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article

The impact of physical distancing on socially vulnerable people needing care during the COVID-19 pandemic in the Netherlands

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What was the impact of physical distancing on socially vulnerable groups needing care during the first COVID-19 pandemic lockdown in the Netherlands? We conducted repeated qualitative interviews with 141 people in care relationships and 106 professionals, and two repeated surveys among older populations outside ($n = 1697$) and inside long-term care facilities ($n = 2619$). Findings show a diversity of experiences, ranging from relative calmness and feeling socially normal, to loneliness and loss of perspective. Care must be seen as essential social traffic needed to guarantee basic quality of life for these groups during disease outbreaks. Findings emphasise an empirical ethics approach to policy interventions.

Key words COVID-19 • social vulnerability • social distance • care

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Introduction

When Dutch policymakers saw the number of COVID-19 cases rise steeply during the first wave of the outbreak, they joined other European countries in a lockdown aimed at shielding the most vulnerable groups and to keep the health system in operation. In the context of protecting intensive care (IC) capacity, scientific publications defined vulnerable groups initially as those at risk of contracting SARS-CoV-2, in particular, people over 70 years of age and those with underlying, often chronic, medical conditions (Luchetti et al,

2020; Torres et al, 2020; Preiser et al, 2020; Zhao et al, 2020). In Dutch policy debates, the dominant concern was with older people, particularly those in long-term care facilities (Tweede Kamer der Staten Generaal, 2020a). These groups were shielded by imposing rules for physical distancing (1.5 metres), restricting public gatherings (for example, closing restaurants, schools and workplaces) and strongly worded public advice to stay indoors and restrict mobility. The government framed the lockdown as 'intelligent' in an effort to appeal to people's sense of solidarity, and was initially also influenced by the idea of group immunity (which was quickly abandoned). The lockdown was generally perceived to be less strict than in many other European countries: there was more freedom of mobility, face masks were not advised and testing and contract tracing were relatively limited.

As the outbreak proceeded, it became clear that the definition of physical vulnerability to COVID-19 needed to be complemented with attention to people experiencing extraordinary inequalities as a result of the broader 'corona crisis' (Lewnard and Lo, 2020). Economic concerns were immediately obvious, as the Dutch economy contracted by 8.5 per cent in the second quarter of 2020, which was a historic decline (van Es and van der Veen, 2020), and worries were expressed about the possible impact that this might have on health-system financing (Kruse and Jeurissen, 2020). Another group of people that slowly became foregrounded as 'vulnerable' in political deliberations (mostly by Christian political parties) were those whose quality of life appeared to be severely threatened by physical distancing and home isolation, or people feared to be experiencing extraordinary loneliness, such as some people with mental disabilities (Tweede Kamer der Staten Generaal, 2020b). These people were typically dependent on social care services and infrastructures, such as day programmes and home-based care, which had ceased operations. Concerns existed that the risks of shielding these people from the social, medical and practical support they needed might outweigh the benefits (Schmidt-Sane et al, 2020).

Social vulnerability

We studied the impact of the COVID-19 crisis on several groups of Dutch citizens initially thought to be at risk of such social exclusion. These were: people dependent on care relationships or in long-term care facilities; people with learning and mental disabilities; people with psychiatric problems; homeless people; people without Dutch-language skills; or families at risk of domestic violence. We see social vulnerability as a societal-historical positionality in which some people are threatened with social alienation and exclusion as a result of disease and policy stressors. This definition also emphasises that 'vulnerability' is not, in itself, a set category, but rather a historical process (Hoffman and Oliver-Smith, 2002). Instead of being an essentialised label that can be experienced as stigmatising, a person is rendered vulnerable through context and circumstances. This specific focus falls into a broader categorisation of vulnerability having social elements. In disaster studies, 'social vulnerability' relates to the degree to which people are able to anticipate, cope with, resist and recover from the impact of a hazard (Cutter, 1996). It is well known that socially vulnerable groups are the most at risk in times of crisis (Blaikie et al, 1994; Wisner and Adams, 2002; Bankoff et al, 2013). For disease outbreaks, this link to impact is both direct and indirect: direct because socially vulnerable populations appear to have a heightened risk of infection (Gaynor and Wilson, 2020; Karaye and Horney, 2020; Freitas et al, 2020; Torres et al, 2020); and indirect because social vulnerability also links to the broader impact of policy measures on quality of life, such as expected loneliness

among shielded populations during a lockdown. Studies have shown how social isolation among older adults can lead to serious public health concerns, including heightened risk of cardiovascular, autoimmune, neurocognitive and mental health problems (Armitage and Nellums, 2020a). Additionally, this also links to the debate on the importance of physical interaction in care contexts (Pols, 2016; Moser, 2010).

