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When life changes: use and effects of behavioral coping strategies among relatives of people with intellectual disabilities during the COVID-19 pandemic

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ABSTRACT

Objectives: The COVID-19 pandemic posed risks to the wellbeing of different groups in society. This study focuses on relatives of people with intellectual disabilities in the Netherlands. Their behavioral coping strategies, effects on psychological quality of life (QoL), and differences according to age, family relationship, and severity of disability were investigated.

Methods: Survey data of 284 relatives were analyzed. Differences in utilization of coping strategies were analyzed using a multivariate test of the means and paired t-tests. Variations according to background characteristics were analyzed using MANOVAs and multivariate regressions. Relations between coping and QoL - and differences according to characteristics - were analyzed using multiple and linear regressions.

Results: Seeking distraction and actively approaching were used most, followed by seeking social support and ignoring. Withdrawal was adopted the least. Seeking distraction and actively approaching were positively associated with QoL. Seeking social support and withdrawal were negative predictors. These associations were unaffected by relatives' characteristics, while use of coping differed according to age and family relationship. Mothers made least use of adaptive coping.

Conclusions: Although relatives used more adaptive than maladaptive coping strategies, it is essential to offer interventions on effective coping and improving social support during life events to protect their QoL.

Introduction

In the Netherlands, as in other countries, there is a great reliance on relatives to provide care for people with intellectual disabilities (Beentjes and Cardol 2012; Brennan et al. 2020). Caring for a family member with an intellectual disability affects different life domains of relatives, such as their leisure activities, employment, and relationships (Spindler et al. 2017; Yoong and Koritsas 2012). Relatives can experience joy that the family member brings and report that caring provides them with a sense of purpose in life (Beighton and Wills 2019; Yoong and Koritsas 2012). At the same time, providing care can be demanding and is related to negative mental health outcomes and a lower quality of life (Gallagher et al. 2008; Panieker and Ramesh 2019; Staunton, Kehoe, and Sharkey 2020).

Quality of life can be regarded as a multidimensional construct reflecting an individual's perception of the position in life with respect to standards, goals, and expectations (Schalock and Verdugo 2002; WHOQOL Group 1995). The psychological domain includes concepts related to a person's cognitive and affective state (WHOQOL Group 1995). A wide range of relatives' characteristics, their social network, and the caregiving setting are related to their psychological quality of life (Gérain and Zech 2019). These factors are subject to change, as the COVID-19 pandemic has recently demonstrated.

During the pandemic, various social distancing and isolation measures were imposed by governments to prevent the spread of the virus (World Health Organization 2020). In addition to the consequences of these measures for people in the general population, relatives of people with an intellectual disability were confronted with reduced access to formal support systems such as respite care and day services, creating a greater reliance on them to support their family members (Budniek et al. 2021; Rogers et al. 2021; Wolstencroft et al. 2021). Additionally, the health risks of a COVID-19 infection were higher for people with intellectual disabilities in long-term care settings than in the general population (Koks-Leensen et al. 2023). Therefore, relatives were limited in visiting their family members in residential facilities (Boeije et al. 2022; Rijksoverheid 2021) and restricted their social lives more stringently to protect their family members (Embregts et al. 2021; Mak, Bu, and Fancourt 2021).

Several studies found a decrease in relatives' quality of life during the pandemic or an increase in risk factors associated with a lower quality of life, such as feeling less competent to care (Cankurtaran et al. 2021; Pecor et al. 2021; Zonneveld, van Schelven, and Boeije 2023). However, not all studies found effects on quality of life (Bailey, Hastings, and Totsika 2021), and positive effects have also been reported (Neece, McIntyre, and Penning 2020; Rogers et al. 2021). Relatives differ in how their wellbeing was affected. For example, relatives who perceived more social support were more likely to have a good quality of life during the pandemic than those who perceived less social support (Willner et al. 2020; Zonneveld, van Schelven, and Boeije 2023). In addition, presence of challenging behavior of the family member was a risk factor for distress (e.g. Gillespie-Smith et al. 2021), and this was correlated with severity of disability (Willner et al. 2020). Furthermore, older relatives had more stress than younger relatives (Cheng, Yang, and Deng 2022), as the pandemic led to increased worries about situations in which they are no longer able to care (Boeije et al. 2022). Following the informal care-giving integrative model (Gérain and Zech 2019) and the transactional model of stress and coping (Lazarus and Folkman 1984), the impact of changes during the pandemic on wellbeing is also influenced by relatives' appraisal of the situation and their response. This response is referred to as coping, which can be defined as cognitive or behavioral efforts to manage stressful situations (Lazarus and Folkman 1984). The knowledge on use and effects of coping strategies during the COVID-19 pandemic among relatives of people with intellectual disabilities is limited. There is a need to understand these processes to facilitate adequate support during major life events.

