Quarantine in a House of Cards. The Impact of The COVID-19 Pandemic on The Quality of Life of Relatives of People With Major Care Needs.

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Abstract

Purpose COVID-19 (or the fear thereof) has an impact on people's quality of life (QoL). It is likely to impose an additional burden on the relatives of people with major care needs (MCN). The aim of this study is to provide insight into the QoL of the relatives of people with MCN, in order to assist policymakers and care professionals in restoring and/or retaining an acceptable level of QoL.

Method The QoL of 2,845 persons (including 697 relatives of people with MCN) was measured using the WHO-QoL BREF before and during the COVID-19 outbreak. The investigation focused specifically on the extent to which living circumstances and burden of care were related to changes in QoL.

Results The COVID-19 outbreak has affected the overall QoL of people both with and without relatives with MCN, and these effects are unrelated to the burden of care for informal caregivers. The QoL of the environment has declined less for people who are living with relatives who have MCN.

Conclusion One remarkable finding is a relative increase in sleep and social support for people who have relatives with MCN, although they did report a more pronounced decline in the extent to which they perceived their lives as meaningful. Specific attention should be paid to people in uncommon and vulnerable situations, who are less likely ask for support (e.g. marginally literate people and people coping with profound care needs), despite their low prevalence in the general population.

Plain English Summary

1. Why is this study needed?

By providing insight into the impact of COVID-19 on the QoL of relatives of people with major care needs (MCN), vulnerability of these families during and after COVID-19 could be prevented or restored.

2. What is the key problem/issue/question this manuscript addresses?

The outbreak of COVID-19 and the measures taken in response to it have been reported to affect quality of life (QoL). Before COVID-19 families around people with major care needs (MCN) tend to be under more pressure than that of families not confronted with MCN.

3. What is the main point of your study?

We compare the QoL of people who do and do not have relatives with MCN, both before and during the COVID-19 pandemic and relate the change in QoL to the perceived burden of care and living circumstances.

4. What are your main results and what do they mean?

The COVID-19 outbreak has affected the overall QoL of people both with and without relatives with MCN. These effects are unrelated to the burden of care, but relate to living circumstances. The QoL of the

environment has declined less for people who are living with relatives who have MCN.

Introduction

The outbreak of COVID-19 (Corona Virus Disease 2019) has affected people around the globe. The disease is transmitted primarily between people through respiratory droplets and contact routes [1]. To prevent the spread of this virus, governments have adopted several social distancing measures, including stay-at-home recommendations and quarantining [2]. The virus (or the fear thereof) and the measures taken in response to it have been reported to affect quality of life (QoL) [3]. The World Health Organization [4] defines quality of life as the way in which individuals perceive their position in life, within the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. This broad-ranging concept is affected by the individual's physical health, psychological state, personal beliefs, social relationships and relationship to salient features of the environment [4].

In addition to posing an obvious threat to the persons' physical health of individuals, COVID-19 affects their environments by limiting their freedom of movement, leading to a life that is largely confined to the family home. Studies have also demonstrated that COVID-19 and the measures associated with it can have a negative effect on psychological health and social relationships [5-7]. The most frequently experienced stressors related to COVID-19 include the inability to engage in leisure activities, loss of social contact and perceived or actual restrictions on leaving home [6].

Older adults and people with major care needs (MCN) – including intellectual and/or physical disabilities and health problems – are more prone to experience serious health issues due to COVID-19. Social-distancing measures therefore apply more strictly to this population [5,6]. Compared to people without COVID-19 risk factors, therefore, they might experience more severe forms of social isolation and for longer periods, possibly leading to increased feelings of anxiety [5] and loneliness [8]. This could also affect their relatives: caregivers of children with intellectual disabilities reported an extremely high level of mental health problems and anxiety during the first lockdown in April, as compared to parents of children without intellectual disabilities [9].

Despite the possibility that relatives and informal caregivers might be affected by the consequences of social distancing measures, most studies focus on people who are at serious risk due to the COVID-19 pandemic, including people with MCN. Informal care is generally defined as the unpaid care provided to persons depending on support in order to function in society by a person with whom they have a social relationship – spouse, parent, child, other relative, neighbour, friend or other non-familial contact [10]. It can include nursing, cooking or other household support, as well as engaging in social activities together and offering companionship. Almost one third of the Dutch population older than 16 years of age provide informal care [11]. Informal caregivers differ in the intensity of caregiving and the type of caregiving tasks.

