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Initiation of activities and alertness in individuals with profound intellectual and multiple disabilities

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Abstract

Background When providing activities to individuals with profound intellectual and multiple disabilities (PIMD), direct support persons (DSPs) often face questions that are, among other things, related to the alertness of the person with PIMD. While previous studies have revealed that stimulation might have a greater impact on levels of alertness than the internal conditions of the individual, they have also emphasized the importance of interaction in order to influence the level of alertness. Because the initiation of this interaction has been described as one of its core components, the present study has focused on the relationship between the stimuli presented, the initiation of the activity (by the person with PIMD or the DSP), and the level of alertness of the person with PIMD.
Method Videotapes of the one-to-one interactions of 24 individuals with PIMD and their DSPs in multisensory environments have been scored using the Alertness Observation List. In a sequential analysis, the percentages of stimuli presented were related to the percentages of initiation. Furthermore, two other analyses focused on the relationship between the level of alertness and the preceding and subsequent percentages of initiation respectively.
Results The results show that high percentages of the activities are initiated by the DSPs. In addition, activities that were initiated by the individual with PIMD were preceded and followed by higher percentages of alert behaviour than those initiated by the DSP. Outcomes differed for the different types of stimuli.
Conclusions These results have striking implications for the lives of individuals with PIMD. It is quite possible that DSPs often act too quickly, whereas they would be better off waiting for a reaction on the part of their client. In general, DSPs need to find a balance between being passive themselves and promoting in the individual with PIMD a state of being as active and alert as possible.

Keywords alertness, initiation, interaction, profound intellectual and multiple disabilities, sequential analysis

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Introduction

Designing activities that fit the abilities and needs of individuals with profound intellectual and multiple disabilities (PIMD) is a challenge for researchers and direct support persons (DSPs), as individuals of the target group form one of the most vulnerable groups of people with intellectual disabilities (Nakken & Vlaskamp 2007). Profound intellectual and multiple disabilities are characterized by the prevalence of profound intellectual disabilities in combination with profound or severe motor problems that affect their abilities in a complex way. This group of people often also has sensory and general health problems, which makes them highly dependent on those who provide direct support in all aspects of their daily life (Van Schrojenstein Lantman-de Valk *et al.* 1997; Evenhuis *et al.* 2001; Van Splunder *et al.* 2006). Therefore, proxies as well as those who provide professional support such as DSPs play an important role in arranging the daily life of an individual with PIMD. Especially in day-care centres, providing activities is one of the DSPs' core tasks. However, they often face questions about 'when' and 'how' to provide activities to individuals of the target group (Vlaskamp *et al.* 2007).

These questions are, among other things, related to the alertness of the person with PIMD. Alertness has been described as an individual's level of interaction and engagement with the environment, which becomes manifest and observable in the individual's behaviour (Munde *et al.* 2009). Alertness, then, is one of the most important preconditions for development and learning in individuals with PIMD (Guess *et al.* 1999). Only if individuals are alert and focused on their surroundings, can they be expected to process the stimuli presented at a conscious level (Nelson *et al.* 2002).

While previous studies have revealed that the optimal moments for activities are those when the individual with PIMD is 'focused on the environment' or 'alert' (Guess *et al.* 1999; Munde *et al.* 2009), detecting those moments in individuals of the target group is difficult. Alertness observations reported in previous studies can be reduced to three general levels (e.g. Green *et al.* 1994; Mudford *et al.* 1997; Guess *et al.* 1999): (1) being alert and actively focused on the environment; (2) being awake, but focused on oneself and not in contact with the environment; and (3) being asleep, without any external focus or contact. Self-injurious behaviour has been added as a fourth alertness level in some studies (e.g. Green *et al.* 1994; Mudford *et al.* 1997; Guess *et al.* 1999); however, other researchers have excluded this behaviour from the observation scales, because they expect self-injurious behaviour to occur at all alertness levels (Woodyatt *et al.* 2004) or because they describe it as a form of communication instead of an alertness level (Siegel-Causey & Bashinski 1997). In professional practice, then, DSPs are faced with the complex task of linking particular expressions of alertness in individuals in the target population to one of these levels. Because of the severity of their disabilities, individuals with PIMD show only subtle signals (e.g. sounds or changes in facial expression or muscle tension) in order to express themselves. These signals can easily go unnoticed by DSPs (Wilder & Granlund 2003), and they are often difficult to interpret. Not only can the meaning of a particular signal differ across individuals, it can also have different meanings in different situations for the same individual (Hogg *et al.* 2001; Petry & Maes 2006). The determination of alertness in individuals with PIMD is further complicated by rapid and irregular shifts between 'being alert' and 'not being in contact with the environment' (Mudford *et al.* 1997).

