

# Effects of the COVID-19 pandemic on quality of life among relatives of individuals with intellectual disabilities: A longitudinal study

Ellen Zonneveld  | Femke van Schelven | Hennie Boeije

Department Perspective of patients and clients in healthcare, Netherlands Institute for Health Services Research (Nivel), Utrecht, the Netherlands

## Correspondence

Ellen Zonneveld, Department Perspective of patients and clients in healthcare, Netherlands Institute for Health Services Research (Nivel), P.O. BOX 1568, 3500 BN Utrecht.  
Email: [e.zonneveld@nivel.nl](mailto:e.zonneveld@nivel.nl)

## Funding information

ZonMw, Grant/Award Number: 10430022010008

## Abstract

**Background:** The COVID-19 pandemic poses risks to the quality of life (QoL) of relatives of individuals with intellectual disabilities. This paper investigates relatives' QoL and associated risk and buffering factors before and during the pandemic.

**Method:** Surveys were administered to three samples of relatives in the Netherlands in 2019 ( $N = 105$ ) and during the first waves of COVID-19 in June ( $N = 207$ ) and October 2020 ( $N = 332$ ). Associations between QoL and care burden, care competence, social support, and resilience, and changes over time were analysed using (logistic) regressions.

**Results:** No significant changes in overall QoL nor its domains were found. Care burden was negatively associated with QoL and increased during the pandemic. Care competence was lower than in 2019. Competence, social support, and resilience were positively associated with QoL.

**Conclusions:** Although relatives' QoL remained stable, the pandemic poses non-negligible risks to their wellbeing. It is, therefore, crucial to provide relatives with adequate support.

## KEYWORDS

COVID-19, family, intellectual disability, mental health, quality of life, relatives

## 1 | INTRODUCTION

Relatives, such as parents and siblings, often play a pivotal role in the lives of and care for people with intellectual disabilities (e.g., Beentjes & Cardol, 2012; Kamstra et al., 2015). Several positive effects of being a relative have been described in the literature, such as an increased sense of purpose in life, having more patience, and being more appreciative of the small things in life. The family member with intellectual disabilities is also mentioned as a source of joy (Beighton & Wills, 2019; Yoong & Koritsas, 2012).

Despite these positive effects, providing care for an individual with intellectual disabilities can be demanding. Considerable research has shown that relatives of individuals with intellectual disabilities can experience physical and psychological strain, depression, and high levels of stress and anxiety (Gallagher et al., 2008; Panicker & Ramesh, 2019; Patton et al., 2018; Raina et al., 2005). Several studies indicate that caring for individuals with intellectual disabilities has a negative impact on relatives' quality of life (Lin et al., 2009; Staunton et al., 2020; Yoong & Koritsas, 2012), which is defined by the World Health Organisation as "an individual's perception of their position in life in the context of the culture and value systems in which they live

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd.

and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1995, p. 1405). The Schalock model of quality of life describes it as a broad concept that is composed of eight core domains, such as emotional wellbeing, physical wellbeing, interpersonal relations, social inclusion, and material wellbeing (Schalock & Verdugo, 2002).

Various factors could influence relatives' wellbeing and quality of life. The stress process model of Pearlin et al. (1990) suggests that a caregiver's wellbeing is influenced by factors such as social support, constriction of social life, the family member's behaviour, overload, self-esteem, and competence. COVID-19 and the preventative measures can be regarded as additional stressors for relatives who care for an individual with intellectual disabilities, and has an impact on buffering and risk factors within their stress process (Budnick et al., 2021). At the beginning of the COVID-19 pandemic, governments worldwide have imposed several social distancing and isolation measures to prevent the spread of infection (Ritchie et al., 2020). These measures gradually changed, depending on the number of infections (Rijksoverheid, 2020; VGN, 2020).

The negative impact of the pandemic and associated preventative measures on the quality of life and mental health of people in the general population has received much attention in research (e.g., Epifanio et al., 2021; Passavanti et al., 2021; Pieh et al., 2020; Xiong et al., 2020). Relatives of individuals with intellectual disabilities might be disproportionately affected by the pandemic (Burnett et al., 2021; Grumi et al., 2020; Mak et al., 2021). In line with this, a study by Willner et al. (2020) during the lockdown showed that relatives of people with intellectual disabilities reported significantly higher levels of anxiety, depression and defeat than relatives of people without intellectual disabilities.

Due to the preventative measures, there were limited possibilities for social and professional support for relatives who care for an individual with intellectual disabilities. Relatives might have decided to follow more stringent restrictions on their social lives to protect the health of their relatives with intellectual disabilities, resulting in reduced experienced social support (Embregts et al., 2021; Mak et al., 2021). Furthermore, the preventative measures have led to an increased reliance on informal caregivers while the majority of services and support systems were withdrawn, making it more difficult to combine professional, domestic and caregiving tasks, and increasing experienced burden (Budnick et al., 2021; Gillespie-Smith et al., 2021; Rogers et al., 2021; Wos et al., 2021). This is especially demanding for people whose relatives with intellectual disabilities show more behavioural challenges as a result of the isolation and change in routine and structure (Bentenuto et al., 2021; Courtenay & Perera, 2020; Gillespie-Smith et al., 2021; Wolstencroft et al., 2021).

Several studies have investigated the experiences of relatives and the impact of the pandemic on mental health outcomes of relatives such as stress, depression, and anxiety (Asbury et al., 2021; Burnett et al., 2021; Linehan et al., 2022; Redquest et al., 2021; Rogers et al., 2021; Willner et al., 2020). Less is known about the impact on their quality of life. Studies on the quality of life among relatives of

individuals with developmental disabilities during the pandemic, suggest a decrease in quality of life compared with 2019 (Cankurtaran et al., 2021; Pecor et al., 2021). It is unknown from these studies what factors are related to these changes in quality of life. Furthermore, relatives in these studies rated their quality of life prior to or during the pandemic retrospectively, creating a risk for recall bias. A longitudinal study among parents of children with intellectual disabilities found no change in life satisfaction (Bailey et al., 2021). However, this study was conducted among mostly mothers of young children during only the first months of the pandemic. These findings are therefore limited to this group of relatives and the short-term impact of the COVID-19 pandemic.