Study goal

As the Netherlands is a relatively egalitarian country with strong social care infrastructure, we specifically studied the social impact of physical distancing, labelled 'social distancing' in popular discourse, in relation to these Dutch care infrastructures. We focused on people who can be rendered vulnerable mostly because of the special care relationships they have due to a limited social network and support structure. These tend to be people who have difficulty fitting into 'normal' society due to social constraints. While social distancing included keeping distance from others in general, it also included home isolation and measures that stopped kin from visiting their loved ones in long-term care facilities. These far-reaching social policy measures were also seen in many other European countries during the period of the first lockdown in the spring of 2020. What was the impact of COVID-19 measures on the well-being of socially vulnerable populations in the Netherlands? How did the lockdown and the relaxation period affect them? What solutions to their challenges were found? What suggestions were made for improved policies to respond to their plight? What does safety mean for these people, and how does that compare to the policy aims?

Methodology

The study was funded by the Netherlands Organisation for Health Research and Development (ZonMw) as part of a rapid first research response to the COVID-19 outbreak. It was set up in a few weeks in order to start data collection quickly and to obtain a first indication of the situation among the most vulnerable in the early stage of the crisis. The study was conducted during the first wave of the virus in the Netherlands, when the Dutch government imposed an 'intelligent' lockdown from 15 March to 23 May 2020, followed by a period of relaxation from 23 May through to 1 July 2020. Our data collection started immediately after the peak of this first wave (see Figure 1), when media attention was predominantly focused on the number of deaths due to the pandemic.

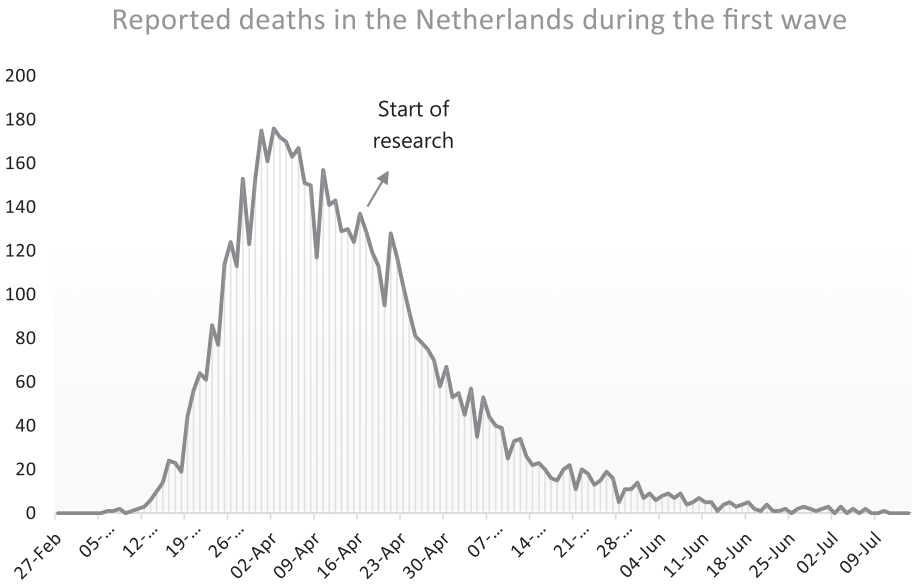
It was a period in which the first shock of the lockdown had been somewhat digested culturally, and many people had begun to move towards new routines. In the second half of the study, the relaxation measures dominated the lives of the people we studied.

Participants and recruitment

The study used existing networks of involved study partners to conduct digital ethnographic and survey research. A total of 39 researchers, connected to different partners, participated in data collection. The main target groups were:

- older adults, among them people living alone, people with dementia, people living in nursing homes and informal carers of older migrants;
- people with severe psychiatric problems;

Figure 1: Number of deaths due to COVID-19 reported by municipal and regional health services by date (RIVM 1 July 2020)



- people with learning and mental disabilities;
- homeless people;
- families with young children; and
- families at risk of domestic violence.

The study also sampled professionals working with any of these target groups. In the case of families at risk of domestic violence, for confidentiality reasons, this was the only source of information.

As a result of home isolation for the general population, we could not conduct traditional fieldwork. Working in teams per target population, most researchers on the project therefore chose to have regular digital or telephone contact with selected participants, many on a (bi-)weekly basis. An advantage of this repeat interviewing was that it provided insight into the development of participants' lived experiences. In the context of home isolation, many study participants stated that the repeated contacts with our researchers had been a positive experience.

In total, we interviewed 141 vulnerable people and 106 supporting professionals, either digitally or by telephone (see Table 1), using ethnographic experience as a point of departure. Respondents' ages ranged from 20 years through to the late 80s.

