



Universiteit
Leiden
The Netherlands

Effect of stress-based interventions on the quality of life of people with an intellectual disability and their caregivers

Hesselmans, S.; Meiland, F.J.M.; Adam, E.; Cruijs, E. van de; Vonk, A.; Oost, F. van; ... ; Meinders, E.R.

Citation

Hesselmans, S., Meiland, F. J. M., Adam, E., Cruijs, E. van de, Vonk, A., Oost, F. van, ... Meinders, E. R. (2023). Effect of stress-based interventions on the quality of life of people with an intellectual disability and their caregivers. *Disability And Rehabilitation: Assistive Technology*.
doi:10.1080/17483107.2023.2287161

Version: Publisher's Version
License: [Creative Commons CC BY 4.0 license](#)
Downloaded from: <https://hdl.handle.net/1887/3731251>

Note: To cite this publication please use the final published version (if applicable).



Effect of stress-based interventions on the quality of life of people with an intellectual disability and their caregivers

Sep Hesselmans, Franka J. M. Meiland, Esmee Adam, Erwin van de Cruijs, Arthur Vonk, Fransje van Oost, Dwayne Dillen, Stefan de Vries, Eric Riegen, Reon Smits, Nanda de Knegt, Hanneke J. A. Smaling & Erwin R. Meinders

To cite this article: Sep Hesselmans, Franka J. M. Meiland, Esmee Adam, Erwin van de Cruijs, Arthur Vonk, Fransje van Oost, Dwayne Dillen, Stefan de Vries, Eric Riegen, Reon Smits, Nanda de Knegt, Hanneke J. A. Smaling & Erwin R. Meinders (30 Nov 2023): Effect of stress-based interventions on the quality of life of people with an intellectual disability and their caregivers, *Disability and Rehabilitation: Assistive Technology*, DOI: [10.1080/17483107.2023.2287161](https://doi.org/10.1080/17483107.2023.2287161)

To link to this article: <https://doi.org/10.1080/17483107.2023.2287161>



Published online: 30 Nov 2023.



Submit your article to this journal [↗](#)



Article views: 161



View related articles [↗](#)



View Crossmark data [↗](#)



PRODUCT REVIEW

Effect of stress-based interventions on the quality of life of people with an intellectual disability and their caregivers

Sep Hesselmans^a, Franka J. M. Meiland^{b,c}, Esmee Adam^{b,d}, Erwin van de Crujjs^a, Arthur Vonk^a, Fransje van Oost^a, Dwayne Dillen^a, Stefan de Vries^a, Eric Riegen^a, Reon Smits^a, Nanda de Knegt^e, Hanneke J. A. Smaling^{b,d} and Erwin R. Meinders^a

^aMentech, Eindhoven, The Netherlands; ^bDepartment of Public Health and Primary Care, Leiden University Medical Center, Leiden, The Netherlands; ^cDepartment of Medicine for Older People, Amsterdam UMC, Location VUmc, Amsterdam Public Health Research Institute, Amsterdam, The Netherlands; ^dUniversity Network of the Care Sector Zuid Holland, Leiden, The Netherlands; ^ePrinsentichting, Care Center for People with Intellectual Disabilities, Purmerend, The Netherlands

ABSTRACT

Purpose: People with intellectual disabilities often show challenging behaviour, which can manifest itself in self-harm or aggression towards others. Real-time monitoring of stress in clients with challenging behaviour can help caregivers to promptly deploy interventions to prevent escalations, ultimately to improve the quality of life of client and caregiver. This study aimed to assess the impact of real-time stress monitoring with HUME, and the subsequent interventions deployed by the care team, on stress levels and quality of life.

Materials and methods: Real-time stress monitoring was used in 41 clients with intellectual disabilities in a long-term care setting over a period of six months. Stress levels were determined at the start and during the deployment of the stress monitoring system. The quality of life of the client and caregiver was measured with the Outcome Rating Scale at the start and at three months of use.

Results: The results showed that the HUME-based interventions resulted in a stress reduction. The perceived quality of life was higher after three months for both the clients and caregivers. Furthermore, interventions to provide proximity were found to be most effective in reducing stress and increasing the client's quality of life.

Conclusions: The study demonstrates that real-time stress monitoring with the HUME and the following interventions were effective. There was less stress in clients with an intellectual disability and an increase in the perceived quality of life. Future larger and randomized controlled studies are needed to confirm these findings.

> IMPLICATIONS FOR REHABILITATION

- Assistive technology such as real-time stress monitoring enables caregivers to timely intervene and contributes to the reduction of challenging behaviour.
- Real-time stress monitoring contributes to the quality of life of clients and caregivers in healthcare.
- There is a reduction in the levels of stress of people with an intellectual disability by using stress-monitoring technology.

ARTICLE HISTORY

Received 21 December 2022
Revised 3 November 2023
Accepted 18 November 2023

KEYWORDS

Stress; intellectual disability care; wearables; artificial intelligence; challenging behaviour; quality of life

Introduction

Intellectual disability

Deficits in intellectual and adaptive functioning are the main characteristics of intellectual disability [1,2]. The onset of intellectual and adaptive deficits has their start during the developmental period from infancy thorough adolescence [3]. The World Health Organization classifies intellectual disability as; "Disorders of intellectual development are a group of etiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and adaptive behaviour that are approximately two or more standard deviations below the mean (approximately less than the 2nd/3rd percentile), based on appropriately normed, individually administered standardized tests" [4]. Persons with an

intelligence quotient (IQ) ≤ 50 are considered to have severe intellectual disability, whereas, persons with an IQ >50 are considered to have mild intellectual disability. Persons with profound ID have IQ less than 20–25 [5,6]. An underlying genetic, biological or neurological can be identified in more than 75% of persons with a severe intellectual disability [3]. Some disorders, such as Autism Spectrum Disorder, Depressive Disorders, Dementia, and Attention Deficit Hyperactivity Disorder, occur more commonly than in the general population [5].

Challenging behaviour

People with an intellectual disability have deficits in cognitive abilities, such as reasoning, problem-solving, learning, and understanding. These limitations can significantly affect individuals' daily

functioning and their ability to adapt to and to interact with their environment. People with an intellectual disability show often challenging behaviour [7,8]. Challenging behaviour is defined as 'behavior of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion' [9]. Examples of challenging behaviour include aggression, apathy, self-injury, and resistance to care. A recent survey among Dutch professional caregivers showed a prevalence of 37–86% of challenging behaviour in people with an intellectual disability [10].

