



Assessing the quality of support and discovering sources of resilience during COVID-19 measures in people with intellectual disabilities by professional carers

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ABSTRACT

Background: During COVID-19 measures face-to-face contact is limited and professional carers have to find other ways to support people with intellectual disabilities. COVID-19 measures can increase stress in people with intellectual disabilities, although some people may adapt to or grow from these uncertain situations. Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress and trauma. The current study aims to provide professional carers with new insights into how they can support people with intellectual disabilities.

Method: An online survey was shared through the social media and organizational newsletters of MEE ZHN (a non-governmental organization for people with disabilities). The resilience framework by Ungar (2019) was adapted to fit to people with intellectual disabilities during COVID-19 measures. Statistical analyses were performed in SPSS statistics version 26.

Results: Results show that professional carers applied diverse and distal methods to maintain contact with people with intellectual disabilities during the COVID-19 measures. Professional carers reported a significant decrease in the quality of contact with clients with intellectual disabilities, but overall high levels of resilience in the same clients.

Implications: Online methods of communication are possibly insufficient for professionals to cover all needs of people with intellectual disabilities. During this pandemic professionals should be aware of stress but also of resilience in people with intellectual disabilities.

What this paper adds?

In the current study alternative methods of maintaining high quality contact with people with intellectual disabilities (ID) during COVID-19 measures are evaluated and new insights are presented on how people with ID deal with COVID-19 measures from the perspective of resilience. Professional carers evaluated how they adapted their means of communication with their clients and rated the quality of this contact. Furthermore when dealing with COVID-19 measures, besides negative aspects of the pandemic, professionals report about client resilience. Emphasizing resilience could help professional carers and clients with ID to cope better with the impact of the pandemic. In the current study it is shown how the resilience framework of Ungar (2019) can be adapted and used by professional carers when supporting people with ID. People with ID should be encouraged to recognize their own sources of resilience

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and find ways to expand these sources. Recognizing and emphasizing resilience can help to improve client quality of life.

1. Introduction

Since the outbreak of COVID-19 (coronavirus disease 2019) everyday life has changed significantly. A global pandemic has evolved due to international spread of the disease (Vinkers et al., 2020; Zhou et al., 2020). The greatest worry for health care is not just the spreading of the disease but also the limited number of people who can be admitted to Intensive Care Units in hospitals, putting the health care system under serious pressure (Verelst et al., 2020). To avoid the further spread of the disease stringent measures are taken in countries worldwide. One of the consequences of these measures is that vulnerable people become more isolated with high risks for mental health problems (Druss, 2020; Torales et al., 2020).

The COVID-19 pandemic is stressful for most people for a number of reasons. People fear becoming ill or losing someone close to them. Some people have lost their jobs, are experiencing financial distress or are simultaneously balancing work with childcare. These changes may result in higher levels of stress and stress-related symptoms (Fiorillo & Gorwood, 2020; Fofana et al., 2020; Vinkers et al., 2020). The increased risk for experiencing stress in people with ID when dealing with COVID-19 measures has been highlighted in a number of studies (Bertelli et al., 2020/2020; Rose et al., 2020). For instance, for people with ID it is often not possible to work from home or to attend activities in day care centres due to the nature of their (work) activities. Daily activities provide emotional security in everyday life through structure, a sense of belonging, and achievement (Scheffers et al., 2020a). Unfortunately, we expect that without these daily activities it is very hard for people with ID to organise a daily structure and find distraction from negative thoughts.

Up to half of people with ID already experience chronic loneliness (Gilmore, & Cuskelly, 2014) and COVID-19 measures can put them at even higher risk of social isolation and loneliness (Courtenay, & Perera, 2020). Because of a lack of understanding, there is a high risk for people with ID to, although often unintentionally, display inappropriate behaviour leading to either conflict situations or to unnecessary avoidance of all social contact. Professional carers are often the most significant persons in the network of people with ID - not only offering practical but also emotional support (Giesbers et al., 2019; Scheffers et al., 2020a, 2020b). During COVID-19 measures people with ID will, amongst other people, rely on professional carers for emotional support and practical guidance in daily life (Embregts et al., 2020). However direct contact is often difficult because of the COVID-19 measures and professional carers have to explore new means of contact to support their clients.

Loneliness, confusion, fear, and incomprehension of what is going on can elevate stress in people with ID. Increased levels of stress may trigger emotional or psychiatric problems, self-harm, and outward directed aggressive behaviour in people with ID (Bertelli et al., 2020/2020). But, it is possible that not all people with ID will show negative symptoms. Some people may adapt to or grow from these uncertain situations. The process of effectively negotiating, adapting to, or managing significant sources of stress and trauma is called resilience (Windle, 2011). Three concepts are associated with resilience: 1) the occurrence of adversity, 2) the presence of internal and external resources to counter the effects of adversity and 3) the positive adaptation to or avoidance of a negative outcome (Windle, 2011). Resilience is a process that occurs within a system and is not an individual characteristic (Northway, 2017; Ungar, 2019). Research by Ungar (2019) shows that there is not one exclusive method to assess resilience since it is an unique process for every person depending on a variety of contextual factors. However, the Ungar framework can provide people with insight into their own internal and external resources of resilience.

Among the general population research on resilience dates back from the 1960s (Masten et al., 2002). However, recent systematic literature reviews identified only 15 articles on resilience in people with ID dated from 2006 onwards (Scheffers et al., 2020a, 2020b). In a review by Scheffers et al. (2020a), it was found that social connectedness is a key factor in facilitating resilience in people with ID. Resilience in people with ID can be promoted through having a supportive social network and by being able to perform daily activities. Contact with a professional carer can be a source of resilience, but is endangered by COVID-19 measures (Bertelli et al., 2020/2020; Courtenay, & Perera, 2020; Rose et al., 2020). The United Nations (2006) have urged for the importance of accessible and comprehensible information for people with ID, as was specifically addressed by the World Health Organization at the start of the global pandemic (World Health Organization, 2020). Whilst face to face contact is greatly reduced, people with ID are now reliant for receiving information about the COVID-19 measures from social media, newspapers, radio, and television (Courtenay, & Perera, 2020; Zaagsma et al., 2020). We would expect that, without adequate assistance, it is very difficult for people with ID to find comprehensible and reliable information and follow the COVID-19 measures adequately. Potentially, the lack of information or misinformation about COVID-19 measures may result in confusion in daily life and the loss of a sense of control.

