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Content and Quality of Motor Initiatives in the Support of People With Profound Intellectual and Multiple Disabilities

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Abstract

Motor activation is rarely integrated into the support of people with profound intellectual and multiple disabilities (PIMD), which might be the result of the limited evidence-based knowledge in this field. Practitioners have recently been developing several motor initiatives for people with PIMD, but it remains unclear about what core elements the motor initiatives actually consist of and to what level of quality it is implemented in practice. This study aims to offer an overview and analysis of the content and quality of motor initiatives actually in use for people with PIMD. Motor initiatives were explored by asking practitioners to complete an online inventory form. Documents, expert knowledge, and observations were used to collect data about the characteristics of the motor initiatives. The quality of the motor initiatives which met our eligibility criteria, was analyzed on the basis of the level of evidence for their effectiveness. The inventory yielded 118 motor initiatives of which 17 met the eligibility criteria. We identified four motor initiatives reflecting an approach to motorically activate people with PIMD within various activities, three including power-assisted exercises, three with aquatic exercises, two frameworks which integrated motor activities into their daily programs, two methods which included small-scale activities, two rhythmic movement therapies, and one program including gross motor activities. We found limited indications for descriptive evidence from 17 initiatives, limited or no indications for theoretical evidence from 12 and five initiatives respectively, and none of the initiatives provided a causal level of evidence for effectiveness. A wide variety of motor initiatives is used in current practice to activate persons with PIMD, although their effectiveness is actually unproven. Science and practice should cooperate to develop an evidence-based understanding to ensure more evidence-based support for the motor activation of people with PIMD in the future.

Keywords: effectiveness, intellectual disabilities, motor activation, physical activity, profound intellectual and multiple disabilities

Introduction

People with profound intellectual and multiple disabilities (PIMD) are at increased risk of being physically inactive (Bjornson, Belza, Kartin, Logsdon, & McLaughlin, 2007; Draheim, Williams, & McCubbin, 2002; Hilgenkamp, Reis, Van Wijck, & Evenhuis, 2012; Van der Putten, Bossink, Frans, Houwen, & Vlaskamp, 2017). People with PIMD have little understanding of verbal language and the functional use of their arms and legs is very limited (Nakken & Vlaskamp, 2007). They also have an overall risk of sensory problems (e.g., visual impairment) and several health problems (e.g., epilepsy, dysphagia, and reflux) (Nakken & Vlaskamp, 2007; Van Timmeren, Van der Putten, Van Schroyen, Lantman-de Valk, Van der Schans, & Waninge, 2016). Therefore, people with PIMD are dependent on

personal assistance and consequently, some form of intervention is needed for them to be able to perform and benefit from physical activity (Houwen, Van der Putten, & Vlaskamp, 2014).

Activating support is a recent development in the support of people with PIMD and is very important for ensuring that people with PIMD benefit from physical activity and overcome the adverse health conditions which result from physical inactivity (Hortobágyi, 2014; Lee et al., 2012). Although existing physical activity prescriptions do not apply to people with PIMD (ACSM, 2013; Gezondheidsraad, 2017; WHO, 2010), there is sufficient evidence that these people can benefit from motor interventions (Houwen et al., 2014) and strategies which facilitate the movement of the whole body or parts of the body (motor activation) (Van der Putten et al., 2017). Motor activation for people with PIMD can improve health, but may also provide an improvement in functional skills, fewer behavioral problems, and an increased alertness and well-being (Aherne & Coughlan, 2017; Jones et al., 2007; Munde & Vlaskamp, 2015; Van der Putten, Houwen, & Vlaskamp, 2014; Van der Putten, Vlaskamp, Reynders, & Nakken, 2005). It is also suggested that the communication and participation of people with PIMD can

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be increased by obtaining motor skills through motor activities, such as pushing buttons (Lancioni et al., 2004; Van der Putten et al., 2017).

Unfortunately, motor activation is not yet fully included in the daily support of people with PIMD. Most of the activities offered to people with PIMD have been shown to be passive in nature (Vlaskamp, De Geeter, Huijsmans, & Smit, 2003; Vlaskamp & Nakken, 2008; Zijlstra & Vlaskamp, 2005) and mainly consist of sensory stimulation such as the use of multi-sensory environments (Vlaskamp, Hiemstra, Wiersma, & Zijlstra, 2007). In addition, leisure time activities often include watching television or listening to music (Van der Putten & Vlaskamp, 2011; Vlaskamp et al., 2003, 2007; Zijlstra & Vlaskamp, 2005). This is confirmed by recent studies which show that the support of people with PIMD rarely focused on motor activation (Van der Putten et al., 2017; Waninge et al., 2013). The study by Van der Putten et al. (2017) even showed that more than half of the participants ($n = 58$) on average were not even engaged in one motor activity (e.g., encouraging someone to play with a mobile, manipulating objects, playing on a mat or rolling around in a pool of plastic balls) per weekday.

All in all, this minimal provision of motor activation may result from the limited number of evidence-based motor interventions available for people with PIMD (Houwen et al., 2014; Van der Putten, 2010). Only a few studies with people with PIMD specifically focused on interventions which target the motor domain, but also these interventions and/or studies have limitations with regard to the applicability and generalizability to people with PIMD. For example, relevant therapeutic interventions including an integrated motor component (e.g., Neuro Development Treatment and Sensomotor integration) (Nakken, Reynders, Vlaskamp, & Procee, 1998) seem to be based on obsolete ideas of the process of motor development and motor learning in people with PIMD (Van der Putten, 2010). In addition, the Mobility Opportunities Via Education (MOVE) curriculum, which consists of functional movement activities that show promise for improving the independence of children with PIMD (Van der Putten et al., 2005), does not seem to be used to support people with PIMD within the Netherlands and Belgium (Vlaskamp & Nakken, 2008). The use of technology to improve hand response, appropriate head position and correct posture also seems promising, but performed studies of this kind of motor activation lack external validity (i.e., generalizability) due to the exclusiveness of single-participant designs used (Lancioni et al., 2004, 2005). In addition, the effects of a power-assisted exercise intervention have recently been studied with a randomized controlled trial (Bossink, Van der Putten, Waninge, & Vlaskamp, 2017; Wessels, Bossink, & Van der Putten, 2017). However, for this intervention only an improvement in oxygen saturation was found, while the researchers noting that the exact meaning of this finding is unclear (Bossink et al., 2017). Furthermore, it is also known that the applicability of motor activities designed for people with less severe disabilities to people with PIMD is limited (Van Schijndel-Speet, Evenhuis, Van Empelen, Van Wijck, & Ehteld, 2013). It is also unclear if the results in people with less severe disabilities (e.g., active support: Beadle-Brown, Hutchinson, & Whelton, 2012) can be generalized to people with PIMD (Maes, Lambrechts, Hostyn, & Petry, 2007). Altogether, evidence-based knowledge on motor activation for people with PIMD is scarce and it remains unclear from the literature what

kind of motor activation should be used for what reason in the support of people with PIMD.

In recent years, a wide variety of practitioners (e.g., physical therapists, movement instructors, managers, and direct support professionals) have developed several practical initiatives to activate people with PIMD motorically. Some of these motor initiatives have been presented in practitioner periodicals, on the internet or at practitioner conferences. As a result, the limited, implicit although probably valuable knowledge in this field is incorporated in ongoing practice. To date, however, it remains unclear from a scientific perspective what the core elements really are constituting motor initiatives and to what level of quality it is implemented in practice. This practice-based knowledge is important, because it could rapidly improve the success rate of implementing evidence-based motor activation for people with PIMD.

