Contextual support and quality of life of individuals with intellectual disability and severe and persistent challenging behaviour

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CHAPTER 4

Adults with intellectual disability in long-term, intensive support care: the relationship between communication and challenging behaviour

ABSTRACT

Background Deficits in communication are a well-known risk factor for developing challenging behaviour (CB), especially in persons with intellectual disability. The objective of this study was to gain more insight into the relative contribution of different aspects of communication to different forms of CB in individuals with ID who receive intensive support due to their severe challenging behaviour.

Methods Cross-sectional study of 169 adults with ID and persistent challenging behaviour, residing in long-term high-support care were included. Level of cognitive functioning (CF) was estimated on the basis of cognitive assessment, resulting in 80 adults with a level of cognitive functioning (CF) below 48 months, and 89 adults with a level of CF at or above 48 months. Participants were assessed for adaptive behaviour with the Vineland-II Adaptive Behavior Scales, differentiating between expressive communication and receptive communication (comprehension). Challenging behaviour was measured with the Developmental Behavioural Checklist-Adults.

Results For all participants, regarding subdomains of CB, the strongest relationship was observed between receptive comprehension and internalizing problems such as self-absorbed behaviour, anxiety and problems in interactive behaviour. Less receptive comprehension and being male was associated with higher risk for overall challenging behaviour in persons with relatively higher cognitive functioning.

Conclusions More difficulties in comprehension of communication seem to result in more social withdrawal (self absorbed behaviour and less interaction) and more anxiety in persons across the whole range of ID. This underlines the importance of supporting communication abilities in people with ID.

Adults with intellectual disability in long-term, intensive support care: the relationship between communication and challenging behaviour

A substantial amount of individuals with intellectual disability (ID) need lifelong care, offered by specialized service organizations. This support by service organizations can vary in intensity. When severe and persistent challenging behaviour (CB) is present, the highest level of intensive support is needed, supporting all areas of daily life. Challenging behaviour is defined as behaviour which is culturally abnormal, endangers the physical safety of the person (or others), and/or limits the use/access to ordinary community facilities (Emerson, 2001). People with ID living in these specialized residential care settings show a higher prevalence of challenging behaviour, i.e. 50-80% versus 10-18% in the total population with ID (Bowring et al., 2019). Challenging behaviour can result in multiple negative outcomes for the individual (lower quality of life, risk of self-harm, seclusion/separation), or for their support team (risk of harm, distress). In order to mitigate the impact of challenging behaviour by support and intervention, it is necessary to understand its mechanisms.

Intellectual disability is characterized by significant limitations in cognitive functioning and adaptive behaviour (Schalock et al., 2021). When personal competencies do not meet contextual demands of the environment, this person needs specific support to be able to function in that given context. Targeted contextual support, aimed at reducing the discrepancy between individual support needs and contextual demands is a major component of care to promote individual growth and wellbeing (Schalock et al., 2021). For people with ID and severe challenging behaviour, their living environment often is a high support specialized care setting (CBS, 2023), which therefore in itself is the foremost instrument of support.

Challenging behaviour is viewed as resulting from the interaction between a person's psychosocial or biological vulnerabilities, maintaining processes (i.e. functions of challenging behaviour for *that* individual, including carers' behaviour as a contributing factor) and impact factors (impact of challenging behaviour as a cyclical relationship with more risk factors, i.e. social exclusion) (Hastings et al., 2013). For example, psychosocial factors that are consistently associated with higher levels of challenging behaviour are an individuals' limited understanding of communication or being non verbal, severity of intellectual disability, but also having no daytime activity or living in an institutional setting (Bowring et al., 2019).

According to van den Akker et al. (2021) underlying mechanisms for challenging behaviour should be seen as multifactorial. For aggressive behaviour, multiple behavioural, psychiatric and psychosocial factors interact. The causes of challenging behaviour, they argue, are specific for a person in its particular context and intervention targets should be formulated following functional assessments of the individual to optimize support. This means that it is necessary to further identify mechanisms in severe challenging behaviour and develop support and interventions targeted at these factors. An important priority of staff in specialized settings should be to tailor their interactions based on an individuals' specific needs. Positive and meaningful interactions between staff and persons with ID contribute to a higher quality of life. For persons with persistent challenging behaviour, these interactions are even more complicated and a mismatch between a staff members' communication skills and a person's ability to communicate can worsen the challenging behaviour (Simons et al., 2021).