Mortality rates overall are found to be significantly higher in people with ID compared to those in the general population (Heslop et al., 2015). A study by Cuyppers et al. (2020), found that mortality rates were up to three times higher in people with ID during an earlier epidemic, therefore it can be expected that people with ID are also at an increased risk during the COVID-19 epidemic. Since it could be a long time before an effective vaccine is available, it is important for professional carers to find alternative ways to support people with ID. And, since the COVID-19 measures have a direct effect on the level of social connectedness of people with ID (Bertelli et al., 2020/2020), further research is needed to enhance our understanding of resilience in people with ID during the COVID-19 pandemic. For the current study, it was not possible for researchers to meet people with ID in person due to the contagiousness of COVID-19. Since many people with ID have great difficulty reliably answering questions online or by telephone it was not possible to include people with ID themselves. Therefore the focus of the current study was on professional carers supporting clients with ID during the COVID-19 measures - who are often the most important persons in the network of people with ID (Giesbers et al., 2019). Two research questions were formulated with the intention of providing guidelines to professional carers for dealing with the next COVID-19 waves (Xu & Li, 2020).

The first research question of this study was: *How do professionals stay in contact with the people with ID they support and how do they*

rate the quality of this support compared to the situation before COVID-19 measures?

The second research question was: *Which sources of resilience are identified by professionals in people with ID during the COVID-19 measures?*

2. Method

2.1. Participants

A survey was completed by professional carers supporting people with ID during the first COVID-19 lockdown in The Netherlands. The National Institute for Health and Environment (RIVM; Rijksinstituut voor Volksgezondheid en Milieu) advises Dutch government, citizens, and professionals on specific COVID-19 measures (Rottinghuis, 2020). Next an overview is provided of Dutch measures from March 9th until June 1st 2020. (Table 1)

A total of 290 surveys were collected between April 21st and June 8th 2020. All professional carers (84.8 % female) were working with people with ID (16 years and older) before and during the first wave of COVID-19 measures. People with ID are a very heterogeneous group and the survey was open to anyone working as a professional in the field of social work who support people with ID. The average age of the participants was 43 years ($SD = 11.31$) and varied from 23 to 64 years. The average years of work experience was 15 ($SD = 10.95$) and ranged from 1 to 45 years.

Most participants worked in an organization or institution specialized in the care for people with ID (53.9 %). Further, participants reported working in an organization or institution specialized in the care for people with ID in combination with other psychiatric problems (30.9 %), youth care services (2.3 %), or an institution for mental health care (1.4 %). A total of 11.5 % percent of the participants specified their organization as 'other', namely: community services, institution for people with ID and behavioural problems, institution for people with ID and psychiatric or addiction problems, institution for people with psychiatric and judicial problems, and special education.

2.2. Procedure

The study was approved by the Ethical Committee of the University of Amsterdam. Data collection started on April 21st and ended on June 8th 2020. The link to the survey was shared on social media and in organization newsletters of MEE ZHN (a non-governmental organization for people with disabilities). Professionals were asked to share the link with colleagues. The survey started with a brief summary of the goals, a guarantee of anonymity, and a statement of informed consent. If respondents did not wish to participate in the study they could answer 'No, I do not want to participate'. The survey would then automatically stop. If respondents agreed: 'Yes, I do want to participate', they were directly led to the first question. Next the professional were asked to indicate whether this was the first or second time the survey was answered. Professional that answered the survey for a first time were directed to the start of the survey. After answering all questions it was possible for the professional to answer the questionnaire a second time regarding a different client. When professionals answered the survey for a second time the questions regarding demographics and the quality of the contact were skipped, only the questions regarding resilience in a specific client were answered again.

2.3. Sampling procedure

Since not all questions were answered entirely by all participants, two different datasets were created to answer both research

Table 1

Most important Dutch COVID-19 measures March 9th until June 1 st 2020 (Rottinghuis, 2020).

09 March 2020	12 March 2020	15 March 2020	11 May 2020	01 June 2020
Shaking hands and hugging no longer allowed.	Everyone (with the exception of people working in vital professional services) has to work from home and stay home as much as possible. All events with over 100 participants are prohibited. Everyone with symptoms (fever, coughing or a cold) has to stay home. Contact with older adults, physically vulnerable people and people with intellectual disabilities living in institutions is to be avoided.	Schools and childcare centers are closed (except for children of parents working in essential services). Restaurants, bars, sports clubs, sauna's, sex clubs and coffeeshops are closed. It is still possible to order from takeaway restaurants or bars. Social-distancing measures start. Everyone should keep 1.5 m distance from people from other households.	Elementary schools are opened again. Everyone can exercise outside. Sport competitions and the use of shared bathrooms are still prohibited. Professions working in so called contact professions can start working again with adequate measures.	People can meet each other if they keep 1,5 m distance. In all public accessible buildings up to 30 people are allowed to enter (for example, restaurants, bars, museums, theatres and cinemas) For everyone above the age of 13, the use of a face mask in public transportation is mandatory.

questions. See Fig. A1 (Appendix A) for a flowchart of the decision process. For the first research question - ‘How do professionals stay in contact with people with ID they support and how do they rate the quality of this support compared to the situation before COVID-19 measures?’ - 217 surveys were included. One hundred seventy-four surveys were fully completed, and some of the partially answered surveys were included ($n = 43$). Sixty-eight surveys were excluded as only the first two or three questions were answered ($n = 30$) or because the questions regarding the means of support and the quality of the contact during COVID-19 measures were missing ($n = 38$).

For the second research question - ‘Which sources of resilience do professionals identify in people with ID during the COVID-19 measures?’ - 175 completed surveys were analysed, including those of the 5 professionals who answered the questionnaire for a second client. Four surveys were excluded because the clients had no ID.

