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Laura W. M. E. Beckers, Rob J. E. M. Smeets & Jan J. W. van der Burg

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ORIGINAL ARTICLE

Therapy-related stress in parents of children with a physical disability: a specific concept within the construct of parental stress

Laura W. M. E. Beckers[a,b], Rob J. E. M. Smeets[a,c] and Jan J. W. van der Burg[d,e]

[a]Department of Rehabilitation Medicine, Care and Public Health Research Institute (CAPHRI), Maastricht University, Maastricht, the Netherlands; [b]Centre of Expertise in Rehabilitation and Audiology, Adelante, Hoensbroek, the Netherlands; [c]CIR Revalidatie, Eindhoven, the Netherlands; [d]Department of Paediatric Rehabilitation, Sint Maartenskliniek, Nijmegen, the Netherlands; [e]School of Pedagogical and Educational Sciences, Radboud University, Nijmegen, the Netherlands

ABSTRACT

Purpose: The aim of this article is to conceptualise the phenomenon of therapy-related parental stress in parents of children with a physical disability.

Methods: Three models related to parental stress were reviewed, i.e., general parental stress, burden of caregiving in parents of children with physical disabilities, and experiences of these parents with their child's therapy.

Results: The proposed definition of therapy-related parental stress is "the subjective stress and subsequent changes of functioning and health experienced by a parent of a child with a physical disability in response to paramedical therapies (i.e., physical, occupational, and/or speech and language therapy)". A theoretical model is proposed to describe the process of therapy-related parental stress. Available questionnaires will most likely not be valid and responsive to capture the (changes in) stress parents experience related to therapy their child receives.

Conclusions: This article provides a first definition of therapy-related parental stress and a theoretical model to visualise the processes with regard to this topic. Empirical testing of the presented components and their coherence is needed to confirm or improve the model. A questionnaire that specifically measures the concept of therapy-related parental stress is needed, along with evaluating therapy-related parental stress in clinical practice and research.

➤ INDICATIONS FOR REHABILITATION

- It is imperative to recognise paramedical therapies (i.e., physical, occupational, and speech and language therapy) as a potential stressor for parents of children with a physical disability, both in paediatric rehabilitation practice and research.
- A definition and theoretical model of therapy-related parental stress is proposed and the need for measures to evaluate this phenomenon is argued.
- The authors provide a starting point for the evidence base of the concept of therapy-related parental stress.

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Parental stress; family-professional collaboration; adverse effects of therapy; paediatric rehabilitation; theoretical model

Introduction

Family-professional collaboration and shared planning and implementation of an intervention are recognised as crucial steps in the rehabilitation of children with physical disabilities. To accomplish this collaborative service delivery, parental engagement is essential [1]. The parents' engagement can vary in type and degree, with parents being coached by therapists to be the primary interventionists as the most extreme.

Various papers have reported that family-professional collaboration is effective in improving child functioning. Examples include caregiver-provided, home-based bimanual training in children with cerebral palsy (CP) [2], and family-supported rehabilitation for children with traumatic brain injury [3]. On the other hand, literature recognises drawbacks of such therapy programmes. Most protocols require high doses, and thus many hours of training, to be successful [4]. It has been found that therapy adherence is limited and parents sacrifice employment-related activities, leisure time, and family activities to enable commitment to therapy [5]. A negative correlation between such parental sacrifices and family well-being has also been confirmed [5]. Similarly, data from previous research suggest that parents feel pressure to adhere to therapeutic activities, and the required efforts to do so negatively impact their family relationships [6,7]. Parents may also encounter a conflict between their attitude as a parent and their approach as a therapy provider. The parenting role is relationship-oriented and characterised by, for instance, sensitivity and responsiveness to the child's feelings and needs, in order to establish or sustain a supportive parent–child relationship with a focus on their child's happiness, enjoyment, and well-being [5,8]. Many physical, occupational, and speech and language therapy interventions,

CONTACT Laura W. M. E. Beckers laura.beckers@maastrichtuniversity.nl Maastricht University, Department of Rehabilitation Medicine, P.O. Box 616, 6200 MD Maastricht, the Netherlands

however, focus on improving (motor) performance of the child, which often requires a task-oriented approach [4]. Hence, implementation of therapeutic strategies can interfere with the parent–child emotional availability and interaction [6,9]. These potential disadvantageous consequences of collaborative service delivery can lead to an increase of perceived parental stress as a secondary, adverse effect of paramedical therapies (i.e., physical, occupational, and speech and language therapy) [7]. This can be considered therapy-related parental stress.