While ample research has been carried out regarding quality of life and potential risk and buffering factors among relatives of individuals with intellectual disabilities (Lin et al., 2009; Staunton et al., 2020; Yoong & Koritsas, 2012), longitudinal knowledge is limited in the context of COVID-19. Investigating the impact on quality of life and its buffering and risk factors is vital to gain insight into how relatives could be supported in their caregiving role and how their mental health could be protected during the pandemic. The current study therefore aimed to monitor the overall and separate domains of quality of life experienced by relatives of individuals with intellectual disabilities at two time points during the pandemic, and compare this to 2019 (i.e., the year before the outbreak in the Netherlands). Based on the stress process model (Pearlin et al., 1990), four potential buffering and risk factors were monitored and investigated to provide insight into the process of potential changes in quality of life during the pandemic: care burden, care competence, social support, and resilience. These factors might have been influenced by the restrictive measures during the pandemic or could play a vital role in protecting quality of life. To this end, two research questions were investigated:

1. What is the quality of life among relatives of individuals with intellectual disabilities in June 2020 and October 2020 (i.e., the first two waves of the COVID-19 pandemic in the Netherlands), and how has this developed since 2019?
2. What is the relationship between quality of life and care burden, perceived competence, social support, and resilience during the pandemic, and how have perceived care burden and competence developed during the pandemic and in comparison to 2019?

## 2 | METHODS

### 2.1 | Design and procedure

Three surveys were conducted among relatives of individuals with intellectual disabilities in the Netherlands. In different compositions, four relatives were involved as experiential experts in developing the surveys. They received the draft versions of the surveys and provided feedback regarding the use of language, the lengths of the surveys

and the content. These ensured topics relevant in practice were covered and questions were correctly interpreted.

Surveys were sent out at two time points during the COVID-19 pandemic. The first survey was conducted at the end of the first wave of COVID-19 in the Netherlands, from June 4, 2020 to June 30, 2020 (Wave 1). The second survey was conducted during the second wave of COVID-19 in the Netherlands, from October 19, 2020 to November 9, 2020 (Wave 2). Reminders for these surveys were sent after 10 days. Data from a survey on quality of life that was conducted from August 22, 2019 to November 8, 2019 was used as a comparison (2019). Reminders to complete this survey were sent after 2 weeks.

### 2.1.1 | Preventative measures during the first two waves

In the Netherlands, the first wave of the pandemic occurred from March until June, 2020. From March 12th, a work-from-home order was implemented. From the second half of March, measures proceeded into a lockdown. Childcare centers and various recreational facilities (e.g., restaurants and sport accommodations) had to close, and supported daytime activities for people with intellectual disabilities were cancelled. Additionally, no more than three visitors were allowed at home, and visitors were not allowed in care organisations and other living arrangements for people with intellectual disabilities. With restrictions, most facilities reopened from May 11th on. By the end of June, most measures were relaxed to some extent. However, when the second wave commenced in September, new measures were imposed. In October 2020, a partial lockdown was declared. No more than three visitors were allowed at home, and further restrictions and guidelines regarding hygiene and physical distance were in place for visitors in living arrangements for people with intellectual disabilities. Restaurants were only open for takeaway, working from home was mandatory, and public events were forbidden. This lockdown was strengthened on November 3rd, with additional restrictions for visitors and a lockdown of recreational facilities (Rijksoverheid, 2020; VGN, 2020).

### 2.1.2 | Ethical considerations

Prior to enrolling for the study and upon receiving each survey, participants were informed about the aim and procedure of the study, presentation of results retrieved from the data, and privacy regulations. The e-mail address and telephone number of a fieldwork coordinator were provided, and participants were encouraged to contact in case they desired any further information. Participating was voluntary and all participants provided informed consent. The data were analysed anonymously, and processed in accordance with the General Data Protection Regulation. According to Dutch legislation, approval by a Medical Ethics Committee is not obligatory for carrying out this type of research.

## 2.2 | Participants

### 2.2.1 | Study population

Relatives were included if they were immediate family members (i.e., parents, siblings, partners or children), extended family members (i.e., aunts, uncles or cousins), close friends or otherwise closely related to an individual with intellectual disabilities. Professional caregivers were not included. The surveys were distributed among 443 relatives during Wave 1, and 542 during Wave 2. As a result of the recruitment procedure in 2019, it is unknown how many people were invited for this survey. The response rates at Wave 1 and Wave 2 were 60% and 65%, and data from 105 participants in 2019, 207 participants at Wave 1, and 332 participants at Wave 2 were included in the analyses. The demographics of participants and their family members with intellectual disabilities are shown in Table 1.

Not all participants who responded to the survey in 2019 or at Wave 1, took part in the subsequent survey(s). From the included participants, 37 responded to all surveys, 26 to the first two surveys, 16 to the survey in 2019 and at Wave 2, and 124 during both waves. Some participants took part in just one of the surveys, with 26 only participating in 2019, 20 only at Wave 1, and 155 participants who responded solely to the Wave 2-survey.

### 2.2.2 | Recruitment

Participants for the 2019 survey were recruited using two different sources. First, the survey was distributed among all members of the Dutch Panel Living Together, consisting of approximately 350 relatives of people with mild or moderate intellectual or developmental disorder. These relatives were previously recruited by care organisations for people with intellectual disabilities and general practitioners. These panel members receive a yearly survey on the social participation of their family member (Boeije & Voss, 2021). Solely panel members who stated online participation as their preference, rather than on paper, were invited. Second, participants were recruited through the networks of two Dutch Academic Collaborative Centers. These centers collaborate, among others, with health care organisations for people with intellectual disabilities. Associated health care organisations sent out (digital) invitation letters through staff, parent associations, and local client councils. Participants received the surveys online.