Coping strategies are often categorized into different types. A first distinction can be made based on the orientation toward or away from the stressor (i.e. approach or avoidant strategies; Roth and Cohen 1986). Another categorization distinguishes emotion-focused strategies that aim to manage emotional distress, from problem-focused strategies that aim to modify the stressor itself (Lazarus and Folkman 1984). Not all strategies were effective to mitigate negative mental health effects of the COVID-19 pandemic (Budimir, Probst, and Pieh 2021; Göttsmann and Bechtoldt 2021), and coping is contingent on demographic factors such as gender, age, employment status, and caring for children (Fluharty and Fancourt 2021; Russell et al. 2022).

Studies among relatives have shown that strategies such as denial and behavioral disengagement were related to increased distress (Gillespie-Smith et al. 2021; Urizar et al. 2022). Little is known about the influence of specific characteristics of relatives such as age, family relationship and the severity of the disability on the use and effects of coping strategies during the pandemic. Challenging behavior by the family member might impact the use of coping strategies, as Berry, Burke, and Carr (2021) found that parents of children with clinical levels of externalizing behavior problems engaged more in avoidant-focused coping strategies during the pandemic than other parents. In studies prior to the pandemic, differences according to the type of family relationship have been reported. Glidden, Billings, and Jobe (2006) reported more use of seeking social support and, depending on the situation, more playful problem solving by mothers than by fathers. In a study by Hastings et al. (2005), mothers more frequently used active avoidance strategies and problem-focused strategies than fathers. The situation of siblings, and whether the effects of coping strategies on quality of life during the pandemic differ according to relatives' characteristics, is unknown from these studies.

Given that relatives faced unique challenges during the pandemic, and experienced significantly more anxiety, depression and defeat than people in the general population (Willner et al. 2020), further insight into the use and effects of coping strategies among relatives is essential to support them adequately in their roles during major transitions in their lives, of which the pandemic is a case in point. The aim of the current study is therefore to gain insight into the use and effects of different coping strategies among relatives, and how these differ according to several characteristics. To this end, the following research questions will be investigated:

1. What coping strategies were used most frequently by relatives of people with intellectual disabilities in the second year of the COVID-19 pandemic?
2. To what extent did relatives differ in their use of coping strategies according to their age, type of family relationship, and the severity of disability of their family member?
3. What was the association of different behavioral coping strategies of relatives with their psychological quality of life during the pandemic?
4. Did the associations of coping strategies with psychological quality of life differ according to relatives' age, type of family relationship, and the severity of disability of their family member?

[Table 1]

Materials and methods

Design and procedure

As a part of a larger project, a survey was conducted among relatives of people with an intellectual disability in the Netherlands. The survey was sent out on April 16, 2021 and could be completed online or on paper until May 7, 2021. A reminder was sent after two weeks.

Preventative measures during the survey period

In the Netherlands, the beginning of 2021 was marked by a lockdown (Rijksoverheid 2021). There was a curfew, no more than one visitor a day was allowed at home, schools and daycare facilities were closed, and there were strict measures and quarantine guidelines in care facilities. Despite the vaccine uptake and the rising availability of self-tests, the third wave of COVID-19 became apparent by the end of March 2021. The peak of this wave was on April 20th and 21st. From April 28th on, the curfew was lifted, two visitors were allowed at home each day, and people could visit stores without appointment. The second step of relaxations commenced on May 19th.

