



COVID: first wave in the Netherlands

- More infections in migrant communities
- First wave in The Netherlands: face masks, gloves, testing etc: too little, too late in community care and nursing homes
- Many infections and deaths in Dutch nursing homes
- Mid March: physical distancing and block / limitations of nursing home visits.



Study: Social Isolation in Covid times

ZonMw

- Social impact of Physical distancing on vulnerable populations during COVID-19
- Various substudies: groups in vulnerable situations: older adults, mental health patients, homeless citizens, multi problem families
- Substudy on migrant family carers
- Findings and recommendations to national Outbreak Management Team
- Coronatijden.nl





Experiences of migrant family carers

- 5 family carers with migration background: Turkish, Moroccan, Moluccan, Indonesian
- Person with dementia: living at home in the community or in a nursing home
- Participants: son, daughter, husband of person with dementia
- Repeated, semi-structured telephone interviews: 4-9 interviews per respondent
- March-May 2020
- Audio recordings and Thick descriptions
- Interviewers:



Findings: emotions

- Varying degrees of sadness, anxiety and stress
- Frustration, powerlessness
- Information stress
- Hygiene stress
- Persistance and resilience: 'I'm all right, with ups-and-downs, a full agenda and people around me'





Findings: Benefits

- More use of communication technology
- Some relationships between informal networks strenghtened
- Impulse to resilience and creativity
- Awareness of personal care role strenghtened



Findings: 3 themes

- Quality of life of relative with dementia versus health threat
- Digital care: everyday communication technology and implementation of new technology halts. 'Staring at eachother on a tablet. My wife does not know how to look at it. She was very startled'
- Disrupted care networks and care infrastructure > threats to person centered /culture sensitive care: 'Before Corona everything went smoothly, I was used to it (caregiving). It had been my normal life

for twelve years'

> After easing of the social isolation measures: balance restoration, but remains vulnerable.



Case: 5.1.2e

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512 cares for her mother with dementia with 2 sisters. **5.1.2** is used to interpreting for her mother, **5.1.2** does not speak Dutch and cannot read or write. **5.1.2** lives in a nursing home with no other Turkish residents. **5.1.2** offers practical support with eating, bathing and going to bed. Agreements on culture sensitive care have been hard fought for over the years.

Due to corona relatives cannot visit the nursing home. Agreements on culture sensitive care between ^{5.1.2e} and the nursing home are broken. Most days there is no Turkish speaking staff on the ward. <u>5.1.2e</u> recognizes early symptoms of a bladder infection, but it takes weeks before action is taken. <u>5.1.2e</u> becomes more confused, beating staff and shouting at them.

The nursing home organises 'window /plexi glass meetings' for relatives. These confuse ^{5.12e} even more. ^{5.12e} is not allowed to calm her mother. In the end she defies the regulations and takes her mother out for a walk.

'Every time these rules and that mistrust, that struggle. Customized care is no longer possible. My sisters and I lessen the burden of staff, but we do not get the opportunity. All those years of collaboration are thrown away in week's time, at the expense of my mother!'.



Conclusion: Covid and family care experiences

- Experiences of Covid and of Covid measures are entwined
- Some Covid stress can be avoided by better communication and collaboration.
- Some family carers feel that their care contribution is denied and that culture sensitive care is lost.
- Continuity of collaboration in networks of formal and informal care deserves time and attention
- Rules and measures deserve discussion
- Expertise and creativity of family carers may be helpful, as ever!



Thank you!

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Publications:

- Pharos.nl
- Coronatijden.nl