At Wave 1 and Wave 2, all members of the Panel Living Together were invited to participate. For panel members who preferred receiving questionnaires on paper, a paper version of the survey was developed. Additionally, all participants who were previously recruited through the Dutch Academic Collaborative Centers and who had indicated in 2019 they were interested in participating in future research on quality of life, were invited to fill out a subsequent online survey. Moreover, an invitation was distributed through a newsletter for a national program on people with disabilities and their relatives of the Dutch Ministry of Health, Welfare and Sport at Wave 2. Participants recruited in this manner received the survey online.

**TABLE 1** Demographic characteristics of participants and their family members with intellectual disabilities on each survey

	2019 (N = 105)		Wave 1 (N = 207)		Wave 2 (N = 332)	
	n	%	n	%	n	%
<b>Age participants</b>						
<65 years old	61	58	88	43	139	43
65+ years old	44	42	119	57	188	57
<b>Gender participants</b>						
Female	66	63	147	71	220	67
Male	39	37	60	29	109	33
<b>Relationship participant-family member</b>						
Mother (step-/foster-/adoptive-/–in law)	34	34	88	43	133	41
Father (step-/foster-/adoptive-/–in law)	12	12	41	20	70	21
Brother/sister (in law)	38	38	68	33	103	32
Daughter/son (step-/–in law)	0	0	2	1	5	2
Uncle/aunt/cousin	2	2	1	1	6	2
Partner	1	1	0	0	3	1
Close friend	0	0	4	2	2	1
Other	13	13	3	1	5	2
<b>Age family members</b>						
≤30 years old	22	21	23	11	68	21
31–49 years old	41	39	100	50	129	39
50–64 years old	23	22	46	23	78	24
65+ years old	19	18	33	16	53	16
<b>Gender family members</b>						
Female	36	35	96	46	147	45
Male	68	65	111	54	180	55
<b>Severity of intellectual disabilities</b>						
Mild	30	29	85	41	132	44
Moderate	25	24	90	43	105	35
Severe/profound	50	48	32	15	63	21
<b>Living situation family members</b>						
Care organisation	81	77	91	44	128	41
Small-scale residential facility	7	7	69	33	117	37
Family home	9	9	35	17	40	13
Living independently	8	8	12	6	31	10

Note: Missing values are not included in the table and in calculating the percentages.

## 2.3 | Measures

### 2.3.1 | Outcome variables

Quality of life was measured using the Dutch version of the WHOQOL-BREF, which contains 26 items (de Vries & van Heck, 1996; WHO, 1996). Participants rate all items based on their experiences during the past 2 weeks on five-point scales. On two items, participants rate their overall quality of life (“How would you rate your quality of life?”) and general health (“How satisfied are you with your health?”). The overall quality of life was established with the first item in all three surveys. The other 24 items are related to

four domains of quality of life: physical health (e.g., “How much do you need any medical treatment to function in your daily life?”), psychological health (e.g., “How often do you have negative feelings such as blue mood, despair, anxiety, depression?”), social relationships (e.g., “How satisfied are you with the support you get from your friends?”), and relationship with the environment (e.g., “How healthy is your physical environment?”). Items measuring the separate domains were included in 2019 and Wave 2. In accordance with the guidelines, the domain scores were transformed into a linear scale from 0 to 100 (WHO, 1996). Internal consistencies for all scales were satisfactory at both time points, with Cronbach's alpha values ranging from .83 to .88 for the physical health domain, .81 to .84 for the

psychological health domain, .65 to .76 for the social relationships domain, and .80 to .83 for the relationship with the environment domain.

### 2.3.2 | Buffering and risk factors

The Self-Rated Burden Scale (van Exel et al., 2004) was included in all three surveys to measure experienced care burden. This is a single-item scale in which participants rate their care burden on a scale of 0 (no burden) to 10 (too much burden). All three surveys also included a question to measure perceived competence to care (“Do you feel competent enough to support and provide guidance to your relative with a disability in this period?”), which was answered on a scale ranging from 1 (absolutely) to 5 (absolutely not).

Social support was measured in Wave 2 using a modified version of the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988). The MSPSS consists of 12 items covering three subscales (i.e., support from a special person, family, and friends) and was translated to Dutch. The items were rated on a scale ranging from one (very strongly disagree) to five (very strongly agree) instead of the original seven-point Likert scale. Reliability for the global score of MSPSS was satisfactory ( $\alpha = .92$ ). Internal consistencies of the three subscales were good, with Cronbach's alphas ranging from .91 to .94.

To measure resilience, a Dutch version of the Resilience Evaluation Scale (van der Meer et al., 2018) was included in Wave 2. This questionnaire measures resilience with nine self-rating items rated on five-point Likert scales. Scores on these items can be added to compute a total score and scores on two subscales: self-efficacy and self-confidence. Higher scores reflect more resilience. Internal consistencies for the total score ( $\alpha = .94$ ), self-efficacy subscale ( $\alpha = .93$ ), and self-confidence subscale ( $\alpha = .90$ ) were satisfactory.

### 2.3.3 | Demographics

In addition to the outcome, buffering and risk variables, several demographic questions were included about the relatives and the individuals with intellectual disabilities. These included the living situation of individuals with intellectual disabilities, the severity of their disability, the relationship between relatives and people with intellectual disabilities, age, and gender.

## 2.4 | Data analysis

Results were analysed using Stata 16.0 (StataCorp., 2019). Differences over time in quality of life, care burden, and care competence were analysed using logistic and linear regressions. To this end, the three measurement times were dummy coded. These analyses were adjusted for clustering. In cases of missing values on the unique identification number, participants were therefore excluded from the analyses. For the analyses, overall quality of life, as measured using the

single item of the WHOQOL-BREF, and care competence were dummy coded.

To increase the likelihood that retrieved differences were a result of changes over time rather than differences between samples, results were weighted for gender and age of the participants, and for the living situation of the people with intellectual disabilities and the severity of their disability. Since no information is available regarding the size and composition of the population of relatives of people with intellectual disabilities in the Netherlands, this weighting was based on the characteristics of relatives participating at Wave 2. Accordingly, results concerning the associations of buffering and risk variables with quality of life at Wave 2 were not weighted.