Challenging behaviour has negative consequences on quality of life (QoL). The behaviour can harm other residents, makes care difficult for healthcare professionals, and increases sick leave and staff turnover [11,12]. Challenging behaviour is one of the most important reasons for transitioning from community care to expensive intramural care [13]. The exact costs of challenging behaviour in care for people with an intellectual disability are unknown, but they are related to self-harming, additional care costs (psychotropic drugs), sick leave and staff drop-out [11]. Timely and effective prevention and management of challenging behaviour may lower the burden on caregivers and may prevent early admission to long-term care.

Individuals with intellectual disabilities often face challenges in effectively expressing their level of perceived stress and in applying coping strategies to navigate stressful situations. As a result, they are particularly sensitive to stress. The presence of stress and communication difficulties often contribute to challenging behaviour in this population. A strong relationship between stress and challenging behaviour makes early notification of stress a meaningful instrument for caregivers to adequately and timely respond to the person with intellectual disabilities needs [14–18]. Insight into factors that cause stress and challenging behaviour will give caregivers means for prevention and to improve care [19].

Stress monitoring

Stress is a pattern of both appraisal (cognitive interpretations) of a stimulus and physiological reactions (arousal or tension) of the body [20]. Stress is generally the result of a person's reaction to either internal or external stressors. Stressors can be defined as stimuli that are perceived as a disbalance between the demands of the stressor and the resources of the individual, needed to meet those demands [21]. Stress can be determined by physiological reactions (activation or arousal, for instance, increases in heart rate), changes in activity in the autonomic nervous system (ANS), blood pressure responses, skin responses, pupillary responses, brain waves, and heart responses [22,23]. Several studies have shown that stress recognition is possible through a combination of physiological parameters, such as heart rate (HR) and electrodermal activity (EDA) [24–26]. Shu et al. [26] and Giannakakis et al. [27] both present a comprehensive review on physiological signal-based emotion recognition.

To make physiology-based stress detection useful for problem behaviour, real-time physiology signals are needed via assistive technology such as wearable sensors. A review of wearable sensors for physiological parameters is described in [28], giving guidance to relevant physiological parameters for stress detection. Mentech developed the HUME, a system for real-time stress detection, based on wearables to capture the time-resolved heart rate and skin conductance, and trained artificial intelligence models to retrieve stress predictions. The application of a sensor system to measure stress levels was specifically beneficial for people with a severe

intellectual disability, who often have difficulty in verbally communicating their stress level. The sensor acted as an extra sense for the caregiver to timely intervene in case of increase in development of stress. The application of sensor-based stress detection in people with a severe intellectual disability was described in detail in a recent publication of the same authors [29]. Such assistive technology could enable caregivers to determine the client's state or needs based on empirical data.

The objective of the study was to assess the effect of real-time stress monitoring with the HUME, and the interventions deployed by the care team based on the assistive technology, on the quality of life of both the care professional and the client. Additionally, the interventions deployed by care teams were grouped in clusters to investigate their effects on stress reduction and quality of life.

Materials and methods

Design of the study

A one-group pre-test and post-test design using a convenient sample was used, with the application of real-time stress monitoring with HUME. Prior to the active use of stress monitoring, a reference stress level was determined with HUME (baseline; one month). The HUME was actively deployed during the subsequent period of five months by caregivers. A period of five months appeared to be sufficient to fully exploit the benefits of stress-based interventions. Data collection was done between January 2022 and July 2022.

Participants and setting

Clients with an intellectual disability were recruited from 16 long-term care (LTC) institutions in the Netherlands and Belgium. These individuals experienced significant limitations in both intellectual functioning and adaptive behaviour, and had a profound or severe intellectual disability (IQ range 20 to 40). These individuals require substantial levels of support and assistance in their daily lives, including help with activities of daily living, social interactions, and vocational skills. These LTC institutions were interested in the HUME and therefore entered into a partnership with Mentech. Care institutions were interested in the HUME and therefore entered into a partnership with Mentech. The following inclusion criteria were used to recruit the clients:

1. The client was diagnosed with an intellectual disability.
2. The client showed challenging behaviour.
3. The client accepted the wearable sensors, based on an adjustment period before the start of the study (the acceptance was checked for approximately one daypart together with Mentech and was closely monitored by the care team for the following period).
4. Informed consent was given by the legal representatives of the client.
5. The care team around the client was willing to participate.

Reasons for rejecting to participate included lack of time for the client ($n=1$), staff shortage ($n=2$), and physical limitations that made it impossible to wear the sensor devices ($n=2$). A total of 41 clients with their care teams were included in the study. Male as well as female clients were included, with ages varying between 14 and 70 years.

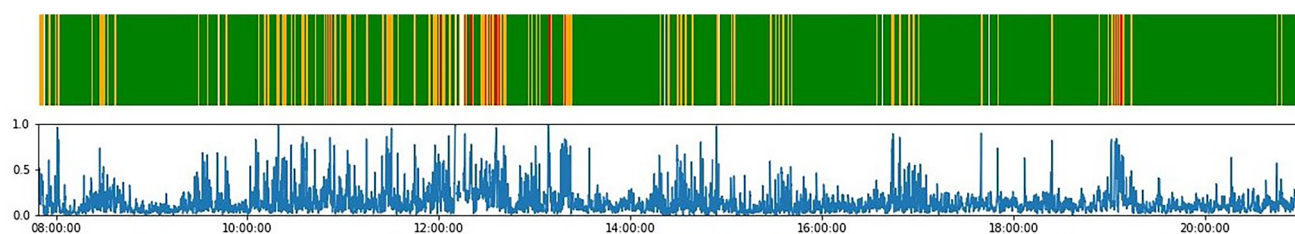


Figure 1. Stress output of the HUME during a day of use.

Interventions based on real-time stress monitoring

The HUME was designed for people with intellectual disabilities and validated in a clinic trial [29]. The HUME was selected for the current study since alternative devices for stress detection were based on heart rate only and were less suitable for the current application. A SentiSock with sensors was used to capture the galvanic skin response (EDA) at the inner side of the foot [30]. The real-time heart rate (HR) as well as the inter-beat interval (IBI) was captured with an ECG sensor [31], attached to a strap or patch. The real-time IBI was filtered using a method by Rand et al. [32]. The signals were averaged using a sliding window of 20s and decomposed into 30 different features describing the signals. The HUME model architecture was based on two layers, a shared layer for the general physiological changes related to stress, and personal layers representing the person-specific physiological changes related to stress. The HUME was trained with data from over 200 healthy subjects who were exposed to stress-inducing experiments (video, VR video and games, and exercises). The model was validated with a 5-fold cross-validation method. The balanced accuracy was 83.4%, with a sensitivity of 81.3% and a specificity of 85.5% [29].