Furthermore, DSPs are left wondering how to promote those very alertness levels that are optimal for providing an activity. While the first studies on alertness in individuals with PIMD revealed that the presentation of stimuli might have a greater impact on levels of alertness than the internal conditions of the individual, they have also emphasized the importance of interaction with another person in order to influence the level of alertness (Guess *et al.* 1995, 1999; Arthur 2004). Studies differentiating between different components of the interaction, then, have investigated active choice-making, microswitch-based stimulation and frequent prompts (Kennedy & Haring 1993; Lancioni *et al.* 2000, 2005). A relationship with higher levels of alertness was found. However, no studies about the relationship of alertness and the initiation of the interaction are available.

At the same time, the initiation of the interaction has been described as one of the core components of the interaction (Hostyn 2011). Initiation can be defined as introducing or starting an interaction or activity. Because interaction is a reciprocal process, a balance between initiations and responses of both interaction partners is essential. However, the study also shows that initiation by individuals with PIMD is one of the core problems in interaction with a

DSP. The complexity of their disabilities often leads to little initiating and mostly responding behaviour (e.g. Rowland & Schweigert 1993; Bruce & Vargas 2007; Wilder 2008).

Although these studies show that there are several factors that may make an important contribution to the promotion of the level of alertness, an analysis combining these factors is lacking. Therefore, the present study has focused on the relationship between the stimuli presented, the initiation of the activity (by the person with PIMD or the DSP), and the level of alertness of the person with PIMD. The central questions of the present study are the following:

Do preceding *stimuli have an impact on the initiation of subsequent activities?*
Does the preceding *level of alertness have an impact on the initiation of subsequent activities?*
What is the relationship between the initiation of an activity and the alertness level following *the activity?*

Methods

Participants

Because activities are mostly provided during the daily care for individuals of the target group, different day-care centres were included in the present study. A total of nine day-care centres and schools for special education situated in Flanders (Belgium) and the Netherlands participated in this study. Depending on their age and the organization of care in the country concerned, participants attended either day-care centres or schools for special education. The facilities were randomly selected from the overall population of care centres and schools for individuals with PIMD. Between one and four clients within each facility participated in the study, yielding a total of 24 participants. The number of male and female participants was equal. The mean age was 15.66 years (SD = 12.02), ranging from 4 to 49. All participants could be described as individuals with PIMD according to the definition of Nakken & Vlaskamp (2007). While no test results were available for the participants, all the DSPs indicated that the cognitive development of their clients was severely delayed, and that they experienced such serious constraints in terms of their motor skills that they were not independently mobile. In addition, 15 of the participants had epilepsy, 17 had been diagnosed with visual impairments and 4 had been diagnosed with auditory impairments. An overview of the characteristics of the participants is provided in Table 1. Informed consent for participation in this study, including video registration, was obtained from their parents or legal representatives. All DSPs also gave their informed consent to participate in the study.