Knowledge about the quality of these motor initiatives based on theory and scientific evidence is also of utmost importance in the promotion of motor activation for people with PIMD, especially because currently little is known about the functional relationships between the components of motor interventions and their outcomes (Houwen et al., 2014). Without a sound theory and evidence-based understanding of the motor initiatives used in practice, organizations, and support professionals are unable to identify the outcomes of their interventions (Glanz, Rimer, & Viswanath, 2008; Van Yperen, Veerman, & Bijl, 2017). People with PIMD are particularly vulnerable. Therefore it is important that practitioners invest their precious time and money in the most effective and appropriate forms of motor activation when supporting people with PIMD. Accordingly, an evidence-based support approach to the motor activation of people with PIMD is of major clinical relevance.

As a first step toward an evidence-based support approach to the motor activation of people with PIMD, this study offers an overview and analysis of the content and quality of the motor initiatives actually in use for people with PIMD in the Netherlands. This will increase the available body of knowledge on the content and quality of motor initiatives which can flexibly meet the needs of people with PIMD, and the components of motor initiatives which can be related to specific benefits for people with PIMD.

Method

A two-phase exploratory approach was applied. Phase 1 explored the motor initiatives actually in use within the support of people with PIMD in the Netherlands. In Phase 2, we collected data about the content and quality of the investigated motor initiatives.

An online inventory form, accessible between October 2015 and May 2016, was used to explore motor initiatives. Documents, expert knowledge, and observations were used to gather data about the content and quality of the motor initiatives investigated. This study collected data on motor initiatives for people with PIMD and did not include the personal data of people with PIMD or their direct support professionals. Therefore, in accordance with the Dutch ethics rules for research involving humans, ethical approval was not required. However, the practitioners that completed the online inventory form were informed about the research purposes and personal data have been treated

confidentially and were saved anonymously. Throughout the research we did act in accordance to the Netherlands code of conduct for research integrity.

Phase 1

Data collection. We collected motor initiatives by asking practitioners to complete an online inventory form, which was published on the websites of knowledge networks related to the support of people with PIMD. Practitioners were also addressed directly through various forms of social media. We only addressed practitioners who were engaged in providing support to people with PIMD (Nakken & Vlaskamp, 2007): people with severe or profound intellectual disability (intelligence quotient (IQ) under 35 points or a developmental age of up to 36 months) and severe or profound motor disability (classified as Gross Motor Function Classification System (GMFCS) IV or V; Palisano et al., 2000) with a continuous need for support for all activities in daily life (Nakken & Vlaskamp, 2007; WHO, 2001). Forty-three practitioners from 40 different settings from 31 different organizations distributed across the Netherlands completed the inventory form. These 40 settings consisted of centers for special education, day services centers, and residential facilities. The practitioners included physical therapists ($n = 17$), direct support professionals ($n = 10$), movement instructors ($n = 7$), health care psychologists ($n = 2$), and professionals with an advisory, coordinating, or managerial role ($n = 7$).

An online inventory form was used to gather information about motor activation integrated into the support for people with PIMD. This study only used one of the open questions on this form, thereby aiming at the exploration of the initiatives used in practice with a focus on motor activation: activities with the purpose of facilitating movements of the whole body or parts of the body of people with PIMD (Van der Putten et al., 2017). We asked practitioners to share the motor initiatives (i.e., interventions, methods, and programs) used at their setting to activate people with PIMD motorically. To perform movement, people with PIMD are heavily dependent on support. Consequently, we used a broad definition of motor activation including activities that assumed facilitating either actively (e.g., active resistive training on a movement trainer), passively (e.g., swinging in a hammock), or assisted performed movements of the whole body or the limbs (e.g., encouraging someone to play with an object).

Data procedure. Based on the inventory, motor initiatives were selected on the basis of a number of inclusion criteria to only include the motor initiatives within a defined framework aimed at facilitating movements of people with PIMD. We used the available materials about the motor initiatives and, where relevant, observations of the motor initiatives in practice and personal communications with practitioners or motor initiative developers to select the motor initiatives. Motor initiatives were included in this study if they met the four inclusion criteria presented below.

Primary focus

We included initiatives with a primary focus on bodily movement: initiatives which aimed to improve the movement of the whole body or parts of the body (Houwen et al., 2014; Van der

Putten et al., 2017) and initiatives relying on movement of the whole body or parts of the body as the main elements for improving other domains of human functioning, also beyond the motor domain.

Target group

We included initiatives that were originally designed and developed for people with PIMD or modified to fit people with PIMD. We also included motor initiatives designed for people with intellectual disabilities, thereby paying additional attention to people with PIMD.

Purpose

We included initiatives intended for integration in the daily support and available for use for therapeutic purposes.

Application

We included initiatives within a defined framework (including methods, programs, and interventions) and those being clear about their major components (which at least in part had to be made explicit within the available materials). We excluded initiatives which were disciplines (e.g., physical therapy) or facilities (e.g., swimming pool).

Phase 2

Data collection. Documents, expert knowledge, and observations were used to collect data about the content and quality (i.e., practice-driven indications and scientific evidence for the effectiveness) of the selected motor initiatives. We collected per initiative practical documentation, scientific literature, and website information coming from the internet, scientific databases, and the Phase 1 practitioners and motor initiative developers. We complemented this data collection with expert knowledge and observations when documentation was missing, incomplete, or unclear. The expert knowledge is based on personal communications with the Phase 1 practitioners and the developers of the motor initiatives, as relevant. Observations were made during the performance of the motor initiatives in daily practice, during a conference workshop about the motor initiative and by watching the intervention design principles and implementation strategy on video. For the descriptions per motor initiative, we indicated the source of the information through a reference to the sources used (see Table 3). Information from practitioners was only referred to in relation to the content, intended application, and materials. These practitioners included direct support professionals and physical therapists that actually guided the initiatives in daily practice.

Data procedure and analysis. We collected data on, and described the following characteristics for, each motor initiative: use (locally or widely applied in the support of people with PIMD within the Netherlands), target group, (sub)goals, content and application, available documentation/other material, theoretical rationale, and research performed (Van Yperen et al., 2017). In addition, we described the content, application, and theoretical rationale of the motor initiatives in relation to the goals to provide a first insight in the components that may be related to specific outcomes. Subsequently, the quality of the motor initiatives was

determined based on the development model for the assessment of the effectiveness of interventions formulated by Veerman and Van Yperen (2007) (see Table 1). This model comprises four levels of evidence (descriptive, theoretical, indicative, and causal) and a classification of the indications for effectiveness based on the degree of documentation (Veerman & Van Yperen, 2007). A motor initiative is potentially effective if descriptive indications of how effects can be achieved are obtained through a detailed description of the motor initiative's essential elements (e.g., target group, goals, methods, and activities). We used several evaluation criteria based on the criteria formulated by Siebes, Wijnroks, and Vermeer (2002), to evaluate the available documentation on the descriptions of the target group, goals and subgoals, content and intended application (see Table 2). A motor initiative can be classified as probably effective (i.e., supported by a theoretical level of evidence) if it has a plausible rationale for why it should work with whom. We analyzed the available documentation for their descriptions of the underlying elements and their rationales as an indication of the theoretical underpinnings that may explain the effectiveness in people with PIMD (see Table 2). Functionally effective motor initiatives (i.e., those supported by an indicative level of evidence) are described in detail, have a plausible rationale and also include a systematic evaluation showing that the desired outcomes can be achieved in the target group. We did not collect data on individual goal attainment and the monitoring of outcomes within the daily support of people with PIMD, but we analyzed the practical documentation on the descriptions focused on systematic evaluation to indicate if the desired outcomes of the motor initiatives are potentially evaluated on a systematic basis in the support of people with PIMD. For a motor initiative to be documented as effective (i.e., supported by a causal level of evidence), a research design is required to establish that it is probable that its outcomes were caused by the motor initiative. We described the nonpeer reviewed and peer reviewed sources to indicate the quantity of research performed (see Table 3). In addition, the scientific and peer review studies were further analyzed to assess the causal level of evidence for the effectiveness of the motor initiatives in people with PIMD.

