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Professionals' motivation to support parental self-management regarding children with physical disability in Dutch rehabilitation services: 'Please mind your gap'

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Abstract

Background: Professionals in child healthcare increasingly endorse the support of self-management in paediatric rehabilitation services for children with physical disability. Less understood though are their views regarding the role of the children's parents, as well as their own role in supporting parents. This study aimed to investigate the motivation of rehabilitation professionals to support self-management of parents regarding their child with physical disability, professionals' beliefs about parental self-management, and the perceptions underlying their motivation.

Methods: A mixed-methods strategy was followed using a survey among rehabilitation professionals ($n = 175$) and consecutive semi-structured interviews ($n = 16$). Associations between autonomous (intrinsic) versus controlled (extrinsic) motivation and beliefs on parental self-management were tested. For deeper understanding of their motivation, directed content analysis was used to address key themes in the qualitative data extracts.

Results: Professionals reported autonomous motivation for parental self-management support more often than controlled motivation ($t[174] = 29.95, p < .001$). Autonomous motivation was associated with the beliefs about the importance of parental self-management ($r = .29, p < .001$). Approximately 90% of the professionals believed that parents should have an active role, though less than 10% considered it important that parents also are independent actors and initiative takers in the rehabilitation process. Interviews revealed that individual professionals struggled with striking a balance

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between keeping control and 'giving away responsibility' to parents. A 'professional-like' attitude was expected of parents with 'involvement' and 'commitment' as essential preconditions. Furthermore, professionals expressed the need for additional coaching skills to support parental self-management.

Conclusion: Professionals were predominantly autonomously motivated to support self-management of parents. However, the dilemmas in giving or taking responsibilities within the partnership with parents may limit their effectiveness in empowering parents. Reflection on the potential gaps between professionals' motivation, beliefs and actual behaviour might be crucial to support parental self-management.

KEYWORDS

coaching skills, motivation, paediatric rehabilitation, parental self-management support, partnership, professionals' beliefs

1 | INTRODUCTION

Self-management is becoming the guiding principle for addressing needs emanating from chronic diseases for patients and their families (Kirk et al., 2012; Zwar et al., 2006). Parents play an essential role in the management of their child's disability and its consequences for daily life, especially when they are young (Geense et al., 2017). Healthcare professionals working with children with disability therefore are increasingly expected to support this parental self-management (Schwartz & Axelrad, 2015; Vallis, 2015). Intrinsic motivation, appropriate beliefs about the role of parents and sufficient capabilities may be relevant for professionals supporting parents in self-management regarding their child with disability (King et al., 2019).

Nowadays, self-management support regards the support of patients' daily life with disability in its entirety (Morgan et al., 2016). Healthcare professionals within this current interpretation must aim to support parental self-management by empowering parents for *active engagement* in managing the daily life consequences of their child's disability, in accordance with the parents' own personal interests and capabilities. This includes improvement of knowledge, active goalsetting in partnership with parents, taking into account their needs, values and desires and involving child, carers and family in care planning (Australian Health Ministers' Advisory Council, 2017). Although the body of literature on self-management support is growing (e.g. Coventry et al., 2014; Duprez et al., 2017; Kirk et al., 2012), still little is known about the motivation and beliefs behind professionals' support for parents' self-management regarding their child with disability.

1.1 | Professionals' motivation to support parental self-management

According to the *Self Determination Theory* [SDT], *motivation* is a key driver for effort and behaviour change. There are different types of

Key messages

- Professionals expressed autonomous motivation to support parental self-management regarding their child with disability, but only few found it important that parents are also independent actors and responsible for taking the initiative in the rehabilitation process.
- Rehabilitation professionals sought to balance between what they consider their own professional responsibilities and parents interests.
- Professionals desired a professional-like attitude of parents and asked for additional training in coaching and attunement with parents.
- Rehabilitation institutes should recognize the organizational preconditions for supporting parental self-management.

motivation. *Autonomous (intrinsic) motivation* means that people are motivated from within themselves, while *controlled or extrinsic motivation* means that motivation depends on positive or negative consequences external from the self (like rules, rewards and penalties). In SDT, autonomous motivation for certain behaviour originates from the satisfaction of three basic needs. First, people need to feel supported in their *autonomy* to make own choices. Second, they need to feel *competent* to actually perform a certain behaviour, and third one must feel related to other people involved (Deci & Ryan, 2008; Ryan et al., 2008). SDT, as applied to the self-management supportive behaviour of healthcare professionals, highlighted that they were more likely to actually support self-management of their patients when they had autonomous motivation, felt supported in their own autonomy and felt competent regarding self-management support (Kosmala-Anderson et al., 2010).