Participants

Study population

Relatives were included if they were immediate or extended family members or otherwise closely related to someone with an intellectual disability. They were mostly parents or siblings. Professional caregivers were excluded. The survey was distributed among 522 relatives, of which 305 filled out the survey, resulting in a response rate of 58%. Of these respondents, 20 did not indicate their family member had an intellectual disability, and one indicated their family member had passed away. These respondents were removed from the dataset. The survey included demographic questions to gather information about characteristics of the relatives and their family members (see Table 1). The age of the included 284 participants ranged from 26 to 92 years old ($M = 65.6$, $SD = 10.7$).

Recruitment

Participants were recruited in two ways. First, 250 relatives of the Dutch Panel Living Together received the survey. Members of this panel are relatives of people with mild or moderate intellectual or developmental disabilities and were previously recruited by general practitioners and care organizations. Second, 272 relatives who participated in previous studies on quality of life and indicated their interest to participate in future studies, received the survey. These relatives mostly had a family member with a moderate or severe intellectual disability. For these prior studies, participants were recruited through a newsletter for a national program on people with disabilities and their relatives of the Dutch Ministry of Health, Welfare and Sport, and through the networks of two Dutch Academic Collaborative Centers.

Ethical considerations

Participation was voluntary. Participants were informed about the aim and procedure of the study and privacy regulations prior to enrolling in the study and upon receiving the survey. They were encouraged to call or send an email to the project's fieldwork coordinator if they desired any further information. All participants provided informed consent. The data were analyzed and processed anonymously, in accordance with the General Data Protection Regulation. Approval by a Medical Ethics Committee is not obligatory for this type of research, according to Dutch legislation.

Measures

Psychological quality of life

Quality of life was measured using the six items from the psychological domain of the Dutch version of the WHOQOL-BREF (de Vries and van Heek 1996; WHO 1996). On these items, participants rate their experiences of the past two weeks on five-point scales (e.g. 'How often do you have negative feelings such as blue mood, despair, anxiety, depression?'). The mean of these items was calculated to compute a domain score. When one item was missing, this item's value was substituted by the mean of the remaining five items. The domain score was not computed when more than one item

was missing. The scores were then converted into a linear scale from 0 to 100, in accordance with the guidelines (WHO 1996). Reliability of the scale was satisfactory ($\alpha = .83$).

Coping

Coping was measured using the Behavioral Emotion Regulation Questionnaire (BERQ; Kraaij and Garnefski 2019). This questionnaire measures five conceptually distinct coping scales: seeking distraction (i.e. doing something else to distract from emotions), withdrawal (i.e. drawing back from situations and social contacts), actively approaching (i.e. active behavior to deal with the situation), seeking social support (i.e. actively sharing emotions and asking for support and advice), and ignoring (i.e. behaving as if nothing has happened). Each scale consists of four items with five-point scales ranging from (almost) never to (almost) always, indicating to what extent participants performed certain behaviors during the COVID-19 pandemic. Sum scores were calculated to compute scale scores. For each scale, one missing could be substituted by the mean score of the remaining items. No scale score was computed when more items were missing. Internal consistencies for the seeking distraction ($\alpha = .71$), withdrawal ($\alpha = .75$), actively approaching ($\alpha = .76$), seeking social support ($\alpha = .79$), and ignoring ($\alpha = .78$) scales were satisfactory. However, the internal consistency of the withdrawal scale would be higher when the item 'I avoid other people' would be dropped. A plausible explanation is that social distancing was one of the main elements of the preventative measures imposed by the government. Therefore, it was decided to compute this scale without this item, resulting in a Cronbach's alpha of .85. Since this altered the range of scores on this scale, all scale scores were transformed to a range from 0 to 10 to facilitate comparisons of scores on the different scales.