2.4. Instrumentation

Data were collected by means of an online survey. The survey was designed by a team of researchers with expertise on professional carers for people with ID. The survey started with questions concerning the demographics of the professional carer, i.e., gender, type of organization, the personal working conditions, and years of experience working with persons with ID. The next questions focused on how professionals adapted to the current COVID-19 measures and how these alterations affected the support they provided for the person with ID. To understand the context of the alteration, the means of contact before the COVID-19 measures and the quality of these contacts were also rated.

Finally, every professional was asked to share information anonymously about one specific client. As well as questions about the personal circumstances of this client (i.e., age in years, gender, housing situation, and the client’s level of intellectual functioning), questions were asked about resilience. In accordance with the resilience framework of Ungar (2019), the following sources of resilience were identified: 1) structure/routine, 2) consequences/ accountability, 3) intimate relationships, 4) other relationships, 5) a powerful identity, 6) a sense of control, 7) a sense of belonging/culture, 8) rights and responsibilities, 9) safety and security, 10) positive thinking, 11) physical well-being and 12) financial well-being. The wording of every source of resilience was adapted with regard to the COVID-19 measures; see Appendix B for a full overview. For all sources of resilience, professionals had to answer if their client with ID benefited from this specific source and if so rate the importance of the source on a scale from 1 (unimportant) to 10 (very important). Respondents were encouraged to add additional sources of resilience if applicable. The survey ended with an invitation for suggestions and remarks. Participants were also invited to answer the questions concerning resilience for a second client with ID.

2.5. Analytic strategy

Statistical analyses were performed in SPSS statistics version 26. Descriptive statistical analysis were conducted for both the first and second research question. The first research question - regarding the means and quality of support - was tested using a paired sample t-test. To evaluate the sources of resilience, the mean ratings reported by professional carers were compared to the total mean score.

3. Results

3.1. Means of support and quality of contact during COVID-19 measures

All participants were asked about the level of cognitive functioning of the clients they supported. Multiple answers were possible. The majority of professional carers supported clients with different levels of cognitive functioning. Most professional carers worked with people with mild ID (90.3 %). Further, 53.9 % of the professional carers reported working with people with moderate ID, 30.8 % with people with borderline intellectual functioning, 24 % with people with severe ID, and finally 12 % with people with profound ID. See Table 2 for an overview of the level of intellectual functioning of the persons with ID that professional carers supported.

All professional carers reported that they could still perform their work but a substantial number changed to working from home (49.3 %). Forty-three point three percent of the professional carers reported that they worked as an essential worker (i.e., people with professions that were deemed necessary to ensure everybody can be safe through the nationwide lockdown) and still travelled to their workplace. Finally, 7.4 % of professional carers stated that they were not considered to be essential workers but still travelled to their workplace.

An overview is presented in Table 3 of the different means of communication professional carers used before and during COVID-19

Table 2
Overview of the level of intellectual functioning professional carers support.*.

	Yes	No
Borderline	31.8 %	68.2 %
Mild	90.3 %	9.7 %
Moderate	53.9 %	46.1 %
Severe	24.0 %	67.0 %
Profound	12.0 %	88.0 %

* Note: multiple answering was possible.

measures. Professional carers could choose from seven different means of communication. When multiple answers were given the professional could rank answers from 1 (most frequently used) to 7 (least frequently used). Before the COVID-19 measures, 'face to face conversations' were the most frequently used method. During the COVID-19 measures 'face to face conversations' were significantly diminished, $t(113) = -4.50, p < .001, 95\% \text{ CI } [-0.97, -0.38], d = 0.45$, with a small to medium effect size. In contrast, some methods of support increased during COVID-19 measures significantly. The difference in use of telephone calls showed a small to medium positive effect, $t(136) = 4.20, p < .001, 95\% \text{ CI } [0.16, 0.45], d = 0.35$. Video calling increased significantly, $t(53) = 3.53, p = .001, 95\% \text{ CI } [0.32, 1.16], d = 0.43$, with a small to medium effect. The use of WhatsApp or text messaging also increased significantly, $t(113) = 2.00, p = .048, 95\% \text{ CI } [0.00, 0.34], d = 0.17$, however the effect size was small. There were no significant differences before and during COVID-19 measures in communication by means of e-mail, a family-member, or when there was no personal contact. When there was no personal contact the professional provided support by communication with a legal guardian or by communicating with another professional organizations.

The quality of the support was rated by the professional carers as 1 (very poor) to 5 (very good). Professional carers reported on average that the quality of contact before COVID-19 measures was significantly better ($M = 3.90; SD = 0.71$) than the quality of contact during the COVID-19 measures ($M = 3.08; SD = 0.71$) with a large effect size, $t(216) = 14.60, p < .001, 95\% \text{ CI } [0.71, 0.93], d = 1.15$.

3.2. Which sources of resilience can be identified in people with ID by professionals during the COVID-19 measures?

The professional carer had to indicate which sources of resilience were applicable during the COVID-19 measures in a specific client with ID by answering 'yes' or 'no'. The percentage of professional carers that answered 'yes' was calculated for each source of resilience. Percentages ranged from 39.3 to 85.9. The most frequently reported source of resilience of clients with ID by professional carers was 'positive thinking' (85.9 %), followed by 'other relationships' (82.8 %), and then 'intimate relationships' (68.1 %). For an overview of all sources and percentages see Table 4.

Next, carers rated the sources of resilience from 1 (unimportant) to 10 (very important) based on the importance of the source to their client. The ratings ranged from 3.75 to 9.50, with a total average of $M = 7.15, SD = 1.22$. For every source of resilience the mean rating was calculated and compared to the total average ($M = 7.15$). For an overview of all mean ratings see Table 5. The source 'structure and routine' received the highest mean rating ($M = 8.03, SD = 1.53$) and was found to be significantly more important compared to the total average, $t(143) = 5.73, p < .001, 95\% \text{ CI } [0.57, 1.18]$, with a medium effect size, $d = 0.64$. The sources 'intimate relationships' ($M = 7.83, SD = 2.13$), $t(142) = 3.83, p < .001, 95\% \text{ CI } [0.33, 1.03], d = 0.39$, and 'other relationships' ($M = 7.66, SD = 1.91$), $t(150) = 3.29, p = .001, 95\% \text{ CI } [0.20, 0.82], d = 0.32$, were also rated significantly more important than the total average by professional carers supporting clients with ID.