In addition to motivation, also professionals' beliefs about the role of parents in the management of their child's health can affect their

decision to support self-management. In a study of Bos-Touwen et al. (2017), professionals who assumed motivation and capacities of their patients to be inadequate for self-management were less prone to support self-management than professionals with more positive views of patients. Moreover, according to Nam et al. (2011), the beliefs of professionals will ultimately also influence the actual self-management of patients. As such, both motivation and beliefs might be important factors for professionals to support self-management of parents.

This study was aimed to investigate the levels of autonomous and controlled motivation of paediatric rehabilitation professionals to support self-management of parents regarding their child with physical disability and their beliefs towards parental self-management and to understand how professionals' motivation is related to those beliefs. Gender, age and years of working experience were studied as background for potential differences in motivation and beliefs regarding working with parents, following Feeg et al. (2016). Subsequently, professionals' perceptions were explored for understanding why rehabilitation professionals differed in their motivation to support parental self-management.

2 | METHODS

2.1 | Design

A mixed-methods sequential explanatory strategy (Creswell, 2009) was used. Phase 1 of the study investigated the motivation of professionals with a cross-sectional survey. In Phase 2, semi-structured interviews explored professionals' underlying views on parental self-management support. Data integration was performed by *connecting* quantitative data to the qualitative 'interview' data, with participants purposively selected across the full range of the spectrum in the survey (Fetters et al., 2013). In accordance with a *contiguous approach*, Section 3 will describe quantitative and qualitative data extracts in two subsections. Qualitative data will be presented as *narratives*. Synthesis of quantitative and qualitative data is reported in Section 4. The study was approved by the ethical boards of the involved institutes and the scientific committee of the Amsterdam Public Health research institute (ID:WC2014-076).

2.2 | Reflexivity

The study was conducted within a context of a critical-emancipatory research paradigm (Tijmstra & Boeije, 2009). The researchers believe that for optimal support of parental self-management professionals should have the opportunity to reflect on their own beliefs, motivations and roles regarding their collaboration with parents. To promote trustworthiness of the investigation, two researchers, one with and one without a clinical role, were involved in the process of data analysis. Integration and presentation of the results were achieved by continuous reflective discussion within the research group.

2.3 | Sample and procedures

In total, 213 paediatric rehabilitation professionals—physiotherapists, occupational therapists, speech and language therapists, rehabilitation physicians, psychologists, social workers, toddler group workers and nurses—of nine treatment teams, in two Dutch rehabilitation centres were invited to participate in an online survey on support of parental self-management. Professionals had to be directly involved in the treatment of children aged 0–12 with physical disability receiving outpatient treatment or while attending a specialized toddler group or special school connected to the rehabilitation centres. The age range was based on Dutch legislation regarding 'Medical Treatment Agreement' (Dutch Ministry of Health, Welfare and Sport, 2018) because up to this age, parents have full decision rights about the intervention. To optimize response, posters were put up in team meeting rooms before and during data collection. Various locations had 'site ambassadors' who promoted the study within their teams. The survey itself was sent by email, and four reminders were sent when there was no response. For the interviews, maximum variation purposeful sampling was used (Palinkas et al., 2015). To obtain as wide as possible variation in views, characteristics and perspectives, professionals were invited over the full range of scores on their beliefs towards parental self-management. Additionally, with each successive invitation of an available respondent, diversity of professionals with regard to their motivation, age, sex, years of working experience and profession was sought. Interviews were cyclically conducted and analysed until saturation occurred.

2.4 | Instruments

Professionals' motivation to support self-management of parents was investigated with the Treatment Self-Regulation Questionnaire (TSRQ). This instrument differentiates between two types of motivation, controlled (extrinsic) motivation and autonomous (intrinsic) motivation. The TSRQ was originally developed by Williams et al. (1996) and since then has been adapted and used to investigate motivation for a wide range of health behaviours. A later study of Levesque et al. (2007) validated the TSRQ across three health behaviours: smoking, diet and physical exercise in the United States. The constructed TSRQ versions showed acceptable Cronbach's alpha from .73 to .93 (Levesque et al., 2007). The TSRQ version used in this study consisted of 12 items equally divided over two 7-point Likert subscales: controlled and autonomous motivation. For an overview of the items of the TSRQ used in this study, see Addendum 1.

