Early communicative abilities in young children with a significant cognitive and motor developmental delay

Abstract

Background: Children with a significant cognitive and motor developmental delay are presymbolic communicators, however, more specific knowledge is scarce. The primary aim of this study is to reveal the variability within the communicative functioning of this group of children in terms of communication level, the reasons to communicate and behavioural expressions.

Methods: 26 children between 14 and 58 months with a significant cognitive and motor developmental delay were recruited. The Communication Matrix of Rowland (2011) was used to integrate different sources of information on the children's communicative functioning.

Results: These children primarily communicate at the level of pre-intentional and intentional behaviour, aimed at refusing, obtaining and, to a lesser extent, social purposes.

Conclusions: To develop or adapt early intervention strategies, and to monitor progress in communicative development, an even more nuanced view on these children's communicative utterances in terms of frequency, duration, idiosyncrasy and context-relatedness is needed.

Keywords: developmental delay; intellectual disability; motor disability; profound intellectual and multiple disabilities; communicative functions; communicative behaviours; communication

1. Introduction

During early childhood, children's communicative skills develop rapidly from the prelinguistic to the linguistic phase. In this latter phase, children acquire language skills starting with single words and evolving to the use of full sentences (Berk, 2007; Golinkoff, 2013). Concurrently, communication progresses from pre-intentional to intentional, while the communicative behaviours change from idiosyncratic (only understood by those who know the child well) to conventional and referential (Bates, Camaioni, & Volterra, 1975; Brady et al., 2012; Rowland, 2011; Siegel-Causey & Bashinski, 1997). In Bates et al. (1975), the most remarkable shift is described as the transition from perlocutionary to illocutionary acts. McLean and Snyder-McLean (1987) describe perlocutionary acts as those "that produce an effect on the receiver" and illocutionary acts as those "that express a communicative intent of the speaker". Further differentiating these global shifts in communicative functioning, Rowland (2011) describes seven levels of communicative development (I-VII), where the transition from level II to level III encompasses the shift from the perlocutionary to the illocutionary acts (Bates et al., 1975). Level I refers to pre-intentional behaviour, where adults assign purpose to the child's actions, which shapes later intention. Level II is described as the level of 'intentional behaviours', but these actions are not yet communicative. An example would be touching an object of interest. Intentional communication emerges at Level III, but is pre-symbolic and non-conventional. At Level IV, communication is still pre-symbolic, but has evolved from idiosyncratic to more conventional. An example of a behaviour at this level would be holding up the palm of the hand to request an object. Level V, often bypassed in typically developing children, refers to symbolic communication, where the child communicates through concrete tangible representations, whereas at level VI abstract symbols are used to communicate. At the highest level (VII), children combine two or three abstract symbols and eventually make use of language to communicate their messages.

In children with developmental disabilities however, the communicative development is often disturbed, which results in a delayed and/or different development of communicative skills (e.g., Abbeduto et al., 2007; Brady et al., 2004; Grove et al., 1999; Hostyn et al., 2009; Roberts, Price, & Malkin, 2007; Visser et al., 2017). In persons with profound intellectual and multiple disabilities (PIMD; Nakken & Vlaskamp, 2007), communicative development is challenged even more due to the complex interplay between their cognitive, motor and often additional (e.g. sensory) limitations (Ogletree, Wetherby, & Westling, 1992; Olsson, 2005). The communicative abilities of persons with PIMD are described as primarily pre- or protosymbolic, including many idiosyncratic and subtle behaviours. Also their movements are not always under voluntary control, which makes it difficult to correctly interpret behaviour as potentially communicative (Goldbart, 1994; Ogletree, 2012; Olsson, 2005). Therefore, communication partners consistently need to use contextual information and prior knowledge of the person to interpret their communicative utterances (Goldbart, 2014; Grove et al., 1999; Hostyn et al.,

2010; Petry, Maes, & Demunyck, 2004; Vlaskamp & Oxener, 2002; Weis, 2014). However, even if the communication partner knows the person well, perlocutionary acts might not be recognized and illocutionary acts might not be interpreted as such. The lack of appropriate responses from communication partners potentially impedes these person's further development (Olsson, 2005). Also, persons with PIMD experience difficulties in exploring the environment, which for example impedes their ability to provide communicative signals indicating a focus of interest (Markova, 1990).

In short, limited by cognitive, motor and sensory impairments, persons with PIMD often communicate on a pre-symbolic level. This gives the impression of limited variability in this group with regard to their communicative functioning. However, pre-symbolic communicators can function on different levels of pre-symbolic communication (from pre-intentional to conventional), can be driven by different reasons to communicate and can differ in their behavioural expressions (Rowland, 2011). Furthermore, heterogeneity regarding communicative abilities is found to lead to variety of individual growth curve outcomes (Brady et al., 2004). Therefore, in the present study, we want to investigate the variability in communicative abilities of young children (age < 5 years) with a significant cognitive and motor developmental delay.

The **primary aim of this study** is to reveal the communicative variability within this group of children in terms of communication level, reasons for communicating and behavioural expressions. At the moment, knowledge on the communicative abilities of these children is very scarce.

There is however also a **secondary aim** of this study, in addressing the relation between communicative functioning and three child characteristics. First, we are interested in the relation with chronological age as communicative skills typically develop with age (Berk, 2007; Roberts et al., 2007). A second child characteristic of interest is the severity of the motor problems. Previous research revealed an influence of intellectual disabilities as well as motor impairments on the acquisition and occurrence of communicative skills. More specifically, it has been found that the severity of the impairments are related to more communicative difficulties (Bhat, Galloway, & Landa, 2012; Houwen, Visser, van der Putten, & Vlaskamp, 2016; Lipscombe et al., 2016; Pennington, 2012; Voorman, Dallmeijer, Van Eck, Schuengel, & Becher, 2010). We hypothesise that children with more severe motor disabilities will have more limited communicative abilities (Cobo-Lewis, Oller, Lynch, & Levine, 1996; Gernsbacher, Stevenson, Khandakar, & Goldsmith, 2008; Iverson, 2010; Karasik, Tamis-LeMonda, & Adolph, 2011). Thirdly, the relation between communicative functioning and sensory impairments will be investigated as earlier research revealed the impact of these impairments on communicative behaviours (Bigelow, 2003; Tröster & Brambring, 1992). For example, children with a significant visual impairment might have a more restricted repertoire of facial expressions (Tröster & Brambring, 1992).