Three groups of informal caregivers during the COVID-19 outbreak can be distinguished, each facing different difficulties [12]. The first group consists of informal caregivers who are living with their relatives. The difficulties faced by this group include the possibility of less or no assistance from the social network (whether formal or informal) that would normally be available to help, the cancellation of therapy and the closure of facilities such as schools or day-care centres [13], all of which place considerable pressure on the informal caregivers involved. The second group consists of relatives of people with MCN who are living independently, who might need more care due to the lack of other care. Alternatively, the caregiving tasks of these caregivers might disappear if the people for whom they are providing care have decided to limit social contact. The last group consists of relatives of people living in care facilities (e.g. care homes for older adults or people with intellectual disabilities). The difficulties faced by this group include the possibility that visits will be strictly limited or prohibited, and that services will be severely reduced. In this case, visits and physical contact between the people with MCN and their informal caregivers can be extremely limited for long periods of time, or possible only at a distance of 1.5 metres, and digital solutions may not always be an appropriate alternative [eg. 14]. Long-term separation and/or the lack of physical contact with relatives have been identified as amongst the most burdensome stressors experienced during the COVID-19 pandemic [6].

Following family-systems theory, the QoL of people with MCN and their relatives can influence one other [15,16]. Various studies have demonstrated that, before COVID-19, the QoL of family members related to people with MCN tended to be under more pressure than that of families not confronted with MCN [e.g. 17-20]. Alongside their own caregiving responsibilities, many of these families have skilfully built up delicate constructions that balance the needs of the individuals with MCN with those of other family members, based on a combination of informal support, care facilities and care providers [12]. During the COVID-19 outbreak, this construction may have come to resemble an unstable house of cards. Families with members who have MCN who are normally able to retain their QoL might succumb to the difficulties posed by these extraordinary times.

The aim of this study is to assess the impact of COVID-19 and the associated measures on persons with relatives with MCN, in order to develop insight into the QoL of these potential 'houses of cards' and to identify whether/where these delicate constructions require reinforcement. This information could help to restore QoL during the COVID-19 outbreak, in addition to providing knowledge about the vulnerability of relatives of people with MCN in future precarious situations (whether individual or collective). To this end, we compare the QoL of people who do and do not have relatives with MCN, both before and during the COVID-19 pandemic. The following research questions are central to this study:

- How have various aspects of the COVID-19 pandemic affected the QoL of people who do and do not have relatives with MCN?
- What is the impact of (i) the burden of care and (ii) the living circumstances on the QoL of people who have relatives with MCN before and during the COVID-19 pandemic?

Methods

3.1. Design

The data in this study were collected by means of two questionnaires submitted to an online probability-based panel (3.2). The first questionnaire (T1), which measured QoL, burden of care and caregiving tasks, was sent to the panel on 1 November 2019. The second questionnaire (T2) measured QoL and was sent to the panel on 22 April 2020, five weeks after the introduction of social distancing measures in the Netherlands. The 'intelligent lockdown' in the Netherlands involved the closure of cultural and sports organizations, as well as schools and restaurants, although shops stayed open. Individuals were allowed to receive visitors in their homes and to go outside for exercise or walks [2].

3.2. Participants

Both questionnaires were sent to Panel Fryslân, an online probability-based panel hosted by the Frisian Institute of Social Research [21]. The reference population of Panel Fryslân consists of all inhabitants of the province aged 18 years or older. The sample frame for Panel Fryslân is the Personal Records Database (Basisregistratie Persoonsgegevens, BRP) of all Frisian municipalities, from which a simple random sample was drawn. The sampled individuals were recruited in (i) October/November 2016 and (ii) February/March 2019. Panel Fryslân currently includes approximately 6,000 inhabitants of Fryslân.

The first questionnaire (T1) was completed by 2,845 respondents (48% of the panel) and the second questionnaire (T2) was completed by 3,181 respondents (55% of the panel). In all, 2,397 respondents completed both questionnaires. During T1, the respondents were asked whether they had any relatives with MCN. A relative was defined as 'someone who is close to you and with whom you have a personal connection (for example a partner, a parent/parent-in-law, a child, a sibling, a good friend or a neighbour with whom you have close contact)'. People with MCN were defined as 'people who are in need of support from professionals and/or their own networks and who are unable to function independently in daily life without such support'. The characteristics of the respondents are displayed in Table 1.