Participants were mostly recruited through previously existing networks developed by our researchers through professional engagement, regular panel interactions or previous studies conducted on the same populations. Every potential participant received a written invitation with an explanation of the project, together with a verbal telephone follow-up. Each team took care to select participants to capture the widest diversity of types of care existing for that group, and to take into account the differential impact of COVID-19 within some populations. Many study participants had forms of employment offered through social services as part of day programming.

Table 1: Number of qualitative interviews by group and subgroup

Population group	Study groups	Number of interviews
Vulnerable older people	Older people	34
	People with mental health problems	26
	Caregivers (informal)	19
	Care professionals (formal)	22
People with learning disabilities	People with learning disabilities	22
	Professional client supporters	15
	Behavioural experts	3
	Case observation	6
Homeless people	Homeless people	18
	Programme professionals	7
	Caseworkers	6
Young families	Families with young children	41
Families experiencing domestic violence	Programme professionals	28
Total		*247*

Table 2: Number of quantitative interviews

Population group	Study groups	Number of interviews
Older people living independently	Older people	1,697
Older people living in a long-term care facility	Residents	193
	Family members	1,609
	Care professionals	811
Total		*4,310*

All interviews were conducted by professionals or researchers with previous experience of working with the target groups, and who were therefore familiar with, and trusted by, the participants. Most interviews lasted 30–45 minutes. Interviews with care professionals tended to be less frequent and a bit longer. Researchers used a semi-structured interview instrument that was developed after first findings from the field were obtained following a few weeks of open-ended interviewing. Central were questions regarding the impact of the lockdown and daily life, quality of life (social relationships, living at home, mental and physical health, day activities, and finances), access to care and care facilities, the meaning of safety, experiences and impact of social isolation, and limits and possibilities afforded by digital communication. In cases where it was impossible to cover all these topics, the most important ones covered included impact on mental and physical health, and experience with COVID-19 policies. With participants who worked as professionals, interviews also included the policies of the institutions they worked with and the continuation of care. Follow-up interviews also paid attention to temporal dynamics, like the recurrence or introduction of new concerns. Researchers took notes directly during the interviews instead of elaborate transcripts in order to provide quick results. Notes taken during each interview were elaborated directly after the interviews and further developed into raw data.

In addition to qualitative interviews, we also conducted digital surveys with 1,697 older people living independently (Stolte et al, 2020; van Tilburg et al, 2020) and 2,619 older people living in a long-term care facility, or their family members or care professionals (Van der Roest et al, 2020a) (see Table 2). (For methodological details, please see the original publications.)

Analysis

Due to the need to provide rapid results for the Dutch COVID-19 response, interview reports were typically analysed manually, without qualitative analysis software. As multiple researchers were involved in each team, peer consultations occurred to align the overall coding scheme and discuss approaches. All research teams were motivated to report their findings using four broader categories that had emerged as central during the first rapid results analysis after four weeks of fieldwork: (1) quality of life and health threats; (2) networks and care infrastructures; (3) digital care; and (4) good practices and suggestions for policy.

A special integration team developed these findings further. To do this, three collective-analysis sessions were organised with all researchers involved, using the Stanford D-School design methodology (Stanford University D-School, 2020), which was facilitated by one of the partners. Using this method, we translated findings into relevant actions and policy recommendations.

Ethics

Ethical approval for this study was provided by Amsterdam Institute for Social Science Research (AISSR) Ethical Advisory Board (2020-AISSR-12148). Researchers were carefully instructed on the ethical procedures, and repeated debriefing with researchers was carried out within the teams, led by the team leader. During participant recruitment, we used established relationships first and made sure to explain the differences between any previous projects and the current project clearly. When recruitment was made through contact persons, we also provided supporting information about the project for contact people to use. As some of our partners provided direct care, we ensured that the contact person or participant understood that the study would not influence their relationship with the organisation conducting the study.

All participants were mentally stable enough to participate. Some of the participants received small tokens of appreciation. During and after the informed consent procedure, repeated checks were conducted on participant understanding of the study and information provided. The informed consent procedure was repeated at the start of each new interview with the same person. Information about the study was developed using appropriate information materials and interview topic lists at basic language level. In qualitative interviews with professionals or carers, we made use of limited oral consent. For interviews with people with diminished cognitive capabilities, we obtained both oral consent from the informant and written consent from a coach, caretaker or other formal carer, using a person-centred approach (Dewing, 2002; Hellström et al, 2007). Topics that appeared to be sensitive were only discussed when a good relationship with participants was established (Hardon et al, 2001: 169), and when a third person (such as a trusted independent care professional,

a family member or a friend) was appointed by the study participant as someone who could be turned to for advice on the matter of the conversation. With respect to data collection with professionals working on domestic violence, information collected was not shared without approval of the organisation and professionals involved. Vignettes resulting from this population were generalised and discussed with the professionals before publication. We did not include any personal identifiers in the data collected.