Summarized, the two research questions to be answered in this manuscript are:

(1) Which communicative abilities are shown by young children with a significant cognitive and motor developmental delay in terms of communication level, reasons for communicating and behavioural expressions?

(2) What is the relation between chronological age, motor functioning and sensory impairments on the one hand and the communicative abilities of this group of children on the other hand?

2. Method

2.1 Participants

In this, study, children were included when they met the following criteria: (a) age between 6 months and 59 months; (b) severe cognitive delay characterised by children functioning at a quarter of their chronological age or lower on the Tandemlijst (Stadeus, Windey, Vermier, & Van Driessche, 1994), (c) severe motor dysfunctions operationalised by children functioning at level IV or V (or level III for children below two years old) on the Gross Motor Function Classification System (GMFCS; Palisano, Rosenbaum, Bartlett, & Livingston, 2007). Children were not excluded when having additional problems (e.g., visual impairment) and/or by means of the cause of the developmental delay. The used criteria are in line with the criteria of PIMD in adulthood. hes children are at risk to meet the criteria of individuals with PIMD as described by Nakken and Vlaskamp (2007) later on in life. At this young age, however, the level of the intellectual disability has often not yet been determined and it is not easy to predict the developmental outcomes of these children when they grow older.

Children were recruited through various organisations and facilities (e.g., hospitals, diagnostic centres, early intervention teams, parent groups) in Flanders and the Netherlands. We contacted them via telephone and/or email and sent information about the project and the inclusion criteria. When children met the inclusion criteria, the researcher informed the parents or legal guardian about the project during a telephone contact and provided additional information by means of a folder and a website about the project (www.ojko.be; Dutch only). The parents or legal guardian gave written consent for participation of the children

26 children between 14 to 58 months old with a significant cognitive and motor developmental delay participated in the study. Half of the children are male participants. Most of the children (n = 25) have additional visual and/or health problems. Table 1 presents detailed information about the participants.

< Insert Table 1 here >

2.2 Procedure

Researchers visited the children at their home and/or day care facility, except for two children living in full-time residential provision. As this research is part of a broader project on the functioning of young children with a significant cognitive and motor developmental delay on different

developmental domains, an extensive assessment battery was used. Therefore, the administrations were divided over two visits, which took place within a two week period. Observations, tests, and questioning the primary caregiver were alternated to avoid children being overloaded. In this study, the information from three different observational protocols, one questionnaire and two semi-structured interviews with caregivers was integrated and used to obtain a clear overview of the children's communicative functioning (cf. by using this information to fill in the Communication Matrix). Detailed information on all of these instruments is presented in the next section (2.3). This study was performed in accordance with the guidelines of the Ethical Committee of the faculty Psychology and Educational Sciences at the University of Leuven, and reported to the Privacy Commission in Belgium.

2.3 Instruments

2.3.1 Communication Matrix

The Communication Matrix of Rowland (2011) is an assessment tool designed to develop communicative profiles of individuals who are at the earliest stages of communicative development. The Matrix provides a clear overview of the expressive communicative abilities of the individual with the emphasis on what they can do (i.e. 'the functional use of communication'). As all the children that participated in this study have significant cognitive and motor developmental delays and therefore are at risk of not reaching the level of intentional communication, the Communication Matrix provides the appropriate perspective to study the behavioural expressions of these children. The Communication Matrix is based on research on typically developing infants between 0 and 24 months (Rowland, 2011). It is structured around seven levels of communication development (pre-intentional behaviour, intentional behaviour, unconventional behaviour, conventional communication, concrete symbols, abstract symbols, language) and four global reasons to communicate (refuse things, obtain things, engage in social interaction, seek/provide information). Twenty four states (at level I), functions (at level II), or intents (at level III to VII) are binary questioned throughout the Matrix, all corresponding with one of the four reasons to communicate. When answering 'yes', more specific communicative behaviours can be selected by choosing from nine behavioural categories (body movements, early sounds, facial expressions, visual behaviour, simple gestures, conventional gestures/vocalizations, concrete symbols, abstract symbols, language). An overview of the 24 states, functions, and intents by level and global reason to communicate is provided in Table 2. A communicative state/function/intent is regarded as surpassed when a child masters the communicative state/function/intent on a subsequent level (e.g., a child has surpassed the function 'A1: Expresses discomfort' when (s)he masters the function 'B1: Protests'; see figure 1). The scoring system results in a one-page profile consisting of 80 cells (cf. figure 1), representing all possible combinations of states, functions, and intents within the seven levels of communication. Rowland (2011) clarifies that "where multiple behaviours are used to express a given intent at a given level, the cell is shaded according to the highest level (mastered or

emerging) at which any behaviour in that cell is coded" (p. 194). Therefore, an additional overview of the communicative behaviours used by the child to communicate the function (e.g., a child cries to express discomfort) can be composed. Also, a total score (from 0 to 160) can be computed by awarding 2 points to a cell that is checked as mastered or surpassed and by awarding 1 point to a cell that is checked as emerging. Even though the Communication Matrix is seldom used for research purposes (Rowland, 2011), previous studies have proven the added value of the Communication Matrix in research on individuals with language delays (e.g., Hategan & Talaş, 2014; Parker, 2009: Rowland & Schweigert, 2000) and with various types of disabilities (Rowland, 2011).