The HUME model outputs the likelihood of real-time stress of a client in a number between 0 and 1. This stress index output can be used for diagnostics to assess the effectiveness of an intervention. The HUME model output can also be converted via a threshold into a traffic light, displayed on a smartphone or tablet to signal the caregiver in case of increased stress. A typical example of HUME stress output during a day of use is given in Figure 1. The upper plot displays the HUME stress output as a traffic light in time. The lower plot displays the HUME output as a data trend.

Ethical considerations

The HUME was validated in a clinical study with 10 care institutions for people with intellectual disabilities in the Netherlands [29,33]. The study protocol was reviewed by the medical ethical committee of the Amsterdam University Medical Center (VUmc, the Netherlands, protocol number 2019-255), and deemed exempt from the Medical Research Involving Human Subjects Act. The HUME is registered as a class 1 medical device for stress detection.

Quality of life

The QoL of the caregivers as well as the QoL of the clients were measured with the Outcome Rating Scale (ORS), consisting of four questions about individual-, relational-, social- and general well-being [34]. The caregiver rated the QoL of the clients due to their considerable language and communication deficits, and significant cognitive impairments. The ORS can be seen as a global measure of QoL given its strong correlation with other questionnaires that measure QoL [35]. The ORS has proven to have

excellent reliability and validity in comparison to other longer questionnaires [36,37]. Moreover, the ORS was chosen given the high work pressure of staff members after COVID-19 [34,36,37]. Answers were given on a 5-point scale, with the lowest score of 1 for very bad well-being and the highest score of 5 for very good well-being. Although questions on the ORS are normally answered via a slider, it has been used as a discrete scale before [38]. Moreover, research found that changing the scale format does not compromise the comparability of the data [39]. The questions are given in Appendix A.

The QoL domain scores between the baseline and after three months were statistically tested for both caregivers and clients. It was decided to apply multiple one-sided *T*-tests and correct for possible unequal variances using the Welch correction method. The increase in type 1 error due to applying multiple *T*-tests was addressed using the Holm–Bonferroni correction.

Procedure

After the deployment of the HUME, the first period of approximately one month was used to define the baseline. HUME data were collected, and the HUME output was blinded to the caregiver (the caregiver did not see HUME data in this period). In the subsequent months, the HUME was used as an early warning or diagnostics instrument on 41 clients, and subsequently, care interventions were deployed. The intensity of data collection with the HUME (duration and frequency) varied between clients and during the study. The stress monitoring system was deployed on the basis of the need. In case the HUME was used as an early warning system, the HUME warned the caregiver via an acoustic signal and colour change in the traffic light when a specific stress level was exceeded. Upon HUME warning on the smartphone, the caregiver deployed an intervention based on what he/she deemed best (e.g., making contact, starting a conversation, providing comfort and proximity, starting an activity). In this way, stressful situations could be timely addressed, and escalations and aggression could be prevented. In case the HUME was deployed as a diagnostics instrument, the caregiver used the HUME to assess the effectiveness of an intervention. Levels of stress before the intervention, during the intervention, and after the intervention were measured with the HUME. In this way, the effectiveness of interventions could be assessed by the caregivers, and causes of stress were identified. At intervals of one month, the HUME stress data were analyzed. The averaged HUME stress data were based on all collected HUME data in that specific month.

In addition, the QoL questionnaire (ORS) was administered at the start of the deployment of the HUME to generate the baseline. Subsequently, the QoL questionnaire was administered after three months of use. To avoid too excessive burden on healthcare workers, the ORS questionnaire was not administered again in case the HUME was longer used than three months. The questionnaires were ideally administered face-to-face, but due to

COVID measures answers were sometimes collected online through Google Forms. The professional caregiver of the client filled in the questionnaires, representing the opinion of the care team around the client.

Moreover, the different interventions deployed by caregivers were clustered and studied on their effectiveness. The content about the various interventions was collected in collaboration with caregivers. The timeframe of the various interventions was established so that a comparison could be made between the two periods. If the duration of the intervention was e.g., three weeks, that period was compared to the stress measurements before the intervention was deployed. Clustering was done independently by several authors of the study based on their content, after which the different clusters were made in agreement.

Data analysis

Data were pseudonymized and stored in a secured database. Analyses were done with Pandas (v1.1.0) and Pingouin (v0.5.1), both Python libraries. The data quality was analysed based on box plots and interquartile ranges (IQR). Based on this analysis, no outliers were identified, and all data were included in the study. The selected variables included the average stress levels over time, the ORS scores of the client, the ORS scores of the caregiver, and the scores on the different clusters. The independent variable was the period of use of HUME in number of months. The average stress level during the first month of use (reference period, plotted at zero months of use) was normalized to 1. The stress measurements recorded in the subsequent months were averaged for all clients and normalized in comparison to the baseline value. To relate the identified intervention clusters to measured levels of stress and quality of life, the Z-score was calculated for the baseline and for the period in which the intervention was deployed. The Z-score is the number of standard deviations by which the value of a raw score is above or below the mean value [40]. Thereafter, the effectiveness of an intervention is expressed as delta, the difference between the values at three months of deployment and the values at the start of the deployment.

Results

Stress levels

An overview of the average measuring time each month is given in Table 1. The measuring time is given in hours. The sample size, standard deviation, median and interquartile values for each month are given in the table as well.

Figure 2 shows the stress levels over a period of six months of measurement. The normalized stress level showed a gradual

Table 1. HUME stress measurement statistics.

Month	0	1	2	3	4	5
n	41	41	40	32	18	9
Mean	169.37	136.49	125.65	111.25	94.23	97.75
Standard deviation	124.70	84.14	91.49	84.39	56.59	40.95
First quartile	112.83	66.23	61.51	55.76	48.80	81.91
Median	138.33	118.95	107.86	96.73	85.09	88.19
Third quartile	197.85	209.03	178.93	153.35	126.35	110.02

Average measuring time and standard deviation of HUME deployment in hours per month. *M*, *n*, and *SD* represent the mean, the number of clients, and the standard deviation, respectively. Also, values for the median and interquartile ranges are given. Note that the baseline is indicated as month 0.