Little attention has been paid to the phenomenon of therapy-related parental stress in either paediatric rehabilitation treatment, intervention research, or stress-oriented research in parents of children with physical disabilities so far. However, therapy-related parental stress may affect the well-being of parents as well as the child and siblings, because it adds to the more general stress of parenting a child with physical disabilities. Parental stress in general has been associated with less nurturing, supportive, patient, and involved parenting. Instead, parents can be irritable, negative or punitive [10]. This in turn puts the parent–child interaction and relation even further under pressure. Therapy-related parental stress may also negatively impact the quality of the execution of therapy, hereby reducing its effect on child functioning. Consequently, it is imperative to recognise paramedical therapies as a potential stressor for parents. To allow evaluation of therapy-related parental stress, its concept should be defined. A theoretical model can provide a more detailed understanding of the concept. In addition to parents of children with a physical disability, therapy-related parental stress may also occur in, for instance, parents of children with autism spectrum disorder or intellectual disability. As different factors may be of importance to (parents of) children from these diagnostic groups, the current conceptual description exclusively concerns parents of children with physical disabilities in order to optimally adapt the definition and model to this population of interest.

Purpose statement

The purpose of this article is to conceptualise the phenomenon of therapy-related stress in parents of children with a physical disability. A definition and theoretical model are proposed. Furthermore, this article reflects on how to assess therapy-related parental stress in clinical practice and research. The authors aim to provide a starting point for the evidence base of therapy-related parental stress.

The construct of parental stress

Stress is difficult to define and conceptualise. In threatening situations, stress can be useful as it supports physiological, cognitive, and behavioural responses. In this article, however, the focus is on the negative variant, also referred to as psychological distress, which is "the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person" [11]. For parents of children with a physical disability three related and accumulating concepts of parental stress are distinguished in this article:

1. general parental stress, which can be experienced by anyone raising a child;
2. stress that is unique for parenting and caring for a child with a physical disability; and
3. therapy-related parental stress.

General parental stress

Parental stress arises from attempts to adapt to the demands of parenthood. De Brock [12] described a theoretical stress process model, considering parental stress as an interactive chain of factors. A stress-provoking condition (*stressor*) acts as a stimulus. Stressors can vary from minor everyday annoyances to life changing events. The primary response to a stressor is defined as the *subjective stress experience*, which can be physical and/or psychological. Moderating variables of the subjective stress experience are social resources (e.g., social support) and psychological resources (i.e., personality characteristics such as sense of competence). Depending on one's degree of psychological resilience, a subjective stress experience may lead to a secondary stress response, which is a change of *physical and/or psychological functioning* (depression, for instance) and tends to be more enduring. This secondary stress response will again influence *parental behaviour* and, indirectly, the *development of the child*. For example, a parent with a depression may not have sufficient energy to perform necessary exercises with the child. These pedagogical and developmental consequences can then in itself become stressors for the parent [12].

Stress unique to parenting and caring for a child with a physical disability

Parents of children with a physical disability face particular stressors [13]. Often, there is uncertainty during the search for a diagnosis and prognosis. Once the diagnosis is confirmed, parents have to adjust their expectations regarding the child's and their own future. Depending on the severity of the disability, more effort of the child and family is required for acquisition of skills, performance of daily activities, and participation [14,15]. Often, the functional prognosis is predicted to be dependent on stimulation of the child's development. This may impose a feeling of pressure and responsibility on the parents. Moreover, due to the complex care needs, parents have to fulfil the role of "case manager." These additional demands tend to result in elevated stress levels [16]. In this section, two models are discussed regarding stress unique to parenting and caring for a child with a physical disability. The first model explains the overall process and burden of caregiving in parents of children with CP and other disabilities, while the second model specifically addresses parents' experiences with physical and occupational therapy for their child with CP.

Raina et al. [17,18] developed a multidimensional model to describe the process and burden of caregiving in parents of children with CP and other disabilities (Figure 1). The model was developed based on literature review and has thereafter been empirically tested on data of 468 Canadian primary caregivers of children with CP, using a structural equation modelling (SEM) approach. *Psychological health* and *physical health* are included in the model as outcomes. Stress is the main indicator of psychological health. *Caregiving demands* and *perception of formal care* constitute the caregiver strain. The former are daily demands as well as conflicts between the caregiving and occupational roles. Perception of formal care is considered the perceived family-centeredness of services. *Caregiving strain* is affected by the child's impairment (motor severity and cognitive functioning, dependency in daily life, and medical problems), and leads to stress through several mediating coping factors: *social support from others*, *family function,* and *stress management* [17,18]. Raina et al. provide a more detailed discussion of their model, which is out of the scope of the current article [17,18].