Table 1 Characteristics of the participants

	Gender	Age	Epilepsy	Visual impairment	Auditory impairment
1	Male	10		×	
2	Male	4		×	
3	Male	16		×	
4	Female	23		×	
5	Female	13	×	×	
6	Male	11	×	×	
7	Male	47	×		×
8	Male	28	×		
9	Male	20	×		
10	Female	31	×	×	
11	Male	49	×	×	
12	Male	10		×	
13	Male	10			×
14	Female	12	×	×	
15	Male	10	×	×	
16	Female	13			
17	Male	15		×	
18	Female	6	×		
19	Female	11	×	×	
20	Female	13	×		
21	Female	13	×	×	×
22	Female	16		×	×
23	Female	6	×	×	
24	Female	5	×	×	

For each client, one DSP who had known that client for at least 18 months had to be willing to participate in the study as well. The 24 participating DSPs were qualified by secondary education or vocational training as teachers or support workers and had been working with individuals of the target group for 8.8 years on average, with a range of 2–19.1 years.

Instruments

The Alertness Observation List (AOL, Dutch translation; Vlaskamp *et al.* 2010) was used to determine alertness levels. The observation list distinguishes four levels of alertness, each of which is associated with a colour: (1) active, focused on the environment (green); (2) inactive, withdrawn (orange); (3) sleeping, drowsy (red); and (4) agitated, discontented (blue). Information recorded on four different forms was used to formulate an individual alertness profile. The overall description of each of the individual's alertness levels was supplemented with concrete examples of behaviour.

Previous research has shown that the AOL is a reliable instrument for determining alertness in individuals with PIMD. Both inter-observer and intra-observer agreement exceeded the 80% criterion, when 78 videotapes of 24 children with PIMD were scored (Munde *et al.* 2011).

Procedure

For the present study, we needed data from a situation where the presented stimuli could be controlled and alertness levels could be observed in detail. Because multisensory environments (MSEs) yield such possibilities, these were chosen as the experimental condition. Different kinds of stimuli (e.g. auditory, visual, tactile or vestibular) are at hand to be presented. Distractions by other individuals or stimuli beyond the actual stimulating situation can be excluded. At the same time, accurate registration of the individuals' behaviour and reactions is possible.

Data were gathered in two stages. First, the AOL was completed for all participants by their DSPs. The individual alertness profiles were based on observations that were conducted during entire days in the day-care centre or at school. Furthermore, situations in an MSE were observed to gather detailed information about the alertness reactions of the participants to different types of stimuli. Second, at least three sessions in MSEs were videotaped for each participant. In these sessions, participants were offered stimuli during one-to-one-interaction with a DSP. The DSPs were instructed to consider the individual's alertness profile when choosing stimuli. The choice as well as the presentation of the stimulus had to be based on the preferences of the individual participant in order to include only stimuli that were expected to be salient for the participant and, therefore, increase the participant's alertness. Consequently, the stimuli presented were not the same for the various participants but comparable in terms of perceived salience. Because the DSPs were free to discontinue the activity whenever they deemed it appropriate for the client, the length of sessions varied from 5 to 30 min.

A total of 76 MSE sessions were videotaped. Because of low recording quality or the absence of interaction with a DSP, 14 tapes were excluded from further analyses. From the remaining pool of 62 tapes, one session with each participant (24 sessions in total) was selected at random.

The videotapes were scored by three observers. The observers were two Master students in Special Needs Education and the first author, all having worked with individuals with PIMD in professional practice before. All of the observers had been trained in the use of the AOL, and they were familiar with the aim of the study. Because DSPs' knowledge has been found to be especially valuable in alertness observations in individuals of the target group (Munde *et al.* 2011), DSPs had completed the AOL (see step 1 of the gathering of the data), resulting in an individual alertness profile for each participant. The observers then used the individual alertness profiles as frameworks for determining alertness levels. For scoring purposes, the alertness level 'alert' was subdivided into two levels (i.e. 'actively alert' and 'passively alert'), in order to separate reactions including or excluding motor action. The initiation of the activity was scored in two categories: 'by the client' and 'by the DSP'. Thereby, 'initiation' was defined as a behaviour to introduce or start any new episode of an interaction or activity. The stimuli presented could be the following: visual, auditory, tactile and vestibular. Because stimuli are always present in combinations, we focused on the primary stimulus. Depending on the preferences and abilities of the individual with PIMD, stimuli could range from a bubble tube to a coloured stuffed animal for the visual stimuli and from music to the voice of the DSP for auditory stimuli. Examples of tactile and vestibular stimuli are: receiving a massage or supportive touch, and swinging in a hammock respectively. Continuous scoring was used for the observations. Because of the short alert periods experienced by individuals with PIMD, the first minutes of the sessions were expected to reveal the most information. For this reason, only the first 5 min after the start of the activity were included in the subsequent analyses.