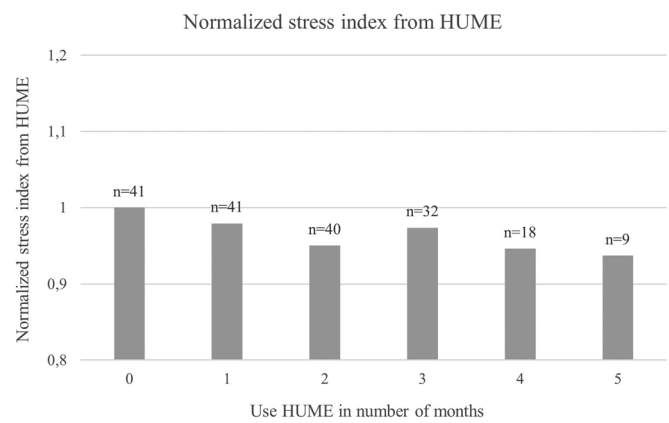


Figure 2. Averaged stress level as a function of months of use of the HUME.

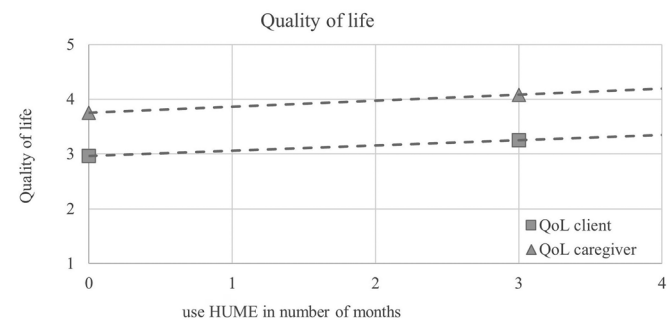


Figure 3. Quality of life for client and caregiver.

decline at the time of deployment, with a small exception at three months after the baseline, where a small increase can be seen in the trend.

Quality of life

A total of 31 professional caregivers completed the ORS questionnaire at the baseline (with complete data on client and caregiver). The averaged ORS numbers are given in Figure 3. For both caregiver and client, the averaged QoL increased with the period of use of stress monitoring. An increasing trend regarding the quality of life of the client and caregiver can be seen throughout the averaged values.

The scores for the personal, interpersonal, social, and general constructs for both the caregiver and client are given in Table 2. The mean scores and standard deviations at the baseline and at the 3-month deployment are listed. All QoL scores showed a positive increase for both caregivers and clients over time. For the general QoL domain in the caregiver group, the increase was significant. In the other groups, the statistics indicated moderate effects with a trend in the expected direction.

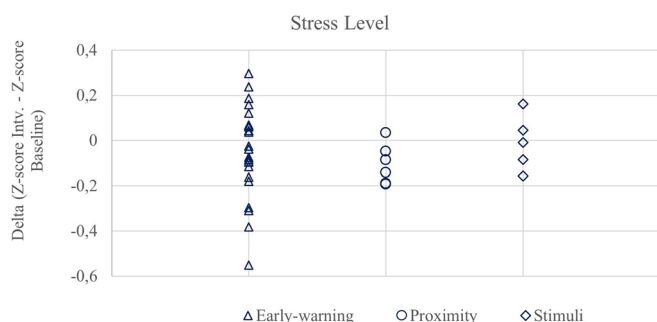
Impact of different types of interventions

The interventions were subdivided into two types, reactive and planned interventions. The planned interventions were divided into two groups, namely proximity-related interventions (e.g., starting a conversation, having a walk together) and stimuli-related interventions (e.g., another environment during a meal, giving a toy during a transition). The reactive interventions were related to the early warning use of the HUME. In the case of early

Table 2. Outcome Rating Scale results.

Participant	Domain	Baseline (n=31)		Three months (n=26)		Paired T-Test		Cohen-D effect size
		M	SD	M	SD	p-Value	p-Value adjusted	
Caregiver	Personal	3.767	0.667	4.080	0.483	0.027	0.186	0.520
	Inter-personal	3.710	0.850	4.040	0.720	0.064	0.256	0.408
	Social	3.903	0.689	3.960	0.662	0.380	0.394	0.082
Client	General	3.581	0.610	4.080	0.483	0.001	0.006	0.880
	Personal	2.806	0.965	3.231	0.799	0.040	0.200	0.467
	Inter-personal	3.161	1.167	3.500	1.010	0.127	0.380	0.303
	Social	2.645	1.002	2.885	1.050	0.197	0.394	0.230
	General	2.871	0.942	3.346	0.917	0.032	0.193	0.502

M, *n*, and *SD* represent the mean, the number of clients, and the standard deviation, respectively. The paired *T*-test with *p*-value, *p*-value-adjusted and effect size, was performed to assess the effectiveness after three months of use.

**Figure 4.** Overview of the impact of clusters on stress levels.**Figure 5.** Overview of the impact of clusters on quality of life.

warning, the caregiver responded to a HUME alert by checking on the client and performing a care intervention. There were several interventions that a caregiver could perform after the warning. A total of 25 cases used the early warning function as an intervention. Six interventions were classified as “proximity”-related and five interventions were classified as “stimuli”-related. The delta values are plotted in Figure 4 for the three types of interventions. Proximity had the highest decrease in stress level ($M = -0.10$, $SD = 0.09$), followed by the early warning cluster ($M = -0.04$, $SD = 0.20$). Stimuli had hardly any effect on the measured averaged stress level ($M = 0.01$, $SD = 0.13$).

The effectiveness of an intervention can also be expressed in the difference in QoL of the client and caregiver after three months of HUME deployment compared to the QoL at the start of the deployment (baseline). These delta values are given in Figure 5 for the three different types of interventions. All groups of interventions had an improvement in QoL, with the early-warning intervention as the largest improvement ($M = 0.50$, $SD = 0.68$).

Proximity had a similar improvement ($M = 0.42$, $SD = 0.52$), whereas stimuli-related interventions had a lower impact ($M = 0.06$, $SD = 0.61$).

Discussion

Stress detection with wearables

The objective of the study was to assess the effect of real-time stress monitoring with the HUME, and the interventions deployed by the care team based on the assistive technology, on the quality of life of both the care professional and the client. The real-time stress was provided as a traffic light on a smartphone, to warn the caregiver in case a client showed increased levels of stress, ultimately to deploy interventions to prevent for instance escalations or self-mutilation. In addition, stress monitoring was used for diagnostics, to measure the stress levels before and after the deployment of care interventions.