Most of the respondents were between the ages of 46 and 66 years (40%) and had completed higher education or training (51.6%), with 40.9% holding jobs or being self-employed and 47.6% being retired. The majority of the respondents were living with partners (81.4%), and 10% had children living at home. A small share of the respondents (3.7%) personally had MCN. Almost 30% of the respondents had at least one relative with MCN (29.1%). There were two significant differences between individuals who did and did not have relatives with MCN: in age and employment status. People who had relatives with MCN were less likely to be retired and more likely to be between 46 and 66 years of age.

3.3. Procedure

Before the first questionnaire was sent to the members of the panel, it was presented to and tested by two people who had experienced living with a relative with MCN. During a meeting, they had the opportunity to provide feedback on the questionnaire and, in consultation with the researcher, to adjust questions (or their formulation). The questionnaire was subsequently tested by eight people, including the three authors. After the testing phase, the panel members received an invitation link to the questionnaire, as well as up to two reminders. Panel members had three weeks to complete the questionnaire. At the end of both questionnaires, respondents had the opportunity to evaluate and comment on the questionnaire. The panel management team kept a close eye on these comments, responding to them as needed. The Ethics Committee of pedagogical and educational sciences of the University of Groningen evaluated and approved the study protocol and informed consent procedure (Ped 1920-S-002).

3.4. Data and Instruments

3.4.1. Quality of Life

The WHOQOL-BREF [4] was developed as part of the WHOQOL project, which was initiated in 1991. This questionnaire is a cross-culturally comparable QoL assessment instrument. The WHOQOL-BREF instrument comprises 26 items in four domains: physical health, psychological health, social relationships and environment. The WHOQOL-BREF is a shorter version of the original instrument that may be more convenient for use in large research studies or clinical practice.

In this study, we used 18 items of the WHOQOL-BREF. At T2, eight questions were omitted in order to enable respondents to complete the questionnaires without spending too much time on them. These questions concerned subjects that we did not expect to have changed during the relatively short period of the lockdown (e.g. 'How happy are you with your bodily appearance?' and 'To what extent do you feel that physical pain prevents you from doing what you need to do?'). The four domains of the WHOQOL were nevertheless preserved. The questions are presented in Table 2.

As a measure of the internal consistency, Cronbach's alpha scores ranged from .31 to .81. The lowest value (.31) was found for the social relationships scale, which was therefore excluded from further analysis. The alpha scores for the remaining three scales ranged from .73 to .81, which can be considered acceptable to good. The correlation coefficients (Pearson) between the three scales ranged from .55 to .68 (all significant at $p < .01$). The Cronbach's alpha score for all 18 QoL items was .87.

3.4.2. Burden of care

An existing Dutch questionnaire [18,22] was used to determine the burden of care for relatives. This questionnaire consists of 15 items (see Table 3).

The number of items with positive responses (i.e. 'yes' or 'agree/strongly agree') provide an indication of the burden of care [18]. In addition to the perceived burden of care, respondents were asked to indicate the caregiving tasks that they perform. Analysis

The respondents were divided into two groups, based on whether they did or did not have relatives with MCN. The impact of the COVID-19 pandemic on the QoL of the two groups was assessed for total QoL, as well as for the three scales and the 18 items, using paired t-tests. An additional MANCOVA was conducted for the second research question (regarding the characteristics of the relatives with MCN), this time including only the respondents who had relatives with MCN. In the analyses, the dependent variable was the difference in scores for the three domains of QoL (physical health, mental health, environment). The independent variable was the living situation of the respondent and the person with MCN (both parties living together, each party living in a separate home or the person with MCN living in a care facility). The burden of care, caregiving tasks and age of the relative were added as control variables. When a significant relationship was found, a post-hoc Bonferroni analysis was performed to provide more insight into the precise relationship between living arrangements and the scores on the specific domain.