< Insert Table 2 here >

< Insert Figure 1 here >

2.3.2 Sources of information

Due to the idiosyncratic behaviours and fluctuating performance levels of children with a significant cognitive and motor developmental delay, it is a challenge to get an objective and representative view on their communicative functioning. Therefore, in our study, the Communication Matrices were completed by a researcher, based on multiple sources of information collected during home visits. The specific instruments (i.e. sources of information) were chosen based on their previous or possible application in this study's target group as well as on the variability in instrument type (i.e. observation, questionnaire or interview), degree of structure and freedom to support/encourage child behaviour (i.e. highly structured, semi-structured or free) and type of interaction partner (i.e. familiar caregiver or unfamiliar researcher).

First, an adapted version of the Early Social Communication Scales (ESCS; Mundy et al., 2003) was used. The ESCS is a videotaped standardized observation measurement to elicit early nonverbal communication skills, more specifically joint attention, behavioural requests, and social interaction (Mundy et al., 2003). The adapted protocol is available upon request and mainly encompasses an abridgement of the original protocol, motivated by the severity of the disabilities and the limited attention span of the target group. Second, parents or professional caretakers filled in the Communicative and Symbolic Behavior Scales (CSBS; Wetherby & Prizant, 2002), a questionnaire about the communicative behaviour of the child. It consists of questions about seven clusters: emotion and eye gaze, communication, gestures, sounds, words, understanding, and object use. The questions can be answered on a 3-point Likert scale indicating if a skill is not yet mastered or whether a mastered skill is used sometimes or frequently (Wetherby & Prizant, 2002). Third, a brief semi-structured conversation was conducted with the informants to gather information on how the child reacts when he/she likes/does not like something and what he/she does when he wants/does not want something. Fourth, the three communicative scales (emotional communication, receptive language, and general communicative behaviour) as well as the category 'additional information' of the Behavioral Appraisal Scale (BAS)

provided information on the communicative functioning of the children. This instrument is a combination of observation, testing, and questioning people who are familiar with the child (Vlaskamp, Van der Meulen, & Smrkovsky, 1999). Fifth, an interview about the social and emotional development was conducted by means of the revised Scale for Social and Emotional Development (SEO-R; Claes & Verduyn, 2012). A proxy was questioned about 13 domains in which children's social and emotional abilities are discussed (e.g., handling your own body, dealing with emotionally important persons, communication, emotion differentiation). Finally, a free play interaction between a child and a familiar caregiver of approximately 15 minutes was used to observe spontaneous communicative skills in the children (based on Mahoney, 1998 & 2008).

We combined information provided by persons who are very familiar with the child (i.e. parents or professional caregivers who experience the child's functioning throughout different situations and time points) as well as by researchers who are able to observe the child relatively unbiased since they have no previous experience with the child. Next to different perspectives, information on the child was collected in three different situations by looking at a strictly structured observation protocol in which each child is given the same instructions and feedback (cf. ESCS), a semi-structured observation protocol in which the child is given the maximum possibility, encouragement and support to achieve the provided tasks (cf. BAS) and finally an unstructured play interaction. Throughout these tasks, the child can be observed in interaction with at least one known (i.e. caregiver) and at least one unknown (i.e. researcher) person.

2.3.3 Child characteristics

General information on child, family, and contextual factors was collected by means of a researcher-developed questionnaire on basic demographic and health-related information, including the variables of interest in the second research question: child's age as well as visual functioning (within three categories: normal vision, visual impairment, blind) with or without the use of glasses, as reported by a primary caretaker and presented in Table 1. Initially, the aim was also to take the auditory functioning of the children into the analysis. As only two of the caregivers reported some kind of hearing loss in the questionnaire, this variable could not be incorporated statistically.

The children's motor abilities were assessed by means of a separate questionnaire, based on the motor questions of the Portage Program and focuses on the gross and fine motor abilities of young children (Hoekstra et al., 2011). It consists of 145 items scored on a three-point scale: score 2 when a child masters the skill, score 1 when a child is almost mastering the skill and score 0 when a child does not master the skill. The items in this questionnaire range from questions about if the child can move his or her head, to standing or moving independently, or manipulating a toy with one or two hands. For each child, a total score was calculated by adding up the item scores and a mean score was calculated by dividing this total score by 145 (as presented in Table 1). Therefore, this mean score reflects the

global motor functioning of the child, on both the gross and fine motor domain. Children with the lowest mean score (0-0.5)are developing towards turning their head and some control over upper limbs (e.g. turning head or moving arm towards stimulus). Children with a mean score between 0.5 and 1 show a development towards sitting independently for a short period of time and using their upper limbs in a more controlled way (e.g. touching and holding objects). Mean scores between 1 and 1.5 are seen in children that are developing towards being able to move independently, can stand with support and use their upper limbs in a more exploratory way (e.g. pushing and taking objects). A mean score of 2 would mean that the child can walk independently and uses upper limbs in a more functional way (e.g. picking up a toy and put it in a box), which is for none of the participants the case.

2.4 Data processing and interrater reliability

The online version of the Communication Matrix (Rowland, 2018) was used to integrate the aforementioned sources of information (cf. 2.3.2) by means of a researcher-developed protocol (available upon request). The first part of the protocol consists of general guidelines (e.g., score conservative when doubting) and steps that need to be followed to fill in the Matrix (e.g., check the behaviours first and only then conclude if a state/function/intent is not used, emerging or mastered). The second part of the protocol contains the coding rules to decide whether a function is not used, emerging or mastered. A child is mastering a skill when it was observed or described in minimum two of the instruments. When a communicative skill was only observed or described in one instrument or it was observed in two instruments but the skill was not fully present (e.g., a child sometimes alternates between an object and a communication partner), it was coded as emerging. And finally, a skill is not used when it was not displayed in one of the instruments or when it was observed in one instrument but the skill was not fully present.