Principle findings

A stress-detection system for individuals with severe intellectual disabilities has the potential to help caregivers identifying signs of stress. Early notification allows for prompt interventions. Patterns of stress can provide valuable insights into stress triggers and coping mechanisms, enabling caregivers to tailor the required support more effectively. Also, it can improve the quality of care since stress detection with wearables provides an objective measure of stress. However, when utilizing wearables to mitigate stress, privacy, ethical, and practical issues need to be considered. Measurement of stress might infringe on autonomy and dignity of people with an intellectual disability [29].

The use of HUME to detect stress hardly presented any practical problems. The smart sock integrates well into the daily rhythm of dressing and undressing. The printed electrodes on the inside could not be felt by the people during use. Also, the actions required to deploy and use the stress detection sensors did not place any additional burden on the client in terms of distracting attention. Stress detection based on wearables was also accepted by healthcare providers. After instruction and training, they use the stress detection system as an extension of their actions. They valued the technology as equally valuable as an objective tool to determine the stress level of someone with limited verbal communication capabilities. The use of wearables for stress detection also did not pose any ethical problems. We used informed consent to inform and request consent from the clients' legal representatives. The data is treated carefully and stored anonymously according to a data management plan (GDPR-proof).

All legal representatives recognized that the outcome of stress detection in terms of quality of life and better care outweighed the release of physiological and personal data.

The measurements over time show a gradual reduction in the average stress level of clients with an intellectual disability. An exception is at three months of use, which showed a slight increase.

Most caregivers indicated an improvement in QoL after the usage of the HUME, both for themselves and their clients. All constructs improved for the caregivers as for the clients. Caregivers improved the most in their general well-being. Clients improved most greatly in their personal well-being and general well-being.

The early-warning cluster and the proximity-related cluster appeared to contribute the most to the perceived increase in QoL. Also, the stress reduction was most noticeable for the early-warning cluster and the proximity-related cluster.

The paired *T*-test analysis supported the findings that stress-based interventions had a positive impact on the QoL of both the client and caregiver. Although not significant for all constructs, the paired *T*-test outcome indicated that the QoL increased in time for both caregiver and client.

Comparison to Prior work and relevance of current work

Dillon et al. [41] found a reduction in stress for healthy adults in a short intervention using biofeedback through a smartphone. The same study mentioned the potential scalability of working with smartphones that give biofeedback. In the current study, the results over a longer period create a similar image. Another study by Nath et al. [42] stated the potential of a physiological stress detection device to counteract the harmful effects of stress on health. Ultimately, it could prevent cognitive decline. Moreover, earlier research found that interpersonal relations were the most referenced indicator of QoL [43]. The improvement on the interpersonal relations found in this study can have a mutually positive effect if the improvement relates to the relationship with the clients. Moreover, the results found on the clustered interventions fit well with earlier results from Heyvaert et al. [44] on people with an intellectual disability, stating the positive effects of several social-contextual interventions in studies with small sample sizes.

Because of higher work pressure in health care after COVID-19, AL-Abrow et al. [45] found that there is a significant impact on the attitudes of caregivers to quit the health sector and start working in other sectors. The impact of COVID-19 on health is still very present, but it also enhances the need for technological solutions [46]. As stated by Marschollek et al. [47] there is a need for validation that wearable monitoring provides valuable information and can have an additional impact. The work of Taj-Eldin et al. [48] added that when selecting a wearable device the validity and effectiveness of the device are important. The validity of a stress detection system was already investigated by several researchers [29,33,49,50], and the first step toward its effectiveness is made in this study.

Study limitations

The caregivers labelled moments of stress and relaxation during the reference period (first month of use) to train a personalized stress detection model. Therefore, caregivers needed to label moments of stress and relaxation during the reference period (first month of use) to train a personalized stress detection model. The number of labels given by caregivers could be limited and placed at the wrong

moment in time, whereas unlabelled data collection is enormous [51]. Moreover, during moments of escalation, the caregiver was occupied with mitigating the situation rather than labelling the stress. In these cases, the stress events were retroactively labelled which could have introduced errors. This effect was mitigated by fine-tuning the model during the deployment of HUME. Semi-supervised learning in combination with active labelling will further improve the accuracy and reliability of stress detection.

Another limitation of this study is that the physiological responses to stress can also be provoked by physical activity [52]. For instance, there is a noticeable difference in average heart rate between standing and sitting [53]. The trained stress models can only partly compensate for physical activity. Therefore, stress estimations may be influenced by physical activity and can lead to wrong interpretations of stress. A similar problem in stress recognition is the difference between eustress and distress. Where eustress is the “healthy” stress response, distress comes with negative feelings and physical impairment [54]. The used stress models were trained for distress and were therefore not suitable for measuring eustress.

The accuracy and reliability of stress predictions depend on the quality and availability of data. Data quality relates to the application of wearables to capture real-time physiological responses to stress. If the wearables are not correctly worn, data might be compromised and contaminated with noise and movement artifacts. This is a problem because bio-signals are very sensitive to noise and the stress estimations could therefore be affected [27]. If the connection with the cloud is lost, data are not properly transmitted, also leading to malfunctioning of stress prediction.

Another point that needs attention is one of the side effects of using wearables. By attaching wearables to a client, the client gets attention. Proximity is very important in the well-being of persons with ID so the stress level will also be related to this [55]. The results found in the average levels of stress, as well as the results found in the QoL questionnaires, may be influenced by proximity. Invisible garment-integrated sensors might mitigate this effect.

Seasonality is a possible limitation of this study. Sharif and Riaz [56] for example found that participants experienced more stress during autumn. Moreover, structured life is very important for people with ID and sudden loss of structure can lead to reduced self-resilience [57]. During the holiday season and public holidays (for instance Christmas) people with ID often lose their daily structure, e.g., due to flex workers who are not familiar with the daily routine. The period in which the HUME was deployed was between January and July 2022. Since a lot of data were collected during the summer holiday season, this could have had an impact on the results.

Since caregivers needed to get familiar with stress monitoring and needed to implement it in their daily care process, it can be assumed that in particular the early warning interventions were not always strictly deployed. In addition, client care was typically provided by a team of different caregivers, which introduced a variance in the type of intervention. The support and interest of caregivers in using assistive technologies to provide better help and personalized care was essential for the course of this study. Also, interventions were mostly adapted to the personal needs of a client. The project team provided training and instruction material for optimum acceptance and use of the stress-detection system during this study.

Finally, we used a rather small convenient sample and no comparison group, which makes the claims about the effectiveness of the HUME and the effect on the QoL preliminary on group level. To be able to make stronger claims, a larger sample size is

recommended. However, on individual level, we see encouraging evidence of the effectiveness of stress-based interventions. A randomized controlled trial study could better support the claims made in this study.