Some sources were considered significantly less important by professionals supporting people with ID: physical wellbeing ($M = 6.70, SD = 2.01$), $t(131) = -2.55, p = .012, 95\% \text{ CI } [-0.79, -0.10], d = 0.27$; a powerful identity ($M = 6.67, SD = 1.95$), $t(128) = -2.78, p = .006, 95\% \text{ CI } [-0.81, -0.14], d = 0.30$; consequences ($M = 6.63, SD = 1.81$), $t(130) = -3.27, p = .001, 95\% \text{ CI } [-0.83, -0.20], d = 0.34$; financial wellbeing ($M = 6.34, SD = 3.44$), $t(136) = -3.90, p < .001, 95\% \text{ CI } [-1.23, -0.40], d = 0.31$; rights and responsibilities ($M = 6.05, SD = 2.07$), $t(132) = -6.12, p < .001, 95\% \text{ CI } [-1.45, -0.74], d = 0.65$.

Additional sources of resilience that were considered by the professional carers as being important for their client with ID were: experiencing emotional security, caring for pets, (less) restrictions of freedoms, finding distraction through games, sports, or daily activities, continuation of face to face contact in real life, spirituality (praying), and carers who provided clear and understandable information regarding COVID-19 measures. It was mentioned by professional carers that COVID-19 measures also had some positive side-effects. According to professional carers there were less moments of transition in daily life which provided the client with more tranquility and stability.

4. Discussion

In the current study an online survey was administered to gain insight into two research questions. First, the means and the quality of communication between clients with ID and the professional supporting them during the COVID-19 measures. Second, the process of resilience during COVID-19 measures in people with ID as reported by their professional carers.

Table 3
Means Ranking of Communication Before and During COVID-19 Measures (the lower the number the more frequently used).

	Before COVID-19 measures		During COVID-19 measures		<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Telephone	2.28	0.83	1.97	0.92	0.000***
Video calling	3.33	1.88	2.59	1.56	0.001**
WhatsApp or text messages	2.75	0.96	2.58	1.01	0.048*
E-mail	3.58	1.16	3.74	1.42	0.230
Face to face conversations	1.54	1.28	2.22	1.70	0.000***
By means of a family member	3.60	1.68	3.60	1.69	1.000
No personal contact	4.85	2.35	4.52	2.50	0.078

Note: * $p < .05$, ** $p < .01$, *** $p < .001$.

Table 4

Percentages of sources of resilience as recognized by professional carers among people with ID (in order of frequency).

	Percentage 'Yes applies to my client'
Positive thinking	85.9 %
Other relationships	82.8 %
Intimate relationships	68.1 %
Safety and security	67.1 %
Financial wellbeing	64.8 %
Structure/ routine	63.0 %
Consequences/ accountability	55.3 %
Rights and responsibilities	54.3 %
A sense of belonging/culture	51.8 %
Physical wellbeing	50.3 %
A powerful identity	45.1 %
Experiencing a sense of control	39.3 %

Table 5

Sources of resilience in people with ID as rated by care professionals.

	Mean rating '1 (unimportant) to 10 (very important)'	SD
Structure/ routine	8.03***	1.53
Intimate relationships	7.83***	2.13
Other relationships	7.66**	1.91
Safety and security	7.40	1.72
Positive thinking	6.97	1.84
Experiencing a sense of control	6.97	2.09
A sense of belonging/culture	6.95	1.75
Physical wellbeing	6.70*	2.01
A powerful identity	6.67*	1.95
Consequences/ accountability	6.63**	1.83
Financial wellbeing	6.34***	3.44
Rights and responsibilities	6.05***	2.07

Note: The individual means scores for each source were compared to the total mean score (test value: 7.15) for all the sources * $p < .05$, ** $p < .01$, *** $p < .001$.

The first research question was: *How do professionals stay in contact with the people with ID they support and how do they rate the quality of this support compared to the situation before COVID-19 measures?* During COVID-19 measures a significant decrease in the use of face to face conversations was reported, as was an increase in the use of distal methods of support such as telephone calls, video calling, and WhatsApp or text messaging. These results support the findings by [Zaagsma et al. \(2020\)](#) that service providers for people with ID could benefit from the use of online and distal methods by increasing their responsiveness. Also by sending recorded video or sound messages the client could be enabled to relisten to conversations or advice in their own time, which could lead to a better understanding of information. Meanwhile service providers should also be aware of the risks of using online services. In a video call there could be other people in the room with the client that influences the contact. Thus, reliability of online assessment could potentially be endangered by third parties. It is therefore suggested that online and distal methods of support and assessment should be considered with care since they cannot replace onsite services ([Frielink et al., 2020](#)). Even so, they could offer an important addition to existing services ([Oudshoorn et al., 2020](#)).

This suggestion is also supported by the finding that the quality of contact from the perspective of the professional caregiver significantly decreased. As care professionals are often very important for people with ID, it is advised that organizations working with people with ID implement a protocol or policy on how to maintain direct contact during a pandemic. However it is important to keep in mind that current results are only based on the professional carer's perspective. Professional carers within disability services are often not used to offering distal support ([Buchholz et al., 2020](#)). Offering support through online services such as video-calling offers opportunities and risks at the same time ([Roos et al., 2020](#); [Seuren et al., 2020](#); [Zaagsma et al., 2020](#)), for instance in video-calling non-verbal signals can be interpreted differently through a delay in the response. This could lead to problems in turn-taking, uncomfortable silences or other difficulties in non-verbal attunement that would come naturally during face-to-face contact. Professional carers that are not aware of these risks could experience difficulties in maintaining high quality contact or interpret the social skills of the client incorrectly. Therefore, we could hypothesize that only carers themselves felt uncertain about the quality of contact. In the current study there is a lack of comparison of results based on client quality assessment. Nevertheless, organizations can offer support to the professional carers to improve online skills and facilitate sharing experiences by means of training courses, supervision and peer coaching ([Scheffers et al., 2020b](#)).

The second research question was: *Which sources of resilience are identified by professionals in people with ID during the COVID-19 measures?* A list of potential sources of resilience was used to gain insight into which sources were recognized by professional carers working with people with ID. The professional carers were also asked to rate the importance of these sources of resilience

relevant to their client.