The relation between quality of life and buffering and risk variables were analysed using logistic regression analyses. On account of the number of observations, a separate analysis was conducted for each potential predictor. To reduce the risk for Type 1 errors due to multiple comparisons, all results were considered significant when  $p < .01$ .

Some participants did not complete all items in the surveys. In cases of missing data on weighting variables at 2019 and Wave 1, participants were excluded from the analyses. Most results are based on the number of responses on a specific question. The results of the WHOQOL-BREF form an exception. Missing data in the WHOQOL-BREF were imputed as prescribed by the procedure for this instrument (WHO, 1996). Analyses on quality of life were subsequently executed on complete cases on the relevant items.

## 3 | RESULTS

### 3.1 | Developments over time

Table 2 depicts the quality of life, buffering and risk variables on the three measurement points. Overall quality of life was rated as good or very good by over 75% of participants on the single item of the WHOQOL-BREF across all time points. Logistic regression analyses revealed no significant changes in quality of life during the pandemic. No significant change in overall quality of life between Wave 1 and 2019 ( $p = .438$ ), Wave 2 and 2019 ( $p = .336$ ), nor between the two waves ( $p = .789$ ) was found. Additionally, the physical, psychological, social relationships, and environment domains of quality of life did not significantly differ between Wave 2 and 2019 ( $p = .653$ ,  $p = .012$ ,  $p = .260$ , and  $p = .144$ , respectively).

At Wave 2, the mean rating of care burden was 5.2 (range 0–10). This was significantly higher than at Wave 1, when the mean was 4.2,  $b = 1.00$ ,  $SE = 0.25$ ,  $p < .001$ , 95% CI [0.51, 1.49]. No significant differences with 2019 were found for Wave 1 ( $p = .261$ ) and Wave 2 ( $p = .459$ ).

Approximately 84% of participants perceived themselves to be probably or certainly competent to care for their relatives at Wave 2. This is significantly lower than in 2019, when 96% felt competent,  $b = -1.48$ ,  $SE = 0.47$ ,  $p = .002$ , OR = 0.23, 95% CI of OR [0.09, 0.57]. A similar decrease was found from 2019 to Wave 1,  $b = -1.49$ ,  $SE = 0.50$ ,  $p = .003$ , OR = 0.23, 95% CI of OR

**TABLE 2** Estimated means and percentages of quality of life, care burden, care competence, social support, and resilience, as reported by participants at each time point

Quality of life/predictor	Domain	2019		Wave 1		Wave 2	
		M/% [95% CI]	n	M/% [95% CI]	n	M/% [95% CI]	n
Quality of life	Total (% good)	81.1% [71.3, 91.0]	105	76.5% [70.5, 82.5]	206	75.6% [70.8, 80.3]	315
	Physical	76.1 [70.5, 81.6]	105			74.8 [73.0, 76.6]	307
	Psychological	75.0 [71.2, 78.9]	105			70.1 [68.5, 71.6]	308
	Social relationships	70.0 [65.3, 74.7]	104			67.3 [65.3, 69.3]	298
	Environment	82.0 [78.3, 85.6]	104			79.2 [77.8, 80.6]	307
Care burden		4.8 [3.8, 5.9]	93	4.2 [3.8, 4.7]	182	5.2 [4.9, 5.6]	291
Care competence (% competent)		95.9% [92.3, 99.4]	93	83.9% [78.5, 89.3]	203	84.0% [80.0, 88.0]	319
Social support	Total					3.5 [3.4, 3.6]	289
	Significant others					3.7 [3.6, 3.8]	300
	Family					3.5 [3.4, 3.6]	301
	Friends					3.5 [3.4, 3.6]	298
Resilience	Total					3.9 [3.8, 3.9]	292
	Self-efficacy					3.9 [3.8, 3.9]	296
	Self-confidence					3.8 [3.8, 3.9]	301

**TABLE 3** Perceived care burden, care competence, social support, and resilience in relation to overall quality of life at wave 2

Predictor	Subscale	(Very) Good quality of life		Logistic regression of quality of life				
		M/% [95% CI]	n	b	SE	p	OR	[95% CI of OR]
Care burden		4.7 [4.4, 5.1]	212	-0.31	0.06	<.001	0.73	[.65, .83]
Care competence (% competent)		88.1 [83.9, 92.3]	235	1.02	0.33	.002	2.77	[1.46, 5.25]
Social support	Total	3.6 [3.5, 3.7]	215	0.66	0.18	<.001	1.93	[1.35, 2.76]
	Significant others	3.8 [3.7, 3.9]	222	0.46	0.13	.001	1.59	[1.22, 2.07]
	Family	3.6 [3.4, 3.7]	224	0.36	0.13	.007	1.43	[1.10, 1.85]
	Friends	3.5 [3.4, 3.6]	221	0.43	0.15	.005	1.53	[1.14, 2.07]
Resilience	Total	3.9 [3.8, 4.0]	217	0.63	0.20	.001	1.87	[1.27, 2.76]
	Self-efficacy	3.9 [3.8, 4.0]	221	0.42	0.18	.019	1.52	[1.07, 2.15]
	Self-confidence	4.0 [3.9, 4.1]	224	0.83	0.19	<.001	2.30	[1.59, 3.34]

Note: n = number of respondents that rated their overall quality of life as (very) good.

[.08, .60]. This indicates that the odds of feeling probably or certainly competent were 77% lower at each wave than in 2019. There was no significant change in perceived care competence between both waves ( $p = .974$ ).

On average, total social support, and social support from family and friends was rated as a 3.5 (range = 1–5) at Wave 2. Social support from significant others was rated as a 3.7. Total resilience and both resilience domains had mean scores of 3.8 to 3.9 at Wave 2 (range = 1–5).

### 3.2 | Quality of life predictors during the second wave of the pandemic

Table 3 provides information regarding care burden, care competence, social support, and resilience in relation to experiencing a (very) good overall quality of life at Wave 2. All predictors were significantly related to overall quality of life.

Lower scores on perceived care burden significantly predicted a (very) good overall quality of life at Wave 2. The mean of perceived

care burden was 4.7 when overall quality of life was rated as (very) good. The odds of having a (very) good quality of life decreased when more care burden was experienced.