Communication – as an important part of adaptive functioning - is often affected in people with ID (Schalock et al., 2021). Communication abilities can be distinguished in expressive, receptive and written communication (Sparrow et al., 1984). Expressive communication refers to spoken language, for example, to express one's needs to others. Expressive communication is not limited to verbal language, it also involves the ability to express intentions by gestures, eye gaze, and facial expressions. Receptive communication is the ability to understand the communication of others, to comprehend interaction and intention. The use of written language refers to the ability to integrate both into writing or reading.

The relationship between communication difficulties and challenging behaviour is well established for typically developing children. Receptive and expressive communication difficulties predict challenging behaviour in children, more than other aspects of risk status, like low socio-economic status or age (Chow & Wehby, 2018). Adaptive behaviour, including the ability to communicate, similarly is a well-known predictor for challenging behaviour in people with ID, with lower levels of communicative functioning associated with more challenging behaviour (Bowring et al., 2019; Felce & Kerr, 2013). Studies that focus on the relation between communication difficulties and challenging behaviour often reduced the concept of communication difficulties to, for example, speech present or not present, or 'limited understanding', i.e. not taking severity of communication deficits, or type of communication

difficulties, into account. This approach precludes to study eventual differential effect of various types of communication difficulties and their interaction with challenging behaviour and the impact of severity of these difficulties (Bowring et al., 2019; Bowring et al., 2017; Smith et al., 2020). Therefore, this study will fill this gap by evaluating severity and type of communication difficulties in relation to severity and type of challenging behaviour in persons with ID and persistent challenging behaviour. The outcome may help to determine focus on individual and contextual support needs on the basis of assessed communication profiles. We hypothesize that for people with more severe ID, more serious communication difficulties are associated with more severe challenging behaviour.

METHOD

Procedure

Data in this study were collected in the first measurement period [2017-2018] of the longitudinal SCORE study. This study evaluates the regular care of people with ID and persistent challenging behaviour and intensive support needs, living in group homes in four service organisations specialized in care for persons with ID (Ipse de Bruggen, de Hartekamp Groep, Cordaan and Ons Tweede Thuis).

Ethical approval for the study was granted by the ethics committee of the Faculty of Social and Behavioural Sciences, Department of Clinical Neurodevelopmental Sciences, University of Leiden, The Netherlands (ECPW-2015/094), and the ethical committee of the largest participating service organization (Ipse de Bruggen).

Participants

Persons were eligible for inclusion when individuals met the following criteria: Adults with intellectual disability, living in residential care facilities in group homes, with a very intensive support need due to severe and persistent challenging behaviour. Typically, in intensive support the client-staff ratio is 4/3:1.

Candidates meeting the inclusion criteria (*N*=543) and their legal representatives were invited to participate in the study. Legal representatives (where applicable, the person with ID themselves) were informed about the

study by written and online information and asked for informed consent. Seventy percent of the candidates of the four service organizations responded to the invitation (*N*=381) of which *N*=92 (24.4%) declined participation after receiving information and *N*=289 agreed to participate.

N=56 participants dropped out during the course of the study, due to e.g. moving to another service organization, illness or death, logistic problems within the support team, or withdrawal of consent Furthermore, participants were only included for analyses if they had complete data on all variables of interest for analysis, i.e. DBC-A, cognitive functioning (recent intelligence score, <5 years at inclusion), and Vineland-II, resulting in a final total of *N*=169 participants (115 men, 54 women) whose data were subjected to analysis.