Two independent research assistants conducted the integration of the information into the Communication Matrix. The first author explained the coding protocol and trained the research assistants until they reached a minimum of 90% exact interrater agreement. After training, each research assistant completed the communication profiles of 13 participants. To assess the reliability of the coding protocol, the first author double-coded 40%, randomly selected, of the participants (20% per research assistant). The exact agreement was determined by dividing the number of agreements by the total number of items multiplied by 100. This resulted in an agreement of 95.1% and 97.2%, which indicated a good reliability (Cordes, 1994). Cohen's kappa for both research assistants were .724, which is substantial (Cohen, 1988).

2.5 Data analysis

First, descriptive analyses were conducted to gain insight into the communicative abilities of the children. Therefore, we calculated the number of participants who show either unused, emerging or mastered communicative states, functions or intents at the associated communicative levels. Also, we calculated the number and percentage of participants who show specific behavioural expressions. These behaviours are predefined in the Communication Matrix as mentioned before (Rowland, 2011) and exclusively linked to specific communication levels as well as specific states, functions or intents. We did not distinguish between emerging or mastered behavioural expressions, but combined (i.e. added up) the number of participants. The denominator in calculating the percentages corresponds to the number of participants who used the specific states/functions/intents.

Second, the relationship of children's communicative functioning (total score on the Communication Matrix) with chronological age (in months) and motor functioning (total score on the motor questionnaire) was addressed using the Spearman's Rho correlation test. We excluded one participant from the analysis due to missing data. We opted for a non-parametric test because of the small sample size and the presence of non-normality in the data. Additionally, bootstrapping (a resample method with replacement) was used to determine confidence intervals for these correlations (Lee & Rodgers, 1998). The relationship with visual functioning was addressed using a Mann-Whitney U test, distinguishing children with normal vision (n=13) and impaired vision or blindness (n=10). Since visual functioning was unknown in three of the children, we excluded them from the analysis.

3. Results

Preliminary analyses revealed no significant differences between male (n=13) and female (n=13) participants with regard to their communicative functioning as well as their motor functioning, visual functioning and chronological age. Therefore data of both groups were combined in subsequent analyses.

3.1 Descriptive analyses

Figure 2 provides an overview of the number of participants showing specific communicative states, functions or intents according to the level of mastering. In table 3, an overview of specific communicative behaviours that are used by all participants is presented.

< Insert Figure 2 here >

< Insert Table 3 here >

At level 1 (pre-intentional behaviour), most children master the three accompanying states. All 26 children 'express discomfort' and 'express comfort'. The state 'expresses interest in other people' is mastered in 16 children and emerging in 7 children, which means it is not expressed by 3 of the

participants. To express (dis)comfort, nearly all children use body movements as well as early sounds and facial expressions. However, body movements are seen in more children in relation to discomfort (96%) than comfort (73%); especially changes in posture (69% vs 35%). Limb movements are also often observed for this purpose (i.e. by 46% and 42% of the children), while head movements are rarely observed (19% and 8%). Of the 23 children who express interest in other people, most use early sounds (91%) and facial expressions (87%) while body movements are less frequently used (22%).

More variation is noticed at level 2 (intentional behaviour). More specifically, 'protesting' and 'continuing an action' is emerging (n = 10 for both) or mastered (n = 11 resp. n = 7) by most participants while 'obtaining more' and 'attracting attention' are approximately equally distributed between 'not used' (n = 14 and n = 12) and 'emerging' or 'mastered' (n = 7 + 6 and n = 5 + 8). Protesting is primarily expressed through body movements (71%) and early sounds (95%), but not often through facial expressions (29%). With regard to the body movements, 57% and 38% of the children use head and arm movements, respectively, while only a few children use leg movements (10%, n=2) or move away from the person or object (5%, n=1). Wanting an action to be continued is expressed by early sounds (82%) and facial expressions (65%), but not often by visual behaviour (35%) or movements (6%, n=1). To obtain more of something, children use body movements (75%), early sounds (67%) and visual behaviour (58%), but not often facial expressions (25%). Body movements primarily include approaching or taking the desired object (67% and 42%, respectively). When children attract attention, they use sounds (79%) and visual behaviour (71%); while facial expressions (43%) and body movements (i.e. approaching a person, 21%) are used less often.

At levels III (unconventional communication) and IV (conventional communication), only nine of the children (35%) use one or more of the related intents. A few children refuse or reject something by using unconventional communication (n=7, of which 4 children master this intent). For this purpose, all children use a simple gesture (i.e. pushing away the person or object), but in only one child this is accompanied by a facial expression and none of the children use related movements. In two of these seven children, the use of conventional communication to refuse or reject something is also emerging, which means they are learning 'to shake their head deliberately shake for no'. Further, on level III, requesting more of an action is emerging in one child (who is learning to deliberately take the hand of the communication partner) and mastered in one other (who uses leg movements and reaches towards or taps the communication partner). Showing affection through unconventional communication is present in four children (of which two children master this intent). Simple gestures (i.e. arm/hand movements and touching the communication partner) and facial expressions are mostly used (n=3), followed by visual behaviour (n=2) and early sounds (n=1). Two other children show affection through conventional communication by hugging, kissing or patting the communication partner. In one child, the ability to greet people by waving 'hi' or 'bye' (level IV) is emerging. Lastly, in three children, the ability to direct the communication partner's attention to something by looking back and forth between

the communication partner and an object, person or place (level IV) is emerging, with one child also learning to deliberately point at something. Intents and communicative behaviours at levels V to VII are not observed within the research group.

3.2 Relation with child characteristics

To address the relation between the communicative abilities and child characteristics, a total score on the Communication Matrix for each child was calculated. The mean score is 10.3 (*SD* = 3.83), with scores ranging between 4 and 20 (on a total of 160). Correlational analysis (Spearman's Rho) revealed a significant positive relation between total scores on the communication matrix and chronological age (r_s = .391, p = .024), 95% CI [-.035, .708]. Secondly, we found that higher scores on the Communication Matrix were associated with higher scores on motor functioning (r_s = .835, p = .000, 95% CI [.651, .911]). However, no significant correlation between chronological age and motor functioning was found (r_s = .279, p = 0.089). Using a Mann-Whitney U test, no significant relation between total scores on the Communication Matrix and visual functioning (normal vision vs. visual impairment/blindness) was found (U = 52.00, p = .446).