High perceived care competence significantly predicted a (very) good overall quality of life. The odds of experiencing a (very) good quality of life were 2.77 times higher for participants who perceived themselves to be competent than for those who did not feel competent.

Total social support significantly predicted quality of life, with higher degrees of perceived social support being associated with a greater odds of experiencing a (very) good quality of life. This association was found for total social support, and social support from significant others, family members and friends. Total resilience and its subscale self-confidence were similarly found to be significant positive predictors of a (very) good quality of life. Self-efficacy, however, was no significant predictor of a (very) good quality of life.

## 4 | DISCUSSION

The COVID-19 pandemic has been shown to negatively impact people's mental health and quality of life (e.g., Epifanio et al., 2021; Passavanti et al., 2021; Pieh et al., 2020; Xiong et al., 2020). For relatives of individuals with intellectual disabilities, who are already under more pressure than the general population (e.g., Lin et al., 2009; Patton et al., 2018; Staunton et al., 2020), the pandemic can be regarded as an additional stressor that has an impact on various factors within their stress process (Budnick et al., 2021; Pearlin et al., 1990). This makes it relevant to be vigilant about their situation. This study monitored relatives' quality of life and potential buffering and risk factors during the first two waves of the pandemic in the Netherlands, and compared them to 2019, the year before the pandemic.

The overall quality of life was rated as (very) good by over 75% of the relatives on all three measurement points. Contrary to what might have been expected from findings in the general population (e.g., Epifanio et al., 2021), the mental health of relatives during the pandemic (e.g., Grumi et al., 2020; Mak et al., 2021; Pieh et al., 2020; Xiong et al., 2020), and retrospective studies concerning changes in quality of life among relatives (Cankurtaran et al., 2021; Pecor et al., 2021), no significant changes were found in overall quality of life nor its separate domains. This extends the longitudinal study by Bailey et al. (2021) in the United Kingdom, which found no significant difference in general life satisfaction between the period 2.5 years prior to lockdown and the first lockdown in March 2020.

Importantly, the present study indicates that the pandemic poses a considerable risk for relatives' quality of life, as there was an increase in risk factors and a decrease in buffering factors. In the current study, higher levels of perceived care burden lowered the odds of having a good quality of life. Care burden can, therefore, be seen as an important risk factor. Perceived care burden increased during the pandemic. This is consistent with previous findings (e.g., Budnick et al., 2021), and could be explained by an increased care intensity due to the limited access to respite care, residential schools, and day services (Gillespie-Smith et al., 2021; Rogers et al., 2021; Wolstencroft et al., 2021;

Wos et al., 2021). Research suggests that the impact of the pandemic on perceived care burden is especially high for relatives who usually rely on these types of professional support (Budnick et al., 2021; Courtenay & Perera, 2020).

Quality of life was buffered by perceived care competence. This study found a decrease in perceived competence between the year prior to COVID-19 and the first two waves of the pandemic. A potential explanation for this finding is that it could be challenging for relatives to explain the situation and preventative measures in a way that is suitable for people with intellectual disabilities (Courtenay & Perera, 2020; Gillespie-Smith et al., 2021). Consequently, it is difficult for people whose relative with intellectual disabilities lives at home or independently, to explain the situation to them and support them in implementing these measures (Boeije et al., 2021; Courtenay & Perera, 2020). Recent studies indicate that the isolation and change in routine and structure have led to an increase in behavioural challenges in individuals with intellectual disabilities, making care provision especially demanding (Bentenuto et al., 2021; Courtenay & Perera, 2020). People whose relative with intellectual disabilities resides in a care organisation or small-scale residential facility were faced with different challenges that could have had a negative impact on their perceived competence. Studies show that these groups of relatives sometimes felt unable to provide their family members with sufficient social support during the lockdown (Araten-Bergman & Shpigelman, 2021).

The current study further corroborates that social support buffers the impact of stressors on wellbeing (Cohen & Wills, 1985; Patton et al., 2018; Pearlin et al., 1990), as higher degrees of perceived social support were associated with a better overall quality of life during the second wave of COVID-19. This was found for all sources of social support. During the pandemic, the possibilities for social and professional support were limited, for instance because access to daycare and respite care was reduced (Budnick et al., 2021; Gillespie-Smith et al., 2021; Wos et al., 2021). Apart from the influence of the imposed measures, some caregivers decided to follow more stringent restrictions on their social lives in order to protect themselves as primary caregivers and their relatives (Embregts et al., 2021; Mak et al., 2021).

This study indicates that resilience is associated with a good quality of life. This was found for overall resilience and self-confidence, but not for self-efficacy. These results complement prior research relating resilience to a lower impact of COVID-19 on psychological well-being (Barzilay et al., 2020). Resilience, as measured in the current study, reflects an individual's ability to maintain a relatively stable and healthy level of psychological and physical functioning when faced with a potentially traumatic or disruptive event (Bonanno, 2004; van der Meer et al., 2018). It is therefore unlikely that this factor has changed during the COVID-19 pandemic. Rather, resilience can be regarded as a buffering trait that was already present at various degrees in relatives of individuals with intellectual disabilities.

Remarkably, the changes in risk and buffering factors are not reflected in actual lower scores on overall quality of life nor its subscales. The reason for the lack of significant change in quality of life is an interesting topic for future research. A possible explanation could

have to do with relatives' frame of reference within which they perceive their quality of life (Howard et al., 2011). Caring for an individual with intellectual disabilities is associated with several changes in relatives' daily lives (e.g., Yoong & Koritsas, 2012). In a study by Wolstencroft et al. (2021), mothers of a child with intellectual and developmental disabilities described social distancing as part of their daily lives, even before the pandemic. As a result of these changes, relatives might have redefined what aspects constitute a good quality of life and what a "good" quality of life entails (Howard et al., 2011). The pandemic could be regarded as just another challenge to adapt to. A different explanation could be that the pandemic was also related to positive outcomes for relatives. Research has identified several positive aspects and benefits of the pandemic experienced by relatives, such as spending more time together as a family, and a slower pace of life (Neece et al., 2020; Rogers et al., 2021). The questions used to measure quality of life might therefore not be adequate to determine more nuanced visions on changes in quality of life. Future research should investigate what factors relatives take into account when rating their quality of life and whether they have experienced changes in their quality of life themselves.