Measures

Level of Cognitive Functioning

IQ scores were derived from scores on standardized cognitive assessments, performed within the last 5 years to inclusion, such as the BSID-II-NL/Bayley-III (Baar et al., 2014), WISC-III-NL, WPPSI-III-NL, WAIS III-NL (Wechsler, 1991; Wechsler, 2012; Wechsler et al., 2011), SON-R, SON 2-8 nonverbal-test (Tellegen & Laros, 2011; Tellegen & Laros, 2017). These tests had sufficient reliability and validity. Variation in developmental/IQ tests was due to variation of use in clinical practice. Participants' own psychologist decided which assessment instrument was most suitable according to each individuals' profile, based on their cognitive level of functioning (including as well language use, motor skills etc.) and aim of assessment, in line with clinical guidelines (Embregts et al., 2019). To facilitate comparability and interpretation of scores, all outcomes were converted to cognitive age equivalents. To further explore the impact of the intellectual disability on challenging behaviour, participants were divided in two groups based on level of cognitive functioning (CF), i.e. CF age equivalent < 4 years vs. CF ≥ 4 years. This division aligns with Došen's (2014) proposed cognitive developmental age differentiation between severe and moderate ID, which is roughly in line with Piagets' (sub)stages of cognitive development (Piaget, 1952). It also corresponds with literature associating lower levels of cognitive functioning (in age equivalents) with more severe levels of intellectual disability (Toffalini et al., 2019).

Communication Skills: Vineland Adaptive Behavior Scale (Vineland II)

The Vineland II (Sparrow et al., 2005), is a commonly accepted measure of adaptive skills and has been used extensively in research in subjects with ID. Data were collected by certified master students and research assistants, who completed training and supervision in Vineland II interviewing. The Vineland II is administered as a semi-structured interview, conducted with the professional primary caretaker, and consists of 577 questions resulting in a total score for adaptive behaviour, as well as scores on four domains of which the domain Communication skills will be used, i.e. age equivalents in months of Expressive and Receptive communication. Written communication was left out as virtually none of the participants were able to write. The Vineland II has good to excellent reliability and validity (Sparrow et al., 2005).

Challenging behaviour, Developmental Behaviour Checklist – Adult (DBC-A)

The DBC-A is a carer-completed 107-item questionnaire that assesses a comprehensive range of emotional, behavioural and mental health problems in adults with mild, moderate and more severe levels of ID (Mohr et al., 2011). Professional primary caretakers were asked to fill out the questionnaire. Questions can be answered by assigning number 0, 1, or 2, a higher number reflecting higher frequency of the particular challenging behaviour. Next to a Total composite score, six problem domains are distinguished, i.e. Disruptive behaviour, Communication Disturbances and Anxiety, Antisocial behaviour, Self-absorbed behaviour, Depressive and Problems Relating Social. Mean item scores (MIS) will be computed for the Total composite and domain scores for a valid comparison between domains. A higher score denotes more challenging behaviour. The DBC-A is a reliable and internally consistent instrument with Cronbach's alpha for the total score of α = .95 and for the subscales α = .71 - .91 (Mohr et al., 2011).

Statistical analyses

The Vineland age equivalent scores on Receptive and Expressive communication were used. Differences between the groups (lower CF vs. higher CF) in age at assessment, cognitive age equivalent and total Challenging Behaviour (CB)

were assessed through independent samples *t*-tests. Two MANOVAs were performed to evaluate eventual differences between groups in receptive and expressive communication and subdomain scores on the DBC-A, respectively.

To test the hypothesis that severity of communication difficulties is associated with severity of CB, a series of regression analyses were planned. First, to identify possible predictors of CB, correlational analyses for lower CF and higher CF, separately, were performed for CB total score, receptive and expressive communication, gender, and age. As the CB total score is the resultant of substantively different domains, i.e. internalizing vs externalizing behaviours, correlations of these predictor variables with the subdomains of CB were also performed for both groups.

For the group with lower CF, total CB did not correlate with any of these variables which allowed us to omit a regression analysis on total CB in this group. For the higher CF group total CB correlated with both Receptive (r=-.464, p<.001), and Expressive communication (r=-.328, p=.002). Receptive communication and Expressive communication appeared to be highly correlated in the higher CF group (r=.68, p<.001), therefore the interaction term of these predictors was added as a predictor and both variables were centered to facilitate interpretation of the coefficients of predictors and the interaction term.

To estimate the contribution of each of the predictors to the amount of explained variance in CB, a hierarchical regression analysis was performed (method ENTER). Gender was added in the first step, level of receptive communication and expressive communication were added in the second step, and the interaction term of the latter two predictors (REC*EXPR) was added in the third step. Exploratory regression analyses were conducted with the same predictors as used in the main analysis for the different domains of CB (DBC), using method BACKWARD, for lower CF and higher CF group.