4. Discussion

4.1 Conclusions

With regard to the first research aim, the study's results demonstrate that children with a significant cognitive and motor developmental delay primarily communicate at the level of pre-intentional and intentional behaviour, particularly aimed at refusing, obtaining and, to a lesser extent, social purposes. The low mean total score on the Communication Matrix indicates that these children score very low on the acquisition of communicative functions that typically occur between 0 and 24 months of age (Rowland, 2011). Children use various communicative behaviours, depending on the communicated function, state or intent. This variety of communicative modalities is also found in the research of Iacono, Carter and Hook (1998), although within older children with severe and multiple disabilities.

More specifically, at a pre-intentional level, in all children, their behaviour can be interpreted as expressing (dis)comfort, while more social communication (i.e. expressing interest in other people) is evident in most, but not all, children. All of these three states are primarily seen in early sounds and facial expressions. However, we observed that body movements are a very important way for these children to communicate comfort and especially discomfort, for which posture change is additionally important.

At the level of intentional behaviour, most children communicate to refuse (in the form of 'protesting') or, to a slightly lesser extent, to obtain (i.e. a continuation of an action). Further, approximately half of the children (also) communicate to obtain more of something or for social purposes (i.e. attracting attention). Early sounds seem to play a major role in communicating all of these four functions. Body movements are regularly used to protest and to obtain more of something, but seldom to continue an action or attracting attention. Facial expressions are not used by a lot of children, but do seem to play a role in trying to continue an action. In more than half of the children who show these functions, visual behaviour is related to attracting attention and obtaining more of something.

By definition, children with a significant cognitive and motor developmental delay function on a pre-symbolic level, so we do not expect them to master intents beyond level IV. However, even at the pre-symbolic level of intentional communication (level III and IV), children never communicate with the intent to give or receive information and rarely communicate to obtain something. If the children intentionally communicated on levels III and IV, protesting/refusing and social interactions were the reasons they would communicate for.. Still, children with significant cognitive and motor developmental delay rely highly on their communication partners in order to 'make meaning' together. They depend therewith very much on the sensitivity and responsivity of their partners to contextualise their reactions in response to the situation (Van keer, 2017).

The second research question addressed the correlation between communicative functioning and three child characteristics. Correlational analyses showed that older children have a higher total score on the Communication Matrix, although this result needs to be carefully interpreted as the bootstrap 95% confidence interval included zero (Hesterberg, Monaghan, Moore, Clipson, & Epstein, 2003). Furthermore it was found that children with better motor skills also have a higher total score on the Communication Matrix. As no significant correlation was found between chronological age and motor functioning, we can carefully conclude that both age and motor functioning have a unique relation with the children's communicative abilities. The strong relationship between the communicative and motor functioning can be partly explained by the interrelatedness of developmental domains in child development, especially in atypical populations (Diamond, 2000; Houwen et al., 2016; Roebers & Kauer, 2009; Wang, Lekhal, Aarø, & Schjølberg, 2012). Particularly in the early stages of communicative development, severe motor impairments can impede children's communication as messages are often communicated through motor behaviour (e.g., body movements, head movements, simple gestures).

With regard to visual functioning, no significant association was found between communicative and visual functioning. It might be that visual behaviour is less decisive in (measuring) these earliest stages of communicative functioning, which is substantiated by the structure of the Matrix in which visual

behaviour cannot be chosen in relation to the first communicative level. Also, it is possible that children with visual impairments express the same states/functions/intents through different behavioural modalities and therefore no differences in total scores can be found (Bigelow, 2003; Tröster & Brambring, 1992). Finally, for both sensory functions of vision and hearing, prevalence is known to be underestimated in persons with severe disabilities in general (Evenhuis, Theunissen, Denkers, Verschuure & Kemme, 2001; van den Broek, Janssen, van Ramshorst & Deen, 2006; van Splunder, Stilma, Bernsen & Evenhuis, 2006). Therefore, the responses of the caregivers on this items in the questionnaire, should be interpreted with caution.

It is important to note that all results are based on a general analysis of the whole group, and that next to looking at the global relation between communicative functioning and three child characteristics, no further differentiation has been made based on the children's specific (additional) disabilities such as level of cognitive and motor functioning, visual and hearing impairments as reported by the caregivers, etc. Since this study aimed to provide a global characterization of the group of young children with SDD, a group for which individual variation in the severity and interplay of different impairments is very inherent, a global analysis was in accordance with this study's aim. However, we certainly acknowledge the possible influence of these characteristics, especially on the use of specific communicative behaviours. Subgroup or even individual analysis, despite being challenged by difficulties in obtaining reliable differentiation as well as sample size issues, are an important area for future research; as further discussed in the next section.

4.2 Strengths, limitations and future research

A major strength of this study is its integrative nature, by looking at different aspects of communicative functioning (i.e. levels, reasons and behavioural expressions) as well as combining several information sources. Even though previous studies already used several instruments to gain insight in the communicative abilities of children, it has rarely been integrated to obtain a comprehensive picture of their communicative functioning. In particular, information collected through proxies (questionnaires and interviews) has been alternated with observations made by the researcher. A major advantage of this type of data triangulation is that subjectivity and bias is reduced (Brady et al., 2012; Thurmond, 2001). Also the influence of timing (e.g., an observation at a moment when the child has little attention or had an epileptic seizure) decreased because proxies give information on the daily functioning while the researcher is more dependent on the time of the observation. To reduce the impact of the latter, the observations were made on different time points (unless this was not possible) but within a period of approximately two weeks.