Results

Respondents who had relatives with MCN exhibited a significant decline from T1 to T2 in terms of total QoL, psychological health and environment (but not in physical health), while those who did not have relatives with MCN exhibited a decline in all domains and total QoL (see Table 1 and Figure 1). There were no significant differences in this decline between respondents who did and did not have relatives with MCN.

Several significant item-level differences were observed in the change from T1 and T2 between respondents who did and did not have relatives with MCN: sleep, the extent to which they perceived their lives as meaningful and support from family and friends. Respondents who had relatives with MCN reported significantly more improvement in sleep compared to those without a relative with MCN. They also reported receiving additional support from family/friends, while those who did not have relatives with MCN reported a decrease (albeit minimal). Respondents with a relative with MCN nevertheless exhibited a significantly greater decline in the extent to which they perceived their lives as meaningful, as compared to those without a relative with MCN.

Based on the Wilks' statistic, living arrangements were significantly related to the three domains of burden of care ($\eta^2 = .980$, $F(6, 1372) = 2.334$, $p > .05$). A review of the relationship between the three domains of QoL and the living arrangement of the person with MCN and the relative revealed no significant relationship with physical ($F(2, 688) = 1.56$, $p < .05$) or psychological ($F(2, 688) = 2.70$, $p < .05$) health. There was nevertheless a small but significant relationship between environment ($F(2, 688) = 6.36$, $p < .01$),

$R^2 = .023$) and living arrangement, in which respondents who were living with someone with MCN reported less decline in their QoL compared to those whose relatives with MCN were living independently ($p < .01$) or in a care facility ($p < .05$). Burden of care had no impact on the decline in any of the three QoL domains for respondents who had relatives with MCN. Closer examination of the items measuring the QoL of the environment revealed significant differences between the groups for three items (see Figure 2).

Respondents whose relatives with MCN were living with them reported less decline in the QoL of the environment compared to those whose relatives with MCN were living independently or in a care facility.

Significant item-level differences in living arrangements were identified for three items in this domain: financial resources to meet needs, the opportunity to participate in leisure activities and feeling safe in daily life. Respondents whose relatives with MCN were living with them reported a relatively strong increase in financial resources ($F(2, 680) = 7.51, p < .01$) and a relatively small decline in the possibility of engaging in leisure activities ($F(2, 687) = 6.04, p < .01$) as compared to those whose relatives with MCN had other living arrangements (i.e. independent or in a care facility). While those whose relatives with MCN were living independently or in a care facility reported an increase in feelings of safety, those whose relatives with MCN were living with them reported a minor decrease ($F(2, 691) = 5.32, p < .01$).

Conclusions And Discussion

5.1. Conclusion

The COVID-19 outbreak affected the overall QoL of respondents who did and did not have relatives with MCN, and these effects were unrelated to the burden of care for informal caregivers. The amount of sleep and the availability of support from friends even appears to have increased for people who had relatives with MCN. At the same time, however, people who had relatives with MCN exhibited a relatively large decrease in the extent to which they perceived their lives as meaningful. The QoL of the environment decreased less for people who had relatives with MCN, an explanation can be found in the living arrangements of people with MCN and their relatives. On average, respondents who were living with someone with MCN reported a relatively large increase in financial resources and a relatively small decline in the possibility of engaging in leisure activities.

5.2. Discussion

The COVID-19 pandemic has had an impact on people who have relatives with MCN, as well as on those who do not. Our results nevertheless do not provide any evidence to support the suggestion that the QoL of people who have relatives with MCN has been more reduced than that of other people. The 'houses of cards' that are built around people with MCN and their relatives appear to be surprisingly well constructed. The results did reveal several differences between these two groups, however, and these differences deserve attention.

One striking finding is the relative increase in sleep and social support. Sleep is related to both psychological and physical health, and people who sleep better are generally able to cope more effectively with stressful situations [24]. As is known from other studies, social support (whether perceived or actual) is important and positively related to a variety of characteristics of informal caregivers, including resilience [25], caregiving burden [26] and life satisfaction [27]. This finding might suggest that people who have relatives with MCN are coping with the new circumstances by trying to sleep well and by asking for/receiving social support. People who experience a decline in QoL might therefore do well to pay additional attention to sleeping well and building or maintaining a social network.