To investigate the beliefs of professionals on parental self-management regarding their child's disability, the Clinicians-Patient Activation Measure [CS-PAM] (© insignia Health) was used. Rademakers et al. (2015) validated a Dutch version of the CS-PAM that was originally developed by Hibbard et al. (2009). In the Dutch study, internal consistency was measured over three subsamples, showing Cronbach's alpha between .82 and .97. Rasch measurement confirmed the accumulating order of items for the Dutch population and validated the 0–100 progressing difficulty score.

The CS-PAM version used in the current investigation consisted of 13 items, expressed in a 4-point Guttman scale in which the order of items indicated a unidimensional level from low to high expectations of parental self-management. Cutoff scores determined by Hibbard et al. (2009) transformed the scores in four accumulating stages, equally divided over the 100% range. Stage 1 was described as professionals find that it is important that parents show knowledge and behaviour to prevent symptoms associated with their child's health condition. Stage 2 as parents make independent judgement and actions. Stage 3: parents take an active role during consultations. Stage 4: parents act as independent information seekers. The accumulating stages implied that at Stage 4, professionals believe it to be important that parents are knowledgeable, active and independent actors who take the initiative in the context of the rehabilitation process.

Before use, the TSRQ was translated into Dutch. International standards were followed, including translation, synthesis, back translation, testing and final adaptation (Beaton et al., 2000). Additionally, in both the TSRQ and the CS-PAM, some items were slightly rephrased to improve suitability to measure professionals' motivation and beliefs towards support of parental self-management. Cronbach α 's based on data in this study suggested adequate reliability for both instruments (Table 1). Confirmatory factor

analysis indicated an appropriate two-factor model fit of the TSRQ. Rasch analysis implicated an adequate fit of the CS-PAM and justified its usage in the study, suggesting further validation within the Dutch population in line with Rademakers et al. (2015).

The interviews in Phase 2 were structured around nine basic questions about parental self-management support; see Table 2. Before use, the interview questions were piloted, discussed and adapted by the research group.

2.5 | Data analysis

2.5.1 | Phase 1: Quantitative analysis

Descriptive group statistics for central tendency, variation, skewness and kurtosis, missing values and outliers were computed in SPSS version 25. Skewed data were log transformed for computing parametric statistics. The level of autonomous versus controlled motivation was tested with a paired t test. Pearson correlations were assessed between motivation and beliefs (significant at $p < .05$). Finally, associations with gender, age and years of working experience (0–10 years; 11–20 years; >20 years) were tested by General Linear Model Multivariate Analysis of Variance.

2.5.2 | Phase 2: Qualitative analysis

Qualitative analysis, using NVIVO version 11, followed an iterative process of coding and re-coding according to directed content analysis with identified key concepts (Hsieh & Shannon, 2006). To improve trustworthiness, a summary of each transcript was member checked by corresponding respondents. All transcripts were coded by the first researcher. A second researcher consecutively reviewed each transcript, commenting on data extracts and proposing new codes. According to the discussions between both researchers, adjustments were made until no new codes were identified. If the discussion about a code remained inconclusive, a third researcher was consulted who also gave peer feedback regularly to the appropriateness of the followed procedures and interpretation of data.

TABLE 1 Internal consistency reliabilities of the TSRQ and the CS-PAM NL

| Instrument | | Cronbach's α |
|---|----------|---------------------|
| Treatment Self-Regulation Questionnaire (TSRQ) | | |
| Autonomous motivation | 6 items | .76 |
| Controlled motivation | 6 items | .70 |
| Clinicians-Patient Activation Measure (CS-PAM NL) | 13 items | .81 |

TABLE 2 Interview guide

| |
|---|
| What does parental self-management mean to you? |
| How do you value support of parental self-management? |
| How competent do you feel with regard to support of parental self-management? |
| To what degree do you support parental self-management yourself? |
| What do you expect of parents regarding self-management? |
| How do you experience the collaboration with parents with regard to self-management? |
| How do you determine how much and what kind of support parents need? |
| Which facilitating factors do you experience regarding support of parental self-management? |
| Which barriers do you experience regarding the support of parental self-management? |