Some limitations of the present study should be acknowledged. To start from a statistical point of view, the relatively small research sample affects the type of data analyses that could be applied and

the generalizability of the results. A larger sample could make it possible to conduct statistical analyses to reveal differences in the specific communicative behaviours of the children (e.g., children with and without visual impairments), to study the relationship between the influencing child characteristics, and to identify subgroups of children. Nevertheless, considering the characteristics of our target group, the research sample can be considered as rather large. In addition, bootstrapping was conducted to cater this shortcoming and to find more robust and solid results regarding the correlation between communicative functioning and chronological age, motor functioning and visual functioning (Lee & Rodgers, 1998; Zhu, 1997).

Another limitation of the study is related to the study design. Longitudinal research (if possible with a larger sample) is needed to get a more comprehensive representation of the communicative development of these children whereby the developmental sequence (e.g. of communicative reasons, behaviours,…) and possible critical periods can be identified, which can help to give direction in individual support plans. Additionally, it would have been interesting to study other child characteristics and contextual factors as this has proven its importance for child development (e.g., Berk, 2007; Kahn, 1996; Stephenson & Dowrick, 2005). For example, the importance of sensitivity and responsivity of the primary caregiver is addressed in previous research (De Bal, 2011; Van keer et al,, 2017; Warren & Brady, 2007). Also the development of other domains (e.g., motor development) can play an important role in the total support of these children. It can be assumed that children put energy in one of the developmental domains and make a progress in that area, where the other domains stabilise or even decline. Or, as Wang et al. (2012) pointed out, that the relationship between communication and motor skills is rather multifaceted instead of directional.

A final remark can be made regarding the theoretical background and structure of the Communication Matrix in relation to our specific target group. Since each profile was unique, the Matrix allows us to identify useful variability in the children's communicative functioning. However, the Matrix consists of a top-down procedure in which specific communicative behaviours are predefined and exclusively linked to specific levels of communication, states/functions/intents and reasons to communicate. All of this is defined based on research in typically developing children (Rowland, 2011). Therefore, it is possible that the communicative functioning of these children is to some extent overrated (i.e. due to biased expectations based on the predefined behavioural categories), underrated (i.e. because certain meaningful behaviours are possibly not part of the predefined categories) and/or oversimplified (i.e. because a myriad of different behavioural expressions are possibly taken together in one predefined category). We know that these children often make use of idiosyncratic signals (Daelman, 2003), for example through changes in muscle tone, which are often strongly person- or context-bound and are easily misinterpreted or ignored (Grove et al., 1999). Even when recognized, the Matrix does for example not allow the registration of posture changes beyond level I. Further, the Matrix does not take

into account differences in frequency, duration and context-relatedness of communicative utterances. Also, by shading a cell according to the highest level at which any behaviour in that cell is coded, individuals with very limited means of expression "may have a similar profile to someone with an extensive repertoire of behaviours" (Rowland, 2011; pp. 194). Additionally, children in our target group may not only show a delayed, but also a different developmental trajectory (Vlaskamp, 2011). This renders the use of a 'surpassed'-category questionable. To conclude, the Communication Matrix is a very useful instrument within the studied target group to establish a general estimation of the children's functional use of communication, however, we suspect there is still a lot more variability that is not elucidated by this instrument as it is currently used. A more detailed view on this variability is especially necessary when adopting a longitudinal viewpoint aimed at mapping these children's (often slow) development, since their developmental steps may need to be defined in terms of 'broadening' communicative skills (i.e. in terms of frequency, duration, context-relatedness,..) rather than solely in terms of learning new skills.

4.3 Relevance of the study

The present study supports the idea that children with a significant cognitive and motor developmental delay vary in their communicative functioning although most of them particularly function on a pre-intentional level. The acknowledgment of this variability is important for early intervention strategies, which need to consider both the general description of the communicative abilities of these children and their uniqueness. Moreover, the detailed description of the children's communicative functioning can provide early interventionist strategies in stimulating the communicative development of this vulnerable group of children (Brady et al., 2012). This can, in its turn, result in positive outcomes on other developmental domains as communication is widely recognized as a base for general development (Bukatko & Daehler, 2004; Fogel, 1992; Stephenson & Dowrick, 2005; Vygotsky, 1978). As Brady et al. (2016) state in their Guidance for Assessment and Intervention (2016), assessment and intervention are often intertwined and co-occurring. However, assessment should preferably be dynamic , in order to identify the individual's potential to learn new skills when provided with appropriate support, which in turn should lead to setting and evaluating new goals .

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Table 1

Overview of participant characteristics as reported by a primary caretaker (*n*=26)

Variable	**Range (Mean)**	***n* (%)**
Age (in months)	14 – 58 (36.12)	
Sex		
Male		13 (50.00)
Female		13 (50.00)
Aetiology		
Acquired brain injury		2 (7.69)
Drug and alcohol abuse during pregnancy		1 (3.85)
Epilepsy		1 (3.85)
Genetic disorder		11 (42.31)
Infection during pregnancy		1 (3.85)
Lissencephaly and epilepsy		1 (3.85)
Perinatal asphyxia		2 (7.69)
Perinatal asphyxia and genetic disorder		1 (3.85)
Unknown		6 (23.08)
Visual functioning[a]		
Normal vision		13 (50.00)
Visual impairment		8 (30.77)
Blind		2 (7.69)
Unknown		3 (11.54)
Motor functioning[b]	0.04 – 1.67 (0.60)	
< 0.5		12 (48.00)
0.5 - < 1		8 (32.00)
1 - < 1.5		3 (12.00)
≥ 1.5		2 (8.00)
Health problems		
Epilepsy		19 (73.08)
Gastrointestinal problems		14 (53.85)
Respiratory problems		13 (50.00)
Heart problems		2 (7.69)
Feeding tube		14 (53.85)

[a] When defining visual functioning, the use of glasses is taken into account (n = 3). Caregivers were given the possible option regarding their children's visual functioning in the questionnaire by means of checkboxes. No explicit operational definitions of the categories were given.