Preliminary *t*-tests for independent samples were performed to verify whether those who were subjected to data analysis did not differ from those who were lost to analysis, due to missing data on at least one variable of interest. These groups did not significantly differ on calendar age, cognitive functioning, DBC-A total score, and receptive communication (.149<p<.641). The group that was lost to analysis had a significantly lower score on expressive communication (t(220)=-2.306, p=.022). We have demonstrated that the sample with subjects that have all data of all variables of interest, do not differ on main outcome variables from those that have missing values on at least one variable, except for expressive communication. Data were analysed using SPSS statistics version 29 (SPSS, 2023).

RESULTS

With regard to the use of parametric tests, all key assumptions pertaining to the variables of interest were met. The lower CF group (*N*=80) and the high CF group (*N*=89) did not differ at distribution of gender (*p=.239*) nor at mean age of assessment in years (*p*=.699) (lower CF *M*=41.18, *SD*=14.83; higher CF *M*=40.33, *SD*=14.03). The groups did differ on total CB (*t*(167)=2.528, *p*=.012, *d*=.389), and, indeed, on mean cognitive age equivalent in months (*t*(17)=-15.885, *p*<.001, *d*=-2.447), to the disadvantage of the lower CF group, see Table 1. A significant effect of group on communication scores was found as well (*F*(2,166)=90.796, *p*<.001, η_p^2=.522), with the lower CF group having lower levels for both Receptive Communication (*F*(1,167)=129.867, *p*<0.001, η_p^2=.437) and Expressive Communication (*F*(1,167)=174.477, *p*<.001, η_p^2=.511.

Furthermore, the multivariate test on the subdomain scores of the DBC-A was significant, (*F*(6,162)=13.113, *p*<.001, η_p^2=.327). Differences between the two CF groups pertain only to the subscale Self-Absorbed, the group with lower CF having a significantly higher score (*F*(1,167)=53.034, *p*<.001, η_p^2=.241), see Table 2. On all other subdomains, differences were non-significant (.104<*p*<.400). This result suggests that self-absorbed behaviour is the main contributor to differences in CB between groups.

Table 1

Participants descriptives of level of cognitive functioning (cognitive age equivalent in months from recent IQ/developmental test), challenging behaviour (Developmental Behaviour Checklist-Adults MIS total PBS, range 0-2) and adaptive behaviour (Vineland II age equivalent in months for level of Receptive and Expressive communication) for two groups with lower and higher cognitive functioning (i.e. cognitive age equivalent below or above 48 months).

Group	**lower CF *N*=80**	**higher CF *N*=89**
	Mean *(SD)*	**Mean *(SD)***
Gender (male, %)	72.5%	64%
Age equivalent of cognitive functioning	27.79 (13.62)	85.86 (29.93)
Challenging Behaviour	.60 (.24)	.51 (.23)
Receptive communication	23.63 (13.54)	59.06 (24.66)
Expressive communication	24.95 (17.08)	68.35 (24.52)

Table 2

Domain scores of challenging behaviour (DBC-A, Mean Item Score (MIS, range 0-2) for each domain for lower and higher cognitive functioning (i.e. cognitive age equivalent below or above 48 months).

Group	**lower CF *N*=80**	**higher CF *N*=89**
	Mean *(SD)*	**Mean *(SD)***
Disruptive	.79 (.37)	.72 (.36)
Communication Disturbances/Anxiety	.63 (.33)	.56 (.30)
Self-absorbed	.68 (.35)	.34 (.24)
Antisocial	.46 (.34)	.55 (.35)
Depressive	.46 (.31)	.52 (.32)
Social relating	.77 (.39)	.71 (.39)

For both the lower CF and the higher CF group, MIS scores on domains of CB significantly correlated with receptive and expressive communication or their interaction [Table 3 and Table 4] .

Table 3

Lower Cognitive Functioning (N=85): Correlations of challenging behaviour (Developmental Behaviour Checklist-Adults, Mean Item score for each domain) with receptive and expressive communication scores (Vineland adaptive age equivalent in months) + interaction term.

