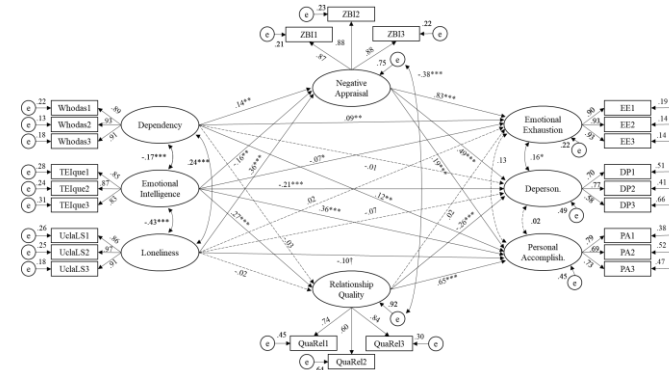
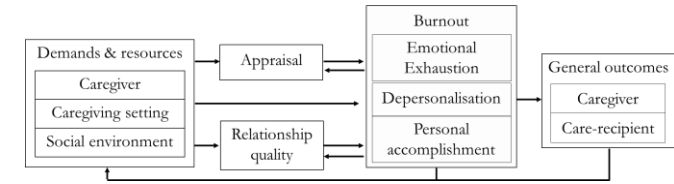
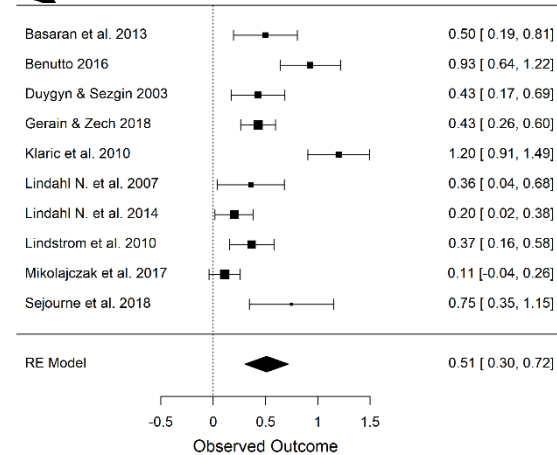
Mostly physical

Violence brings violence

Take home messages

Informal caregivers ...

- Are at risk of professional and parental BO
- Can experience a form of BO associated with informal care
- Their subjective evaluation is a key to understanding their risk
- Emotional exhaustion and received violence increase the risk of violence



So what?

Talking about "burnout" for informal caregivers

- Mostly talking about exhaustion
- Other dimensions to clarify

Increase awareness about informal caregiving

- In informal caregivers themselves
- In healthcare professionals
- In public policies

Account for the subjectivity

- Equal objective situations do not lead to the same outcomes

The SCOHPICA-IC project



- Necessity to have large samples
 - Better understand of caregiver difficulties
 - Across different contexts
- Follow them up
- Mixed-method approach
- Validate a new tool for informal caregiver burnout

SCOHPICA-IC questionnaire

Open from April 15 to August 15 2024

On www.scohpic.ch