Data analysis

Analyses were performed using Stata 16.0 (StataCorp 2019). Results were considered significant if $p < .05$. Mean scores of the five coping strategies were calculated, with higher scores indicating more frequent use of a strategy. A multivariate test of the means (Hotelling's T^2) was performed to analyze whether the coping strategies were used to the same extent. To further investigate differences in use of the coping strategies, ten separate paired t-tests were performed. A Bonferroni correction was applied ($p < .005$) in order to reduce the risk of Type 1 errors.

Separate one-way MANOVAs were run to determine the independent effects of the type of family relationship, and the severity of intellectual disability on the use of the five coping strategies. These were interpreted using Pillai's trace (V). Subsequent multivariate regression analyses were performed to further investigate the significant effects of these characteristics on the use of the five coping strategies, and the independent effect of relatives' age. To this end, family relationship and severity of the disability were dummy coded.

A robust standard multiple regression analysis was used to test if the adoption of the five coping strategies significantly predicted relatives' psychological quality of life. To analyze whether the associations of coping strategies with quality of life differed according to the family relationship, age of relatives, and severity of the disability, separate robust linear regression analyses were performed. For each characteristic, a regression model was created with the main effect of this characteristic, the main effects of the five coping strategies, and the interactions of the coping strategies with the characteristic. In these analyses, relatives' age was centered on the mean, and dummies were created for the types of family relationship and the severity levels of disability of their family member. Only parents and siblings were included in the analyses of effects and differences in coping according to types of family relationship.

Results

Use of behavioral coping strategies

A multivariate test of the means indicated a significant difference in frequency of engagement in the five coping strategies for the total group, $T^2 = 481.48$, $F(4, 255) = 118.97$, $p < .001$. The strategies seeking distraction and actively approaching were used most frequently (see Table 2). Paired t-tests indicated that the difference in mean use of these two strategies ($t(261) = 2.32$, $p = .021$) was not significant after Bonferroni correction, and both strategies were used significantly more than withdrawal, seeking social support, and ignoring ($ps < .001$). Withdrawal was the least used strategy among participants in general, and was used significantly less than all other strategies ($ps < .001$). No significant difference was found between the frequency of seeking social support and ignoring, $t(268) = 1.39$, $p = .166$.

[Table 2]

A significant difference in coping between the types of family relationships was found using a MANOVA, $V = 0.10$, $F(10, 466) = 2.48$, $p = .007$. A subsequent multivariate regression analysis revealed that the strategy seeking distraction was used more often by fathers ($b=0.677$, $SE=0.31$, $t=2.16$, $p=.032$) and siblings ($b=0.615$, $SE=0.29$, $t=2.14$, $p = .034$) compared with mothers. No significant difference between siblings and fathers was found concerning this strategy ($p = .858$). The strategy actively approaching was adopted more frequently by siblings than mothers, $b=0.673$, $SE=0.31$, $t=2.16$, $p = .032$. Use of this strategy did not differ between siblings and fathers ($p = .133$), nor between mothers and fathers ($p = .732$). Compared with fathers, the strategy seeking social support was used more by siblings ($b = 0.635$, $SE= 0.32$, $t = 1.99$, $p = .048$) and mothers ($b = 0.843$, $SE= 0.29$, $t = 2.87$, $p = .005$). Mothers and siblings did not differ in seeking social support ($p = .433$). No differences in withdrawal were found between mothers and fathers ($p = .116$), mothers and siblings ($p = .144$), nor siblings and fathers ($p = .830$). Similarly, no differences in ignoring were found between these groups ($p = .954$, $p = .786$, and $p = .860$, respectively). No significant differences were found in a second MANOVA, regarding the independent effect of the severity of intellectual disability on the five coping strategies, $V = 0.02$, $F(10, 496) = 0.45$, $p = .920$. Therefore, no further regression analyses were performed. A multivariate regression analysis revealed a significant negative effect of age on the use of withdrawal as a coping strategy, $b = -0.034$, $SE= 0.01$, $t=-3.31$, $p = .001$, indicating lower frequencies of withdrawing by older relatives. Relatives' age did not significantly relate to their use of seeking distraction ($p = .277$), actively approaching ($p = .762$), seeking social support ($p = .075$), nor ignoring ($p = .155$).