	Disruptive	**Communication Disturbance/ Anxiety**	**Self Absorbed**	**Antisocial**	**Depressive**	**Social relating**
Gender	.187, *p*=.087	n.s.	n.s.	n.s.	n.s.	n.s.
Receptive Communication	n.s.	.237*	-.579**	.186, *p*=.088	n.s.	-.260*
Expressive Communication	n.s.	.343*	-.494**	.355**	n.s.	-.249*
Interaction REC*EXPR	n.s.	-.238*	n.s.	n.s.	n.s.	n.s.

*$p < .05$. **$p < .001$

Regression analysis in the higher CF group resulted in a significant final model (F (4, 84)=6.846, p<.001), predicting 24.6% of the variance in CB (see Table 5). Rerunning the same analysis with only the significant predictors yielded the same results. Receptive communication and gender contribute significantly to the prediction of total CB for the group with higher CF, with less receptive communication skills and being male as risk factors for more CB.

Table 4

Higher Cognitive Functioning group (N=89): Correlations of challenging behaviour (DBC-A, Mean Item Score for each domain) with receptive and expressive communication scores (Vineland adaptive functioning age equivalent in months) + interaction term.

	Disruptive	Communication Disturbances/ Anxiety	Self Absorbed	Antisocial	Depressive	Social relating
Gender	n.s.	n.s.	.211*	-.246*	n.s.	n.s.
Receptive Communication	-.412**	-.455**	-.426**	-.220*	n.s.	-.296*
Expressive Communication	-.266*	-.388**	-.417**	n.s.	n.s.	-.354**
Interaction REC*EXPR	-.200, *p*=.061	0.196*	n.s.	-.239*	n.s.	n.s.

*$p < .05$. **$p < .001$

Table 5

Coefficients in final model for higher CF group.

	B	Std error	β	t	p	95% CI	
Predictors						**lower**	**upper**
Constant	.607	.067		0.107	*<.001*	.475	.740
Gender	-.078	.045	-.168	-1.750	.084	-.167	.011
Receptive communication	-.004	.001	-.477	-2.993	.004	-.007	-.001
Expressive communication	.000	.001	-.032	-.234	.816	-.003	.002
Interaction REC*EXPR	.000	.001	.060	.517	.606	.000	.000

The exploratory regression analyses for the group with higher CF, predicting specific subdomains of CB, resulted in significant models for Depressive (p=.019) and all other subdomains (p<.001). The explained variance was 27.3% for Self-Absorbed Behaviour (Gender β=-.253, Receptive Communication β=-.231), 20.7% for Communication Disturbance and Anxiety (Receptive Communication, β=-.455), 17.0% for Disruptive Behaviour (Receptive Communication, β=-.412), 12.6% for Social Relating (Expressive Communication, β=-.354), 11.1% for Antisocial Behaviour (Gender β=-.251, Receptive Communication, β=-.225), 8.9% for Depressive Behaviour (Expressive Communication β=.303, Receptive Communication, β=-.404). Negative β coefficients indicate that lower communication skills were associated with higher CB.

Post hoc analyses were performed in the higher CF group on the regression results for the subdomain Communication Disturbance/Anxiety, in which

we separately analysed the items regarding Communication Disturbances and items relating to Anxiety. Regression models remained significant with Expressive Communication as remaining predictor for Communication disturbances (β=-.341) and Receptive Communication for Anxiety (β=-.435), suggesting that Expressive communication difficulties are more linked to Communication disturbances and Receptive communication to Anxiety, the former predictor being weaker, causing its deletion in the analysis of the total subdomain score.

The exploratory regression analyses for the lower CF group, predicting specific subdomains of CB, resulted in significant models for all subdomains except for Disruptive Behaviour. Positive β denotes higher communication skills associated with higher CB. The explained variance was 33.6 % for Self-absorbed (Receptive Communication, β=-.579), 23.1 % for Communication Disturbances-Anxiety (Expressive Communication, β=.432, interaction REC*EXPR, β=-.348), 12.6% for Antisocial Behaviour (Expressive Communication, β=.355), 11.1% for Depressive behaviour (Expressive Communication, β=.556, Receptive Communication, β=-.483), and 6.7% for Social Relating (Receptive Communication, β=-.260).