Despite such positive changes, our results also identified changes of a more negative sense for people with MCN or their relatives. These respondents reported a more pronounced decline in the extent to which they perceived their lives as meaningful. Earlier studies have indicated that, in addition to being a burden, caring for someone can provide a sense of reward. For example, 70% of all caregivers in a large survey reported that helping had made them 'feel good about themselves' and 'appreciate life more' [28]. As we have learned, however, the COVID-19 pandemic has caused adjustments in many informal care situations [12,21]. Some of these changes may involve at least some extent of deterioration in the caregiving role, due to restriction or prohibition of visits to residential care facilities. In other situations (e.g. the loss of a loved one), it is known that the loss of the caregiving role can affect the caregiver by causing changes to their daily activities and making it difficult to maintain or replace their sources of support, which often consist of friends in similar situations [29]. In this study, only the burden of care before the pandemic was queried and included. Future studies should specifically examine what changes in care situations mean for the emotional life of the stakeholders involved.

People living with relatives who have MCN seem to be a distinct group. Before the COVID-19 outbreak, they were less positive about their financial situations as compared to the rest of the sample. The relatively large increase in financial resources that they experienced might have been due to a decrease in expensive professional care [12]. Their relatively small decline in the possibility of engaging in leisure activities could possibly be explained by a general lack of possibilities to engage in leisure activities even before the pandemic [e.g. 30]. Previous research has demonstrated that relaxation and leisure time are of great importance as means of coping with the stresses of everyday life [31], and not only during the COVID-19 outbreak. As noted by a parent of a boy with multiple disabilities during the first month of the lockdown: 'There is a parallel to be drawn. The daily life of a person with a MCN is comparable to what the whole of the Netherlands is experiencing now. It isolates, it determines everything and eliminates most of the things that make life fun' [32].

Our statistical model included living arrangement, burden of care and the age of the caregiver/relative. The QoL of people with relatives who have MCN might also be affected by other variables, however, including personal characteristics (e.g. employment status or educational level). It might also be related to characteristics of the person with MCN (e.g. the type and severity of the need for care). Finally, the type and severity of care needs might interact with living arrangements. Because of the high prevalence of health problems [33], parents might see their children as vulnerable, leading them to be afraid that they

will be infected with COVID-19. This might make them more prone to impose a strict quarantine on themselves, thus causing them to miss out on necessary support from others. Given the way in which the data were collected (i.e. as a sample of the general population), subgroups with less common and more severe health problems or disabilities (e.g. parents of children with profound intellectual and multiple disabilities) might not be represented in the sample. Additional research is needed in order to assess the needs of specific groups.

Because the survey was conducted as a digital questionnaire, its reach was large and the barriers to participation were low. At the same time, however, some groups who are less capable in reading and using written language (e.g. marginally literate people and those with migration backgrounds) are under-represented in study. This is a matter of concern, in light of the assumption that these groups are more likely to experience major consequences from the COVID-19 outbreak, for example, due to the further weakening of their position in the labour market [34]. Moreover, these groups are largely under-represented in studies on relatives of people with MCN [35].

The etymology of the word ‘pandemic’ can be traced to a Greek word used to describe things that affect the entire population. The word is derived from *pan* (‘all’) and *demos* (‘people’) [36]. It should be emphasized that any true description of the effects of this pandemic on *all people* would require additional attention to people who are dealing with profound care needs, despite their low prevalence in the general population. Attention should also be devoted to people whose voices are less likely to be heard and who therefore tend to be overlooked. The outbreak of COVID-19 has generated a tendency to refer to these people as vulnerable. Using terms such as vulnerability to talk about people can be both marginalizing and stigmatizing by emphasizing their ‘neediness’ [5]. As demonstrated by the results of this study, despite the burden of care experienced by the relatives of people with MCN, the ways in which their QoL has been affected are similar to those experienced by the general population. In other words, rather than being needy or vulnerable, these people are resilient, and we could learn from them.

Declarations

Funding

This research was carried out by researchers employed by the University of Groningen and the FSP and funded from current resources.

Conflicts of interest/Competing interests

Not applicable

Availability of data and material

Given the nature of the data collection (panel data from an ongoing panel) and the type of data (data about perceived quality of life, including some health related information), we are cautious about publishing anonymised data files online. The anonymised databases could, in combination with earlier or

future panel data, be traceable to natural persons. The raw data is stored on a safe disc and in the possession of FSP. The data can be looked into in consultation with the authors.