After all videotapes had been scored by one of the observers, 20% of these were scored by a second observer, employing the general agreement formula (Mudford *et al.* 1997). Inter-observer agreement was 86.2%.

Analysis

The data were analysed employing sequential analysis (Bakeman & Gottman 1997). Sequential analysis reveals information about sequences in the behaviour observed. To investigate whether a given behaviour causes a target behaviour to occur more or less often than expected by chance, expected transitional probabilities are compared with observed transitional probabilities. In this way, the transitional probability is the chance that the target behaviour will occur relative to the given behaviour. The expected transitional probabilities are calculated based on the total number of possible event sequences and on the chance that one specific behaviour will occur in this sequence. In a subsequent step, Yule's *Q* (Bakeman & Gottman 1997) shows whether the observed probabilities differ significantly from the expected ones. The value of Yule's *Q* can range from −1 to 1, whereby probabilities with a negative Yule's *Q* occur significantly less often than expected by chance and probabilities with a positive Yule's *Q* occur significantly more often. A Yule's *Q* of zero indicates no significant difference. Yule's *Q* can only be calculated when the marginal sums of the frequency table of the two behaviours are larger than 5 (Bakeman & Gottman 1997).

In the present study, several analyses were conducted. First, we looked at the factors preceding the initiation of an activity. In that way, the initiation by the client or the DSP was treated as the target behaviour and the different kinds of stimuli as the given behaviours. In addition, alertness levels preceding an activity were analysed by treating them as a given behaviour followed by initiation on the part of the client or the DSP. Second, our analysis then focused on the consequence of the initiation of the activity. While the initiation was now the given behaviour, the level of alertness became the target behaviour, with the aim being to determine the relation between these two. For each combination of given and target behaviours, the transitional probabilities were calculated. In addition, the values of Yule's *Q* were able to indicate whether the probabilities that might be observed differed significantly from the ones actually observed. Because our aim was to determine the overall tendencies and because marginal sums were low in the individual data, calculations were carried out using the pooled data. In addition, we compared the individual data of some of those individuals who had sufficient marginal sums vis-à-vis the pooled data in order to check for the representativeness of our results.

Results

Initiation following different stimuli (see Fig. 1)

Within this study, we differentiated between four different stimuli: visual, auditory, tactile and vestibular. This differentiation was based on the stimuli presented during the activities.

The results of the sequential analysis including the different stimuli and the initiation of the activity show that all stimuli are followed by large percentages of activities initiated by the DSP. These percentages are 70%, 87%, 79% and 90% for visual, auditory, tactile and vestibular stimuli respectively.

While only a small portion of the activities is initiated by the client, these percentages differ for the different stimuli. Activities that include visual stimuli are followed by an initiation by the client in

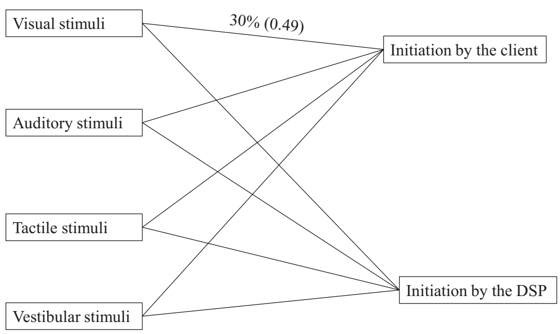

Figure 1 Initiation following different stimuli.
Note. Percentages are complemented by Yule's *Q*s. DSP, direct support person.