Results

Selection of Motor Initiatives

The online inventory form yielded 251 potentially relevant motor initiatives. After removing duplicates, 118 distinct motor initiatives were identified. After application of the inclusion criteria, a total of 17 motor initiatives remained for inclusion. Figure 1 shows the flowchart for the selection process.

Content of Motor Initiatives

Table 3 presents an overview of the motor initiatives and their characteristics. We found 17 motor initiatives that varied in their content including demanding activities depending on specific facilities and equipment, small-scale activities integrated within the daily support, and initiatives referring to the attitude toward a person with PIMD which could be applied to various movement sessions.

More specifically, four motor initiatives (23.5%) reflected a specific approach to motorically activate people with PIMD within various activities (Sherborne, Basic Stimulation, Experience it, and Out of the Chair). Three motor initiatives (17.6%) were based on power assisted or robotized exercises (Powered Exercise Machines, Motomed and Pactive Motion (also known as Therapeutic Motion Simulation or Vita Motion)). Three motor initiatives (17.6%) were based on aquatic exercises (Watsu Therapy, Halliwick Concept, and Swimming Program). Two motor initiatives (11.8%) included a framework for structurally integrating individual-based movement within daily support (Moving On and Exercise Plan). Two motor initiatives (11.8%) consisted of small-scale activities using simple materials (Power of Simplicity and Bag with Movement-stimulated Materials). Two motor initiatives (11.8%) were a form of therapy based on rhythmic movements (Saito Therapy and Wagon-bed Riding), and one motor initiative (5.9%) included a year-long program of gross motor activities conducted within seven themes (Moving Experience).

Content in Relation to the Goals and Subgoals

The motor initiatives reflecting an approach to motorically activate people with PIMD (Sherborne, Basic Stimulation, Experience it, and Out of the Chair) mainly aimed at social-emotional development, including subgoals such as communication, interaction, body awareness, and body perception (see Table 3). These motor initiatives all included an opportunity to

TABLE 1
Development stages of the motor initiatives based on the level of evidence for their effectiveness¹

Level of evidence	Evidence parameters	Effectiveness
4. Causal	Well-designed studies present evidence which shows that the desired outcomes are caused by the motor initiative or elements of the initiative.	Documented
3. Indicative	A systematic evaluation is used to indicate that the motor initiative would lead to the desired outcomes.	Functional
2. Theoretical	The motor initiative is underpinned by a theoretical rationale which describes its effectiveness.	Probable
1. Descriptive	The essential elements of the motor initiative have been described in detail.	Potential

¹ From Veerman and Van Yperen (2007).

interact with others and/or an opportunity to freely move in the environment applied within various activities. The frequency, intensity, and duration of these activities are generally unspecified (see Table 3). As these motor initiatives are based on a variety of, but corresponding elements in content and theories, the underlying principles with regard to the guidance and support for people with PIMD may be related to the aimed benefits in relation to social-emotional development.

The power-assisted exercises (Powered Exercise Machines, Motomed and Pactive Motion) mainly aimed at overall functioning by improving physical health, including muscle strength, blood circulation, endurance, and relaxation (see Table 3). These motor initiatives all included aerobic, strength, and/or flexibility activities adapted to the needs of people with PIMD using technical devices. The frequency, intensity, and duration of these exercises are to be determined at an individual level (see Table 3). The theoretical rationale of these initiatives is

based on the effects of movement in general as well as the underlying elements of specific movement activities/ways of stimulation which may explain the aimed benefits on physical health.

The aquatic exercises (Watsu Therapy, Halliwick Concept, and Swimming Program) are aimed at a wide range of goals including physical health (e.g., reducing pain), mental health (e.g., alertness), and functional skills (e.g., postural control) (see Table 3). The corresponding component within these motor initiatives is the performance of activities in hot water, but the aquatic exercises differed in their content with regard to the level of active participation and the type of movements stimulated (e.g., independent movement vs. being moved (or stretched) in the water). The duration and frequency indications are focused on 30 minutes once a week (see Table 3). The differences in aimed benefits (relaxation and reducing pain vs. independent movement and postural control) may be due to the differences in underlying theoretical elements

TABLE 2

Evaluation criteria for the various characteristics described for each motor initiative¹

Characteristics	Description
1. Target group	1.1 Clear for which target group it is intended?
	++ Yes, described in detail
	+ Limited, only general characteristics are presented
	- No, target group unspecified
	1.2 Are people with PIMD specified in the target group description?
	++ Yes, specified in detail
2. Goals and subgoals	+ Limited, only general characteristics are presented
	- No, unspecified
	2.1 Clear what goals can be pursued?
3. Content and intended applications	++ Yes, clearly defined
	+ Limited, only a brief description is presented
	- No, unspecified
	3.1 Clear how it should be used and implemented?
	++ Yes, program described in detail
	+ Limited, only a brief description is presented
4. Theoretical rationale	- No, method unspecified
	3.2. Are the frequency, duration, and intensity specified?
	++ Yes, described in detail
	+ Limited, only a brief description provided/some variables not described
	- No, neither is provided
	4.1 Clear why it should work and with whom in relation to the goals?
5. Research performed	++ Yes, described in detail
	+ Limited, only a brief description of a theory/technique involved
	- No theory specified
	5.1 Do well-designed scientific studies attest to the effectiveness of the motor initiative in people with PIMD?
	++ Yes, different types of scientific peer-reviewed studies
	+ Limited, only one scientific peer-reviewed study
	- No, not researched at all/only student theses or research reports available

- indicates a lack of description, + indicates that a description was found, although not in complete compliance with the criterion description, and ++ indicates that a complete description was found.

¹ Adaptation of Siebes et al. (2002).

(elements from yoga and massage vs. elements from physiology and learning theories). However, as one of the aquatic exercises (swimming program) is based on another aquatic exercise method (Halliwick Concept) without corresponding goals (see Table 3), it is unclear how to explain the aimed benefits.

The frameworks which integrated motor activities into their daily programs (Moving On and Exercise Plan) mainly aimed at goals such as quality of life and health (see Table 3). The corresponding component between these frameworks can be found within the structural integration of motor activities (of which the content is tailored to individual needs) in the daily support of people with PIMD (see Table 3). The frameworks are focused on daily movement for 30 minutes and are based on the Dutch physical activity guidelines for maintaining health (see Table 3). As an improvement in health is the aim of these motor initiatives, the outcomes on health may be explained by the application of these initiatives.

The methods which included small-scale activities (Power of Simplicity and Bag with Movement-stimulated Materials) aimed at a wide range of goals (e.g., quality of life, health, enjoyment,

and development of skills) and subgoals (e.g., participation and alertness) (see Table 3). The corresponding component between these methods is the integration of motor activation in the daily support by the use of small-scale activities containing elements, such as an active involvement, tactile stimuli, or a game element (see Table 3). As those methods are based on the integration of movement in the daily support similar to the two frameworks which integrated motor activities in the daily program of people with PIMD, the outcomes of these initiatives on quality of life and health may be explained by their content. In contrast, one of the methods which included small-scale activities (Power of Simplicity) was not aimed at goals in relation to social-emotional development, while it contained several of the theoretical elements of the motor initiatives reflecting an approach to motorically activate people with PIMD, making the relation of these elements with social-emotional development unclear.