Professional carers recognized many sources of resilience in people with ID during COVID-19 measures. *Positive thinking* by people with ID was the most recognized source of resilience by professional carers. In resilience research, positive emotions are widely recognized as an important source of resilience (Johnson et al., 2010; Mak et al., 2011; Ong et al., 2010). During a pandemic it is not abnormal to experience feelings of stress or anxiety, however focusing on positive thoughts and emotions could be a first step in the process of resilience (Yamaguchi et al., 2020). In a review by Scheffers et al. (2020b), it was shown that professional carers report positive emotions as important in facilitating resilience in people with ID. However, positive thinking or positive emotions were not identified as a source of resilience in self-reports by people with ID (Scheffers et al., 2020a). It is hypothesized that professional carers could have an important role in making people with ID aware of their positive thoughts to reinforce their capacity for resilience.

The importance of social connectedness was captured by the sources '*other relationships*' and '*intimate relationships*'. Both sources were recognized as very important by care professionals and also received some of the highest ratings. Strong communities are of utmost importance when dealing with adversities such as COVID-19 (Chen & Bonanno, 2020; PeConga et al., 2020). Developing a feeling that 'we are in this together' helps people to find meaning in adversity. In people with ID the support network could reinforce this feeling by showing how to deal with COVID-19 measures in a positive way. For instance, by valuing the work of the health care workers verbally or by crafting banners to hang in front of the window or by offering practical support by making face masks. Studies on resilience during COVID-19 measures also emphasize the importance of maintaining social support (Chen & Bonanno, 2020). Offering online support is mentioned as a way of maintaining contact when direct contact is not possible (Chen & Bonanno, 2020). In the current study, we found that professional carers reported that the quality of the contact decreased when using more online and distal methods of support. Online support could be a possible addition to the direct contact with people with ID. However, it cannot fully replace face to face conversations because, for example, non-verbal cues cannot be properly read through (video)calling or by using WhatsApp. Since people with ID are prone to giving socially desirable answers, direct contact may be necessary in order to notice all non-verbal cues (Perry, 2004; Roos et al., 2020; Seuren et al., 2020).

For many people with ID, daily structure and routine cannot be continued because of COVID-19 measures because it may not be possible for them to work from home or it may not be possible for them to attend activities in day care centres (Bertelli et al., 2020/2020). In the current study *structure and routine* was rated as very important. Experiencing structure offers a feeling of safety through predictability in daily life. Especially in uncertain times it is important to experience a sense of control. Structured daily activities also offer distraction from feelings of stress and anxiety (Conder et al., 2015; Taggart et al., 2009). Some professional carers suggested that people with ID sometimes benefit from COVID-19 measures since there are less moments of transition, which may lead to more stability in daily life. These new insights could be used in the aftermath of the COVID-19 pandemic to evaluate the organisation of structured activities for people with ID.

Some sources of resilience were considered significantly less important by professional carers: *physical wellbeing*, *financial wellbeing*, *a powerful identity*, *consequences and*, *rights and responsibilities*. Since the current study focused on the perspective of the professional carer, these results suggest that professional carers perceive these sources of resilience as less important when supporting people with ID. But, in a review on self-reported sources of resilience in people with ID, *physical wellbeing* was mentioned as an important source of resilience as well as *successfully dealing with money* as a way to achieve a feeling of autonomy (Scheffers et al., 2020a). With regard to the nature of the sources *a powerful identity*, insight into *consequences*, and *rights and responsibilities*, a high degree of complex social skills and mental fitness is expected to be necessary. It is possible that these sources of resilience are overlooked by professional carers or that they underestimate the capacities of clients with respect to these skills. It is important for professional carers to apply a resilience based perspective assessing and working on client sources of resilience in daily practice to gain a mutual understanding of the needs of a person. The framework of Ungar (2019) could be used by professional carers for this purpose. In this study the Ungar framework was adapted to be used by Dutch professionals working with people with ID in times of a global pandemic. It remains unclear if the subjects of this study are representative for all persons with ID in the Netherlands. On an individual level, one must always take into account the unique properties of an individuals' environment, the availability of resources, and the cultural background of a person. As a result, the best mix of resources can differ between individuals. The current framework can best be used as a starting point to question sources of resilience in a person with ID. On a systemic level, the current findings can be used to adapt policies and to provide information for the development of guidelines for organizations and institutions who work with people with ID.

Several limitations should be mentioned concerning the current study. The experiences of people with ID themselves were not researched and it is therefore unclear if people with ID also experience a decrease in quality of contact and would assess their sources of resilience similarly to their professional carer. To gain a fuller understanding future research should include the perspectives of people with ID themselves and of the important people in their social support network. In the current study resilience in people with ID was assessed through professional carers, who mostly worked with people with mild ID. Therefore, more research is needed to better understand resilience of people with different levels of ID (Scheffers et al., 2020a; Scheffers et al., 2020b). For instance, it remains unclear whether people with mild ID use different sources of resilience compared to typically developed people or compared to people with moderate, severe, or profound ID. Finally, results were gathered during the first Dutch COVID-19 lockdown and additional COVID-19 measures implemented by individual service providers were not accounted for. As the pandemic continues, measures alter on a regular basis and thus results should be interpreted with caution.

In sum, current COVID-19 measures influence the communication between professional carers and the persons with ID that they support. Online methods of communication may be insufficient to cover all needs of people with ID. The results of this research could help professionals and their organisations to reflect on their means of communication and the quality of contact they have with the people with ID that they support. Furthermore results can offer a means of reflection on how people with ID deal with adversity. As not all possible resources of resilience are always considered and professional carers have an important role in supporting people with ID, it

is suggested that they communicate with people with ID about the sources of resilience available to them and identify what sources of resilience are truly important to people with ID.