Associations of coping with quality of life

On average, participants had a score of 67.03 on psychological quality of life ($SD= 14.41$). A standard multiple regression analysis revealed a highly significant association between psychological quality of life and the set of five coping strategies, $F(5, 248) = 26.61$, $p < .001$. There was a moderate-to-strong association and the regression model explained 36.0% of the variance in psychological quality of life. Withdrawal was the strongest significant predictor, $\beta = -0.425$, $p < .001$. This strategy negatively predicted quality of life. The coping strategy seeking social support had a less strong but significant negative effect on quality of life, $\beta = -0.174$, $p = .007$. Seeking distraction ($\beta = 0.193$, $p = .002$) and actively approaching ($\beta = 0.194$, $p = .005$) positively predicted quality of life. The effect of the use of ignoring as a strategy was not significant, $\beta = -0.063$, $p = .327$.

Table 3 shows the results of regression analyses with interaction effects of coping and characteristics of the relatives and family members on psychological quality of life. Separate analyses were

conducted for each characteristic. The regression model of family relationship, the five coping strategies, and their inter-actions on quality of life was significant, $F(17, 217) = 8.78$, $p < .001$. This model explained 39.5% of variance in quality of life. As depicted in Table 3, withdrawal was a significant negative *predictor* of quality of life for each family relationship ($ps < .050$). For mothers and fathers, seeking distraction was a significant positive *predictor* ($ps < .045$), but not for siblings ($p = .362$). Actively approaching, seeking social support, and ignoring were not significantly related to quality of life for the separate subgroups ($ps > .123$, $ps > .087$, and $ps > .199$, respectively). Although these findings suggest some differences according to family relationship, there were no significant inter-action effects ($ps > .169$) between the types of family relationships and the coping strategies in their relation with quality of life. This indicates that the effects of coping strategies on quality of life did not vary significantly across the types of family relationships.

The regression model of the severity of disability, the five coping strategies, and their interactions on quality of life was significant, $F(17, 231) = 9.53$, $p < .001$. This model predicted 37.8% of variance in quality of life. As shown in Table 3, seeking distraction was only a significant predictor for relatives of individuals with severe intellectual disabilities ($p = .024$), and was not significant when the disability was mild ($p = .244$) or moderate ($p = .118$). For relatives of individuals with a mild or moderate intellectual disability, withdrawal was a significant negative *predictor* of quality of life ($ps < .001$), but not for relatives whose family member had a severe disability ($p = .063$). Actively approaching was a positive predictor of quality of life for relatives of individuals with a mild intellectual disability ($p = .007$). The effect of this strategy was not significant when the disability was moderate or severe ($p = .259$ and $p = .523$, respectively). Similarly, seeking social support was only a significant negative *predictor* when the intellectual disability was mild ($p = .034$), but was not significant for moderate ($p = .053$) or severe ($p = .690$) disabilities. Ignoring was not significantly related to quality of life for these separate groups ($p > .345$). Although these findings suggest some differences in effects of coping according to the severity of disability, there were no significant interactions between the severity levels of disability and coping strategies ($ps > .200$). This indicates that the effects of relatives' coping strategies on quality of life were not significantly affected by the level of disability of their family member.

Regarding the age of the relatives, the regression model was significant, $F(11, 242) = 14.56$, $p < .001$, and explained 38.1 % of variance in quality of life. There were no significant interactions between age and coping strategies in their relation with quality of life ($ps > .103$). Considering the mean age of the participants, seeking distraction and actively approaching positively predicted quality of life ($p = .002$, and $p = .006$, respectively). In contrast, withdrawal and seeking social support negatively predicted quality of life ($p < .001$, and $p = .004$, respectively). Ignoring was not significantly associated with quality of life ($p = .451$).