The rhythmic movement therapies (Saito Therapy and Wagon-bed Riding) aimed at quality of life including subgoals such as optimal development, enjoyment, relaxation, and decreasing

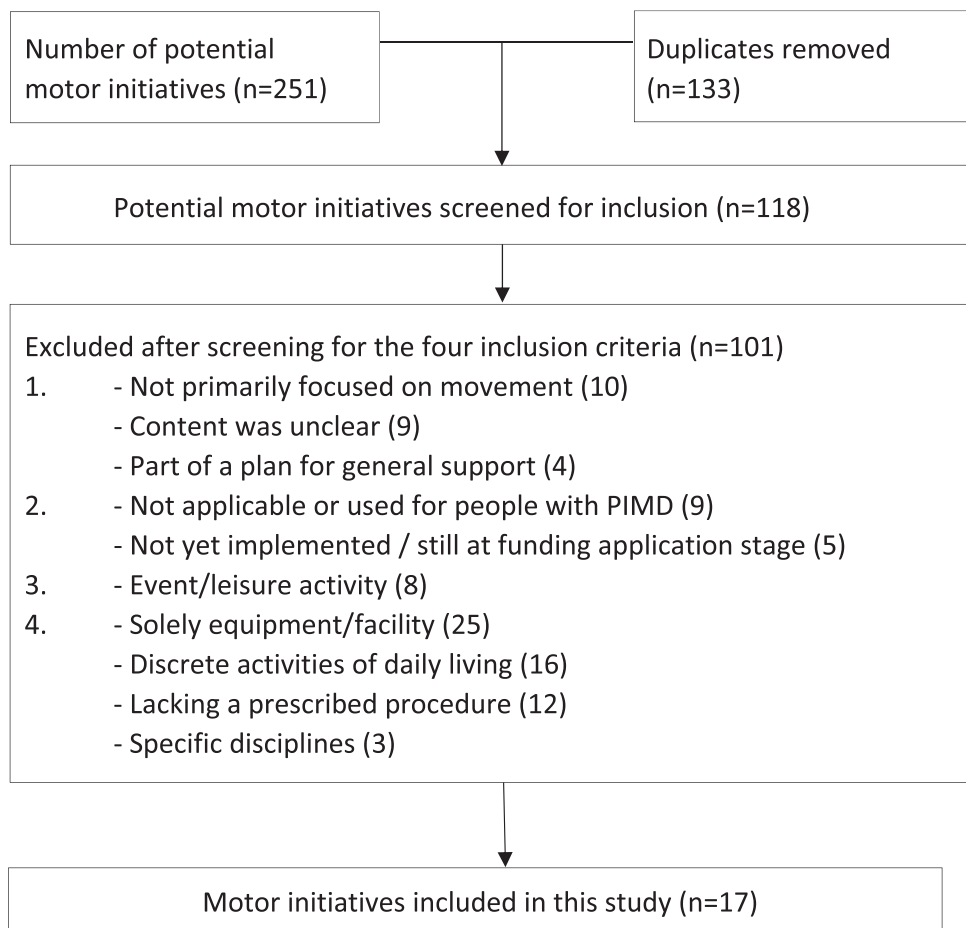


FIGURE 1

Flowchart of the motor initiative selection procedure.

TABLE 3
An overview of the motor initiatives and their characteristics

Motor initiative	Target group and use	Goals and subgoals ¹	Content description	Application	Materials	Theoretical rationale	Research ²
The power of simplicity (in Dutch called "Kracht van eenvoud")	Originally developed for children and adults with PIMD. ¹ Widely applied.	Goal: quality of life. Subgoals: sensorimotor development of alertness, participation and enjoyment. ¹	A method containing small-scale activities, facilitating movement through physical contact or with simple materials integrated into the daily support. ^{1,3-9}	The order, frequency, intensity, and duration need to be determined at an individual level. ¹	The complete package consists of a workshop folder, and list of materials. Activities are also issued as sets of cards. ^{4,5}	Elements of experience-based ordering. Experience it, Haptonomy, Sensorimotor integration, Sherborne and Total communication are used. ¹ The theoretical rationale for the effectiveness is based on underlying elements such as social interaction and integration in daily support. ³	Observational study comparing the power of simplicity with regular support on alertness, emotions, interaction, and enjoyment in people with PIMD (unreported sample size; total of 63 and 49 min observation, respectively). Results are described in a Dutch non-peer reviewed research report (Knibbe, van Veeën, Cornelissen, & Romme, 2015). Has not been researched in people with PIMD.
Moving on	Originally developed for children and adults with intellectual disability including children and adults with PIMD. ¹ Locally applied.	Goal: quality of life. Subgoals: health and functional development. ¹	An organizational structure to offer movement activities, creating conditions for offering these activities and focusing on structural integration within the organization. ^{1,5}	The duration and frequency indications aim for daily movement for 30 min. The intensity of each activity must be individually defined based on difficulty and energy expenditure. ¹	Project description, exercise plan manual, and a book with activities in a special chapter for people with PIMD. ^{1,5}	The underlying rationale is based on the importance of movement in general and the Dutch physical activity guidelines are used for maintaining health. ¹	Has not been researched in people with PIMD.
Exercise plan	Originally developed for adults and adolescents with severe or profound intellectual and visual disabilities including people with PIMD. ^{1,5} Locally applied.	Goal: health. Subgoals: fitness. ¹	Individual plan with daily movement complemented by needs-driven movement activities (e.g., Motomed or swimming). ^{1,5}	The duration and frequency are focused on daily movement for 30 min. The type and intensity of the activities are intended to be determined on an individual basis. ^{1,5}	Exercise plan manual and descriptive information about implementation in daily practice. ^{1,5}	The Dutch physical activity guidelines are used for maintaining health. ¹	Has not been researched in people with PIMD.
Basic stimulation	Originally developed for children with PIMD (Nakken et al., 1998). Widely applied.	Goal: overall development through stimulating the individual learning process. Subgoals: body perception and communication (Fröhlich, 1995).	A concept to approach people with PIMD relying on movements and sensory stimuli integrated within various activities (Fröhlich, 1995; Nakken et al., 1998).	Basic stimulation represents a concept to approach people with PIMD individually, using various activities. The frequency, duration, and intensity of the activities are unspecified (Fröhlich, 1995; Nakken et al., 1998).	The principles of basic stimulation are described in Fröhlich (1995). In addition, information about basic stimulation can be found in Nakken et al. (1998) as well as on several websites. ⁴	Basic stimulation rests on findings from the fields of education, neurology, physiology, and development psychology. In addition, elements of sensorimotor integration and Neuro Development Treatment are also used (Nakken et al., 1998). The theoretical rationale is based on the effects of the underlying principles (Vlaškamp & Nakken, 2008).	Has not been researched in people with PIMD.
Moving experience (In Dutch called "Bewegings-beleving")	Originally developed for children and adults with profound motor disabilities, including people with PIMD. ⁵ Locally applied.	Goal: wellbeing and self-direction. Subgoals: improving health, alertness and participation and decreasing behavioral problems. ⁵	A year-long program including gross motor activities such as swinging and bouncing conducted within seven themes. ¹⁻⁷	Moving experience is a year-long program conducted for 30-45 min per week with themes which vary every 6 weeks. The intensity of the activities is unspecified. ²⁻⁵	Observation descriptions of four themes and a brief summary of the program on the residential facility's website. ^{3,4}	Repeated case studies (n = 7) (3 × 15 min observation) investigating the effects of two themes on alertness and behavioral problems in people with PIMD. Results are published in a Dutch practice-oriented peer-reviewed journal (Van der Putten et al., 2014).	