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CRediT authorship contribution statement

Femke Scheffers: Conceptualization, Methodology, Formal analysis, Data curation, Writing - original draft, Writing - review & editing. **Xavier Moonen:** Conceptualization, Methodology, Writing - review & editing, Supervision. **Eveline van Vugt:** Writing -

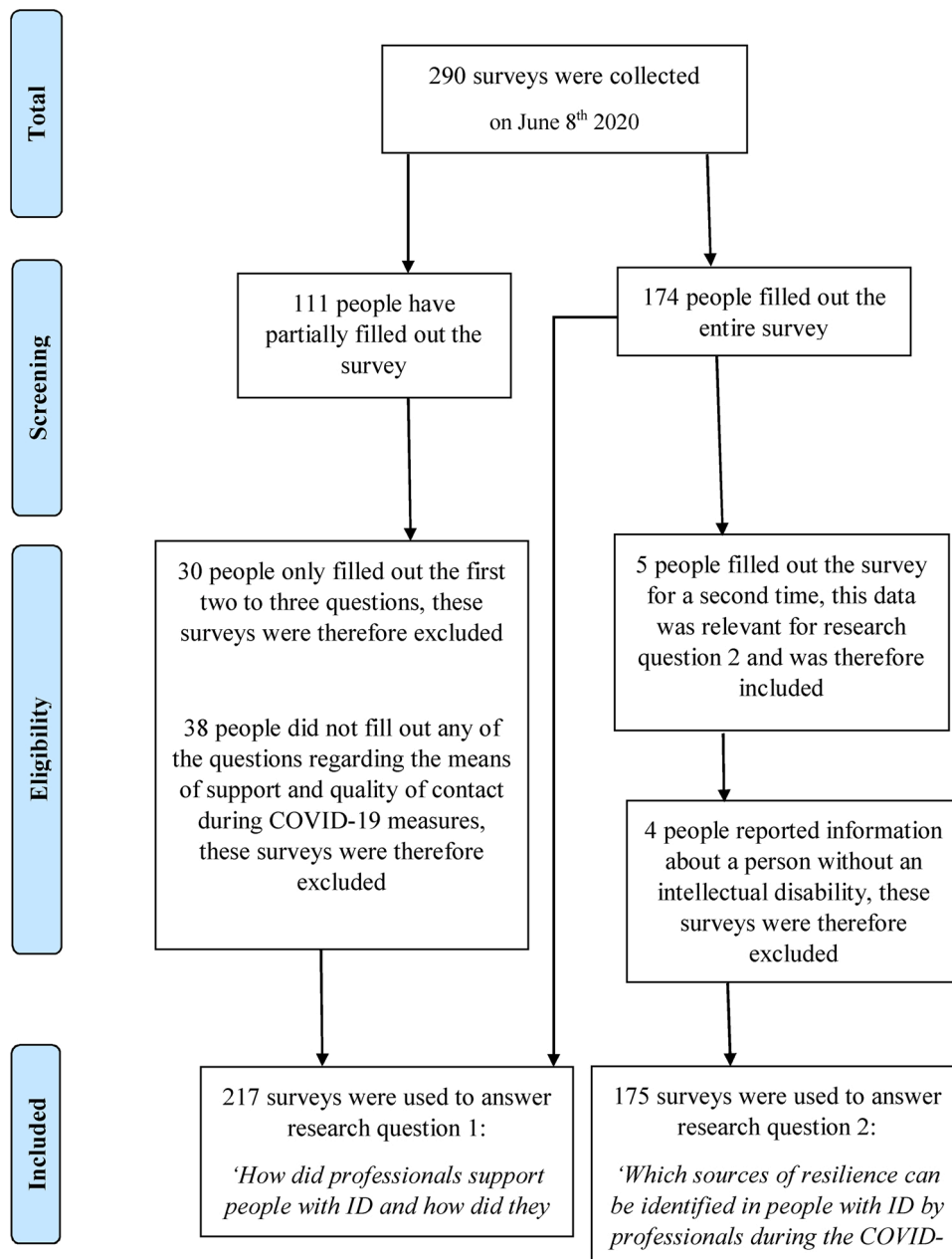


Fig. A1. Flowchart of the selection of surveys that were used per research question.

review & editing, Supervision.

Appendix A

Appendix B. Overview of the sources of resilience adapted to COVID-19 measures

Source of resilience	Question Explanation
Structure	Does the client have a day structure during the COVID-19 measures? <i>Structure helps to deal with chaos through a sense of predictability security is created. Fixed routines and clear expectations enable people to function better during periods of chaos.</i>
Consequences	Does the client have insight into the consequences of measures associated with the spread of COVID-19? Are there realistic expectations about the consequences of COVID-19? Clear expectations create a certain degree of predictability of the world. <i>Everyone sometimes makes mistakes, because clear consequences follow, one is able to learn from this. This also means that people have clear expectations of the world.</i>
Intimate relationships	Does the client experience unconditional love from at least one person? <i>Unconditional love is an important foundation for resilience. Even if someone is no longer physically present in our lives, the memory of ever being loved can suffice. This also applies if someone no longer has physical contact due to the COVID-19 measures, but does have someone in his / her life who gives him / her unconditional love.</i>
Other relationships	Is there a support network available to answer client' questions and to talk to (may also be online) during COVID-19 measures? <i>We all need a community to belong to: family, colleagues, volunteer work, an association, or another group of people where we feel needed. As a result, people experience support during setbacks. It is important that there is still contact even though physical contact is not possible (e.g.: telephone, WhatsApp, video calling or other methods)</i>
Identity	Does the client have a strong sense of identity? Does the client accept himself as a person with both qualities and limitations? <i>An "identity" is about someone having a coherent image of themselves. The image you have of yourself determines how you deal with setbacks, this is partly formed in interaction with others in your environment.</i>
Control	Does the client have a sense of control over his / her own life? Or does the client experience despair because it is not possible to make your own choices through the COVID-19 measures? <i>When people feel in control of life, a greater sense of control is created. This is reinforced, for example, because you can make choices yourself. Control is helpful in dealing with setbacks.</i>
Belonging, spirituality, sense of culture.	Does the client have the feeling that he "belongs" somewhere? <i>There are many different ways through which a person can develop a sense of belonging. This can arise through an association / club, work, spirituality and specific cultural communities etc. A sense of "connectedness with others" and "belonging" makes it easier to deal with setbacks.</i>
Rights and responsibilities	Does the client know what his / her rights are during COVID-19 measures? And does the client take responsibility for himself with regard to the COVID-19 measures? <i>There is a sense of responsibility for one's own actions. One feels responsible for his own actions, one also feels responsible for (possible) persons who are in their care in the context of COVID-19. Think of: keeping a 1.5 m distance, reducing social contact and staying at home as much as possible.</i>
Safety and security	Does the client experience a sense of safety during COVID-19? <i>Feeling safe and being able to rely on others helps us find the right sources of resilience. It is important to know that our home and our community are safe. This allows us to ask for help. Consider, for example: confidence that the government is making the right decisions and that sufficient good care can be provided if you are ill.</i>
Positive thoughts	Does the client have hope that the COVID-19 measures will come to an end? <i>Positive thoughts help us keep hope in difficult situations. From a realistic expectation and positive thoughts one can develop hope and optimism for the future.</i>
Physical well-being	Can the client adequately monitor their own physical health during the COVID-19 measures? <i>Physical health refers to a healthy diet, sufficient physical activity, and timely contact with a GP if there are physical complaints. Does the person concerned know what measures to take if there are symptoms related to COVID-19? Does the person concerned ensure that he / she eats healthy and gets enough exercise?</i>
Financial well-being	Does the client have sufficient financial resources to take care of himself and (if applicable) other family members? <i>By having enough money we manage to support ourselves as well as possible family members. How much money is enough depends on the social norms of the community around us. The person concerned may have lost his / her work due to the COVID-19 measures. Has the person involved organized a benefit or does he / she know who can help him / her?</i>