Code availability

Not applicable

Authors' contributions

All authors contributed to the execution of the study and the content of the manuscript, the first author contributed the most, followed by the second and third author.

Ethics approval

The Ethics Committee of pedagogical and educational sciences of the University of Groningen evaluated and approved the study protocol and informed consent procedure (Ped 1920-S-002).

Consent to participate

Before participating in the panel and responding to the questionnaires, all respondents signed an informed consent form indicating their right to unsubscribe and the way in which the data was processed.

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Tables

Table 1 Respondents characteristics

			Relative with MCN	
			Yes	No
Variable	Categories	N (%)	N (%)	N (%)
		<i>Total N 2,397</i>	<i>Total N 697</i>	<i>Total N 1,700</i>
Gender	Male	1,476 (61.6)	414 (59.4)	1,062 (62.5)
	Female (Ref.)	921 (38.4)	283 (40.6)	638 (37.5)
Age group	18 to 29 years	31 (1.3)	7 (1.0)	24 (1.4)
	30 to 45 years	155 (6.5)*	27 (3.9)	128 (7.5)
	46 to 66 years	958 (40)	324 (46.5)	634 (37.3)
	67 to 75 years	817 (34.1)	215 (30.8)	602 (35.4)
	76 years and older (Ref.)	436 (18.2)	124 (17.8)	312 (18.4)
Highest educational level	Lower education	1,236 (51.6)	368 (25.8)	868 (51.1)
	Vocational education	700 (29.2)	201 (28.8)	499 (29.4)
	Higher education (Ref.)	461 (19.2)	128 (18.4)	333 (19.6)
Living circumstances	With partner and children	218 (9.1)	60 (8.6)	158 (9.3)
	Without partner, with children	21 (< 1)	5 (< 1)	16 (< 1)
	With partner	1,733 (72.3)	532 (76.3)	1,201 (70.6)
	Alone (Ref.)	420 (17.5)	100 (14.3)	320 (18.8)
	Unknown	5 (< 1)	-	5 (< 1)

Employment status	Employed	981 (40.9)	306 (43.9)	675 (39.7)
	Unemployed	274 (11.4)**	90 (12.9)	184 (10.8)
	Retired (Ref.)	1,142 (47.6)	301 (43.2)	841 (49.5)
Person with MCN's relation to the relative	Child		63 (9)	
	Partner		116 (16.6)	
	Parent		205 (29.4)	
	Parent in law		75 (10.8)	
	Brother/sister		78 (11.2)	
	Other		138 (19.8)	
	Unknown		22 (3.2)	
Caregiving tasks	Yes (one or more)		623 (89.4)	
	No (none)		74 (10.6)	
Type(s) of major care need	Age-related physical disability		330 (47.3)	
	Age-related mental disability		214 (30.7)	
	Addiction problems		18 (2.6)	
	Intellectual disability		51 (7.3)	
	Physical disability		203 (29.1)	
	Sensory impairment		68 (9.8)	

Psychological frailty	107 (15.4)
Acquired brain injury	38 (5.5)
Illness or other health problems	178 (25.5)
Behavioural problems	46 (6.6)
Communication problems	43 (6.2)
Unknown	17 (2.4)

Significant differences in respondent characteristics between persons with and without a relative with a major care need are indicated with one or two asterisks (*sig.(p < .05, ** sig. p < .01)

Table 2 *Items of the WHOQOL-BREF used in this study and differences in QoL between T1 (before COVID-19) and T2 (during COVID-19), and between the changes experienced by people with and without a relative.*