Conclusions

The deployment of HUME for real-time stress detection, to timely intervene in case of increased levels of stress, or to analyze the impact of interventions, led to less stress in clients with an intellectual disability. In addition, HUME-based interventions increased the perceived QoL, both of the caregiver and of the client. Proximity interventions and early warning appeared to be the most effective interventions in the reduction of stress and had the strongest effect on the improved QoL of clients.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported there is no funding associated with the work featured in this article.

Notes on contributors

Sep Hesselmans is a data analyst with a Master's degree in Neurosciences from Tilburg University and a Bachelors' degree in Psychology from Maastricht University. He currently is a data analyst at the health-insurance company CZ in the Netherlands.

Franka J. M. Meiland is a senior researcher at the department Elderly Care Medicine on dementia at GERION, Amsterdam UMC. She holds a Master's degree in Psychology from the University of Amsterdam and a Master's degree in Health Sciences from Erasmus University Rotterdam – NIHES.

Esmee Adam is a researcher and PhD candidate at Leiden University Medical Center and holds a Master's degree in Management, Policy Analysis and Entrepreneurship in Health and Life Sciences from Tilburg University.

Erwin van de Cruis is account manager Care at Mentech and worked as a personal care giver in the long-term care for people with a severe intellectual disability. He obtained his social care education from ROC Nijmegen.

Arthur Vonk is account manager Care at Mentech and worked as a personal care giver in the long-term care for people with a severe intellectual disability. He obtained his social care education from Utrecht University of Applied Sciences and Social Pedagogical Assistance, ROC Apeldoorn.

Fransje van Oost is a senior researcher at Mentech and received her Master's degree from Biomedical Sciences at Leiden University and her Master's of Epidemiology degree from the Vrije Universiteit Amsterdam.

Dwayne Dillen is product owner at Mentech. He received his Bachelor's degree in Biometry from the Zuyd University of Applied Science.

Stefan de Vries is a PhD candidate at Amsterdam UMC Radiology and Nuclear Medicine. He holds a Master's degree in Behavioural

Data Science from the University of Amsterdam and a Bachelor's degree in psychology from the University of Groningen.

Eric Riegen is commercial director at Mentech and holds a Bachelor's degree from the Utrecht University of Applied Sciences and a Master's Degree in Organizational Sciences from the University of Tilburg.

Reon Smits is the CTO of Mentech and architect of HUME. He holds a Bachelor's degree in Electrical and Electronics Engineering from Fontys University of Applied Science and a Master's degree in Business Administration from TIAS School for Business and Society.

Nanda de Knegt is a Neuropsychologist and Research Coordinator at the care institution Prinsenstichting and holds a Master of Science in clinical Neuropsychology from the VU Amsterdam.

Hanneke J.A. Smaling is a senior researcher at the Leiden University Medical Center and holds a Masters's of science in Neuropsychology and Organizational Psychology from the VU Amsterdam and a PhD from the Universiteit Leiden.

Erwin R. Meinders is the general director of Mentech and architect of HUME. He holds a Masters's degree in Mechanical Engineering from University of Twente and a PhD in Thermal Physics from the Delft University of Technology.

Data availability statement

The data that supports the findings in this study are available upon request.

References

- [1] Patel DR, Apple R, Kanungo S, et al. Intellectual disability: definitions, evaluation and principles of treatment. *Pediatric Medicine*. 2018;1:11. doi: [10.21037/pm.2018.12.02](https://doi.org/10.21037/pm.2018.12.02).
- [2] Patel DR, Greydanus DE, Merrick J, et al. Introduction to intellectual and developmental disabilities. In: Rubin IL, Merrick J, Greydanus DE, et al. editors. *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*. Cham: Springer, 2016;5–12.
- [3] Patel DR, Cabral MD, Ho A, & Merrick, J. clinical primer on intellectual disability. *Translational pediatrics*, 9(1):S23.
- [4] World Health Organisation. Disorders of intellectual development. Available online: <https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2fcd%2fentfity%2f605267007>. Accessed October 30, 2023
- [5] Schalock RL, Luckasson R. A systematic approach to subgroup classification intellectual disability. *Intellect Dev Disabil*, 2015;53:358–66. doi: [10.1352/1934-9556-53.5.358](https://doi.org/10.1352/1934-9556-53.5.358).
- [6] Shapiro BK, O'Neill ME. Developmental delay and intellectual disability. In: Kliegman RM, St Geme III JW, Blum NJ, et al. editors. *Nelson Textbook of Pediatrics*. 21st edition. Philadelphia, PA: Elsevier, 2020:283–293.
- [7] Buskermolen W, Hoekman J, Aldenkamp AP. Risk factors leading to behavioural problems in individuals with hearing impairments and intellectual disabilities. *Int J Mental Health Deaf*. 2012;2(1):33–45.
- [8] Einfeld SL, Piccinin AM, Mackinnon A, et al. Psychopathology in young people with intellectual disability. *JAMA*. 2006;296(16):1981–1989. doi: [10.1001/jama.296.16.1981](https://doi.org/10.1001/jama.296.16.1981)
- [9] Banks R, Bush A, Baker P. 2007) Challenging behaviour: a unified approach, Royal College of Psychiatrists, British