Figure 1

Adults with ID with lower cognitive functioning: Relation between Expressive communication and Communication disturbances/Anxiety as a function of level of Receptive communication (Vineland-II age equivalents < 24 months vs. ≥ 24 months).

○ Receptive communication <24 months ● Receptive communication ≥ 24 months

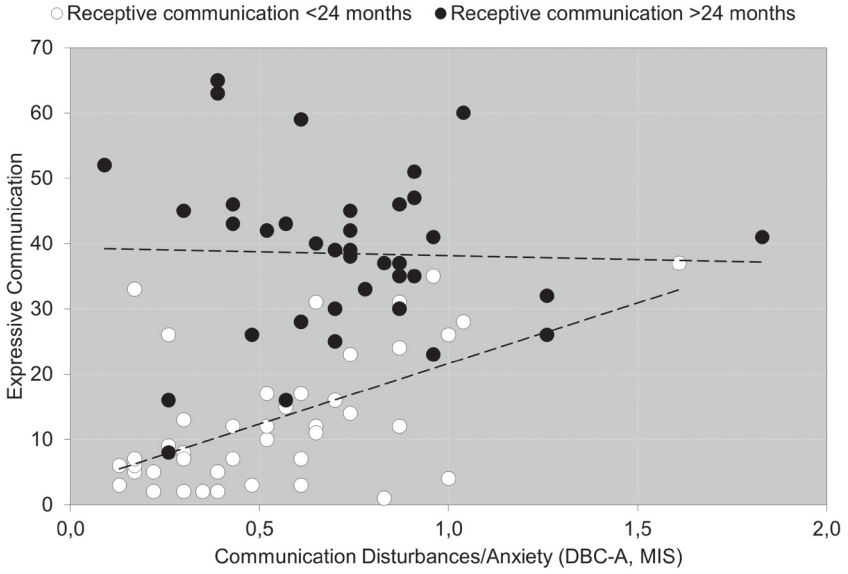

Figure 1 visualizes the significant interaction between receptive and expressive communication as one of the predictors of level of DBC-A Communication/Anxiety in adults with lower CF. For adults with higher receptive skills there is no relation between Expressive communication and Communication/Anxiety. On the other hand, for adults with lower receptive skills, communication disturbances increase with higher expressive skills.

Post hoc analysis showed that level of expressive vs. receptive communication did not differ in the lower CF group (*post hoc analysis p=.265*) and for the higher CF group expressive level was even higher when compared to receptive level (*post hoc analysis <.001)*.

DISCUSSION

The regression analysis in the present study demonstrates that lower comprehension of communication and being male is a risk factor for overall challenging behaviour in adults with ID and challenging behaviour, functioning at a relatively higher level of CF, who reside in high-support care. Although the significance of gender as predictor is only *p*=.08, its contribution is of relevance. We agree with Amrhein et al. (2019) that a p-value alone is not enough to decide if a research idea should be pursued further. Our model is informative, and can serve as a solid foundation for additional research. Individuals with severe to profound ID mostly function on a presymbolic level of communication (Boardman et al., 2014) explaining limited development of behavioural skills. We did not find a relationship between skills in communication and challenging behaviour in general for the group that functions at a lower cognitive level, possibly due to a limited variance in the level of communication in this group.

In typical development, some authors argue that aspects of receptive communication precede the development of expressive communication (Luinge et al., 2006) and this holds for children with intellectual disability as well (Vandereet et al., 2010). However, both level of comprehension and expressive communication in our group with lower cognitive functioning (below 48 months) was equally low. Belva et al. (2012) found a communication profile in a sample of people with profound ID with on average higher receptive than expressive communication, which is in contrast with our results, e.g. level of expressive vs. receptive communication did not differ in the lower CF group and for the higher CF group expressive level was even higher when compared to receptive level. It could therefore be argued that the relatively poor

comprehension in our sample, i.e. no proof of better receptive than expressive communication skills as found in Belva's study, explains that lower receptive communication skills account for a large part of the variance of not all, but of specific forms of challenging behaviour in this group.