Discussion

The COVID-19 pandemic posed risks to the wellbeing of different groups in society, such as relatives of people with intellectual disabilities (Cankurtaran et al. 2021; Gillespie-Smith et al. 2021). Relatives faced the general consequences of the social distancing and isolation measures and were also concerned about health risks for their family members (Embregts et al. 2021; Mak, Bu, and Fancourt 2021), who often relied more on them than before the pandemic (Budniek et al. 2021). Relatives most frequently used the strategies seeking distraction and actively approaching to cope with the situation. Both strategies were positively related to quality of life, indicating that relatives mostly used coping strategies that were adaptive at this point during this life event. Seeking social support and ignoring were used less, and withdrawal was the least adopted strategy. While ignoring was not significantly related to quality of life, withdrawal had the strongest negative effect, suggesting that attention to reducing withdrawal is still warranted in the development of interventions (Kraaij and Garnefski 2019). The pattern in use and effects of behavioral coping

strategies was similar to that of the general population prior to the pandemic, with the surprising exception of seeking social support (Kraaij and Garnefski 2019).

[Table 3]

The negative association of seeking social support with quality of life was a striking result, given that other studies during the pandemic pointed to a buffering effect of social support (Willner et al. 2020; Zonneveld, van Schelven, and Boeije 2023). Studies showed that relatives perceived remote communication with their social network to be insufficient, and that they received less social support than parents of children without disabilities (Willner et al. 2020; Wolstencroft et al. 2021). This finding therefore suggests that the received social support did not match relatives' needs: they did not sufficiently find the support they were seeking, which in general led to a lower quality of life during the pandemic.

When examining differences between groups of relatives, the effects of the coping strategies on quality of life did not significantly vary across types of family relationships, relatives' age, or the severity of disability. However, variation was found in the utilization of coping strategies. Regarding the type of family relationship, the current study found that mothers made least use of coping strategies that were adaptive for their quality of life at this point during the pandemic. Fathers and siblings engaged more frequently in seeking distraction than mothers, and siblings made more use of actively approaching than mothers. Studies prior to the pandemic state that mothers are generally the primary caregivers and therefore often assume more responsibilities for solving problems within the family (Glidden, Billings, and Jobe 2006; Hastings et al. 2005). These responsibilities could explain why mothers sought less distraction than fathers and siblings. However, following the same reasoning, studies before the pandemic found that mothers used actively approaching strategies more frequently than fathers (Glidden, Billings, and Jobe 2006; Hastings et al. 2005). The absence of this difference in the current study might be a result of fathers adopting more childcare responsibilities during the pandemic due to labor market restrictions, and the urgent and inescapable demand to care for their family members (Craig and Churchill 2021; Mangiavacchi, Piccoli, and Pieroni 2021). Another possibility is that mothers reduced their use of this strategy. Among mothers, feelings of powerlessness and hopelessness were reported (Rogers et al. 2021), leaving little resources for actively approaching to cope with the situation. Additionally, with fathers adopting more childcare responsibilities, mothers might have decreased actively approaching, while seeking more social support from their partner. Indeed, mothers and siblings reported seeking social support more frequently than fathers, which complements prior studies comparing mothers and fathers (Glidden, Billings, and Jobe 2006). The observed negative effect of this strategy indicates that especially mothers and siblings might experience difficulties in finding adequate and sufficient social support. This puts them at a higher risk for a lower quality of life, stressing the need for targeted interventions. Future studies should investigate why - in times of crises - mothers use adaptive coping strategies to a lesser degree than fathers and siblings.

Relatives' age was unrelated to the use of most coping strategies. However, age was related to withdrawing, with higher age relating to less use of this maladaptive coping strategy. Similarly, older people in the general population used less avoidant strategies than younger people (Fluharty and Fancourt 2021; Minahan et al. 2021). Interventions focusing on reducing the use of withdrawal should therefore especially be targeted to younger relatives.

Differences in severity of the family member's disability were not reflected in the use of coping strategies among relatives. This is in line with findings among mothers prior to the pandemic (Adams et al. 2018). In contrast, externalizing behavior problems of the family member have been linked to relatives' coping and wellbeing during the pandemic (Berry, Burke, and Carr 2021). This suggests that the accompanying behavioral difficulties are of relevance, rather than the disability itself.

