# Older People Living Alone

## Non-kin-carers' support towards the end of life -Reflections on the Study Protocol

<u>Paulina Wosko<sup>1</sup></u>, Elisabeth Reitinger<sup>2</sup>, Birgit Trukeschitz<sup>3</sup>, Barbara Pichler<sup>2</sup>, Judith Kieninger<sup>3</sup>, Johanna Pfabigan<sup>1</sup>, Sabine Pleschberger<sup>1</sup>

- <sup>1</sup> Gesundheit Österreich GmbH (GÖG, Austrian Public Health Institute)
- <sup>2</sup> University of Vienna / Department of Nursing Science
- <sup>3</sup> Vienna University of Economics and Business / Research Institute for Economics of Aging

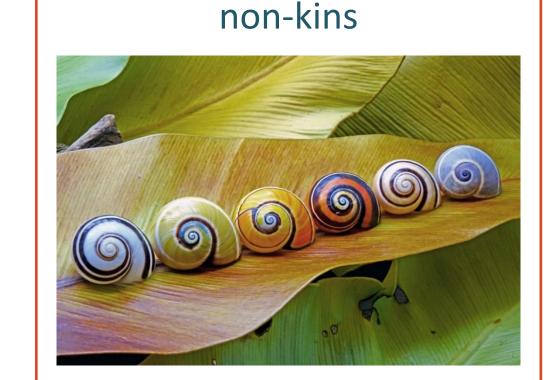
## Background

- Older people, who live alone, form an increasing group in many countries. In Austria, 51% of all households of people aged 65+ were **single-households** in 2018 (Statistik Austria, 2018a).
- In the age group 80+ especially more women are affected than men: 59% vs. 24% (Statistik Austria, 2018b).
- For older people living alone, staying at home may turn out challenging when care needs increase. Those without family nearby have to rely on other support networks, e.g. non-kin-carers.

# **Older People Living Alone**

Support by friends,

neighbours and other



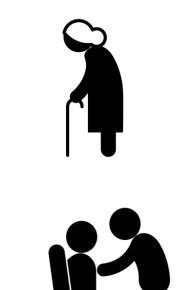
## Aims

- To better understand the **challenges** that older people living alone face in light of increasing care needs towards the end of life.
- To analyse the **potential of non-kin-carers** in care arrangements of older people living alone and identify gender specific patterns therein.
- To work out characteristics of different arrangements which support older people's preferences for staying at home, including access to palliative care.

## Participants

#### Older people

- 65+ living in a single-household, in a progressive state of illness or frailty, no family nearby (rural & urban areas).
- Supported by an informal non-kin-carer, regardless of the intensity or character of support.
- Exclusion criterion: dementia, a terminal state of illness or a situation of crisis.





**Data Collection** 

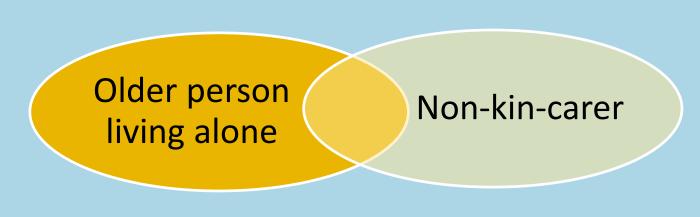
#### Non-kin-carer

- People who support/take care of somebody with whom they are not in a family relationship outside a formal network.
- Group of non-kin-carers encompasses: friends, community members from church, neighbours, voluntary services and others.

## Methods

#### **Study Design**

- Qualitative longitudinal study
- Serial interviews (every 6 month)
  - 30 cases (data sets)
  - → 1 case (2 perspectives/participants):



4 Austrian regions (rural/urban)

### O Data sets consist of:

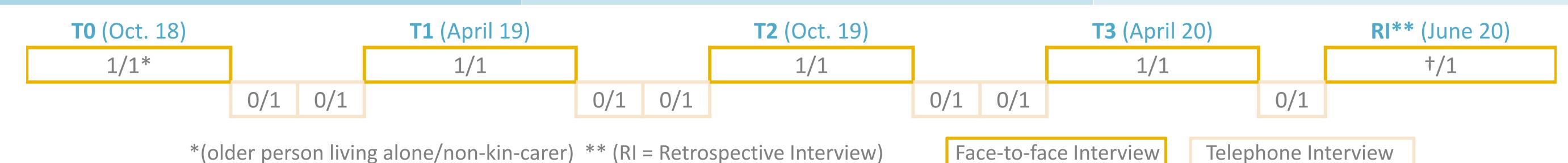
- → Initial interview
  - → Follow-up interviews (>1)

→ Retrospective interview

- Telephone interviews (every 8 weeks)
  - → To recall the study and collect information on the current situation of the care arrangement

#### **Data Analysis**

- Interviews voice-recorded, transcribed verbatim and anonymised
- Iterative process: cross-sectional analysis & analysis of trajectories
  - Grounded theory approach (Corbin & Strauss, 2015)
  - Case reconstructive approach (Hildenbrandt, 2005)
- Supported by MAXQDA software



# Reflections & Adaptions

- Recruiting the "right" participants as major challenge:
  - handling a variety of gatekeepers (GP's, home care nurses, palliative care teams, NGO's) in 4 Austrian regions
  - complex set of recruitment criteria difficult to communicate
  - enormously time-consuming process  $\rightarrow$  low output for high workload; to keep schedule
- Attrition at follow up was higher than expected due to death, deterioration of health or no availability.
- Ethical challenge due to intrusion of the researcher in private care arrangements:
  - change of focus on older people living alone instead of cases (2 perspectives)
- Positive feedback from participants on interviews:

Hildenbrand B. (2005): Fallrekonstruktive Familienforschung. Opladen: Leske & Budrich.

und Alter der Haushaltsreferenzperson-Jahresdurchschnitt 2018 (25.06.2019)

- opportunity to reflect and talk about their life and situation
- joy over small gift for engagement (flowers, shopping voucher, etc.)

Statistik Austria (2018a): Mikrozensus-Arbeitskräfteerhebung 2018. Privathaushalte nach Haushaltsgröße, Bundesländern

<u>Literature:</u>

Corbin J.; Strauss A. (2015): Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory.

4. Auflage, Sage Publications

Gesundheit Österreich

Statistik Austria (2018b): Mikrozensus-Arbeitskräfteerhebung. Lebensformen nach Geschlecht und Alter-Jahresdurchschnitt 2018 (25.06.2019)

universität wien