Difficulties in receptive communication and comprehension seems to result in a higher vulnerability for challenging behaviour, predicting different forms of challenging behaviour with the strongest relation with internalizing behaviour at all levels of ID. More difficulties in being able to understand communication of others relates to more self-absorbed behaviour and higher levels of anxiety. At lower levels of cognitive functioning, this could be due to the inability to initiate communication and interaction. A study in children with language difficulties with an age of 24-28 months, showed that difficulties in intentional communication contributed to internalizing problem behaviour (Jansen et al., 2020). They hypothesized that this might reflect feelings of insufficiency, resulting in withdrawal from social interaction, diminished opportunities to practice, all intertwined with further impediment on language development.

Challenging behaviour may have different functions which are believed to be interrelated (Hastings et al., 2013) like stimulation, access to preferred objects, avoidance of demands, pain reduction (relief from discomfort) or attention from and contact with others. The present findings suggest the importance of considering the communicative aspects of challenging behaviour, in line with Hollo and Chow (2015), i.e. a person communicating through challenging behaviour that they are not understanding social communication or can express themselves otherwise. Challenging behaviour can be maintained by environmental responses, for example by carers' reactions. Staff is most likely to attribute challenging behaviour to an internal cause within a person, more than as an expression of needs or desires in the person due to the incapability of other communication, staff might consider it as something that cannot be changed (Poppes et al., 2016). A conscious effort of staff to better understand the communicative function of challenging behaviour might therefore lessen challenging behaviour. The results of our study suggest that there may be an opportunity to improve someone's feelings of competence and successful-interaction in enhancing communication and therefore wellbeing that might result in reduction of persistent challenging behaviour.

Numerous studies have been conducted in how staff can intervene when communication problems arise in interactions. Augmentative and alternative communication refers to interventions that support communication through

non-verbal communication modes (gestures, objects, symbols) or for example with assisted technology (Beukelman & Light, 2020). In children with developmental delay different augmented communication interventions are carefully matched to level of comprehension, i.e. of initial receptive language, to maximize the facilitation of communication by caregivers (Dada et al., 2021). A recent study in children and adolescents with ID, found that higher individual communication skills were related to a decrease in challenging behaviour over time (Hofmann & Müller, 2022). Studies into communication interventions with *adults* with ID and challenging behaviour however, are more scarce (Heath et al., 2015). Even more so, a large percentage of adults with ID do not have access to appropriate augmentative communication (Light & Mcnaughton, 2015) and staffs' knowledge about augmentative communication systems for adults with ID appeared to be lacking and a need for training was observed (Sutherland et al., 2014). An important mechanism in which direct staff could intervene, could be by facilitating communication through augmentative communication, based on a thorough communicative assessment. Future evaluation of the role of augmentative communication as targeted contextual support in the development of persistent challenging behaviour over time is urgently needed in adults with ID.

The study also has some limitations. Firstly, due to level of ID, proxy assessment by primary staff was used to complete questionnaires regarding challenging behaviour and adaptive functioning. Acknowledging proxy assessment as the only possible way of gathering data, it is recommended to increase reliability in follow-up research by multiple-proxy assessments.

Furthermore, it is noted that the present study was carried out in a group of people with complex presentation of challenging behaviour, residing in long-term, high support care organizations. Results are therefore most likely only applicable to specialized care settings, where persistent and intense challenging behaviour is a criterion of receiving such care. Another limitation is that the present study only focused on communication and did not control for other factors that may be contribute in with the development of challenging behaviour, for example pain may interact with communication skills but also other factors such as mobility problems, epilepsy, genetic factors/syndromes, traumatic life events and autism should be considered. E.g., pain may have a stronger association with challenging behaviour in people with limited abilities to express their pain to others to get appropriate treatment and support. In future research, the combined effect of these other risk factors should be considered.

Conclusion

The present study shows a need for awareness for the risk of internalizing problems such as withdrawal and anxiety in relation to communication problems. It therefore underlines the importance of assessing level and type of communication abilities when challenging behaviour is present. This study further suggests that interventions targeted at the specific communication difficulties of an individual, could support quality of life by diminishing the intensity of challenging behaviour. Further research is necessary to explore this hypothesis.

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