[b] Motor functioning is operationalised by the mean score (on a total of 2) on a questionnaire based on the motor questions of the Portage Program. Information on motor functioning of only 25 children is presented due to missing data.

Table 2

The 24 States (A), Functions (B), and Intents (C) by Level and Reason to Communicate as defined in the Communication Matrix

	Reasons to communicate			
Level	Refuse	Obtain	Social	Information
I	AI. Expresses discomfort	A2. Expresses comfort	A3. Expresses interest in people	
II	BI. Protests	B2. Continues an action B3. Obtains more	B4. Attracts attention	
III-VII	CI. Refuses or rejects	C2. Requests more action C3. Requests new action C4. Requests more object C5. Makes choices C6. Requests new object	C8. Requests attention C9. Shows affection	
IV-VII			C10. Greets people C11. Offers/shares C12. Directs attention C13. Uses polite forms	C14. Answers Yes/No C15. Asks questions
V-VII		C7. Requests absent objects		C16. Names things C17. Comments

Note. Reprinted from Rowland, C. (2011). Using the communication matrix to assess expressive skills in early communicators. *Communication Disorders Quarterly, 32*, 190-201.

Table 3

Number of Participants using Behaviours associated with Specific States (A), Functions (B) and Intents (C)

	States			**Functions**				**Intents**				
Behaviours	A1. (n=26)	A2. (n=26)	A3. (n=23)	B1. (n=21)	B2. (n=17)	B3. (n=12)	B4. (n=14)	C1. (n=7)	C2. (n=2)	C9. (n=6)	C10. (n=1)	C12. (n=3)
Body movements (level I-III)	25 (96%)	19 (73%)	5 (22%)	15 (71%)	1 (6%)	9 (75%)	3 (21%)	0	1 (50%)			
Approaches desired object						8 (67%)						
Approaches person							3 (21%)					
Whole body movement								0	0			
Change in posture	18 (69%)	9 (35%)	2 (9%)									
Limb movements	12 (46%)	11 (42%)	3 (13%)									
Arm movements				8 (38%)	0	0	0	0	0			
Leg movements				2 (10%)	1 (6%)	1 (8%)	0	0	1 (50%)			
Head movements	5 (19%)	2 (8%)		12 (57%)	0	0	0	0				
Takes object						5 (42%)						
Moves away from person or object				1 (5%)								
Early sounds (level I-III)[a]	26 (100%)	26 (100%)	21 (91%)	20 (95%)	14 (82%)	8 (67%)	11 (79%)	0	0	1 (17%)		
Facial expressions (level I-III)[b]	25	26	20	6	11	3	6	1	0	3		

	(96%)	(100%)	(87%)	(29%)	(65%)	(25%)	(43%)	(14%)		(50%)		
Visual behaviour (level II-III)[c]					6 (35%)	7 (58%)	10 (71%)		0	2 (34%)		
Simple gestures (level III)								7 (100%)	2 (100%)	3 (50%)		
Pushes away object or person								7 (100%)				
Takes your hand									1 (50%)			
Reaches towards or taps you									1 (50%)			
Arm/hand movements										1 (17%)		
Touches you									0	2 (33%)		
Conventional gestures and vocalizations (level IV)								2 (29%)	0	2 (33%)	1 (100%)	3 (100%)
Shakes head no								2 (29%)				
Specific vocalizations								0				
Gives unwanted item to you								0				
Beckons you to come									0			
Holds hands up to you									0			
Nods head									0			
Hugs, kisses and pats you										2 (33%)		

Waves 'hi' or 'bye'				1 (100%)	
Points to something					1 (33%)
Looks back and forth					3 (100%)
Concrete symbols (level V)	0	0	0	0	0
Abstract symbols (level VI)	0	0	0	0	0
Language (level VII)	0	0	0	0	0

Note. Specific behaviours as well as states/functions/intents can both be characterized as emerging or mastered. This table shows the number (and percentage) of participants for which the specific behaviours are either emerging or mastered (i.e. both numbers were added up). The denominator in calculating the percentages corresponds to the number of participants who used the specific states/functions/intents. Only the states/functions/intents that are used (i.e. emerging or mastered) by at least one participant are presented. Blank spaces indicate that the specific behaviours could not be chosen in combination with the specific communicative state, function or intent.

[a] Early sounds include crying, grunting, screaming, cooing, squealing, fussing and whining

[b] Facial expressions include grimacing, smiling and frowning

[c] Visual behaviour include looking at a (desired) object and looking at a person