An empathetic approach in interviewing was used, and ample time was taken in each interaction. Participants were monitored regarding their stress levels and were able to stop at any time. One participant decided to discontinue participation because of stress due to the study.

Findings

We have published the quantitative findings on older populations from this study separately (Van der Roest et al, 2020b; van Tilburg et al, 2020). We use some of these findings in this article, referencing the original sources where necessary. The rest of the results are based on the qualitative, ethnographic data collection. We first describe the experience of our participants during the lockdown period. After that, we reflect on the period of relaxation, followed by a review of the most important policy suggestions that arose from this study.

The lockdown period

Loss of regular support services

When the lockdown started, regular face-to-face care and social support services came to a standstill. Group treatments, face-to-face care, physiotherapy, day-care programmes, walk-ins, budget management support, personal assistance, work programmes and debt counselling ceased for all groups. The domestic violence surveillance organisation Veilig Thuis (Safe at Home) visited people only in emergencies. People with outpatient care and older people living independently had no more care professionals coming to their homes. In addition, family or other informal carers stayed away, though some families balanced visits with risks carefully. The dominant principle applied to face-to-face contacts and home-based care was 'No, unless …'.

Care was continued by online means as far as possible, mostly by using social media technologies such as WhatsApp. However, limits to digital connections and communication were obvious. Technical problems made giving care difficult, and people had difficulty keeping their attention focused, as well as concerns about privacy (whether anyone else was listening in) and the lack of aftercare. As a psychiatric patient explained: "You are immediately alone again after the conversation is closed. And then you feel mentally vulnerable." Many care professionals wondered how their clients were really doing. One professional explained to us the major limitation: "Video calling and e-health are safe and positive types of contact. But it also showed us how important daily, mundane communication is. A chat about 'nothing', about how someone is doing … just 'being there' for the other. Without physical closeness, something goes missing." Another issue mentioned a lot was the lack of observation and direct monitoring of the state of clients, including their living environment:

> 'I have a new client, but I really need to see this boy to assess the limitations and estimate his needs. This is impossible to do just by phone. You cannot estimate this just by what people say. I really have to see him. How is he in the conversation? How does he react to questions? These non-verbal signs are very important.'

Collaboration, solidarity and rest

Surprisingly, the lockdown showed many participants that they had more resilience than they had expected themselves. Dialogue and keeping regular structures helped. A long-term care facility resident said:

> 'What helps … is to talk about things. That I enjoy. And the music teacher calls also and comes by, so we can sing together a little bit. I love that. And keeping structure. Get out of bed on time; that's important. The residents are woken up, and we have regular eating times.'

Older people (70+ years old) living independently were not found to be a socially vulnerable group as a whole, despite their physical vulnerability to the virus. Survey results showed that 73 per cent did not need extra help, 78 per cent felt happy and 86 per cent felt calm (Stolte et al, 2020). Another remarkable outcome was that shelter for homeless people was organised relatively swiftly. As a result of continued shelter, many homeless people seemed to fare better physically, and as a result, they started to focus and reflect on ways to build up their lives again, as opposed to being preoccupied with daily routines. A professional told us:

> 'What is going well is that a group of vulnerable people are now being served who are usually not being served. We have seen this group improve quite a bit. It is remarkable what a bed, meal and some attention can accomplish. Suddenly we think: this man can maybe get a job somewhere, or with a good conversation, we can help him to return to his home area.'

Rapid organisation of shelter illustrates how care and civic organisations appeared to be collaborating well during this period across all groups. This was facilitated by the easy online accessibility of professionals working from home.

Among all groups, there were people for whom the loss of daily routines and reduced pressures from organisations (for example, to find employment) translated into relaxation and easing of social pressure. For example, the relative quietness of doing homework at home led one of the autistic participants to obtain better grades in school. The collective feeling held by many participants that they – for once – were in the same position as the rest of society was a positive experience: they were at home, with limited contacts and with an uncertain and insecure outside world. This was a positive experience for participants who did not leave their homes much anyway, often had little employment or suffered from general anxiety. As one participant noted: "There is now mutual understanding among the people, I hope, that one is confronted with difficult things. We are all in the same boat now. That is sort of positive. A strange connectedness, at 1.5 metre distance, but still a connection." Unexpectedly, they experienced what it meant to be 'normal'. In addition, during

the lockdown period, many volunteers assisted these groups by doing their grocery shopping, and neighbours checked in: "A young woman, a neighbour, with her child.... I can get along well with her. She asked if I would enjoy a chat here and there. And so she does this every week, at some distance, on the sidewalk. Really nice! She does this all on her own accord."