Strengths and limitations

A strength of this study is that a diverse group of relatives participated: mothers, fathers and siblings of family members with different levels of disabilities. Although participants' age ranged from 26 to 92, their mean age was relatively high (65.6). Future studies should investigate age effects among younger relatives as well. Moreover, it is unknown why non-responders (42%) did not participate and whether non-responding relates to stress or coping. Comparable to other studies, the number of fathers in our sample was relatively low, potentially reducing statistical power. However, the groups were large enough to make comparisons in use and effects of coping strategies to fill an important research gap and give direction to the provision of adequate and targeted behavioral interventions during life events.

This cross-sectional study provides valuable insights into the coping strategies different groups used and how these were associated with their quality of life during the same phase of the second year of the pandemic. Berry, Burke, and Carr (2021) found that the use of strategies changed between different phases in the first year of the pandemic. More research is needed to investigate long-term use and effects of coping, and how the findings extend to other crises or life events. Additionally, future studies should take relatives' employment situation into account, as this could affect their experienced work-load and coping strategies (Craig and Churchill 2021; Fluharty and Fancourt 2021). Furthermore, future studies should further investigate potential effects of the living situation. These were not studied, as few participants had a family member living at home and this only included parents. This study provided important new insights in behavioral coping strategies. Future research could also investigate differences and overlap in use and effects with cognitive coping strategies, and how the effects of a strategy might be influenced by the use of other strategies (Adams et al. 2018; Kraaij and Garnefski 2019). This knowledge could facilitate cognitive behavioral interventions as well.

Conclusion and implications

This study showed that the use of coping strategies could buffer or pose a risk to relatives' quality of life during the COVID-19 pandemic. Overall, relatives most frequently used the coping strategies seeking distraction and actively approaching, which were adaptive for their quality of life during the pandemic. Mothers, however, made less use of these coping strategies than fathers or siblings. The maladaptive strategy withdrawal was the least used strategy, and the tendency to implement this strategy decreased with age. Additionally, relatives might experience difficulties finding suitable social support, as seeking social support was related to a lower quality of life. This study therefore suggests that relatives could benefit from more social support, and that especially mothers could benefit from psychological help in learning to implement effective ways of coping. Changing the use of coping strategies has previously been linked to changes in wellbeing (Kim et al. 2003), and a problem-focused coping strategy training program yielded positive outcomes for mothers of people with Down syndrome (Pourmohamadreza-Tajrishi et al. 2015). It is vital to offer relatives, and especially mothers, these types of interventions to support them in their roles as caregivers and protect their own quality of life during major life events and crises similar to the COVID-19 pandemic.

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Disclosure statement

The authors report there are no competing interests to declare.

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Data availability statement

Data of the research project are available in DANS Data Station Social Sciences and Humanities at <https://doi.org/10.17026/dans-xsr-tp2v>. Additional data supporting the findings of this study are available from the corresponding author (EZ) upon reasonable request.

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Tables

Table 1. Demographics of participants and their family members with intellectual disabilities.

		N = 284	
		n	%
Age participants	≤65 years old	123	43
	66+ years old	161	57
Sex participants	Female	188	66
	Male	95	34
Relationship participant-family member	Mother*	118	43
	Father*	56	21
	Brother/sister (in law)	81	30
	Other	17	6
Age family members	5–25	37	14
	26–45	113	41
	46–65	90	33
	66–84	34	12
Sex family members	Female	124	45
	Male	150	55
Severity of intellectual disabilities	Mild	132	47
	Moderate	79	28
	Profound	67	24
Living situation of family members	Care organization	103	38
	Small-scale residential facility	110	41
	Family home	26	10
	Living independently	29	11

Note. Missing values are not included.

*This includes step parents, foster parents, adoptive parents, and parents-in-law.

Table 2. Mean scores of the use of coping strategies in total and by mothers, fathers, and siblings.