TABLE 3 Characteristics of the sample ($n = 175$)

| | n | % | M (SD) |
|-----------------------------|-------|----|--------------|
| Age (min-max) | 22–64 | | 42.9 (10.8) |
| Gender (female) | 161 | 92 | |
| Nationality (Dutch) | 173 | 99 | |
| Years of working experience | | | |
| 0–10 years | 56 | 32 | |
| 10–20 years | 65 | 37 | |
| >20 years | 54 | 31 | |

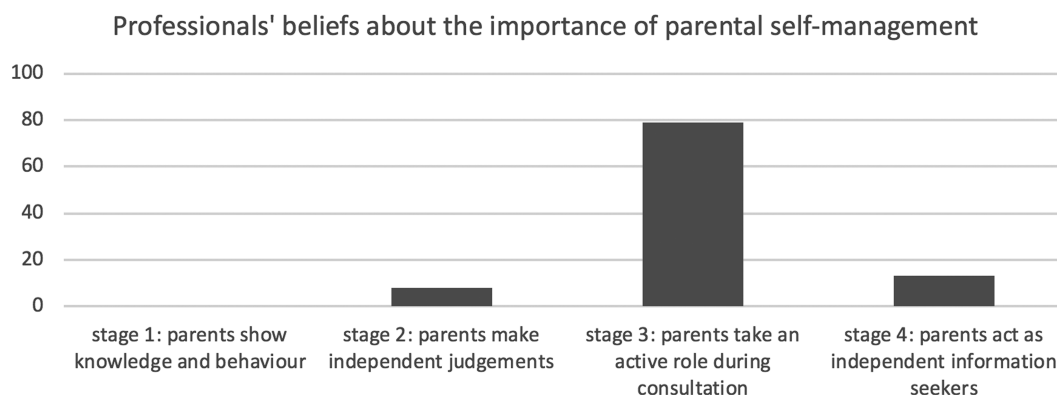
TABLE 4 Descriptive statistics of the TSRQ and the CS-PAM NL

| | n | Min ^a | Max ^a | Mean | Std. Dev | Skew | | Kurtosis | |
|--|------------------|------------------|------------------|-------|----------|-------|------------|----------|------------|
| | | | | | | | Std. error | | Std. error |
| TSRQ: Autonomous motivation | 175 | 4.00 | 7.00 | 5.82 | 0.61 | -0.26 | 0.18 | 0.05 | 0.37 |
| Controlled motivation | 175 | 1.00 | 5.00 | 3.34 | 0.94 | -0.16 | 0.18 | -0.39 | 0.37 |
| CS-PAM: Beliefs regarding the importance of parental self-management | 172 ^b | 42.00 | 100.00 | 63.06 | 11.52 | 1.30 | 0.19 | 2.18 | 0.37 |

Abbreviations: CS-PAM, Clinicians-Patient Activation Measure; TSRQ, Treatment Self-Regulation Questionnaire.

^aPossible range TSRQ (1–7), CS-PAM (0–100).

^bData of three respondents were excluded because of invalid responses according to scoring instructions.

**FIGURE 1** Scores of professionals reflected on the accumulating four-stage ordinal scale of the Clinicians-Patient Activation Measure (CS-PAM) NL

3 | RESULTS

3.1 | Phase 1: Quantitative results

Of 213 invited professionals, 175 took part in the survey (response rate 82%), 14 men and 161 women. While there was a large variability in age and working experience, most professionals were female and almost all had a Dutch nationality (Table 3).

For descriptive statistics of the TSRQ and the CS-PAM, see Table 4. The mean score on autonomous motivation was significantly higher compared to controlled motivation ($t[174] = 29.95, p < .001$), although the standard deviations emphasized inter-individual variations. The scores on the CS-PAM were somewhat above the centre of the scale, with positive skewness and kurtosis. This indicated that professionals tended towards finding it important that parents are active self-managers.

On the accumulating four-stage scale of the CS-PAM (Figure 1), 8% of the participating professionals had scores on Stage 2, which meant they thought it was important that parents ‘make independent judgements and actions’; 79% believed that parents should ‘take an active role during consultations’ (Stage 3). About 13% of the professionals expected parents also to ‘act as independent information seekers’, taking the initiative in the rehabilitation process (Stage 4). None of the professionals scored on Stage 1 of the CS-PAM indicating that they unanimously recognized the importance of parents

‘having knowledge and behaviour to prevent symptoms related to their child's health condition’.