Loneliness and lack of perspective

For vulnerable people with small social networks, however, the absence of care professionals and informal carers in their daily routine meant the collapse of a key aspect of their social network. Situations in which people were home alone with few distractions or activities, and sometimes minimal social contact, presented the most acute social problems. A professional talking about a client with psychiatric issues stated:

> 'Through the protected and accompanied living social service, there were multiple social workers who came three times a week. Because these people do not have any other social network, the coaches end up being the only contact she actually has throughout the week. But the protected living service was stopped from one day to the next. She got really angry about this. But they only said ... "Yes, this is what we are being told from higher up." After that, she retreated socially. She told us that video-calling was not necessary.'

Among all the vulnerable groups we encountered, people experienced extreme forms of anxiety over the intangible threat of an unpredictable and deadly virus. Health problems, depression, passivity and self-destructive behaviour were noted, including more alcohol use, gambling, gaming or online compulsive shopping. These behaviours appeared to be more frequent among those participants who had already struggled with these issues before the lockdown:

> 'Some start using more. A client with alcohol problems ... he is drinking more. Because of the structure of day programming three days a week, he did not drink on those three days, or later. He started buying beer at 16:00. Now he is already drinking at 10:00 in the morning. With crack, it's even double that. The day programming also helped bring in some money. And you have something to do, you are distracted. Now, boredom sets in.'

We could not estimate the relative size of this really vulnerable group of people. Our survey data among independently living older adults showed that in May and June, the particularly vulnerable groups comprised around 3 per cent of the total sample. However, the most vulnerable people generally do not use social media, through which our survey research was conducted.[1] In addition, we also found that older adults in the Netherlands adapted their lives carefully and relatively well shortly after the first lockdown (Steinmetz et al, 2020).

What we do know overall is that the difference in feelings of loneliness before and then during the COVID-19 crisis was relatively small for many of our participants. People with severe psychiatric problems were already experiencing high levels of loneliness before the crisis, with 82 per cent indicating that they had been somewhat to very lonely (Trimbos Institute, 2020). A person with a psychiatric problem told

us: "When it's about loneliness … they always talk about old people. Loneliness is, for me, the most negative aspect of my life. I am always lonely, but now this has gotten even more extreme. It hurts that society barely pays attention to people who are lonely." From our survey among independently living older people, the issue of concern was not so much social loneliness, in the sense of not seeing enough people, but an emotional loneliness, or the feeling that you need someone to talk to and yet there is no one available for real contact (van Tilburg et al, 2020). Among this group, 24 per cent reported loneliness, 58 per cent indicated that they missed having people around them and 26 per cent noted feeling existential emptiness (Stolte et al, 2020). We expect that among the other groups, these percentages might be higher. For example, in long-term care facilities, residents did not have any physical contact with family during the lockdown. Our surveys in these institutions showed that 77 per cent of the residents indicated that they felt lonely, while 85 per cent of family members indicated that their loved ones experienced loneliness, and 82 per cent of the care professionals indicated the same (Van der Roest et al, 2020b).

Our qualitative data indicated that home isolation led to a lack of structure and perspective. A feeling of life without meaning was expressed by many. With an uncertain future and the absence of meaningful daily activities, participants experienced a substantial emptiness in the here and now – life was on hold. Homeless people wondered how long they would be allowed to stay in the shelters and if they would be sent back to the streets again afterwards. Their (small) incomes disappeared with the cessation of work opportunities; "I can only think backwards now", a homeless participant mentioned.

Older people compared the lockdown to feelings of being locked up during the Second World War and to the uncertainty of 'when the bombs would fall'. Some of the older participants mentioned wondering if there would be sufficient food. Those who lived by themselves were afraid to die, not so much because they feared death, but because they feared passing away without being able to say goodbye to their loved ones. Older people living alone noted that they missed the ability to do something for other people, like taking care of grandchildren, cooking for family or friends, or giving gifts. This problem of not being able to contribute to the lives of loved ones was also recognisable among informal carers who were unable to care for their loved ones, especially those in long-term care facilities. They were suddenly no longer included in decisions about the lives of their loved ones, who were often coming towards the end of their lives, leading to a sense of powerlessness.

In long-term care facilities, family members observed from a distance how the health of their loved ones deteriorated. They expressed concern that behavioural and affective disorders worsened in the period that visitation was not allowed. Although older long-term care facility residents did experience a level of calm and rest during the lockdown, the further expectation of remaining cut off from contact with loved ones was unbearable for most. Couples were separated, and parents and children were only able to video-call or see each other through a window or fence. Physical touch was not possible. This especially led to poignant grief among family members of people with dementia, with their loved ones showing no understanding of why they had been separated from their family. As one partner of an Alzheimer patient told us:

> 'Well … touching each other is not allowed, so, now, there is plexiglass in between. I find that so horrible. You love each other, and you are being

> told, "No, you cannot touch each other anymore." It is a nightmare! It is so horrible. I cannot talk with her well anymore anyway. Well, sometimes she forms some words still, sometimes a sentence, but that's it. The only contact we have is through touch. It is the only thing we have left, really.'