(Continues)

TABLE 3
Continued

Motor initiative	Target group and use	Goals and subgoals ¹	Content description	Application	Materials	Theoretical rationale	Research ²
Powered exercise machines	Originally developed for polio victims, but used to date for various groups including people with PIMD. ¹ Locally applied.	Goals: fitness. Subgoals: mobility, muscle strength, endurance, blood circulation, and relaxation. ⁶	Power-assisted exercise training by six separate machines designed to target specific joints and muscles in the legs, torso, upper body, and arms. ^{2,4,6,7}	The machine choice, frequency, duration, and intensity are determined individually on the basis of advice by a physical therapist or doctor. ⁶ In the study of Bossink et al. (2017), the machines were used three times a week for 30 min. over a 20-week period. The machines were set at low, moderate or high speed and low, moderate or high intensity. ²	General instructions and descriptive information about the use of the machines for people with PIMD. ^{2,4,6,7}	The underlying rationale for use to support people with PIMD is based on the importance of movement in general. ^{1,4}	Randomized controlled trial (<i>n</i> = 37) on the effects on functional abilities, alertness, body composition, muscle tone, oxygen saturation, fitness, and quality of life in people with PIMD. Results including an in-depth analysis on alertness are published in peer-reviewed journals (Bossink et al., 2017; Wessels et al., 2017). Has not been researched in people with PIMD.
Out of the chair (in Dutch called "Uit de stoel")	Originally developed for children and adults with PIMD. ¹ Locally applied.	Goal: wellbeing and development. Subgoals: self-direction, interaction, and body experience. ^{1,5}	Method which literally takes people with PIMD out of their chair, giving them the opportunity to play on a mat and move and interact with their peers and direct support professionals. The attitude toward the person with PIMD forms the basis. ^{1,4,6}	In practice, used for around 60 minutes at least once a week. The intensity is unspecified. ^{4,6}	Brief description about origins and implementation. ¹	Based on elements of basic stimulation and Sherborne. ⁵ The theoretical rationale for the effectiveness is based on underlying elements as tactile experiences and postural changes. ^{1,5}	
Pactive Motion (also known as Therapeutic Motion Stimulation and Vita Motion)	Originally developed for people with motor disabilities. Used to date with various groups including people with PIMD. ¹ Widely applied.	Goal: quality of life. Subgoals: various, including reducing physical discomfort and increasing mood, alertness, balance, and relaxation. ¹	Multisensory robotized exercises by different platforms (standing, sitting, or lying) and different programs (film, sound, movements, and/or vibrations). ^{1,6}	The platform type and program, frequency, intensity, and duration are to be determined at an individual level. ^{1,5}	User manuals, product information, and brochures with background and research information. ^{1,5}	Based on elements of various interventions such as exergaming, hippotherapy, whole body vibration, music therapy, and Snoezelen. ¹ The theoretical rationale for effectiveness is based on the effects of the underlying elements and the stimulation of multiple senses at the same time. ^{1,5}	Repeated case studies (<i>n</i> = 4) on the effects of two moving platforms on wellbeing in people with PIMD. Results are described within a student thesis (Bossink, Pop, & De Vries, 2011).
Sherborne	Originally designed based on preschool and primary school children, and children with intellectual and/or motor disabilities. Used to date for various groups including children and adults with PIMD (Daems et al., 2012). Widely applied.	Goal: stimulating motor, cognitive and social-emotional development to improve quality of life. Subgoals: improving body awareness and control, forming relationships, communication, and independence and taking initiative (Sherborne, 2001).	An approach using movement as a basis to focus on body awareness and forming relationships. Sherborne refers to the attitude toward the participant, which can be applied to various movement sessions. ^{1,4,7}	The approach represents an approach which can be applied to various movement sessions. The frequency, duration, and intensity of the movement sessions are unspecified. ^{1,8}	The principles of, and experiences with Sherborne can be found in among others Sherborne (2001), Jaminé (2009), and Daems et al. (2012). There are also various courses and DVDs available about Sherborne (Daems et al., 2012).	Sherborne is based on the development of babies and children and Laban's analysis of movement. ¹ The theoretical rationale for its effectiveness is based on the underlying theory and beliefs that Sherborne can fulfill the two basic needs of children: they need to feel at home in their own bodies and so gain body mastery, and they need to be able to form relationships (Sherborne, 2001).	Observational study describing the effects on movement, communication, and social skills in people with multiple disabilities (<i>n</i> = 6). The results are described in a research report (Althoff, 2007).

(Continues)

TABLE 3
Continued

Motor initiative	Target group and use	Goals and subgoals ¹	Content description	Application	Materials	Theoretical rationale	Research ²
Watsu therapy	Used with various age groups with and without disability, including people with PIMD. ^{1,2,4} Widely applied.	Goal: relaxation. Subgoals: increasing mobility, proprioception, and mental state and decreasing pain and muscle tone (Hovens, 2008).	A form of aquatic massage therapy in a hot water pool with a combination of stretching and twisting moves combined with Shiatsu pressure points. ^{1,3,7,8}	Used in practice for 30 min once a week. The intensity is unspecified. ^{1,7}	The principles of Watsu can be found in Dull (2004). There are also various workshops and training programs for becoming a Watsu instructor. ¹	Watsu is based on Zen-Shiatsu, which is carried out at spas. To date, Watsu contains various elements from yoga to physiotherapy, and from That massage to Shiatsu. ^{1,4} The theoretical rationale for the effectiveness is based on the outcomes of a combination of close holding, strong stretches and various forms of mobilization facilitated by the warmth of the water and the effect of weightlessness; it produces (Dull, 2004).	Has not been researched in people with PIMD (WABA, 2018).
Halliwick concept	Originally developed for children with a physical disability. Used to date for various groups including children and adults with PIMD (Kokaridas & Lambeck, 2015). Widely applied.	Goal: independent movement in the water. Subgoals: various such as improving postural control, balance, and functional capacity (Lambeck & Camper, 2010).	A 10-step motor rehabilitation method focusing on the acquisition of stable posture followed by independent movement in water. ^{2,4,7}	The duration of a session is 20–30 min. The frequency and intensity are not specified (Dorpman & Lambeck, 1992). In the study of Bumin et al. (2003), the Halliwick concept was applied twice a week for 8 weeks. The intensity and duration were unspecified. ²	The principles of Halliwick can be found in Lambeck, Stanat, Kinnaid, and NCTMB (2004). In addition, there are various courses available about Halliwick. ⁴	Halliwick is based on a Ten-Point-Program/Water Specific Therapy (Kokaridas & Lambeck, 2015) which was developed using general system theory and bringing together knowledge from physiology, psychology, learning theories and the field of education (Lambeck et al., 2004).	A single-case study examining the effects on stereotypical movements, functional hand use, hand skills, gait and balance, hyperactive behavior, communication, and social interaction in a girl with stage III Rett syndrome. The results are published in a peer-reviewed journal (Bumin, Uyamik, Yilmaz, Kayihan, & Topcu, 2003).
Saito therapy	Originally developed for children with motor and/or multiple disabilities and further developed for children with PIMD (primarily designed for use by parents at home ²). ⁴ Widely applied.	Goal: improving quality of life through optimal development. Subgoals: relaxation. ⁴	A movement therapy based on rhythmic movements and development of the child accompanied with a fixed repertoire of songs. ^{4,9}	Used in practice at an educational center for at least 1 hour once a week. The intensity is unspecified. ⁶ Primarily designed for daily use by parents at home (Vaskamp & Nakken, 2008). ²	The principles of Saito can be found via Stichting Saito Centrum Nederland and workshops are conducted about the therapy (Stichting Saito Centrum Nederland, 2018). ⁴	Saito therapy is based on the philosophy that each child has the potential to develop through movement. The theoretical rationale for the effectiveness is based on knowledge of the organization and flexibility of the brain through stimulation of the healthy brain cells. ^{2,4}	Has not been researched in people with PIMD.