#### 4.1 | Strengths and limitations

A noteworthy strength of the current study is its longitudinal character. Quality of life, care burden, and care competence were measured during two waves of the COVID-19 pandemic and in the year before the pandemic. As experiential experts were involved, we ensured the study addressed topics relevant in practice. Furthermore, this study investigated a relatively large and diverse sample of relatives of individuals with several degrees of intellectual disabilities.

There are a few limitations as well. To reach a sufficient number of participants, additional participants were recruited during each survey period. Consequently, the sample was not entirely identical for each measurement and only 37 relatives responded to all three surveys. This increases the risk that the findings of the current study have been influenced by differences between the samples rather than actual differences in time. Since results were weighted for demographic factors, potential effects of demographic differences on results regarding changes over time were reduced. One demographic factor that was not included in the surveys, and could therefore not be weighted for, is the socioeconomic status. This might have impacted the results if this was not similar across the three measurement points, since material wellbeing is a core domain of quality of life (Schalock & Verdugo, 2002). Future studies should investigate how changes in quality of life and its predictors differ according to demographic factors during the pandemic. This can contribute to the provision of adequate support targeted at different groups of relatives.

Furthermore, the associations between predictor variables and quality of life were not analysed for the separate domains of quality of life. Future research could further explore what aspects of quality of life are related to these buffering and risk factors during the pandemic.

Additionally, the survey was only distributed online in 2019, thereby relatives who have lower levels of digital literacy or limited access to the internet were less likely to be included in this survey. Since many services for people with intellectual disabilities and their relatives were replaced by online alternatives during the COVID-19 pandemic (e.g., Wos et al., 2021), the findings might have been different for this group.

Finally, not all measures were included at all three time points. The separate domains of quality of life, resilience, and social support were not investigated during Wave 1. This survey focused on immediate and potential risks on a range of aspects in the lives of relatives and their family members. To ensure that the survey was not too lengthy and not an extra burden for relatives, a selection of measures had to be made. This selection was made in collaboration with experiential experts. Similarly, the current study cannot make any inferences about changes or stability in perceived social support and resilience, as these factors were measured cross-sectionally during the second wave of COVID-19. Future research could investigate changes in these factors and could extend this by including more potential predictors to further guide supports for relatives.

#### 5 | CONCLUSION AND IMPLICATIONS

Although the quality of life among relatives of individuals with intellectual disabilities did not significantly change during the COVID-19 pandemic, this study has shown that the pandemic poses a serious risk. Two factors that turned out to be highly predictive of quality of life changed during the pandemic: experienced care burden increased and perceived care competence decreased. The current study therefore emphasises that the pandemic is a non-negligible risk factor for the quality of life of relatives of individuals with intellectual disabilities. This makes it essential to continue monitoring the long-term effects and provide relatives with adequate and accessible professional support. The findings of this study can be used to guide support for relatives, as they suggest that this support should focus on reducing the care burden and increasing perceived competence. By providing access to alternative forms of respite care and expanding the capacity of (temporary) residential care, relatives might experience less care burden. Tools and information on caregiving during the pandemic could increase relatives' perceived competence. Since resilience is an important buffering factor during the pandemic, relatives could benefit from psychological help. Furthermore, facilitating peer contact could be a useful way to increase social support, which is positively related to a good quality of life during the pandemic. Supporting relatives during the pandemic is important for their own mental health and for their caregiving role.

#### ACKNOWLEDGEMENT

We thank all relatives for participating in this study.

#### CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.



## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ORCID

Ellen Zonneveld  <https://orcid.org/0000-0001-7263-9194>

## REFERENCES

- Araten-Bergman, T., & Shpigelman, C. N. (2021). Staying connected during COVID-19: Family engagement with adults with developmental disabilities in supported accommodation. *Research in Developmental Disabilities, 108*, 103812. <https://doi.org/10.1016/j.ridd.2020.103812>
- Asbury, K., Fox, L., Deniz, E., Code, A., & Toseeb, U. (2021). How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? *Journal of Autism and Developmental Disorders, 51*(5), 1772–1780. <https://doi.org/10.1007/s10803-020-04577-2>
- Bailey, T., Hastings, R. P., & Totsika, V. (2021). COVID-19 impact on psychological outcomes of parents, siblings and children with intellectual disability: Longitudinal before and during lockdown design. *Journal of Intellectual Disability Research, 65*(5), 397–404. <https://doi.org/10.1111/jir.12818>
- Barzilay, R., Moore, T. M., Greenberg, D. M., DiDomenico, G. E., Brown, L. A., White, L. K., Gur, R. C., & Gur, R. E. (2020). Resilience, COVID-19-related stress, anxiety and depression during the pandemic in a large population enriched for healthcare providers. *Translational Psychiatry, 10*(1), 1–8. <https://doi.org/10.1038/s41398-020-00982-4>
- Beentjes, J., & Cardol, M. (2012). *Als de begeleiding onder de Wmo valt dan... de mening van familieleden van mensen met een verstandelijke beperking*. Nivel.
- Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities, 32*(5), 1255–1279. <https://doi.org/10.1111/jar.12617>
- Bentenuto, A., Mazzoni, N., Giannotti, M., Venuti, P., & de Falco, S. (2021). Psychological impact of Covid-19 pandemic in Italian families of children with neurodevelopmental disorders. *Research in Developmental Disabilities, 109*, 103840. <https://doi.org/10.1016/j.ridd.2020.103840>
- Boeije, H., Van Schelven, F., & Verkaik, R. (2021). *Gevolgen van coronamaatregelen voor naasten van mensen met een verstandelijke beperking: Onderzoek naar kwaliteit van leven tijdens de tweede golf*. Nivel.
- Boeije, H., & Voss, H. (2021). Panel living together—People with intellectual disabilities and family members. Retrieved May 27, 2022 from <https://www.nivel.nl/en/panel-samen-leven/panel-living-together-people-intellectual-disabilities-and-family-members>.
- Bonanno, G. A. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist, 59*(1), 20–28. <https://doi.org/10.1037/0003-066X.59.1.20>
- Budnick, A., Hering, C., Eggert, S., Teubner, C., Suhr, R., Kuhlmeier, A., & Gellert, P. (2021). Informal caregivers during the COVID-19 pandemic perceive additional burden: Findings from an ad-hoc survey in Germany. *BMC Health Services Research, 21*(1), 1–11. <https://doi.org/10.1186/s12913-021-06359-7>
- Burnett, D., Masi, A., Mendoza Diaz, A., Rizzo, R., Lin, P. I., & Eapen, V. (2021). Distress levels of parents of children with neurodevelopmental disorders during the COVID-19 pandemic: A comparison between Italy and Australia. *International Journal of Environmental Research and Public Health, 18*(21), 11066. <https://doi.org/10.3390/ijerph182111066>
- Cankurtaran, D., Tezel, N., Yildiz, S. Y., Celik, G., & Unlu Akyuz, E. (2021). Evaluation of the effects of the COVID-19 pandemic on children with cerebral palsy, caregivers' quality of life, and caregivers' fear of COVID-19 with telemedicine. *Irish Journal of Medical Science, 190*(4), 1473–1480. <https://doi.org/10.1007/s11845-021-02622-2>
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310–357. <https://doi.org/10.1037/0033-2909.98.2.310>
- Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: Impacts of a pandemic. *Irish Journal of Psychological Medicine, 37*(3), 231–236. <https://doi.org/10.1017/ipm.2020.45>
- de Vries, J., & van Heck, G. L. (1996). *Nederlandse WHOQoL-Bref*. Vakgroep Psychologie.
- Embregts, P., Heerkens, L., Frielink, N., Giesbers, S., Vromans, L., & Jahoda, A. (2021). Experiences of mothers caring for a child with an intellectual disability during the COVID-19 pandemic in The Netherlands. *Journal of Intellectual Disability Research, 65*(8), 760–771. <https://doi.org/10.1111/jir.12859>
- Epifanio, M. S., Andrei, F., Mancini, G., Agostini, F., Piombo, M. A., Spicuzza, V., Riolo, M., Lavanco, G., Trombini, E., & La Grutta, S. (2021). The impact of COVID-19 pandemic and lockdown measures on quality of life among Italian general population. *Journal of Clinical Medicine, 10*(2), 289. <https://doi.org/10.3390/jcm10020289>
- Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology, 33*(10), 1129–1136. <https://doi.org/10.1093/jpepsy/jsn040>
- Gillespie-Smith, K., McConachie, D., Ballantyne, C., Auyeung, B., & Goodall, K. (2021). The impact of COVID-19 restrictions on psychological distress in family caregivers of children with neurodevelopmental disability in the UK. *Journal of Autism and Developmental Disorders*. Advanced online publication. <https://doi.org/10.1007/s10803-021-05132-3>
- Grumi, S., Provenzi, L., Gardani, A., Aramini, V., Dargenio, E., Naboni, C., Vacchini, V., Borgatti, R., & Engaging with Families through On-line Rehabilitation for Children during the Emergency (EnFORCE) Group. (2020). Rehabilitation services lockdown during the COVID-19 emergency: The mental health response of caregivers of children with neurodevelopmental disabilities. *Disability and Rehabilitation, 43*(1), 27–32. <https://doi.org/10.1080/09638288.2020.1842520>
- Howard, J. S., Mattacola, C. G., Howell, D. M., & Lattermann, C. (2011). Response shift theory: An application for health-related quality of life in rehabilitation research and practice. *Journal of Allied Health, 40*(1), 31–38.
- Kamstra, A., van der Putten, A. A. J., & Vlaskamp, C. (2015). The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities, 28*(3), 249–256. <https://doi.org/10.1111/jar.12134>
- Lin, J. D., Hu, J., Yen, C. F., Hsu, S. W., Lin, L. P., Loh, C. H., Chen, M. H., Wu, S. R., Chu, C. M., & Wu, J. L. (2009). Quality of life in caregivers of children and adolescents with intellectual disabilities: Use of WHOQOL-BREF survey. *Research in Developmental Disabilities, 30*(6), 1448–1458. <https://doi.org/10.1016/j.ridd.2009.07.005>
- Linehan, C., Birkbeck, G., Araten-Bergman, T., Baumbusch, J., Beadle-Brown, J., Bigby, C., Bradley, V., Brown, M., Bredewold, F., Chirwa, M., Cui, J., Godoy Gimenez, M., Gomeiro, T., Kanova, Š., Kroll, T., Li, H., MacLachlan, M., Narayan, J., Nearchou, F., ... Tossebro, J. (2022). COVID-19 IDD: Findings from a global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities (IDD) and their caregivers. *HRB Open Research, 5*(27), 27. <https://doi.org/10.12688/hrbopenres.13497.1>
- Mak, H. W., Bu, F., & Fancourt, D. (2021). Mental health and wellbeing amongst people with informal caring responsibilities across different time points during the COVID-19 pandemic: A population-based propensity score matching analysis. *MedRxiv*. <https://doi.org/10.1101/2021.01.21.21250045>
- Neece, C., McIntyre, L. L., & Fenning, R. (2020). Examining the impact of COVID-19 in ethnically diverse families with young children with

- intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 64(10), 739–749. <https://doi.org/10.1111/jir.12769>
- Panicker, A. S., & Ramesh, S. (2019). Psychological status and coping styles of caregivers of individuals with intellectual disability and psychiatric illness. *Journal of Applied Research in Intellectual Disabilities*, 32(1), 1–14. <https://doi.org/10.1111/jar.12496>
- Passavanti, M., Argentieri, A., Barbieri, D. M., Lou, B., Wijayaratna, K., Foroutan Mirhosseini, A. S., Wang, F., Naseri, S., Qamhia, I., Tangeràs, M., Pellicciari, M., & Ho, C. H. (2021). The psychological impact of COVID-19 and restrictive measures in the world. *Journal of Affective Disorders*, 283, 36–51. <https://doi.org/10.1016/j.jad.2021.01.020>
- Patton, K. A., Ware, R., McPherson, L., Emerson, E., & Lennox, N. (2018). Parent-related stress of male and female carers of adolescents with intellectual disabilities and carers of children within the general population: A cross-sectional comparison. *Journal of Applied Research in Intellectual Disabilities*, 31(1), 51–61. <https://doi.org/10.1111/jar.12292>
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30(5), 583–594. <https://doi.org/10.1093/geront/30.5.583>
- Pecor, K. W., Barbayannis, G., Yang, M., Johnson, J., Materasso, S., Borda, M., Garcia, D., Garla, V., & Ming, X. (2021). Quality of life changes during the COVID-19 pandemic for caregivers of children with ADHD and/or ASD. *International Journal of Environmental Research and Public Health*, 18(7), 3667. <https://doi.org/10.3390/ijerph18073667>
- Pieh, C., Budimir, S., & Probst, T. (2020). The effect of age, gender, income, work, and physical activity on mental health during coronavirus disease (COVID-19) lockdown in Austria. *Journal of Psychosomatic Research*, 136, 110186. <https://doi.org/10.1016/j.jpsychores.2020.110186>
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), e626. <https://doi.org/10.1542/peds.2004-1689>
- Redquest, B. K., Tint, A., Ries, H., & Lunskey, Y. (2021). Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic. *Journal of Intellectual Disability Research*, 65(1), 1–10. <https://doi.org/10.1111/jir.12793>
- Rijksoverheid. (2020). Coronavirus tijdslijn. Retrieved August 23, 2021 from <https://www.rijksoverheid.nl/onderwerpen/coronavirus-tijdslijn>.
- Ritchie, H., Mathieu, E., Rodés-Guirao, L., Appel, C., Giattino, C., Ortiz-Ospina, E., Hasell, J., Macdonald, B., & Beltekian, D. (2020). Coronavirus pandemic (COVID-19). Retrieved August 23, 2021 from <https://ourworldindata.org/coronavirus>.
- Rogers, G., Perez-Olivas, G., Stenfort Kroese, B., Patel, V., Murphy, G., Rose, J., Cooper, V., Langdon, P. E., Hiles, S., Clifford, C., & Willner, P. (2021). The experiences of mothers of children and young people with intellectual disabilities during the first COVID-19 lockdown period. *Journal of Applied Research in Intellectual Disabilities*, 34(6), 1421–1430. <https://doi.org/10.1111/jar.12884>
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. American Association on Mental Retardation.
- StataCorp. (2019). *Stata statistical software: Release 16*. StataCorp LLC.
- Staunton, E., Kehoe, C., & Sharkey, L. (2020). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish Journal of Psychological Medicine*. Advanced online publication. <https://doi.org/10.1017/ipm.2020.4>
- van der Meer, C. A. I., te Brake, H., van der Aa, N., Dashtgard, P., Bakker, A., & Olff, M. (2018). Assessing psychological resilience: Development and psychometric properties of the English and Dutch version of the resilience evaluation scale (RES). *Frontiers in Psychiatry*, 9(169), 1–11. <https://doi.org/10.3389/fpsy.2018.00169>
- van Exel, N. J. A., Scholte Op Reimer, W. J. M., Brouwer, W. B. F., van den Berg, B., Koopmanschap, M. A., & van den Bos, G. A. M. (2004). Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: A comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehabilitation*, 18(2), 203–214. <https://doi.org/10.1191/0269215504cr7230a>
- VGN. (2020). Thema coronavirus. Retrieved August 23, 2021 from <https://www.vgn.nl/themas/coronavirus#tjdlijn-tabs>.
- WHO. (1996). WHOQOL-BREF: Introduction, administration, scoring and generic version of the assessment. WHO.
- WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the world health organization. *Social Science & Medicine*, 41(10), 1403–1409. [https://doi.org/10.1016/0277-9536\(95\)00112-K](https://doi.org/10.1016/0277-9536(95)00112-K)
- Willner, P., Rose, J., Stenfort Kroese, B., Murphy, G. H., Langdon, P. E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., & Cooper, V. (2020). Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 33(6), 1523–1533. <https://doi.org/10.1111/jar.12811>
- Wolstencroft, J., Hull, L., Warner, L., Akhtar, T. N., Mandy, W., & Skuse, D. (2021). 'We have been in lockdown since he was born': A mixed methods exploration of the experiences of families caring for children with intellectual disability during the COVID-19 pandemic in the UK. *BMJ Open*, 11(9), e049386. <https://doi.org/10.1136/bmjopen-2021-049386>
- Wos, K., Kamecka-Antczak, C., & Szafranski, M. (2021). Remote support for adults with intellectual disability during COVID-19: From a caregiver's perspective. *Journal of Policy and Practice in Intellectual Disabilities*, 18(4), 279–285. <https://doi.org/10.1111/jppi.12385>
- Xiong, J., Lipsitz, O., Nasri, F., Lui, L. M. W., Gill, H., & Phan, L. (2020). Impact of COVID-19 pandemic on mental health in the general population: A systematic review. *Journal of Affective Disorders*, 277, 55–64. <https://doi.org/10.1016/j.jad.2020.08.001>
- Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research*, 56(6), 609–619. <https://doi.org/10.1111/j.1365-2788.2011.01501.x>
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52(1), 30–41. [https://doi.org/10.1207/s15327752jpa5201\\_2](https://doi.org/10.1207/s15327752jpa5201_2)

**How to cite this article:** Zonneveld, E., van Schelven, F., & Boeije, H. (2022). Effects of the COVID-19 pandemic on quality of life among relatives of individuals with intellectual disabilities: A longitudinal study. *Journal of Applied Research in Intellectual Disabilities*, 1–10. <https://doi.org/10.1111/jar.13035>