Study participants who expressed the least acceptance of the visitor ban were informal carers (*mantelzorgers*). They expressed frustration as they observed how formally hired substitute workers would be able to gain entry to the facility, while they remained banned. They also noted that sometimes they received too little information about the quality of life of their relative, such as happiness and mood. The mostly medical information they did receive was not enough to reduce their anxiety. At the same time, due to the cessation of services, demands on informal carers rose quickly; some were unable to cope with this demand easily, especially those who belonged to vulnerable groups themselves. For example, older people caring for their kin experienced difficulties navigating between their wish to take care of and keep in contact with family, and avoiding getting infected themselves, with possibly fatal consequences. In contrast to this experience, however, our survey results in long-term care facilities found that residents with cognitive problems actually experienced less suffering due to the visitor ban, probably due to their reduced awareness of the situation (Van der Roest et al, 2020a).

Young people with learning disabilities mostly missed social contacts through day programmes and work. Sometimes, they tried to meet, which led to friction with those who tried to maintain order in such institutions. Qualitative data among older people indicated that after weighing up risks on their own, children and other family members often ignored the government-mandated visitor ban.

Mobility and safety

Going outside offered distractions and healthy activity but also increased the fear of infection. Most older people we spoke to shunned public and taxi transport out of fear of infection and because such transport was only meant to be used for 'essential' travel. This was a particular problem for people with mental disabilities and severe psychiatric problems who were unable to travel without accompaniment. Their mobility, just like other people who did not own a car, was restricted to cycling and walking. This also complicated needed visits to medical facilities and increased the need for physical exercise:

> 'Mum is telling us that before the corona-crisis, she just wanted to get started with more exercise. This motivation has stopped with the crisis, which led to an increase in her weight and sugar levels. Because she lives in a small home, she cannot move about or exercise a lot indoors. 'This barrier, I have to get over it. This morning I succeeded. Then I walked around the block a bit.' She sometimes finds it difficult not to lie in bed too much.'

Medical professionals we interviewed expressed concerns about delayed care seeking and neglected care. As everyone was at home, many more notifications of domestic arguments were reported to local police departments. Professionals noted that, at times, neighbours affected by the unrest got frustrated with their observation that "nothing

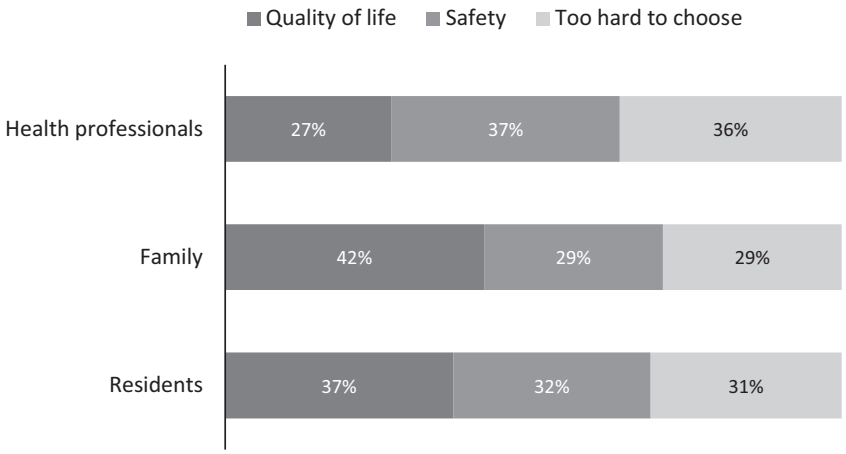
was happening", despite their signalling of problems in their community. They also expressed worry that tensions in families would increase, leading to unsafe situations for family members, in particular, women and children. This worry was exacerbated by the lack of numbers actually showing an increased incidence during this period, which continued until after relaxation:

> 'It is strange because you expect during a time like this more alarms. Everybody is home, on top of each other. But in the first weeks, it was just really quiet. I thought something is not right because you just know there is a certain regularity to this normally. What is happening behind these closed doors?'

When acute unsafe situations were suspected, professionals sought face-to-face contact. At the same time, assessment of new cases where domestic or sexual violence was suspected was severely hindered due to limitations on house visits and the impossibility of face-to-face conversations with children due to school closures: "A home visit, of course, says so much more than a telephone call. How the mother brings her daughter down the stairs. And if you see the child's bedroom and you note that the child never sleeps in her own bed." This challenge of conducting intake assessments from a distance was observed across all vulnerable groups.