- Psychological Society and Royal College of Speech and Language Therapists. London, CR 144: Royal College of Psychiatrists London.
- [10] Olivier-Pijpers VC, Cramm JM, Nieboer AP. Cross-sectional investigation of relationships between the organisational environment and challenging behaviours in support services for residents with intellectual disabilities. *Heliyon*. 2020;6(8):e04751. doi: [10.1016/j.heliyon.2020.e04751](https://doi.org/10.1016/j.heliyon.2020.e04751).
 - [11] Screeningsrapport Gehandicaptenzorg Zinnige Zorg. Netherlands: Zorginstituut Nederland; 2019. <https://www.zorginstituutnederland.nl/publicaties/rapport/2019/01/21/zinnige-zorg-%E2%80%93-rapport-screeningsfase-gehandicaptenzorg>
 - [12] Smyth E, Healy O, Lydon S. An analysis of stress, burnout, and work commitment among disability support staff in the UK. *Res Develop Disabil*. 2015;47:297–305. doi: [10.1016/j.ridd.2015.09.023](https://doi.org/10.1016/j.ridd.2015.09.023).
 - [13] Embregts PJCM, Kroezen M, van Bussel C, et al. Multidisciplinaire richtlijn 'Probleemgedrag bij volwassenen met een verstandelijke beperking. NTZ: Nederlands Tijdschrift voor de Zorg aan Mensen met Verstandelijke Beperkingen. 2020;2020(1):2–9.
 - [14] Can YS, Chalabianloo N, Ekiz D, et al. Continuous stress detection using wearable sensors in real life: algorithmic programming contest case study. *Sensors*. 2019;19(8):1849. doi: [10.3390/s19081849](https://doi.org/10.3390/s19081849).
 - [15] Jansen MA, Hart AA, Korevaar JC, et al. Predictors of the rate of decline of residual renal function in incident dialysis patients. *Kidney Int*. 2002;62(3):1046–1053. doi: [10.1046/j.1523-1755.2002.00505.x](https://doi.org/10.1046/j.1523-1755.2002.00505.x).
 - [16] Rittmannsberger D, Yanagida T, Weber G, et al. The association between challenging behaviour and symptoms of post-traumatic stress disorder in people with intellectual disabilities: a Bayesian mediation analysis approach. *J Intellect Disabil Res*. 2020;64(7):538–550. doi: [10.1111/jir.12733](https://doi.org/10.1111/jir.12733).
 - [17] Scott HM, Havercamp SM. Mental health for people with intellectual disability: the impact of stress and social support. *Am J Intellect Develop Disabil*. 2014;119(6):552–564. doi: [10.1352/1944-7558-119.6.552](https://doi.org/10.1352/1944-7558-119.6.552).
 - [18] Simons R, Koordeman R, de Looft P, et al. Physiological measurements of stress preceding incidents of challenging behavior in people with severe to profound intellectual disabilities: longitudinal study protocol of single-case studies. *JMIR Res Protoc*. 2021;10(7):e24911. doi: [10.2196/24911](https://doi.org/10.2196/24911).
 - [19] Chen J, Abbod M, Shieh JS. Pain and stress detection using wearable sensors and devices—a review. *Sensors*. 2021;21(4):1030. doi: [10.3390/s21041030](https://doi.org/10.3390/s21041030).
 - [20] Everly GS, Lating JM. The anatomy and physiology of the human stress response. In: *A clinical guide to the treatment of the human stress response*. Springer. 2019; p. 19–56. doi: [10.1007/978-1-4939-9098-6_2](https://doi.org/10.1007/978-1-4939-9098-6_2).
 - [21] Crosswell AD, Lockwood KG. Best practices for stress measurement: how to measure psychological stress in health research. *Health Psychol Open*. 2020;7(2):2055102920933072. doi: [10.1177/2055102920933072](https://doi.org/10.1177/2055102920933072).
 - [22] Braithwaite JJ, Watson DG, Jones R, et al. A guide for analysing electrodermal activity (EDA) & skin conductance responses (SCRs) for psychological experiments. *Psychophysiology*. 2013;49(1):1017–1034.
 - [23] Schubert C, Lambert M, Nelesen RA, et al. Effects of stress on heart rate complexity—a comparison between short-term and chronic stress. *Biolog Psychol*. 2009;80(3):325–332. doi: [10.1016/j.biopsycho.2008.11.005](https://doi.org/10.1016/j.biopsycho.2008.11.005).
 - [24] Alberdi A, Aztiria A, Basarab A. Towards an automatic early stress recognition system for office environments based on multimodal measurements: a review. *J Biomed Inf*. 2016; 59:49–75. doi: [10.1016/j.jbi.2015.11.007](https://doi.org/10.1016/j.jbi.2015.11.007).
 - [25] Kusserow M, Amft O, Tröster G. Monitoring stress arousal in the wild. *IEEE Pervasive Comput*. 2013;12(2):28–37. doi: [10.1109/MPRV.2012.56](https://doi.org/10.1109/MPRV.2012.56).
 - [26] Shu L, Xie J, Yang M, et al. A review of emotion recognition using physiological signals. *Sensors*. 2018;18(7):2074. doi: [10.3390/s18072074](https://doi.org/10.3390/s18072074).
 - [27] Giannakakis G, Grigoriadis D, Giannakaki K, et al. Review on psychological stress detection using biosignals. *IEEE Trans Affective Comput*. 2022;13(1):440–460. doi: [10.1109/TAFFC.2019.2927337](https://doi.org/10.1109/TAFFC.2019.2927337).
 - [28] Islam T, Mukhopadhyay SC. Wearable sensors for physiological parameters measurement: physics, characteristics, design and applications. In *Wearable sensors: applications, design and implementation*. IOP Publishing; 2017.
 - [29] de Vries S, van Oost F, Smaling H, et al. Real-time stress detection based on artificial intelligence for people with an intellectual disability Assist Technol. 2023 [cited 2023 September 26]. doi: [10.1080/10400435.2023.2261045](https://doi.org/10.1080/10400435.2023.2261045).
 - [30] Mentech [Internet]. Eindhoven; 2022 [cited 2022 Dec 12]. Available from: https://mentechinnovation.eu/en/home_en/.
 - [31] Movesense [Internet]. Vantaa; 2022 [cited 2022 Dec 12]. Available from: <https://www.movesense.com/>.
 - [32] Rand J, Hoover A, Fishel S, et al. Real-time correction of heart interbeat intervals. *IEEE Trans. Biomed. Eng*. 2007;54(5):946–950. doi: [10.1109/TBME.2007.893491](https://doi.org/10.1109/TBME.2007.893491)
 - [33] De Vries S, Smits R, Tataj M, et al. Accurate stress detection from novel real-time electrodermal activity signals and multi-task learning models. *Cognitive Computing and Internet of Things*. 2022;43:111–117. doi: [10.54941/ahfe1001845](https://doi.org/10.54941/ahfe1001845).
 - [34] Miller SD, Duncan BL, Brown J, et al. The outcome rating scale: a preliminary study of the reliability, validity, and feasibility of a Brief Visual Analog Measure. *J Brief Ther*. 2013; 2(2):91–100.
 - [35] Harris R, Murphy MG, Rakes S. The psychometric properties of the outcome rating scale used in practice: a narrative review. *J Evid Based Social Work*. 2019;16(5):555–574. doi: [10.1080/26408066.2019.1645071](https://doi.org/10.1080/26408066.2019.1645071).
 - [36] Ardebili ME, Naserbakht M, Bernstein C, et al. Healthcare providers experience of working during the COVID-19 pandemic: a qualitative study. *Am J Infect Control*. 2021;49(5):547–554. doi: [10.1016/j.ajic.2020.10.001](https://doi.org/10.1016/j.ajic.2020.10.001).
 - [37] Campbell A, Hemsley S. Outcome rating scale and session rating scale in psychological practice: clinical utility of ultra-brief measures. *Clin Psychol*. 2009;13(1):1–9. doi: [10.1080/13284200802676391](https://doi.org/10.1080/13284200802676391).
 - [38] Cazauvieilh C, Gana K, Miller SD, et al. Validation of the French versions of two brief, clinician-friendly outcome monitoring tools: the ORS and SRS. *Current Psychol*. 2022;41:6124–6136. doi: [10.1007/s12144-020-00992-x](https://doi.org/10.1007/s12144-020-00992-x).
 - [39] Dawes J. Do data characteristics change according to the number of scale points used? An experiment using 5-point, 7-point and 10-point scales. *Int J Market Res*. 2008;50(1):61–104. doi: [10.1177/147078530805000106](https://doi.org/10.1177/147078530805000106).
 - [40] Curtis AE, Smith TA, Ziganshin BA, et al. The mystery of the Z-score. *Aorta*. 2016;04(04):124–130. doi: [10.12945/j.aorta.2016.16.014](https://doi.org/10.12945/j.aorta.2016.16.014).
 - [41] Dillon A, Kelly M, Robertson IH, et al. Smartphone applications utilizing biofeedback can aid stress reduction. *Front Psychol*. 2016;7:832. doi: [10.3389/fpsyg.2016.00832](https://doi.org/10.3389/fpsyg.2016.00832).