Note: This overview is based on the framework of resilience by [Ungar \(2019\)](#).

References

- Bertelli, M. O., Scuticchio, D., Bianco, A., Buonaguro, E. F., Laghi, F., Ghelma, F., Rossi, M., Vannucchi, G., Cavagnola, R., Chiodelli, G., Corti, S., Leoni, M., Gusso, S., Cappa, C., Filighera, L., Simone, S., Zunino, M., Belotti, R., Perrone, F., ... Chiodelli, G. (2020). *Tips voor het omgaan met de psychologische effecten bij mensen met een verstandelijke beperking en/of autisme van de maatregelen tegen de verspreiding van het coronavirus in Nederland* [Tips for dealing with the psychological effects in people with intellectual disabilities and / or autism of the measures against the spread of the coronavirus in the Netherlands.] (J. Wieland, Trans.) (Original work Published in 2020).

- Buchholz, M., Ferm, U., & Holmgren, K. (2020). Support persons' views on remote communication and social media for people with communicative and cognitive disabilities. *Disability and Rehabilitation*, 42(10), 1439–1447. <https://doi.org/10.1080/09638288.2018.1529827>.
- Chen, S., & Bonanno, G. A. (2020). Psychological adjustment during the global outbreak of COVID-19: A resilience perspective. *Psychological Trauma Theory Research Practice and Policy*, 12(S1), S51–S54. <https://doi.org/10.1037/tra0000685>.
- Conger, J. A., Mirfin-Veitch, B. F., & Gates, S. (2015). Risk and resilience factors in the mental health and well-being of women with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 572–583. <https://doi.org/10.1111/jar.12153>.
- Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: Impacts of a pandemic. *Irish Journal of Psychological Medicine*, 1–21. <https://doi.org/10.1017/jipm.2020.45>.
- Cuyppers, M., Schalk, B. W. M., Koks-Leensen, M. C. J., Nägele, M. E., Bakker-van Gijssel, E. J., Naaldenberg, J., & Leusink, G. L. (2020). Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic. *Journal of Intellectual Disability Research*.
- Druss, B. G. (2020). Addressing the COVID-19 pandemic in populations with serious mental illness. *JAMA Psychiatry*, 77(9), 891–892. <https://doi.org/10.1001/jamapsychiatry.2020.0894>.
- Embregts, P. J., Tournier, T., & Frielink, N. (2020). Experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic: A thematic analysis. *Journal of Applied Research in Intellectual Disabilities*. <https://doi.org/10.1111/jar.12812>.
- Fiorillo, A., & Gorwood, P. (2020). The consequences of the COVID-19 pandemic on mental health and implications for clinical practice. *European Psychiatry*, 63(1). <https://doi.org/10.1192/j.eurpsy.2020.35>.
- Fofana, N. K., Latif, F., Sarfraz, S., Bashir, M. F., & Komal, B. (2020). Fear and agony of the pandemic leading to stress and mental illness: An emerging crisis in the novel coronavirus (COVID-19) outbreak. *Psychiatry Research*, 291, Article 113230. <https://doi.org/10.1016/j.psychres.2020.113230>.
- Frielink, N., Oudshoorn, C. E., & Embregts, P. J. (2020). eHealth in support for daily functioning of people with intellectual disability: Views of service users, relatives, and professionals on both its advantages and disadvantages and its facilitating and impeding factors. *Journal of Intellectual & Developmental Disability*, 45(3), 1–11. <https://doi.org/10.3109/13668250.2020.1744878>.
- Giesbers, S. A., Hendriks, L., Jahoda, A., Hastings, R. P., & Embregts, P. J. (2019). Living with support: Experiences of people with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 446–456. <https://doi.org/10.1111/jar.12542>.
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>.
- Heslop, P., Lauer, E., & Hoghton, M. (2015). Mortality in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 367–372. <https://doi.org/10.1111/jar.12196>.
- Johnson, K. J., Waugh, C. E., & Fredrickson, B. L. (2010). Smile to see the forest: Facially expressed positive emotions broaden cognition. *Cognition & Emotion*, 24(2), 299–321. <https://doi.org/10.1080/02699930903384667>.
- Mak, W. W., Ng, I. S., & Wong, C. C. (2011). Resilience: Enhancing well-being through the positive cognitive triad. *Journal of Counseling Psychology*, 58(4), 610. <https://doi.org/10.1037/a0025195>.
- Masten, A. S., Cutuli, J. J., Herbers, J. E., & Reed, M. G. J. (2002). Resilience in development. In S. J. Lopez, & C. R. Snyder (Eds.), *Handbook of positive psychology* (2nd ed., pp. 117–131).
- Northway, R. (2017). Developing resilience or challenging harm? *Journal of Intellectual Disabilities*, 21(4), 275–276. <https://doi.org/10.1177/1744629517732904>.
- Ong, A. D., Bergeman, C. S., & Chow, S. M. (2010). Positive emotions as a basic building block of resilience in adulthood. In J. W. Reich, A. J. Zatra, & J. S. Hall (Eds.), *Handbook of adult resilience* (pp. 81–93). Guilford Press.
- Oudshoorn, C. E., Frielink, N., Nijs, S. L., & Embregts, P. J. (2020). eHealth in the support of people with mild intellectual disability in daily life: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 33(6), 1166–1187. <https://doi.org/10.1111/jar.12758>.
