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Alertness in individuals with profound intellectual and multiple disabilities: A literature review

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ABSTRACT

Direct support persons (DSPs) often face problems in observing and determining alertness in individuals with profound intellectual and multiple disabilities (PIMD).

A literature study was carried out to gather information about the problems just described. A search of two electronic databases and the references found in relevant hits revealed 42 relevant publications. The results show that two types of descriptions of alertness can be distinguished: (1) those with a focus on the individual only or (2) those with a focus on the interaction of individual and environment. Several observation categories were used in the studies that were found. The reliability of the observations turned out to be a core problem in most of the studies. Only a limited number of environmental conditions that were expected to have an impact on alertness in individuals with PIMD were investigated. While modifications of the environment, interaction strategies, stimulation strategies and staff training were found to have a positive impact on alertness, studies about treatment activities led to conflicting results.

Finally, we will formulate the resulting implications for future studies and for the development of an instrument for DSPs in order to observe alertness in individuals with PIMD in clinical practice.

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1. Introduction

> "Tom is lying on the floor and is apparently staring without any focus. A direct support person (DSP) places a toy in front of him: "Look, Tom! I brought a beautiful toy for you!" Tom keeps staring without any visible reaction to the toy. As the telephone rings, the DSP leaves him alone. Some seconds later, Tom slowly begins to move. He turns his head towards the toy and tries to reach the toy with his hand."

DSPs often face similar situations when caring for individuals with profound intellectual and multiple disabilities (PIMD). To an observer, the questions that arise at these moments are: did the DSP choose the right moment to start an activity? Was Tom alert but inactive before the toy was presented? Or was he drowsy and did he become alert some seconds after the toy was placed in front of him? What caused the change in his alertness level? Did Tom become alert because of the new stimulus, because of the contact with the DSP, or because of another factor?

DSPs also ask these questions. They experience difficulties in detecting and understanding expressions of alertness in individuals with PIMD because of the complexity and severity of the disabilities of these individuals. Individuals with PIMD not only have profound intellectual and motor disabilities (Nakken & Vlaskamp, 2007), but sensory disabilities, and a broad range of additional health problems (e.g., epilepsy, dysphagia, constipation, gastro-oesophageal reflux) are also common (Arvio & Sillanpää, 2003; Kapell et al., 1998; Van Schojenstein Lantman-de Valk et al., 1997; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). One complicating factor is the heterogeneity of the target group: the combination and degree of disabilities vary for every individual. The magnitude of the disabilities of individuals with PIMD also has consequences for the way they communicate. Most of them are not able to use spoken language and, as a consequence, have alternative ways of communicating such as through gestures, muscle tensions, a wink or a blink (Grove, Bunning, Porter, & Olsson, 1999). Their limited repertoire of communicative skills and the fact that one signal may have several meanings make it difficult for the DSP to detect and interpret the communicative signals of individuals with PIMD, such as being interested in the environment or in a toy (Petry, Maes, & Vlaskamp, 2005). Unconventional reactions to stimuli and differences in information processing make it even more difficult for DSPs to determine the right moments, approaches and materials to use when offering an activity (Petitiaux, Elsinga, Cuppen-Fonteine, & Vlaskamp, 2006). Observation is, therefore, the most obvious method for taking these difficulties into account, that is, looking at individual behaviors and interpreting these behaviors based on knowledge of the individual. Still, the reliability and validity of observations may be considered as limited (Vlaskamp, 2005).

The right moment to offer an activity can be related to the level of alertness (Guess & Siegel-Causey, 1995), but knowledge of the conditions for optimal stimulation is still missing. We lack a clear description of what is meant by "being alert" for this specific target group. In trying to solve the question about "the right moment," an unambiguous description of the term "alertness" is necessary. Following on that, reliable and valid methods to determine alertness need to be developed. Furthermore, environmental conditions that may have an impact on the level of alertness in individuals with PIMD need to be investigated. Taking into account the relationship between alertness and stimulation (Guess & Siegel-Causey, 1995), we searched for factors that would support individuals with PIMD in reaching an optimal level of alertness for learning and, therefore, the opportunity for development.

Alertness is a term that is not exclusively used in behavioral sciences. In medical science, alertness includes cognitive processing and is determined on the basis of physiological brain measurements (Oken, Salinsky, & Elsas, 2006; Thomas et al., 2000). However, by only looking at the internal changes in an individual's functioning, environmental changes and their impact on alertness are not taken into account. Since relationships with the environment are essential for observations of individuals with PIMD (Vlaskamp, 2005), the medical approach will be excluded in this study.

Based on the above-mentioned considerations, this study aims to review the scientific literature about the behavioral dimension of alertness in individuals with PIMD in order to answer the following research questions: (1) How is "alertness" for individuals with PIMD described in the literature; (2) Which observation methods, as found in the literature, can be employed to determine alertness levels of individuals with PIMD; (3) Which environmental conditions are related to the alertness in individuals with PIMD according to the literature?