Older People Living Alone

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

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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.

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.

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, neighbours, community members from church, voluntary services and others.

Methods

Study Design

Data Collection

Data Analysis

- Qualitative longitudinal study
- Serial interviews (every 6 month)
  → 30 cases (data sets)
  → 1 case (2 perspectives/participants):
  Older person living alone
  Non-kin-carer
- 4 Austrian regions (rural/urban)
- 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
- Interviews voice-recorded, transcribed verbatim and anonymised
- Iterative process: cross-sectional analysis & analysis of trajectories
  → Grounded theory approach (Corbin & Strauss, 2015)
  → Case reconstructive approach (Hildenbrand, 2005)
- Supported by MAXQDA software

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* (older person living alone/non-kin-carer) ** (RI = Retrospective Interview)

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

Literature:


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