- PeConga, E. K., Gauthier, G. M., Holloway, A., Walker, R. S. W., Rosencrans, P. L., Zoellner, L. A., & Bedard-Gilligan, M. (2020). Resilience is spreading: Mental health within the COVID-19 pandemic. *Psychological Trauma Theory Research Practice and Policy*, 12(1), 47–48. <https://doi.org/10.1037/tra0000874>.
- Perry, J. (2004). Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, T. Thompson, & T. Parmenter (Eds.), *International handbook of applied research in intellectual disabilities* (pp. 115–132). John Wiley & Sons Ltd.
- Roos, C. A., Postmes, T., & Koudenburg, N. (2020).). The microdynamics of social regulation: Comparing the navigation of disagreements in text-based online and face-to-face discussions. *Group Processes & Interpersonal Relations*, 23(6), 902–917. <https://doi.org/10.1177/1368430220935989>.
- Rose, J., Willner, P., Cooper, P. E., Langdon, P. E., Murphy, G. H., & Stenfort Kroese, B. (2020). The effect on and experience of families with a member who has Intellectual and Developmental Disabilities of the COVID-19 pandemic in the UK: Developing an investigation. *International Journal of Developmental Disabilities*, 1–3. <https://doi.org/10.1080/20473869.2020.1764257>.
- Rottinghuis, K. (2020). *Drie maanden corona in Nederland een overzicht van de maatregelen*. April 20 Translation: Three months of corona in the Netherlands, an overview of the measures. NRC <https://www.nrc.nl/nieuws/2020/04/20/twee-maanden-corona-in-nederland-een-overzicht-van-de-maatregelen-a3995447>.
- Scheffers, F., van Vugt, E., & Moonen, X. (2020a). Resilience in the face of adversity in adults with an intellectual disability: A literature review. *Journal of Applied Research in Intellectual Disabilities*, 33(5), 828–838. <https://doi.org/10.1111/jar.12720>.
- Scheffers, F., van Vugt, E., & Moonen, X. (2020b). External sources promoting resilience in adults with intellectual disabilities: A systematic literature review. *Journal of Intellectual Disabilities*. <https://doi.org/10.1177/1744629520961942>.
- Seuren, L. M., Wherton, J., Greenhalgh, T., & Shaw, S. E. (2020).). Whose turn is it anyway? Latency and the organization of turn-taking in video-mediated interaction. *Journal of Pragmatics*, 172, 63–78. <https://doi.org/10.1016/j.pragma.2020.11.005>.
- Taggart, L., McMillan, R., & Lawson, A. (2009). Listening to women with intellectual disabilities and mental health problems: A focus on risk and resilient factors. *Journal of Intellectual Disabilities*, 13(4), 321–340. <https://doi.org/10.1177/1744629509353239>.
- Torales, J., O'Higgins, M., Castaldelli-Maia, J. M., & Ventriglio, A. (2020). The outbreak of COVID-19 coronavirus and its impact on global mental health. *The International Journal of Social Psychiatry*, 66(4), 317–320. <https://doi.org/10.1177/0020764020915212>.
- Ungar, M. (2019). *Change your world: The science of resilience and the true path to success*. Sutherland House.
- United Nations. (2006). *Convention on the rights of persons with disabilities*. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>.
- Verelst, F., Kuylens, E., & Beutels, P. (2020). Indications for healthcare surge capacity in European countries facing an exponential increase in coronavirus disease (COVID-19) cases, March 2020. *Eurosurveillance*, 25(13), 2000323. <https://doi.org/10.2807/1560-7917.ES.2020.25.13.2000323>.
- Vinkers, C. H., van Amelsvoort, T., Bisson, J. I., Branchi, I., Cryan, J. F., Domschke, K., Manchia, M., Pinto, L., de Quervain, D., Schmidt, M. V., & van der Wee, N. (2020). Stress resilience during the coronavirus pandemic. *European Neuropsychopharmacology*, 35, 12–16. <https://doi.org/10.1016/j.euroneuro.2020.05.003>.
- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, 21(2), 152–169. <https://doi.org/10.1017/S0959259810000420>.
- World Health Organization. (2020). *Disability considerations during the COVID-19 outbreak* (No. WHO/2019-nCoV/Disability/2020.1). World Health Organization.
- Xu, S., & Li, Y. (2020). Beware of the second wave of COVID-19. *Lancet*, 395(10233), 1321–1322. [https://doi.org/10.1016/S0140-6736\(20\)30845-X](https://doi.org/10.1016/S0140-6736(20)30845-X).
- Yamaguchi, K., Takebayashi, Y., Miyamae, M., Komazawa, A., Yokoyama, C., & Ito, M. (2020). Role of focusing on the positive side during COVID-19 outbreak: Mental health perspective from positive psychology. *Psychological Trauma Theory Research Practice and Policy*, 12(1), 49. <https://doi.org/10.1037/tra0000807>.
- Zaagsma, M., Volkers, K. M., Swart, E. A. K., Schippers, A. P., & Van Hove, G. (2020). The use of online support by people with intellectual disabilities living independently during COVID-19. *Journal of Intellectual Disability Research*, 64(10), 750–756. <https://doi.org/10.1111/jir.12770>.
- Zhou, F., Yu, T., Du, R., Fan, G., Liu, Y., Liu, Z., ... Cao, B. (2020). Clinical course and risk factors for mortality of adult inpatients with COVID-19 in Wuhan, China: A retrospective cohort study. *Lancet*, 395(10229), 154–1062. [https://doi.org/10.1016/S0140-6736\(20\)30566-3](https://doi.org/10.1016/S0140-6736(20)30566-3).