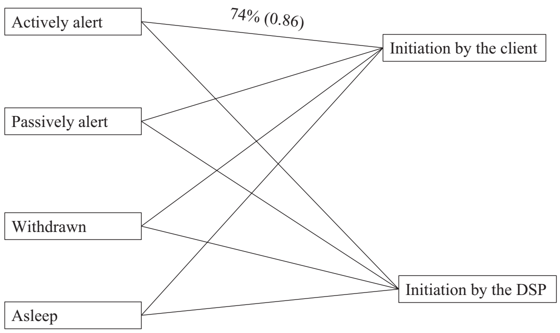

Figure 2 Initiation following different alertness levels.
Note. Percentages are complemented by Yule's *Q*s. Because no agitated behaviour occurred during the observed situation, this behaviour was not included in the figure. DSP, direct support person.

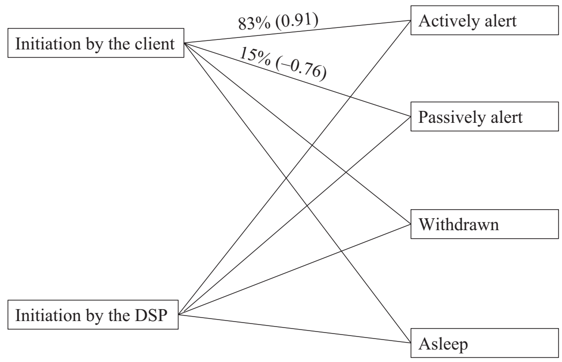

Figure 3 The level of alertness following initiation.
Note. Percentages are complemented by Yule's *Q*s. Because no agitated behaviour occurred during the observed situation, this behaviour was not included in the figure. DSP, direct support person.

30% of the cases. When the activity included an auditory, tactile or vestibular stimulus, the percentages were 12, 21 and 5 respectively.

Initiation following different alertness levels (see Fig. 2)

Relating the initial alertness level to the initiation revealed the following results. Before the individual with PIMD initiated the activity, he/she was actively alert in 74% of the cases, passively alert in 23% of the cases, and withdrawn in 3% of the cases. No situations were observed where the individual with PIMD was asleep or agitated before a self-initiated activity. When the DSP initiated the activity, 18% of the situations were preceded by active alertness on the part of the individual with PIMD, 57% by passive alertness, 20% by withdrawn behaviour and 6% by sleep. No agitated behaviour occurred in any of the observed situations.

The level of alertness following initiation (see Fig. 3)

Looking at the level of alertness that followed the activities, we found that 83% of the individual with PIMD was actively alert after self-initiated activities, 15% passively alert and 2% withdrawn. When the DSP had initiated the activity, the individual with PIMD showed active alert behaviour in 18% of the situations, passive alert behaviour in 56%, withdrawn behaviour in 19% and sleep behaviour in 6% of the situations. No agitated behaviour occurred in any of the observed situations.

Discussion

To investigate the relationship between the different alertness levels of the individual with PIMD and the initiation of the activity and different stimuli used, we conducted sequential analyses including combinations of the variables. The results of the present study point to several conclusions. While all the different stimuli were followed by large percentages of initiation on the part of the DSP, these percentages differed slightly per stimulus. Vestibular and auditory activities were the ones more usually initiated by DSPs. Initiation on the part of the individual with PIMD, on the other hand, occurred only in a small number of situations. Again, percentages differed per stimulus. Therefore, visual and tactile stimuli would seem to activate the individual with PIMD more often than did auditory and vestibular stimuli. When relating the percentages of initiation and the level of alertness to each other, we found that individuals with PIMD were much more actively alert before and after self-initiation of an activity. A similar relationship became apparent for those activities initiated by the DSP and the passive alertness level of the individual with PIMD. The individuals with PIMD were often withdrawn and even asleep before and after the DSP-initiated activities, as compared with only very low percentages of withdrawn behaviour and no sleep before and after the self-initiated activities.