3.1.1 | Correlations between motivation and beliefs towards parental self-management

Beliefs regarding parental self-management were positively associated with autonomous motivation for self-management support ($r = .29, p < .001$), indicating that professionals who were autonomously motivated to support parents in self-management on average expected more self-management from parents than professionals with controlled motivation. No significant association was found between professionals' beliefs and controlled motivation ($r = .06, p = .44$).

3.1.2 | Associated factors of motivation to support parental self-management

Bivariate correlations showed a significant positive association between age and autonomous motivation ($r = .16, p = .034$), meaning that professionals at older age were more likely to score higher on autonomous motivation compared to younger professionals. Age and controlled motivation for self-management were not significantly associated ($r = .14, p = .070$).

TABLE 5 Characteristics of the interviewed professionals ($n = 16$)

| | <i>n</i> | % | <i>M (SD)</i> |
|-----------------------------|----------|-----|---------------|
| Age (min-max) | 27–60 | | 41.1 (6.7) |
| Gender (female) | 11 | 94 | |
| Nationality (Dutch) | 16 | 100 | |
| Years of working experience | | | |
| 0–10 years | 5 | 31 | |
| 10–20 years | 9 | 56 | |
| >20 years | 2 | 13 | |

Univariate analyses of variance showed that years of experience differed according to autonomous motivation ($F[2,169] = 4.87$; $p = .009$). Professionals with less than 10 years of experience were less likely to endorse autonomous motivation compared to professionals with 10–20 and 20 and more years of experience. This effect decreased after controlling for age ($F[2,168] = 3.05$; $p = .050$; $R^2 = .60$) indicating there was overlap in the variance in autonomous motivation explained by age and working experience. Years of experience was not significantly associated with controlled motivation for support ($F[2,169] = 2.50$; $p = .085$). Associations with gender were not computed because of the small number of men participating.

3.2 | Phase 2: Qualitative results

The interviews addressed the underlying views of professionals on parental support. In total, 16 professionals were interviewed; see Table 5.

When taking professionals' motivation for self-management support as reference, the data extracts could be structured around four key topics, each containing multiple themes and subthemes. The variety of professionals' opinions is reflected in the narrative overview of themes and subthemes with accompanying example quotes, listed in Table 6.

3.2.1 | Beliefs regarding (support of) parental self-management

The *value* of parental self-management support was expressed in the subtheme *empowerment of parents*. Parents with strong self-esteem and self-efficacy were assumed to be able to make steps themselves. Also, *mutual respect and trust* were preconditions to collaborate with parents. While for some professionals supporting self-management of parents was a way to increase parental *compliance* with the treatment, others accentuated that for them supporting parental self-management felt as an *enrichment to their own way of working* because they felt that parents learned from the experience of self-management and were being enabled to have control over their lives. *Partnership* was described as an essential aspect of self-management, though several professionals acknowledged that in reality they or their colleagues

tended to try to convince parents that their way was best. This was also expressed in the theme *balance* between giving support and taking over. Professionals regularly struggled in their decisions about keeping control or letting go and giving responsibility to parents. Some professionals occasionally experienced as a dilemma that the goals of parents in their opinion were not in the best interest of the child.

3.2.2 | Perceived autonomy support to empower parents for self-management

Professionals associated a wide variety of external factors with the support they perceived in their autonomy to empower parents for self-management. *Lack of tuning and trust within the team* and *institutional issues* were brought up as *barriers* for support of parental self-management. Identified subthemes of institutional issues were *lack of general self-management policy* within the organization to ensure the preconditions for self-management support, *scheduling constraints* and experienced *financial and organizational turmoil* over the past years, which professionals related to cost reduction policies in Dutch healthcare. This last topic was linked to feelings of overburdening and time pressure. Moreover, several professionals stated that self-management support, implying more structural contact with parents, actually costed more time. *Contact with parents* and finally *teamwork*, were identified as *facilitators* of parental self-management support.

3.2.3 | Professionals' expectations of parents regarding self-management

Professionals expressed several expectations of parents regarding self-management. One theme referred to *parent behaviour* within the framework of the intervention, with important subthemes *taking initiative*, the *ability to formulate needs and wishes* and *fulfilling agreements*. Other expectations related to *parent attitudes*, assuming *involvement* and *openness* towards the professional. Lastly, almost all professionals mentioned, some *parent characteristics* that shaped their opinion of how much support would be needed. Identified subthemes were *demographic factors*, including origin and/or cultural background, socioeconomic status and education, *age and personality* of parents and *family functioning*.