(Continues)

TABLE 3
Continued

Motor initiative	Target group and use	Goals and subgoals ¹	Content description	Application	Materials	Theoretical rationale	Research ²
Experience It (in Dutch called "Ervaar het maar")	Originally developed for children and adults with PIMD. ^{1,4} Widely applied.	Goal: overall development by stimulating motor skills, the senses, and communication. ^{1,4}	An approach focused on communication, the senses and motor skills, directed by individual needs and possibilities. This approach can be applied in various situations and activities. ^{1,4,9}	This approach can be applied in various ordinary activities and situations. The frequency, duration, and intensity were unspecified. ^{1,4,9}	There are various books and films about Experience It, and a course about the method is available. ^{1,4,5}	Experience It is framed by five principles: the theory of Experience-based ordering, Total communication, Basic stimulation, motor coordination skills (as viewed from the neurophysiology and movement-education aspect of Sherborne), and Sensomotor integration. ^{1,4,9}	Has not been researched in people with PIMD.
Swimming program	Originally developed for children and adults with profound motor disabilities, including people with PIMD. ⁵ Locally applied.	Goal: health. Subgoals: alertness and body perception. ⁵	Swimming program structured by a fixed repertoire of movement activities and songs. ^{5,7}	Used in practice (at a 24-hour residential facility) weekly for 30–45 minutes. The intensity is unspecified. ^{4,5,7}	A short reference to the content of the program can be found on the residential facility's website and within presentations given at practitioner conferences (including a short video). ^{4,5}	This swimming program used elements of the Halliwick concept and Sensomotor integration. ⁵ In addition, the Dutch physical activity guidelines for maintaining health was applied. ⁵	Has not been researched in people with PIMD.
Motomed	Originally designed for people with motor disabilities. To date also used for people with PIMD. ¹ Widely applied.	Goal: maintaining or improving overall functioning. Subgoals: reducing spasm and increasing blood circulation, mobility, endurance, muscle strength, and wellbeing. ¹	A form of movement similar to normal cycling, which allows for passive, motor-assisted and active resistive movements of the legs and arms/upper body from a sitting or lying position. ^{1,4,7}	It can be used daily. The duration, resistance level and speed can be increased on the individual advice of a doctor/therapist. Various elements can also be focused on reducing spasm or interval, endurance, and/or strength training. ¹	Information about the Motomed (e.g., instruction manuals, product information and research information) can be found via Motomed.com. ⁴	The theoretical rationale for its effectiveness is based on the fitness and health outcomes of cycling in general and the effects of preserving the full range of motion in the joints. ¹	Has not been researched in people with PIMD (Motomed, 2018).
Wagon-bed riding (in Dutch called "Huilbed rijden")	Originally developed for people with PIMD. ^{1,3} Widely applied.	Goal: increasing enjoyment, relaxation, blood circulation, metabolism, and digestion. Subgoals: decreasing constipation, spasticity, epilepsy, symptoms of pneumonia. ^{1,3}	A form of hippotherapy using a steel construction and a covered carriage (wagon-bed) to enable people with PIMD to move on the back of a horse and experience the movements and warmth of the horses. ^{1,3,7}	Used for around 20 min in daily practice. The frequency varies from daily to a few times a year (Lammers, Viassak, & Van der Zanden, 2002). The intensity is unspecified. ^{1,3}	There are various wagon bed foundations in the Netherlands. ¹ In addition, a course (with an associated practical and theoretical book) is available. ¹	The theoretical rationale for its effectiveness is based on the suggested outcomes of rhythmic alternating movements, reflex inhibiting postures, sensorimotor stimuli, and interaction with horses. In addition, the warmth of the horse may increase tissue perfusion and have a soothing effect on the nervous system (Lammers et al., 2002).	One pilot study with a repeated-measures design performed on people with intellectual disability ($n = 8$) on functioning in activities of daily living (unclear if involving activities of people with PIMD were involved). The results are described in a Dutch research report (Lammers et al., 2002).

(Continues)

TABLE 3
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Motor initiative	Target group and use	Goals and subgoals ¹	Content description	Application	Materials	Theoretical rationale	Research ²
Bag with movement-stimulating materials (in Dutch called "Beweegtas")	Originally developed for people with intellectual or multiple disabilities, including people with PIMD. ⁴ Locally applied.	Goal: enjoyment, health, discovering possibilities and learning new skills. ¹	Bag with movement stimulating materials (e.g., dice, bean bags, balls etc.) and activity descriptions. ^{1,4,9}	The intensity guidelines distinguish sports and play activities from sensory activities. The duration of sessions is focused on 30 minutes. The frequency is not specified. ¹	Bag with materials and activity descriptions with a separate edition for people with PIMD. ^{1,5}	The underlying rationale is based on the importance of movement in general. ¹	Has not been researched in people with PIMD.

The numbers indicate the sources used for data collection: 1. Practical documentation; 2. Published research; 3. Unpublished research (research report/student thesis); 4. Website information; 5. Information from the developer; 6. Information from support professional; 7. Observation in daily support; 8. Workshop observation; 9. Observation through watching a video about the initiative.

¹ Goals in addition to a primary focus on improvement of movement.

² Only research performed on the effects in people with PIMD was explored and presented in detail.

constipation (see Table 3). These motor initiatives include rhythmic movements, but their specific content really differed with regard to forming relationships, the body posture and own initiative during the performance of these motor initiatives (see Table 3). As the rhythmic movement therapies also totally differed in their frequency and duration indications as well as their theoretical rationale, those therapies may be related to relaxation based on the rhythmic movements, while the other components and theoretical elements may explain the other aimed benefits.

The year-long program with gross motor activities (Moving Experience) aimed at wellbeing and self-direction with subgoals, such as improving health, alertness, participation, and decreasing behavioral problems (see Table 3). The core of this program lies in the solid structure with changing themes of gross motor activities (e.g., bouncing and swinging) every 6 weeks conducted for 30–45 minutes per week (see Table 3). The program used elements of Sensomotor integration and the Dutch physical activity guidelines are used for maintaining health. The application based on the Dutch physical activity guidelines may explain the health outcomes, but what specific content and theoretical rationale may be related to the other aimed benefits is unclear.

Level of Evidence for the Effectiveness

Descriptive. An analysis of the documentation regarding the description of the essential elements per motor initiative is presented in Table 4. Only five motor initiatives (29.4%) described the characteristics of people with PIMD in detail. In addition, the (sub)goals were clearly described for seven motor initiatives (41.2%) and for five motor initiatives it was clearly documented how it should be implemented (29.4%). For none of the motor initiatives (0.0%), the frequency, intensity, and duration indications required to be effective were specified within the documentation in detail. Based on the level of evidence (Veerman & Van Yperen, 2007), two of the motor initiatives (11.8%) largely described the essential elements, but the duration, frequency, and intensity of activities were left open and described as being for determination on an individual level. Therefore, we found limited descriptive indications for the potential effectiveness from 17 initiatives (Table 4).

Theoretical. For 12 motor initiatives (70.6%), underlying elements or theories were described explicitly. Five motor initiatives (29.4%) described the underlying components, but did not clearly specify which (combination of) components, or how many and what combination of sessions, yield the specific outcomes. In addition, two motor initiatives (11.8%) clearly described the underlying elements/theories in relation to guidance and support for people with PIMD rather than explaining the intervention's specific effectiveness. For two motor initiatives (11.8%), the underlying elements are generally described without an explicit theoretical rationale to explain why it should work in relation to the goals relevant to people with PIMD. Two motor initiatives (11.8%) are directed by the Dutch physical activity guidelines, which are not specifically tailored to people with PIMD. In addition, one motor initiative (5.9%) is based on the general development of children which is different from the

development of people with PIMD. In sum, the underlying elements or theories of the initiatives do not clearly describe an indication of its effectiveness specifically in people with PIMD. Therefore, limited or no theoretical indications for the theoretical effectiveness were found for respectively 12 (70.6%) and five motor initiatives (29.4%).

