Preliminary results - Impact of home isolation on vulnerable groups in the Netherlands: Balancing infection risk and quality of life

dr Danny de Vries, Prof dr Jeannette Pols, Prof dr Amade M’charek. Amsterdam Institute for Social Science Research, Universiteit van Amsterdam, on behalf of the partners.
Funder: ZonMw. Contact: info@coronatijden.nl
Amsterdam, 25 mei 2020

I Research & Method
Socially vulnerable groups often suffer the most during a crisis like the current corona-crisis. Problems relate to health and wellbeing but are also amplified by government measures necessary to respond.

In our ongoing study we look at the impact of social distance on socially vulnerable populations:
1. Older adults, among those people living alone, people with dementia, people living in nursing homes;
2. People with severe psychiatric problems;
3. People with learning disabilities;
4. Homeless populations;
5. Young families
6. People reporting domestic violence

Research questions: What problems related to home isolation have emerged for vulnerable groups? What policy measures are needed to address these impacts?

Here we report on the most urgent problems and less on what is going reasonably well. The findings are first results based on three weeks of intensive in-depth digital interviewing among professionals, clients and family members, a poll and discussions with people from the panel “Psychologically seen” (Psychisch gezien) and digital observation of casus discussions among professionals. In total 111 people were interviewed, and questionnaires were filled in by 921 family members and 533 health care professionals of older people in long-term care institutions.

II Which problems in relationship to home isolation are at play for socially vulnerable groups?

a. Reduced quality of life and health threats
For the many of the people living independently at home, loneliness is a pressing issue. Day programs and structures have fallen away. Face-to-face care, support and initiation of new care trajectories have reduced dramatically or in some cases stopped completely or swapped with just visual calling. Digital care can do a lot, but it does not solve all noted problems. ‘I am merely thinking backwards’, one homeless client notes. With a diffused, uncertain future and absence of meaningful day a large emptiness has developed for many in the here and now. People focus on the past, and among older people this often means memories from World War II. They recognize in this the feeling of being stuck, locked inside, with the uncertainty of when and where “the bombs will fall.” Older people are afraid to die not so much because they fear death, but because they fear to be alone without the ability to say goodbye to their loved ones.

Across all groups of people there is extreme anxiety about the impact of the disease, which they do not entirely understand. People report health problems, depression, self-destructive behavior such as gambling and drinking, and compulsive online shopping. Going outside offers distraction but is also perceived to heighten the chance of getting infected. With regard to homeless people it is striking that
society has now suddenly managed to find them places to stay, sometimes in hotels. On the other hand, support programs have largely stopped. Because of this, and because it is unsure how long they will have a roof over their heads, their lives feel to be on hold. Ways to earn a little money through day programs have disappeared.

Because of home isolation, tensions can rise within families, leading to unsafe situations for some family members, especially women and children. During acute unsafety, face-to-face contact is sought. However, in new cases where domestic or sexual violence is suspected, the ability to conduct swift and effective home visit is compromised. Also, for other groups, initiatives for new care trajectories are on hold. For all groups the length of the measures plays a role; a few weeks is foreseeable. In some cases, the relative peace was actually seen as welcome. However, the lack of perspective on the future is not sustainable for many in the long run.

Questionnaire results in long-term care facilities show that a large proportion of family members believe that the health of their kin has decreased relatively to before the corona crisis. Data show a clearly observed difference in affect among residents by both their kin and care professionals. Among people with dementia, family members express anxiety that their kin are rapidly regressing due to a lack of stimuli due to the stopping of activities and day programs. One out of ten family members has not spoken with their kin in the past four weeks. Since day programs have stopped and social services are only existing at a limited capacity, people are often dependent on informal caregivers who are becoming overburdened. Some informal carers are struggling with being risk groups themselves, and the extra pressure sometimes leads to domestic violence.

Family and health care professionals were asked which priority they found more important: quality of life or safety. Figure right shows that family members tend to choose quality of life, while health care professionals choose safety. Still, in both cases about a third finds it too hard to make a choice. This dilemma illustrate how informal caregivers and professionals are stuck between the desire to provide quality of life and the need to avoid infection.

b. Limitations of digital care

Professionals, family members, and some of the clients other than those in psychiatric care, are happy with the possibilities of modern visual communication technologies. Making this works demands extra support from involved professionals. However, they also signal the limitations and disadvantages. Visual calling in does provide verbal contact, but care giving is more comprehensive than this. Home visitation and face-to-face contact is necessary in the following circumstances:

- Getting to know new clients, the building of a trusting relationships, and initiation of new care trajectories. An example is an IQ test needed to indicate if a mentally handicapped person is entitled to certain social services (WLZ). Because this is not possible to arrange from a distance, care has stopped;
- For people with a small or absent social support network;
- For situations in which safety of a client is at stake
- For clients with psychiatric issues who are experiencing more anxiety and depression and tend to isolate themselves further.
- For some administrative issues (post, requests of addresses, social benefits, financial banking issues, debts counselling, etc.), and the visual monitoring of home situations (are there letters laying around, or empty bottles?)
- People without a computer, telephone or laptop, or those who do not know how to use them.
- For people who intentionally avoid care or liked to not be found.
- For domestic assistance in housekeeping and physical care.

Some clients disappear from the radar and cannot be traced digitally. Their caregivers do not know how they are doing. For older people, many informal care tasks (like taking care of grandchildren, volunteering) have ceased. Through digital contact it is difficult to do things for others, like cooking, bringing presents and spending time together. Because of this, the meaning of life disappears.

c. Broken networks / defect infrastructures
Stopped care, day programs, social services and home-visits lead to problems. Yet, because social and judicial services are limited, pressure is increasing at law enforcement. While community police have to repeatedly patrol the same situations, relevant social institutions cannot assist and take care of the problem as they are not allowed to conduct home visits or are not sure if they can or cannot. Because of this community level trust is decreasing as “nothing is done”. Conversations with children who are not yet enrolled in social services but where suspicion of sexual abuse is present often fail to develop during corona times. The use of communication technologies requires extra explanation and training particularly when people do not have pre-existing skills or digital infrastructures: this is not uncommonly the case among socially vulnerable groups. These skills are also not easy to acquire for everyone.

III Is policy needed to deal with the problems? In what direction should this go?

Two core policy avenues emerge:

a. Broadening the goal: Next to prevention of infection, facilitate essential social traffic
Essential social traffic is social traffic needed to ensure minimal health and quality of life. Integrating and supporting this essential social traffic is of urgent importance to those who deal with fear, violence, loneliness, lack of hope for the future, and those the professionals that need to signal problems and provide care: relationship building, problem identification, intake, and coaching. This asks for national policy to safely re-introduce face-to-face contact for support and day programming, and creative solutions that safely facilitate social meetings. Because of the long duration of this crisis, it is necessary to prevent major health damage and guarantee a minimal quality of life.

b. Weigh risks in context: local solutions within clear national boundaries
The construction of possibilities for essential social traffic will have to take shape in different ways in the many different places and situations. There are differences between organisations, municipalities, and sectors; between more and less heavily impacted regions and locations; and between clients and the seriousness of their problems. This demands local solutions weighed within clear national boundaries. This also appeals to governments to trust professionals, informal care givers and family members to wisely implement the rules during the difficult weighing of risk of infection and quality of life.