Different explanations for the results can be formulated. It is in line with general expectations that individuals will be more actively alert when they are able to control the situation; in theory, this is also true for individuals with PIMD (Kennedy & Haring 1993; Lancioni *et al.* 2000, 2005). However, because of their severe disabilities they are completely dependent on others. This dependence can make it more difficult for them to determine the situation (Vlaskamp *et al.* 2007) and, as a consequence, lead to a smaller number of self-initiated activities.

Another explanation can be formulated concerning the different reactions to the different sorts of stimuli. The result may actually be related to the nature of the stimuli (Mitchell & Le Pelley 2010; Munde *et al.* 2012a). A coloured toy may, for example, be more likely to tempt an individual with PIMD to explore and show active behaviour than would swinging in a hammock. Furthermore, previous studies have emphasized the importance of tactile methods in the communication with individual of the target group (Hostyn 2011). Possibly, tactile stimuli do promote self-initiation in particular.

A third explanation may be related to the role of the DSPs in the contact of individuals with PIMD and their environment. When a DSP initiates an activity, it is possible that he/she more often than not has a pre-constructed plan for the course of the activity (Wilder & Granlund 2003; Olsson 2004). Therefore, the individual with PIMD may not even get a chance to become active on his or her own. Similarly, DSPs may allow more exploration of a visual stimulus such as a coloured toy than they would when the individual with PIMD is experiencing a vestibular stimulus such as lying in a hammock. It is possible that individuals with PIMD would be able to show even more actively alert behaviour if the DSP created more possibilities for them to do so (Green *et al.* 1994; Munde *et al.* 2012a). In addition, a previous study on the development of alertness over time has shown that alertness in individuals of the target group changes in 'waves' (Munde *et al.* 2012b): a period of alertness is followed by a period of non-alert behaviour, but then another period of alertness often follows after that. DSPs may conclude after the first 'alertness wave' that they should end the activity at that point. However, an individual with PIMD may become alert for a second time shortly thereafter, and use this moment as an opportunity for self-initiation. This leads to the suggestion that DSPs might often be acting too quickly.

A number of limitations should be noted when it comes to interpreting the results. Although this study was based on a quasi-experimental design, random selection was only carried out for the participants, and not for the stimulation. The choice of a stimulus and the way of interacting was different for each participant. Because individualized stimulation is especially important for individuals in the target group, DSPs were instructed to adapt their behaviour to the needs and abilities of the individual with PIMD. Consequently, stimuli were only comparable in terms of their salience for the individual participant. Comparisons including similar stimuli or ways of interaction may reveal supplementary information. Furthermore, no chains of stimuli were taken into account. For example, the results produced by repetition may differ from those produced by presenting a stimulus only once. Moreover, the onset of several stimuli at the same time may well bring about different reactions. Because we did not control for additional stimuli that were presented after the first one in the subsequent time windows, these might also have influenced the reactions in terms of alertness levels. Future experimental studies that control for these aspects would certainly complement the present results.

Applying the results of the present study to situations in daily professional practice leads to several recommendations for DSPs. In order to promote actively alert behaviour, it is essential to search for situations that allow self-initiation and choices for individuals with PIMD. When an individual of the target group is passively alert in the first moment, DSPs may use these moments of passive alertness to start an activity aiming at raising the level of alertness in the course of the activity. To make DSPs aware of the importance of their position in the contact of the individual with PIMD with his/her environment, they could be trained to look for and recognize the level of alertness of their client

(Guess *et al*. 1999; Arthur 2004; Parsons *et al*. 2004). As a consequence, DSPs may target their own behaviour more appropriately. Exploring those situations where there is active involvement and exploring the introduction of different sorts of stimuli may reveal even more information about those situations that have the potential to allow the person with PIMD to self-initiate an activity. In general, DSPs should seek a balance between being passive themselves and promoting in the individual with PIMD a state of being as active and alert as possible.

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