		Relative with MCN				Difference between change t (df)
		Yes		No		
Item	Construct and question	T1 ' (SD)	T2 , (SD)	T1 ' (SD)	T2 , (SD)	
	<u>Total QoL</u>	3.98 (.50)	3.90 (.47)	4.03 (.46)	3.92 (.47)	
	-					
	<u>Environment</u>	4.36 (.54)	4.25 (.52)	4.40 (.52)	4.28 (.50)	
	To what extent ...					
1	... do you have enough financial resources to meet your needs?	4.42 (.86)	4.63 (.75)	4.45 (.83)	4.64 (.73)	
2	... you have access to the information you need for your daily life?	4.63 (.61)	4.67 (.57)	4.64 (.61)	4.72 (.53)	
3	... you have the opportunity to do leisure activities?	4.24 (.93)	3.93 (1.09)	4.36 (.83)	4.02 (1.07)	
4	... do you feel safe in your daily life?	4.50 (.66)	4.50 (.69)	4.52 (.65)	4.53 (.65)	
	How dissatisfied or satisfied were you in the past two weeks with...					
5	... your living conditions?	4.2 (.67)	4.13 (.74)	4.53 (.63)	4.17 (.68)	
6	... your access to (medical) care?	4.21 (.70)	3.88 (.84)	4.27 (.64)	3.96 (.80)	
7	... the means of transport available to you?	4.42 (.69)	4.34 (.69)	4.45 (.66)	4.36 (.65)	
	<u>Physical health</u>	3.87 (.74)	3.84 (.74)	3.95 (.72)	3.90 (.74)	
	How dissatisfied or satisfied are you with					
8	... your sleep?	3.60 (1.0)	3.76 (.95)	3.74 (.95)	3.82 (.91)	x
9	... your ability to perform your daily living activities?	3.95 (.87)	3.86 (.86)	4.03 (.81)	3.91 (.82)	
10	... your capacity for work?	3.86	3.76	3.92	3.85	

		(.95)	(.94)	(.88)	(.88)	
11	Do you have enough energy for everyday life?	4.17 (.82)	4.32 (.82)	4.27 (.79)	4.41 (.78)	
	<u>Psychological health</u>	3.92 (.74)	3.82 (.74)	3.94 (.62)	3.87 (.61)	
	To what extent are you able to...					
12	... enjoy life?	3.95 (.81)	3.69 (.85)	3.96 (.77)	3.76 (.78)	
13	... feel that your life is meaningful?	3.80 (.86)	3.56 (.92)	3.75 (.85)	3.60 (.85)	x
14	... are able to concentrate?	4.31 (.75)	4.34 (.77)	4.39 (.72)	4.41 (.71)	
15	How dissatisfied or satisfied have you been with yourself in the past two weeks?	3.94 (.78)	3.88 (.78)	3.98 (.74)	3.95 (.71)	
16	How often do you experience negative feelings, such as gloom, despair, fear, depression?	2.35 (.78)	2.29 (.82)	2.28 (.77)	2.16 (.76)	
	<u>Social relationships</u>					
	How dissatisfied or satisfied were you in the past two weeks with...					
17	... your intimate life?	3.70 (.99)	3.63 (.96)	3.79 (.93)	3.76 (.90)	
18	... the support you get from your family / friends?	3.95 (.78)	4.05 (.86)	4.05 (.75)	4.05 (.82)	x

* sig. difference between T1 (Nov. 2019) and T2 (Apr. 2020).

x sig. difference between the change in QoL of persons with and without a relative with MCN.

Table 3 *Items measuring burden of care.*

Item	% yes / (strongly) agree (n 623)
The situation of the person I care is always on my mind. ¹	44.8
I never feel free from responsibilities. ¹	42.7
I always have to be ready for the person I care for. ¹	21.1
My involvement with the person I care for makes me feel tied down. ¹	27.1
Because of my care tasks I often run out of time.	11.4
My care tasks make it difficult for me to arrange my household.	8.0
I do my work or other activities less carefully than I am used to.	8.8
I don't get around to the things I need or want to do in my spare time.	12.8
In my spare time I am too tired to do anything.	9.8
Combining the responsibilities for the person I care for and for my work/family is not easy. ¹	16.9
Overall, I feel very pressured by the situation of the person I care for. ¹	15.9
Caring for my relative comes down to me too much. ¹	13.3
My independence is at risk. ¹	13.5
I got ill or stressed because I had too many obligations at the same time.	3.4
My involvement with the person I care for causes conflicts at home and/or at work. ¹	7.7

¹ These items have the following response categories: strongly disagree, disagree, agree nor disagree, agree, strongly agree; the remaining items have answer categories: yes, a little, no.

Figures

Figure 1

Change in QoL between T1 (before COVID-19) and T2 (during COVID-19).

Figure 2

Change in items measuring QoL (domain: environment) between T1 (before COVID-19) and T2 (during COVID-19), divided by living arrangements.