Safety during this period was focused on a specific conceptualisation: being safe from getting infected. In hospitals, the somatic care for terminally ill COVID-19 patients had priority over regular care. Yet, safety challenges appeared in other forms as well. Dying from untreated cancer is the same outcome as dying from COVID-19. Domestic violence, or the threat of it, and the feeling of being 'locked up' point to other safety challenges. In addition, existential, social or psychological problems, like losing grip on reality and life, losing meaningful connection to other people, and fear, led to experiences of unsafety. The meaning of safety as such also has to be balanced against other values that deal with the quality and meaning of life. As

Figure 2: Long-term care facility survey data on the choice of what is more important, either quality of life by allowing visits and accepting a higher risk of infection, or safety and reducing the risk of infection



Source: Van der Roest et al (2020a).

shown in Figure 2, the long-term care facility survey data show how informal carers, residents and professionals balanced quality of life, safety and risks differently (Van der Roest et al, 2020a). What is striking is that about one third of the residents, family members and care professionals indicated that they did not know how to weigh up these needs in May 2020.

The period of relaxation

The second phase of the study period was characterised by a gradual relaxation of lockdown measures throughout the country, including allowing selected visitors into long-term care facilities. Social traffic restarted and day programming and home-based care were made possible again. Many participants noted that they enjoyed the renewed feeling of freedom and possibility of social contact. People gained self-confidence and, to some extent, celebrated their resilience. However, this was not the case for everyone. The relaxation of general lockdown measures was followed by a more diverse range of measures across sectors and organisations. This period, therefore, was one in which confusion and inequalities between our participants' situations surfaced.

One contributing factor to participants' sense of confusion or inequality was due to institutional differences in the implementation of government policies. During the lockdown, different organisations already had differing local policies in this respect, with some more strict and others less so. In some long-term care facilities, the national visitor ban had been rigorously followed, while other facilities tried to find more nuanced solutions. Care organisations for people with learning disabilities sometimes allowed home visits but at other times did not. However, when the 'strict', general lockdown rules were gradually relaxed, they were replaced with detailed, adjusted rules specific to different sectors, and this variable situation became challenging for many participants. Some institutions would adhere to these rules more strictly than government policy intended. The clear fear of 'the virus' during the lockdown period was transformed into a scepticism and distrust about the extent to which the danger had subsided, or not. A homeless service professional told us:

> 'Social services are in full force again from our location. But we are confronted with other organisations, like debt counselling, where there is still a lot of delay. A lot of organisations are very careful and managing their activities from a risk-prevention approach. No one wants to get blamed for bringing their personnel into danger through careless practices.'

Participants noted that some institutions built barriers to social contact, for example, by demanding that staff had to request permission before a home visit could be conducted. Some professional caregivers were hesitant to relax measures if they, or one of their family members, were part of a high-risk group.

People from all groups reported confusion. They experienced differences in rules but could not easily make sense of the reasoning behind these differences. Why can I only see my loved ones for 15 minutes behind glass? Why can a hairdresser come within 1.5 metres, yet my family member cannot? Older people above 70 did not immediately come out of their homes because they questioned the relaxation of lockdown measures. Are we now suddenly done with the virus that was threatening

us earlier everywhere? Many participants noted that they observed how fellow citizens paid less attention and sometimes did not keep sufficient physical distance anymore. This made the outside world more threatening, instead of less. The feeling of solidarity evaporated for people who were still vulnerable due to their health or social circumstances. One participant said: "Most of it is at a standstill. I cannot do anything anymore. And this just goes on. That's the feeling I am having." The experience of a shared fate in the lockdown disappeared. For many, life started again somewhat, but for others – including many of the people we studied – much less so. In addition, new fears developed – of a second wave or of a still-fatal infection from the first wave.

Conclusions

This research was focused on already socially vulnerable people and the impact that the policy of physical distancing had. What mattered for these populations was often not so much medical care, but giving meaning to life and the maintenance and broadening of their social network. Issues such as being part of society, having housing assistance, work and day programming, finding meaning, a sense of connection, and other forms of *social* safety appeared crucial to daily life. It was exactly in these domains that care disappeared during the pandemic, or where home isolation and other policy measures worsened existing problems. Particularly in long-term care facilities, the results were dramatic, but the generic fear that the virus could be and could strike anywhere was also widespread among people with psychiatric problems, with learning disabilities or in other challenging social situations. Participants did not dare to leave their home, being afraid of other people. Hospitalisation – the feeling of having lost one's sense of individuality in a total institutionalisation with external rules (Goffman, 1961) – could now strike even in one's own home.