- [42] Nath RK, Thapliyal H, Caban-Holt A. Machine learning based stress monitoring in older adults using wearable sensors and cortisol as stress biomarker. *J Sign Process Syst.* 2022;94(6): 513–525. doi: [10.1007/s11265-020-01611-5](https://doi.org/10.1007/s11265-020-01611-5).
- [43] Lee J. A phenomenological study of the interpersonal relationships between five music therapists and adults with profound intellectual and multiple disabilities. *Qualit Inquir Music Ther.* 2014;9:43.
- [44] Heyvaert M, Maes B, Van Den Noortgate W, et al. A multi-level meta-analysis of single-case and small-n research on interventions for reducing challenging behavior in persons with intellectual disabilities. *Res Development Disabil.* 2012;33(2):766–780. doi: [10.1016/j.ridd.2011.10.010](https://doi.org/10.1016/j.ridd.2011.10.010).
- [45] AL-Abrow H, Al-Maatoq M, Alharbi RK, et al. Understanding employees' responses to the COVID-19 pandemic: the attractiveness of healthcare jobs. *Glob Bus Org Exc.* 2021;40(2):19–33. doi: [10.1002/joe.22070](https://doi.org/10.1002/joe.22070).
- [46] Clipper B. The influence of the COVID-19 pandemic on technology: adoption in health care. *Nurse Leader.* 2020;18(5):500–503. doi: [10.1016/j.mnl.2020.06.008](https://doi.org/10.1016/j.mnl.2020.06.008).
- [47] Marschollek M, Gietzelt M, Schulze M, et al. Wearable sensors in healthcare and sensor-enhanced health information systems: all our tomorrows? *Healthc Inform Res.* 2012;18(2):97–104. doi: [10.4258/hir.2012.18.2.97](https://doi.org/10.4258/hir.2012.18.2.97).
- [48] Taj-Eldin M, Ryan C, O'Flynn B, et al. A review of wearable solutions for physiological and emotional monitoring for use by people with autism spectrum disorder and their caregivers. *Sensors.* 2018;18(12):4271. doi: [10.3390/s18124271](https://doi.org/10.3390/s18124271).
- [49] Schuurmans AA, de Looff P, Nijhof KS, et al. Validity of the Empatica E4 wristband to measure heart rate variability (HRV) parameters: a comparison to electrocardiography (ECG). *J Med Syst.* 2020;44(11):1–11. doi: [10.1007/s10916-020-01648-w](https://doi.org/10.1007/s10916-020-01648-w).
- [50] Wu M, Luo J. Wearable technology applications in healthcare: a literature review. *Online J Nurs Inform.* 2019;23(3):1–13.
- [51] Yu H, Sano A. Semi-supervised learning and data augmentation in wearable-based momentary stress detection in the wild; 2022. arXiv preprint arXiv:2202.12935.
- [52] Zubair M, Yoon C, Kim H, et al. Smart wearable band for stress detection. In 2015 5th International Conference on IT Convergence and Security (ICITCS), Kuala Lumpur. IEEE; 2015. p. 1–4.
- [53] Sun FT, Kuo C, Cheng HT, et al. Activity-aware mental stress detection using physiological sensors In International conference on Mobile computing, applications, and services. Santa Clara, USA: Springer; 2010. p. 282–301.
- [54] Li CT. Mobile sensing based human stress monitoring for smart health applications. Hong Kong Polytechnic University; 2021.
- [55] Morisse F, Vandemaele E, Claes C, et al. Quality of life in persons with intellectual disabilities and mental health problems: an explorative study. *The Scientist World J.* 2013;2013: 1–8. doi: [10.1155/2013/491918](https://doi.org/10.1155/2013/491918).
- [56] Sharif A, Riaz MN. Longitudinal study on seasonal affective disorder: seasonality and seasonal psychiatric symptoms across seasons in Pakistan. *Rawal Med J.* 2020;45(2):327–330.
- [57] Woittiez I, Eggink E, Klerk MD. Beleidssignalement: Mensen met een verstandelijke beperking; 2020. <https://www.scp.nl/publicaties/publicaties/2020/06/15/beleidssignalement-mensen-met-een-verstandelijke-beperking>

Appendix A

Constructs used to measure the Quality of Life of the caregiver and client with the Outcome Rating Scale. The answers were given on a 5-point scale, with the lowest score of 1 for very bad well-being, 2 for bad well-being, 3 for neutral well-being, 4 for good well-being, and 5 for very good well-being.

Construct	Questions	Scale	Scoring
QoL caregiver	How has it been with you lately on an individual (personal) level? How has it been with you lately on an interpersonal (family, close relationships) level? How has it been with you lately on a social (work/school, friends) level?	1–5	Averaged value used to construct the QoL of the caregiver
QoL client	How has it been with you lately on a general level? How has the client been lately on an individual (personal) level? How has the client been lately on an interpersonal (family, close relationships) level? How has the client been lately on a social (work/school, friends) level? How has the client been lately on a general level?	1–5	Averaged value used to construct the QoL of the client