Indicative. We did find a reference to systematic evaluation in three motor initiatives (17.6%). Based on the documentation, we assume that the outcomes of one motor initiative (5.9%) are evaluated yearly using physical fitness tests. Also practical experiences with one of the motor initiatives (5.9%) are described, but it remains unclear if the outcomes reported in the descriptions were based on systematic evaluation or only contain subjective impressions. In addition, because one of the motor initiatives (5.9%) is described as to be implemented as part of an individual educational/support plan, we assume that goals in relation to the content of this initiative are systematically evaluated. Based on the documentation, we also assume that it is evaluated yearly whether the method still fits the individual needs. Therefore, we conclude that indicative indications for functional effectiveness may be available for at least three motor initiatives (17.6%) (see Table 4).

Causal. The effectiveness with people with PIMD had been described within nonpeer reviewed sources (e.g., research reports and student thesis) for four motor initiatives (23.5%) and within scientific peer-reviewed studies for three motor initiatives (17.6%) (see Table 3). The scientific peer-reviewed studies contained a single and multiple case studies design and a randomized controlled pilot trial design. The powered exercise machines are studied with a randomized controlled pilot trial design ($n = 37$) and a positive effect on oxygen saturation was found (Bossink et al., 2017). Repeated case studies ($n = 7$) have been performed on the effects of two themes (bouncing on a bouncy castle and swinging in a hammock) of Moving Experience, showing early indications of positive outcomes on alertness and existing behavioral problems (Van der Putten et al., 2014). In addition, based on a single case study, a positive effect for Halliwick on functional hand use and walking balance has been shown for a girl with stage III Rett syndrome (Bumin et al., 2003). None of these motor initiatives had been investigated more than once on the same outcome measure and the study sample sizes were limited. Therefore, causal evidence for the documented effectiveness in people with PIMD is very limited (see Table 4).

Discussion

This study examined the content and quality of motor initiatives actually in use for people with PIMD. This study's main finding is that practitioners developed and introduced a wide range of motor initiatives to activate persons with PIMD motorically. We identified four motor initiatives which reflected a specific approach to motorically activate people with PIMD within various activities, three offered power-assisted exercises, three aquatic exercises, two included frameworks which integrate motor activities into the daily program, two comprised small-scale activities, two rhythmic movement therapies, and one

included a year-long program with gross motor activities. The principles underpinning nine motor initiatives (52.9%) are documented through books, DVDs and training materials (see Table 3). However, we found limited descriptive indications for the effectiveness of 17 motor initiatives, limited or no theoretical indications for the effectiveness of 12 and five motor initiatives respectively, and none of the motor initiatives had achieved a causal level of evidence for effectiveness. Effectiveness remained unproven for all of 17 selected motor initiatives.

Based on the analysis of the content of the motor initiatives included, it appears that motor activation for people with PIMD often contains a special approach to more demanding activities as well as small-scale activities integrated within the daily support, such as the activities of daily living. This finding suggests an important development, given the growing attention being paid to motor activation in the support of people with PIMD today (Van der Putten et al., 2017). The integration of motor activation within daily support is important, as it has been proven that functional movement activities can improve the independence and participation of people with PIMD (Van der Putten et al., 2005). Moreover, daily motor activation can contribute to reductions in sedentary time, which offers perhaps the most physiological and health benefits (Levine, 2007; Woodcock, Franco, Orsini, & Roberts, 2010).

In addition, by considering the content of the motor initiatives, it would appear that there is a need for consensus about the description of motor activation and a need for PIMD-specific norms recommending motor activation in the support of people with PIMD. Motor initiatives for people with PIMD seem, to a great extent, to be comparable to motor initiatives for people with less severe or no disabilities (e.g., horse riding, cycling, and swimming) (Kuijken, Naaldenberg, Nijhuis-Van der Sanden, & Van Schrojenstein-Lantman de Valk, 2016; WHO, 2010), but adjustments using technical devices and extensive support are needed to accommodate people with PIMD (Lancioni et al., 2004, 2005). These adjustments can blur whether the people with PIMD are being involved actively. Because a mere relocation (i.e., being walked in a wheelchair)—which might for practical reasons be effected without any active participation on the part of the person with PIMD—can currently be included in the description of motor activation (Van der Putten et al., 2017), further insight into the benefits of various motor activities for people with PIMD and the extent of their active participation in them is needed, as well as a professional consensus about what motor activation should actually consist of. In addition, to date, it would appear that the support provided to people with PIMD focuses on 30 minutes of motor activation, and is based on government guidelines which recommend moderately intense physical activity for 30 minutes on five or more days per week to improve health (ACSM, 2013; Gezondheidsraad, 2017; WHO, 2010). People with PIMD are however dependent on substantial or total assistance (Nakken & Vlaskamp, 2007), which suggests that the intensity of their activities may differ from those of the general population. Therefore, ordinary norms do not apply to people with PIMD, and PIMD-specific norms are required.

Regarding the evidence of the effectiveness of the motor initiatives, it would appear that little has changed in recent years. In 2008, Vlaskamp and Nakken had already called for research

TABLE 4
Quality of the motor initiatives based on the level of evidence available in support of their use with people with PIMD

Motor initiative	Level of evidence									
	Descriptive			3. Content and intended application			Theoretical		Indicative	Causal
	1. Target group		2. Goals and subgoals	3.1		3.2	4. Theoretical rationale			
1.1	1.2	2.1	3.1	3.2	4.1	5.1	5.1			
The power of Simplicity	++	++	++	++	+	+	+	?	-	
Moving On	+	+	+	++	+	+	+	?	-	
Exercise Plan	+	-	+	++	+	+	+	Maybe	-	
Basic Stimulation	++	++	++	+	-	+	+	?	-	
Moving Experience	+	+	-	+	+	-	-	?	+	
Powered exercise machines	+	+	+	+	-	-	-	?	+	
Out of the Chair	+	+	+	+	-	-	-	?	-	
Pactive Motion	++	++	++	++	+	+	+	?	-	
Sherborne	++	++	++	+	-	+	+	?	-	
Watsu Therapy	++	++	++	+	-	+	+	?	-	
Halliwick Concept	+	-	+	+	-	-	+	?	+	
Saito Therapy	+	+	+	+	-	-	+	Maybe	-	
Experience It	+	+	++	++	-	-	+	Maybe	-	
Swimming Program	+	+	-	-	-	-	-	?	-	
Motomed	+	-	++	+	+	+	+	?	-	
Wagon-bed Riding	+	+	+	+	+	+	+	?	-	
Bag with Movement-stimulating Materials	+	+	+	+	+	-	-	?	-	

- indicates no material found, + indicates material found, although not completely conforming to the criterion, and ++ indicates material found, ? not sure if material is available. The descriptive level is based on evaluation of the descriptions of the target group, goals and subgoals, and the initiative's content and intended application. The theoretical level is based on evaluation of the documented theoretical rationale and underlying elements. The indicative level is based on a reference to systematic evaluation within the documentation. The causal level is based on the quantity of research performed in people with PIMD.

into the effectiveness of therapeutic interventions (including three of the motor initiatives selected for this study) (Vlaskamp & Nakken, 2008), but our current study and another recent one (Steenbergen, Van der Schans, Van Wijck, De Jong, & Waninge, 2017) found still little evidence for the effectiveness of motor initiatives. In light of this paucity of theoretical evidence and research, the kinds of outcomes achieved by these motor initiatives in people with PIMD and the relationship with their specific components can only be speculated on. To determine functional relationships between the components of motor initiatives and their outcomes, it is important to report in detail on their essential elements and on how the theory behind them was applied (Houwen et al., 2014). This study found that the combination of the two was regrettably lacking in all motor initiatives. Even though there is limited evidence for their effectiveness, the motor initiatives included here might be appropriate and the outcomes sought for people with PIMD might be achieved. However, without a detailed description of the essential elements of these motor initiatives and without a sound theory and evidence-based understanding to explain their effectiveness, it remains unclear whether other factors (or somehow altered performance) may have caused the outcomes achieved (Van Yperen et al., 2017). An evidence-based understanding is required to ensure that the proper and most effective forms of motor activation will be used in the support of people with PIMD in the future.