Figures

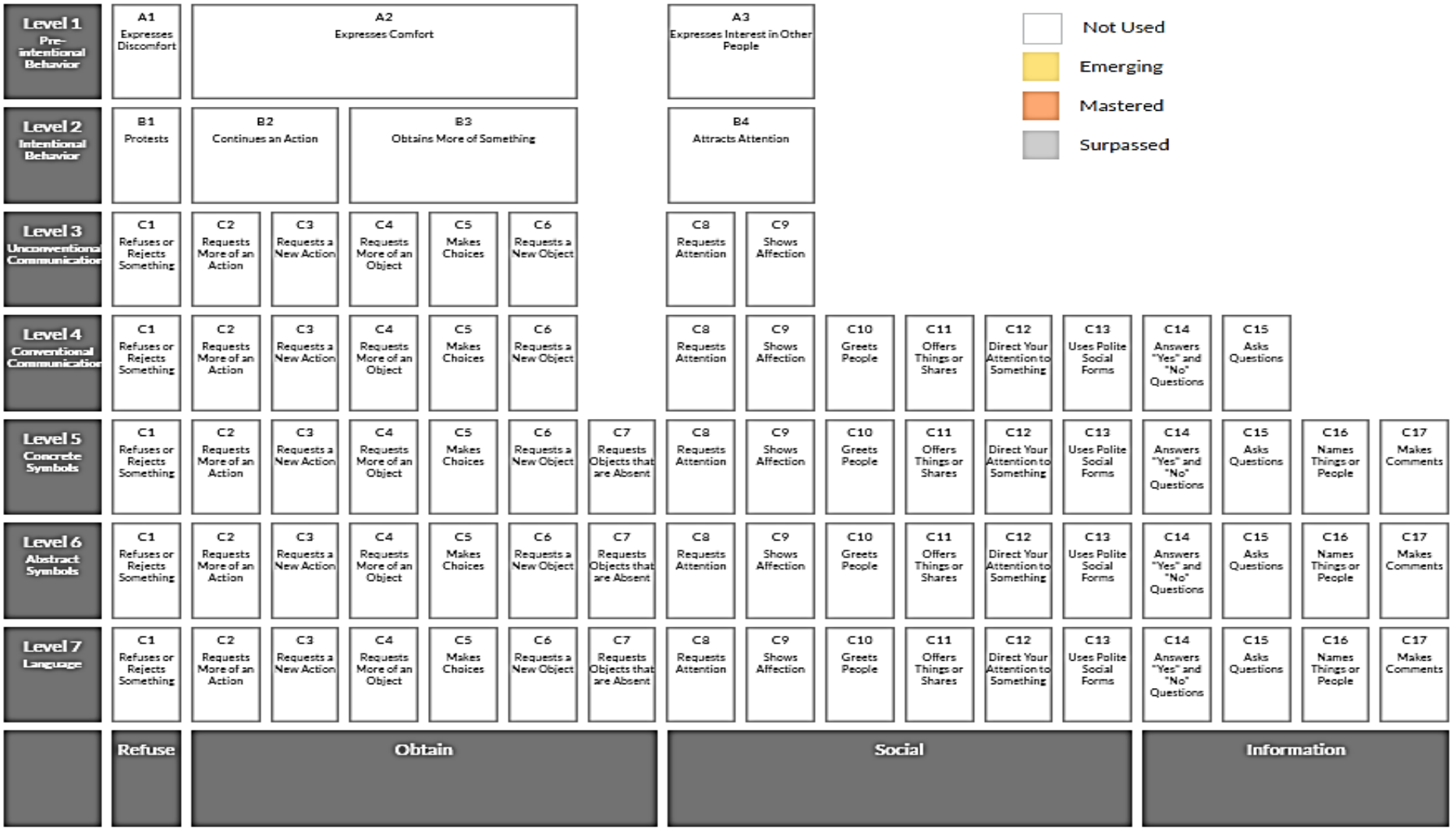
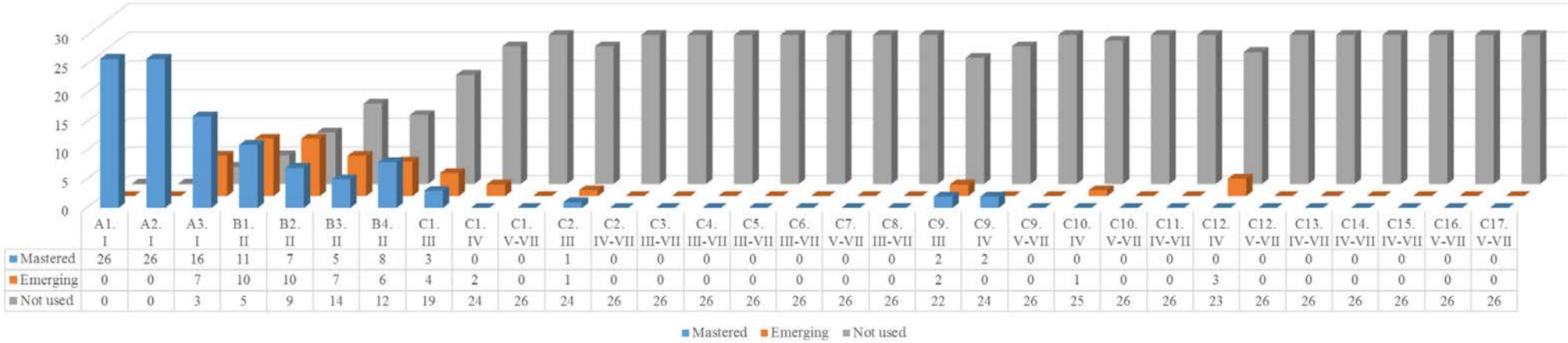


Figure 1. Communication matrix (Rowland, 2018)



	A1. I	A2. I	A3. I	B1. II	B2. II	B3. II	B4. II	C1. III	C1. IV	C1. V-VII	C2. III	C2. IV-VII	C3. III-VII	C4. III-VII	C5. III-VII	C6. III-VII	C7. V-VII	C8. III-VII	C9. III	C9. IV	C9. V-VII	C10. IV	C10. V-VII	C11. IV-VII	C12. IV	C12. V-VII	C13. IV-VII	C14. IV-VII	C15. IV-VII	C16. V-VII	C17. V-VII
Mastered	26	26	16	11	7	5	8	3	0	0	1	0	0	0	0	0	0	0	2	2	0	0	0	0	0	0	0	0	0	0	0
Emerging	0	0	7	10	10	7	6	4	2	0	1	0	0	0	0	0	0	0	2	0	0	1	0	0	3	0	0	0	0	0	0
Not used	0	0	3	5	9	14	12	19	24	26	24	26	26	26	26	26	26	26	22	24	26	25	26	26	23	26	26	26	26	26	26

Figure 2. Number of participants showing communicative states/functions/intents according to the level of mastering.
Note. As is specified in Table 2, communicative states/functions/intents can be shown on different communicative levels. In this figure, the associated levels are only split up when the results vary over different levels. This is the case for C1, C2, C9, C10 and C12.