Although the need for social contact varied among participants, the total loss of any social contact (face-to-face and touch) for a longer time period was not sustainable without falling below a minimal quality of life or existential motivation for life. What we observed among our participants was a lower threshold limit for *essential social traffic*, or social interactions that are needed for minimal psychological and physical health (Armitage and Nellums, 2020a). Guaranteeing such essential social traffic is urgent for groups of people who experience and have to deal with fear, violence, loneliness and lack of perspective. Social interactions are also essential for care professionals to identify and signal problems and provide basic care through relationship building, problem assessment, intake and accompaniment. Particularly when a situation of staying at home continues, social connection is essential to prevent serious health damage and guarantee a minimal quality of life. The policy principle for these populations should be 'Yes, unless …': social contact is allowed unless there are crucial, local objections. National policies seem necessary to enable such essential face-to-face contact for assistance and day programmes during crises, and for creative solutions that make such contacts safe.

We also observed the importance of *informal carers*. Seen by the Dutch government as a necessary complement to professional care, during the crisis, carers were advised – or, in consultation with long-term care facilities, forced – not to visit their family members. This clashes with the government policy of viewing informal carers as partners. Informal carers have responsibilities that are of equal value to those of

professionals. They play a role in care that is focused on the meaning and quality of life, as well as in physical care, domestic care, signalling problems and managing high-technology care at home. Professionals themselves are often overburdened and do not pick up the activities of carers. The breaking of relations between carers and their loved ones, particularly in the difficult period at the end of their lives, seems to be a measure that is too strict or harmful, and that should be taken in consultation with those involved. Representatives of vulnerable groups and their informal carers should have a voice in decisions and policymaking. At a minimum, they should be provided with the same aids as professionals.

This means that people should be involved in the determination of what is an *acceptable risk*. During the period of observation, the emphasis was focused too much on fear of contagion. For clients and family members, other values may be of higher priority. These values, in turn, have to be weighed alongside the priorities of professional healthcare providers. For example, anxious professionals, such as those who are vulnerable family members themselves, could work at a location where risk of infection is reduced. For clients, and certainly for those who reside in institutions, the experience was dominated by the feeling that others were deciding for them. Repeatedly, we received complaints about institutional arbitrariness and a rigid, non-accessible management, with rules that were too strict, sometimes being stricter than government policy.

Based on these results, we recommend that for this group, policies need to reframe safety away from its narrow epidemiological interpretation of infection reduction and towards the broader Greek *phronesis*, or practical wisdom. Practical wisdom is about the art of reading a situation and making the right decision in the moment. From this perspective, safety is not the banning of all risk, but accepting certain risk in order to allow other values to come to fruition in a balancing act. Such an empirical ethics takes as its starting point how values are enacted in practice (Pols, 2016) and is sensitive to context (Musschenga, 2005). It is about giving socially vulnerable people and professionals room to strive for forms of good care, evaluate their own success and adapt accordingly.

On a practical level, this could include broadening social networks of socially vulnerable populations during a pandemic, for example, through social, COVID-19-free bubbles or the involvement of the cultural sector, itself at a standstill during the lockdown (Pols, 2020). It is also clear that possibilities to facilitate essential social traffic should be given form in different ways in different locations. This demands local and sometimes even individual solutions negotiated within nationally determined boundaries and rules. This asks for governments to trust the practical wisdom of professionals, informal carers and clients to deal with the rules during the difficult negotiations between infectious disease control and quality-of-life decisions. At the same time, the government should make clear the boundaries and rules within which these discussions should take place. Particularly for people who have trouble understanding what is going on in the first place, clear public health communication about the why and the how of the rules, including attention to practical applications of rules and offering alternatives, can help to remove much unnecessary anxiety (Armitage and Nellums, 2020b). Finally, it is important to continue experimenting with the new forms of digital care that have been implemented everywhere at a very rapid pace. Systematic development of applications needs to be done in collaboration with end users to tailor the applications to their needs. At the same time, 'old media',

like radio, television and telephone, should not be forgotten because many socially vulnerable people use them for meaningful daily information and activities.

It is important to note that at the time of the study design, very little information was available on the welfare of various 'vulnerable' groups in the Netherlands. As the study was part of the initial response, there was no time to conduct a proper vulnerability assessment. For this reason, the selection and labelling of these groups was done based on anecdotal information from the field, per the request of the funder – in particular, a focus on older people – and based on pragmatic heuristics. While this introduces limitations to the groups included, we still believe that the results generally illustrate dynamics that also affected similar socially vulnerable groups who were not included in this study and who have supportive care relationships.

Note

[1] Our survey among independently living older people through the Langlopende Internet Studies voor de Sociale wetenschappen (LISS) panel recruited people by offering them training in computer use to respond to the surveys.

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Conflict of interest

The authors declare that there is no conflict of interest.

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