Methodological Reflection

A few methodological considerations need to be borne in mind when interpreting the results of this study. As this study depends on the input of practitioners who completed the online inventory form, it may not have been able to discover all the motor initiatives in current use within the support for people with PIMD in the Netherlands. We may also have excluded potential motor initiatives because of the eligibility criteria used. We had to exclude motor initiatives because they had not yet been used in the Phase 1 environment, because they had been used with people with less severe disabilities, because they had only occasionally been part of a program, or because their purpose or implementation was not directed by the motor initiative itself (i.e., performance of discrete activities of daily living, or equipment or facilities which could be used in many different ways) (see Figure 1). In addition, while we did remove duplicates, some motor initiatives, such as those which included swimming (referenced 23 times), may have pursued different content and aims in different settings and even within the same settings for a given person with PIMD. This may have affected the degree to which all the initiatives currently available to support motor activity in people with PIMD were included. However, because we collected data from various settings prior to removing the duplicates, and we did focus on motor initiatives with a defined content and purpose directed by the motor initiative itself, we would argue that we did include all the available motor initiatives for people with PIMD, as defined. Moreover, because we intensively collaborated with many organizations involved in the support of people with PIMD, we are familiar with the latest developments and presume that the 118 distinct motor initiatives identified

in the current study represent a broad picture of the current support provided for motor activity in people with PIMD in the Netherlands. In addition, this study was the first to provide an overview of the motor initiatives used in the Netherlands; however, it does not unfold details about how often and where the initiatives were used. This is a limitation of our study, because the use at different settings can affect the application as well as the priority for research. The data procedure probably did not affect our conclusions on the quality of the motor initiatives. We performed a number of additional searches using the excluded motor initiatives and again found a lack of research-based evidence for effectiveness of these motor initiatives. Causal level evidence, however, is admittedly based on an in-depth analysis of the research performed with people with PIMD. An analysis of the research performed with other groups might have provided additional insights into the specific benefits of the selected motor initiatives. Another important point here is that we did not focus on the clinical evaluation of the outcomes of motor initiatives, which is a limitation with regard to the indicated level of evidence. However, this study is the first to provide an analysis of the level of evidence for motor initiatives, which is important as a first step to developing evidence-based support for motor activity for people with PIMD. As practice-based knowledge might contribute to an evidence-based understanding (Van Yperen et al., 2017), further research into the indicative level of evidence is explicitly requested.

Another point to bear in mind is that this study considered the other aims pursued in addition to the primary focus on improvement in movement, while the motor initiatives may have originally aimed to improve movement alone. In addition, the content of some of the included motor initiatives as prescribed was largely based on implicit knowledge, but this may develop over time in practice and from setting to setting. Therefore, the results must be interpreted with caution. In addition, as this study focused on the content of initiatives in the Netherlands which may vary between countries, caution is needed to compare the content of initiatives between people with PIMD living in different countries. Our data procedure did affect the generalizability of the content but probably did not affect our conclusions on the quality of the motor initiatives. This study showed that hardly any evidence can be presented for the effectiveness of motor initiatives and that the causal level of evidence is mainly based on pilot studies and single-case studies. Based on the international literature, the same picture is brought to the fore for other countries, recently developing motor initiatives studying them within small-scale studies lacking internal/external generalizability (e.g., Aherne & Coughlan, 2017; Dodds, Bjornson, Sweeney, & Narayanan, 2016; Lancioni et al., 2004, 2005; L'Huillier, Pandya, & Plioplys, 2016; Podgorski, Kessler, Cacia, Peterson, & Henderson, 2004). Future research should aim to broaden this work as motor initiatives in other countries also provide an insight into how such initiatives could be adapted or integrated within the Dutch context. For instance, the study of Aherne and Coughlan (2017) did show factors important for successful implementation of aquatics and indications that aquatics can be beneficial for well-being for people with PIMD, which may be reason to study specific outcome measures and ways of implementation for the motor initiatives included in the present study.

Finally, this study also found motor initiatives which did not primarily focus on movement (see Figure 1), such as massage activities (e.g., Shantala massage; Leboyer, 1996) and sensory activities (e.g., Snoezelen; Hulsege & Verheul, 1991), which we considered unsuitable for this study based on our definition of motor activation. As it appears that these activities could be used in some ways to encourage the motor functioning of people with PIMD, consensus about the definition of motor activation for people with PIMD is needed. In addition, since recent studies have found some evidence in support of the use of initiatives like Snoezelen (Hogg, Cavet, Lambe, & Smeddle, 2001), there may be a need for more evidence for the effectiveness of different perspectives on motor activation.

Implications for Research

Because the current study showed that motor initiatives are often used to influence the quality of life of persons with PIMD (see Table 3), we suggest that future studies more explicitly target quality of life domains (Petry, Maes, & Vlaskamp, 2005) and that they uncover the relationships between specific elements of motor initiative content and specific outcomes. Social wellbeing for example, one of the domains of quality of life (Petry et al., 2005), depends on factors including independence, communication, and relationships. Four of the included motor initiatives targeted these factors. Bundling together the content of motor initiatives which target specific domains could be a first step toward an evidence-based understanding of the relationship between the components of motor initiatives and their outcomes with respect to the quality of life of persons with PIMD.

This study also contains an indication of the positive effects that bouncing exercises have on the alertness of people with PIMD (Van der Putten et al., 2014). However, since other studies have found different effects on alertness for motor initiatives targeting self-initiated and passive movements (Lindsay et al., 1997; Munde & Vlaskamp, 2015; Van der Putten et al., 2014; Wessels et al., 2017), future research should distinguish the outcomes of self-initiated movements from those of passive exercise. In addition, because other studies have found different effects on alertness during and after performing active bouncing exercises (Lindsay et al., 1997; Van der Putten et al., 2014), future research should also distinguish the outcomes observed during the intervention from its short and long term effects. Well-designed studies with reliable and valid tests are also needed for the assessment of outcomes (Houwen et al., 2014).

Implications for Practice

In agreement with several other studies (Aherne & Coughlan, 2017; Bossink et al., 2017; Houwen et al., 2014; Jones et al., 2007; Pitchford, Dixon-Ibarra, & Hauck, 2018; Van der Putten et al., 2005, 2017; Wessels et al., 2017) we found that motor activity can be used to encourage the motor domain in people with PIMD, but also to achieve beneficial outcomes beyond the motor domain, for example in social or cognitive functioning, by decreasing behavioral problems and improving the alertness and communication in people with PIMD. Motor

activation should therefore be individually tailored and integrated into the overall support provided for individual goals set and monitored within a multidisciplinary framework (Van der Putten et al., 2005). In addition, the results of this study emphasize the importance of organizational policies which promote reporting on motor activities and individual goals to evaluate the outcomes of the support at an individual level. Moreover, the characteristics of participants with PIMD together with the core elements and application of activities and a theory behind to explain the effectiveness should be explicitly described (i.e., descriptive and theoretical evidence). This is needed to ensure the internal and external validity of outcomes. Science and practice should cooperate in this process and bring together existing practice-based experience to ensure a more effective provision of support for motor activation to improve the quality of life of people with PIMD in the future.

Conclusion

A wide variety of motor initiatives are used in current practice to activate people with PIMD motorically, but their effectiveness actually remains unproven. These are the first results to have explored the content of motor initiatives used to support people with PIMD and analyzed the level of evidence of their effectiveness. These results form a first step toward evidence-based support for motor activation for people with PIMD.

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Conflict of Interest

There are no conflict of interest.

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