Coping strategy	Family					
	relationship	N	M	SD	Minimum	Maximum
Seeking distraction	Total	269	5.13	1.91	.63	10
	Mothers	115	4.88	1.94	.63	10
	Fathers	55	5.49	1.86	.63	9.38
	Siblings	79	5.32	1.96	1.25	10
Withdrawal	Total	270	1.57	1.81	0	10
	Mothers	116	1.71	2.02	0	10
	Fathers	56	1.24	1.58	0	6.67
	Siblings	78	1.37	1.53	0	7.50
Actively approaching	Total	265	4.84	2.05	0	10
	Mothers	113	4.62	1.90	0	9.38
	Fathers	56	4.71	2.16	.63	9.38
	Siblings	76	5.27	2.19	0	10
Seeking social support	Total	269	2.99	1.86	0	8.13
	Mothers	115	3.34	1.90	0	8.13
	Fathers	56	2.45	1.46	0	5.63
	Siblings	78	3.00	1.88	0	8.13
Ignoring	Total	270	2.73	2.16	0	10
	Mothers	115	2.70	2.26	0	10
	Fathers	56	2.70	2.11	0	8.75
	Siblings	79	2.67	2.10	0	9.38

Table 3. Results of three regression analyses of coping strategies, characteristics (i.e. family relationship, severity of disability, or age), and their interactions on quality of life.

	Family relationship											
	Mothers		Fathers		Siblings		Fathers vs mothers		Siblings vs mothers		Siblings vs fathers	
	b	t	b	t	b	t	b	t	b	t	b	t
Seeking distraction	1.671	2.31*	1.723	2.02*	0.843	0.91	0.053	0.05	-0.827	-0.71	-0.880	-0.70
Withdrawal	-3.249	-3.87**	-2.993	-1.98*	-2.959	-2.80**	0.256	0.15	0.291	0.22	0.034	0.02
Actively approaching	1.544	1.54	0.917	1.14	0.957	1.22	-0.627	-0.49	-0.586	-0.46	0.040	0.04
Seeking social support	-1.396	-1.71	-1.556	-1.21	-0.810	-0.87	-0.160	-0.11	0.586	0.48	0.746	0.47
Ignoring	-0.738	-0.98	0.512	0.68	-0.942	-1.28	1.250	1.17	-0.203	-0.19	-1.454	-1.38
Intercept/main effect comparisons between groups	59.919	13.94**	62.917	12.32**	70.908	12.46**	2.997	0.45	10.988	1.54	7.991	1.05
	Severity of disability											
	Mild		Moderate		Severe		Moderate vs mild		Severe vs mild		Severe vs moderate	
	b	t	b	t	b	t	b	t	b	t	b	t
Seeking distraction	0.876	1.17	1.168	1.57	2.663	2.27*	0.292	0.28	1.787	1.28	1.495	1.08
Withdrawal	-3.228	-4.53**	-4.312	-4.56**	-2.909	-1.87	-1.084	-0.92	0.319	0.19	1.402	0.77
Actively approaching	1.940	2.72**	1.076	1.13	0.635	0.64	-0.864	-0.73	-1.305	-1.07	-0.441	-0.32
Seeking social support	-1.538	-2.14*	-1.936	-1.95	-0.427	-0.40	-0.398	-0.32	1.111	0.86	1.510	1.03
Ignoring	-0.246	-0.39	-0.624	-0.94	-0.802	-0.66	-0.378	-0.41	-0.556	-0.41	-0.178	-0.13
Intercept/main effect comparisons between groups	63.175	16.15**	70.664	17.09**	58.395	7.74**	7.488	1.32	-4.781	-0.56	-12.269	-1.43
	Mean age of relatives											
	Mean age:											
	b	t										
Seeking distraction	1.568	3.16**										
Withdrawal	-3.305	-5.88**										
Actively approaching	1.435	2.80**										
Seeking social support	-1.382	-2.88**										
Ignoring	-0.334	-0.76										
Main effect of mean age	0.519	2.10*										
Mean age* Seeking distraction	-0.025	-0.46										
Mean age* Withdrawal	0.040	1.00										
Mean age* Actively approaching	-0.044	-0.74										
Mean age* Seeking social support	-0.023	-0.59										
Mean age* Ignoring	-0.058	-1.63										
Intercept	62.276	22.29**										

*p < .05; **p < .01.