3.2.4 | Competence to support parental self-management

Two themes came up in this topic. *Developing process* was related to professionals' experiences, in work, but also more general in life. Nevertheless, while some professionals felt quite confident, almost all interviewed professionals, with scores over the full range of outcomes on their beliefs regarding parental self-management, indicated that they or their colleagues needed additional coaching skills to optimally support parental self-management.

TABLE 6 Topic, themes and subthemes related to the professionals' motivation to support parental self-management

| Topic 1. Beliefs regarding (support of) parental self-management | | |
|---|--|---|
| What professionals think of the importance of parental self-management (support) | | |
| Themes | Subthemes | Example quotations of professionals |
| Value | Empowerment of parents | 'If you have some control over things that are not pleasant which happen to you, if you can influence them a bit or you can collaborate, then this is also a healing factor or comforting.' |
| | Mutual respect and trust | 'Self-management support is about mutual trust in each other and respect for each others expertise.' |
| | Compliance | 'If you give people the feeling they have control, this will enhance compliance.' |
| | Enrichment to own way of working | 'I like really this way of working, because I think like this people learn the most and can also continue best in life. We in general are only a stopover, a transitional station. My aim is for people to be able to go on themselves.' |
| | Partnership | 'For self-management collaboration in partnership with parents is very valuable for instance to set goals together I think though, that in stead of really doing it together, professionals regularly try to convince parents that our way is best.' |
| Balance | | 'At first I was always working quite hard. I always had the tendency to take over from parents. Like: "parents find it difficult to make that call? Well, then I will do it for them" ... I have learned a lot since then. Nevertheless, I think we all are still quite steering, meaning you want to guide them in a certain direction.' 'It becomes difficult if parents and you do not agree. How far do you go? You also have your own professional responsibility.' |
| Topic 2. Perceived autonomy support to empower parents for self-management | | |
| How professionals feel supported in their autonomy to empower parents for self-management | | |
| Themes | Subthemes | Example quotations of professionals |
| Barriers and facilitators | Barriers: | |
| | Lack of tuning and trust within the team | 'Sometimes there are discussions within the team where a certain doctor says you must do this or that, while I think, but that is my part, I can be responsible for that, I know better about the situation.' |
| | Institutional issues: | |
| | Lack of general self-management policy | 'I think there is insufficient idea in the organisation where we want to go with parents. It is important to know what we can offer and then to communicate this clearly to parents.' |
| | Scheduling constraints | 'As a parent, you have no say in the therapy schedule at all. You just must accept what is scheduled. I think for parents it often is not convenient.' |
| | Financial and organizational turmoil | 'It is a difficult financial situation at this moment. We must care for parents and children with less and less means This financial crisis we are in, just makes things worse. Many colleagues are in a state of constant overload.' |
| | Facilitators: | |
| Contact with parents | 'Direct contact with parents is an important point. But if this is not okay, then parents are sometimes very far away.' 'Home visits are important, not only for practical reasons, but especially as a way to get more knowledge about the context of the family. How do they function? What can you ask?' | |
| Teamwork | 'I like it very much that I can always consult the colleagues in my team. That I can share and discuss together how to approach a situation. That is very supporting to me.' | |

(Continues)

TABLE 6 (Continued)

| Topic 3. Professionals' expectations regarding parental self-management | | |
|---|------------------------------|--|
| What professionals expect of parents concerning their self-management. | | |
| Themes | Subthemes | Example quotations of professionals |
| Parent behaviour | Taking initiative | 'I find it very important that children, and most often their parents, determine their own quality of life and that they are as independent as possible. That they actually ask me the questions they have, and otherwise know where they can be asked.' |
| | Formulating needs and wishes | 'It is important parents can formulate concretely their requests, can think along and ask questions. So, I as professional can connect to that.' |
| | Fulfilling agreements | 'If parents really do not respect what they agreed upon continuously, notwithstanding all tricks we try, that is also inability. Then you need to follow another route.' |
| Parent attitude | Involvement | 'You really need the involvement of parents, if you want to work meaningful. So, I at least expect some engagement.' |
| | Openness | 'What I expect is an open attitude: That parents are open for suggestions you give about how perhaps they can do something at home.' |
| Parent characteristics | Demographic factors | 'You of course work with parents with a foreign background. They are often used differently and sometimes there are also linguistic barriers, then also less is possible.' |
| | Age and personality | 'I think it is as much related to age as well as to how you experience life. One is focused on those things that can be seen as a present, and the other experiences everything as a disappointment and a burden.' |
| | Family functioning | 'Is there a situation that these parents, for what reason ever, can not take care of their child? Are these parents having a problematic and difficult home situation? Finances, work, housing issues?' 'A mother or father looking more tired than normally, or being snappy with their child? Yes, those are signals I pay attention to.' 'Does a parent or a child regularly look not properly groomed?' |
| Topic 4. Competence to support parental self-management | | |
| How competent professionals feel to support parental self-management | | |
| Developing process Additional skills | | 'It also has become easier for me since I got children myself, because you can put yourself better in the position of parents. And of course, by now I have gained a lot of working experience.' 'With respect to the content of my profession I feel confident, but coaching parents? How do you tune in, so it really fits their needs?... This coaching I did not learn during my education. How do I give guidance? How do you coach well? I really would like to get advice and learn techniques on this.' |

4 | DISCUSSION

Synthesis of the quantitative and qualitative findings showed several interesting relations between professionals' motivation, their beliefs and their underlying perceptions regarding parental self-management support. In line with van Hooft et al. (2015), professionals in this study in general valued self-management as essential aspect of paediatric rehabilitation for children with physical disability, although they held various perspectives on the support of parental self-management. The survey showed that the vast majority of professionals appreciated an active role of parents with regard to self-management. Only a small percentage found it important that

parents, besides being knowledgeable and active, would also act as independent seekers taking the initiative in the context of the rehabilitation process. Most professionals considered parental self-management a matter of collaboration with parents, with some tasks clearly in the purview of professionals. This finding is actually in line with perspectives of parents on self-management, also describing parental self-management as a collaborative process (Wong Chung et al., 2019). Nevertheless, given the diversity of professionals' underlying perspectives on what exactly parental engagement in self-management incorporates, also seen in literature (Darrah et al., 2012), there is a risk of mismatch. Qualitative findings related to the theme *Balance* and subtheme *Partnership* suggest that professionals

regularly struggle with their collaboration with parents. Especially when parents have different opinions compared to their own, they have difficulty to give over responsibility to parents and instead try to guide parents in the direction that they think is best. This supports the notion that, in spite of good intentions, professionals are in risk of staying in a position of authority rather than one of partnership with actual shared responsibility and decision-making (Franklin et al., 2018).

4.1 | Differences in perspectives of professionals and parents

Professionals in this study experienced dilemmas in balancing parents' autonomy and desired involvement and their own responsibility to achieve optimal health outcomes for the child, which echoes findings from Dwarsaard and van de Bovenkamp (2015). Professionals also reported 'professional-like' expectations of parents, such as being able to formulate needs and wishes, fulfilling agreements and being involved in the treatment process. Individual parents on the other hand have various expectations, desires and needs related to the treatment their children receive as well, also in time (Terwiel et al., 2017). In a parallel conducted investigation among parents of children who received treatment in the rehabilitation teams participating in this study, some parents reported they expected professionals to take the lead, while others saw themselves in a leading role regarding decision-making in the context of rehabilitation, because it concerned their own child. Nevertheless, also parents who saw themselves as leading in the process struggled with finding balance in wanting to do things themselves and sometimes wanting someone to take over (Wong Chung et al., 2019). Ongoing awareness of possible differences between their own expectations and those of parents may assist professionals in tailoring their approach to individual parents (Fordham et al., 2011; Rosenbaum & Gorter, 2011).

4.2 | The role of professionals' motivation on parental self-management support

In the survey, professionals reported to be more autonomously than controlled motivated. Also, autonomous motivation was positively associated with professionals' beliefs regarding parental self-management. In the interviews, professionals expressed several work-related factors limiting their autonomy to empower parents for self-management, such as lack of time, scheduling problems, austerity and general lack of self-management policy in the institute, echoing earlier findings (Coyne, 2015; Khairnar et al., 2019). General work issues encountered by professionals interfered with their motivation to change their behaviours or led them to refrain from investing extra time and energy, like, for instance, taking up contact with parents outside of the scheduled treatment sessions. Professionals mentioned parent contact and teamwork as factors facilitating the support they perceived regarding their autonomy.

As perceived autonomy support in SDT is seen as a possible pathway to autonomous motivation, rehabilitation institutes aiming to implement self-management-oriented policies should take into account the possible impediments to the autonomy support perceived by professionals that might negatively influence their autonomous motivation, and successively their actual support of parental self-management (Kosmala-Anderson et al., 2010; Nguyen et al., 2016).

4.3 | Age and life experience

Professionals reported supporting parental self-management as a learning process, positively related to their own life and working experience, which was in line with the associations between age, working experience, and beliefs regarding parental self-management with autonomous motivation found in the survey. This was also reported in a study of Dall'Oglio et al. (2018) about the perspectives of healthcare providers in family centred service, reporting that professionals at older age with more working experience tended to perceive self-management as more important.

4.4 | Need for supplementary skills

Professionals stated that further learning to develop *additional skills* was needed for them or their colleagues to optimally support parental self-management. A nationwide study in the Netherlands on self-management confirmed that expectations of self-management support often are more general than specific to the chronic condition (van Houtum et al., 2014). Also, according to studies on parental engagement in mental healthcare, professionals should possess discipline transcending skills to attune to parents, to be sensitive and responsive to their context and to increase engagement by emotional attendance, empathy, mindful listening and utilizing interpersonal skills (King et al., 2014). Specific training programs for professionals to increase the skills necessary for adequate support of self-management appears to be a necessity (Harris et al., 2008; Young et al., 2015).

4.5 | Limitations and practical implications

The single-informant, self-reporting structure of the survey means that only the professionals' own perspectives were included. Furthermore, the investigation was performed in just two rehabilitation centres in a central region of the Netherlands. Although the internal consistencies of the TSRQ and CS-PAM in the sample appeared reasonable to good, as far as we know both instruments were not used before in the setting of paediatric rehabilitation. Generalization of the findings beyond the investigated sample therefore asks for caution. The cross-sectional design of the study impedes conclusions regarding causality of the presented associations. Nevertheless, the associations between autonomous motivation for

parental self-management support, beliefs towards parental self-management and years of working experience were relevant and provide input for personal reflection among professionals. Future research could address the development of specific trainings focusing on professionals' self-management supporting abilities, including necessary coaching skills. The organizational barriers to support self-management of parents identified by professionals in this study may be addressed by rehabilitation institutes to facilitate an optimal climate for improvement of parental self-management support.

5 | CONCLUSION

Rehabilitation professionals were in majority autonomously motivated to support self-management of parents and valued parental self-management as important. Nevertheless, only a small group of professionals went as far as viewing parents as independent actors, taking the initiative in the rehabilitation process. Experienced dilemmas between staying in control or giving away responsibility to parents may limit professionals' contribution to the empowerment of parents for self-management regarding their child with physical disability. Reflection, especially on the potential gaps between one's motivation, beliefs and one's actual behaviour, could well be a key competence for professionals to proficiently support self-management (Coyne, 2015; van Hoof et al., 2015).

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

ETHICS STATEMENT

The study was approved by the ethical boards of the involved institutes and the scientific committee of the Amsterdam Public Health research institute (ID:WC2014-076).

DATA AVAILABILITY STATEMENT

The data are not publicly available due to privacy or ethical restrictions. The data that support the findings of this study are available from the corresponding author upon reasonable request.

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APPENDIX: Addendum 1: Treatment Self-Regulation Questionnaire (TSRQ) (adapted for professionals' motivation to support parental self-management regarding their child with physical disability)

The following question relates to the reasons that you would either start or continue to support self-management of parents. Different professionals have different reasons for doing so, and we want to know how true each of the following reasons is for you. All 15 responses are to the same question. Please indicate the extent to which each reason is true for you, using the following 7-point scale

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|------------------------|---|----------------------|---|---|------------------|---|
| <i>Not at all true</i> | | <i>Somewhat true</i> | | | <i>Very true</i> | |

The reason I would support parental self-management or start with it:

1. Because I think that parents themselves should take responsibility for the health of their child.
2. Because I would feel uncomfortable towards my colleagues if I would not support self-management.
3. Because I personally believe it is the best approach for the parent(s) and child.
4. Because others would call me to account if I would not support self-management
5. Because I find self-management support important for many aspects of my profession.
6. Because I would feel bad about myself if I would not support parental self-management.
7. Because I chose for this myself.
8. Because I feel pressure from others.
9. Because it is consistent with my professional goals.
10. Because if I do others will respect me.
11. Because supporting self-management of parents is important for the health of the children I treat.
12. Because I want others to see I can do it.