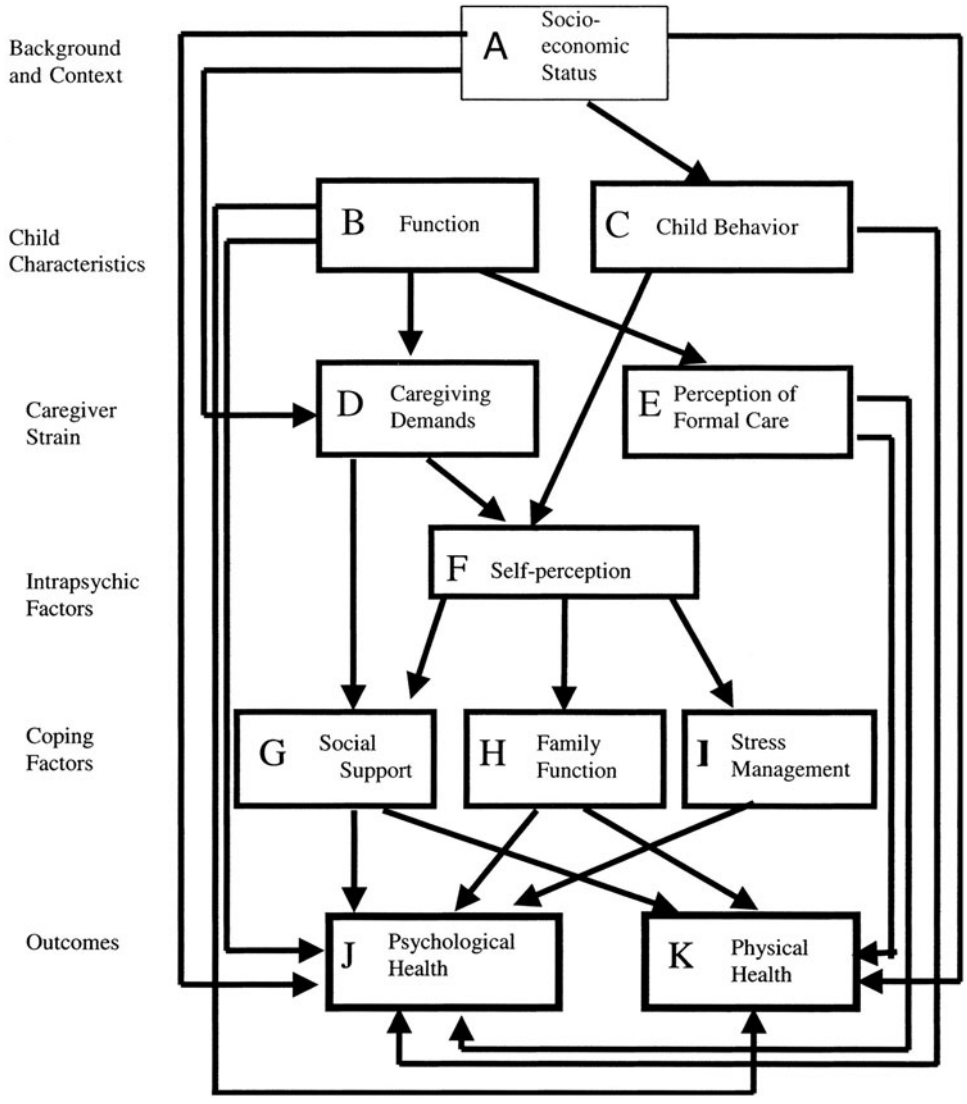

Figure 1. Process and burden of caregiving in parents of children with disabilities [18]. Reproduced with permission from Journal Pediatrics, Vol. 115, Page e628, Copyright© 2005 by the AAP.

Despite their similarities, this model and the stress process model by De Brock differ on important fundamental aspects. First, the model of Raina et al. is a linear model, considering parental stress exclusively as an outcome. The stress process model by De Brock deservedly acknowledges parental stress as a cyclic process, meaning that this stress can affect parental behaviour and child development and, consequently, be maintained by it. This perspective respects the impact of parental stress itself. Second, in Raina et al.'s model functioning of the child is only incorporated as an initiator of caregiver strain. De Brock, on the other hand, describes development of the child as both a consequence of parental stress and a stressor. Third, a strength of the model of Raina et al. is the incorporation of perception of formal care, as this may either contribute to or relieve stress in parents of a child with a physical disability. This factor is specifically relevant in parenting and caring for a child with a physical disability, making the model appropriate for this population.

Perception of formal care

Raina et al. [17,18] hypothesise that increased family-centeredness of services is associated with less parental stress. It must be acknowledged, however, that stress is a possible adverse effect of certain types of collaborative service delivery, such as parent-delivered therapy, as it may tax family resources [5]. Paramedical therapies are important components in these services. Kruijsen-Terpstra et al. [19] elaborate on the experiences of parents of children with CP with these kinds of therapies. Based on their mixed studies review, they describe a model of context- and process-related factors that may influence outcomes of physical and occupational therapy (Figure 2).

Context-related factors are clustered within the subdomains *culture*, *community*, and *family*. The family factor contains support from the extended family as well as shared responsibility and roles within the family. Another context-related factor is balancing the demands of daily life with the child's therapy. The process domain in this model can be perceived as a more detailed elaboration of the perception of formal care domain in Raina et al.'s model. Within the *process* domain, several factors are clustered within two subdomains: family–professional partnership and intervention. *Family–professional partnership* includes factors such as shared decision-making and open communication. The *intervention* subdomain includes implementation of the intervention at home, therapist–child relationship, and design and content of the

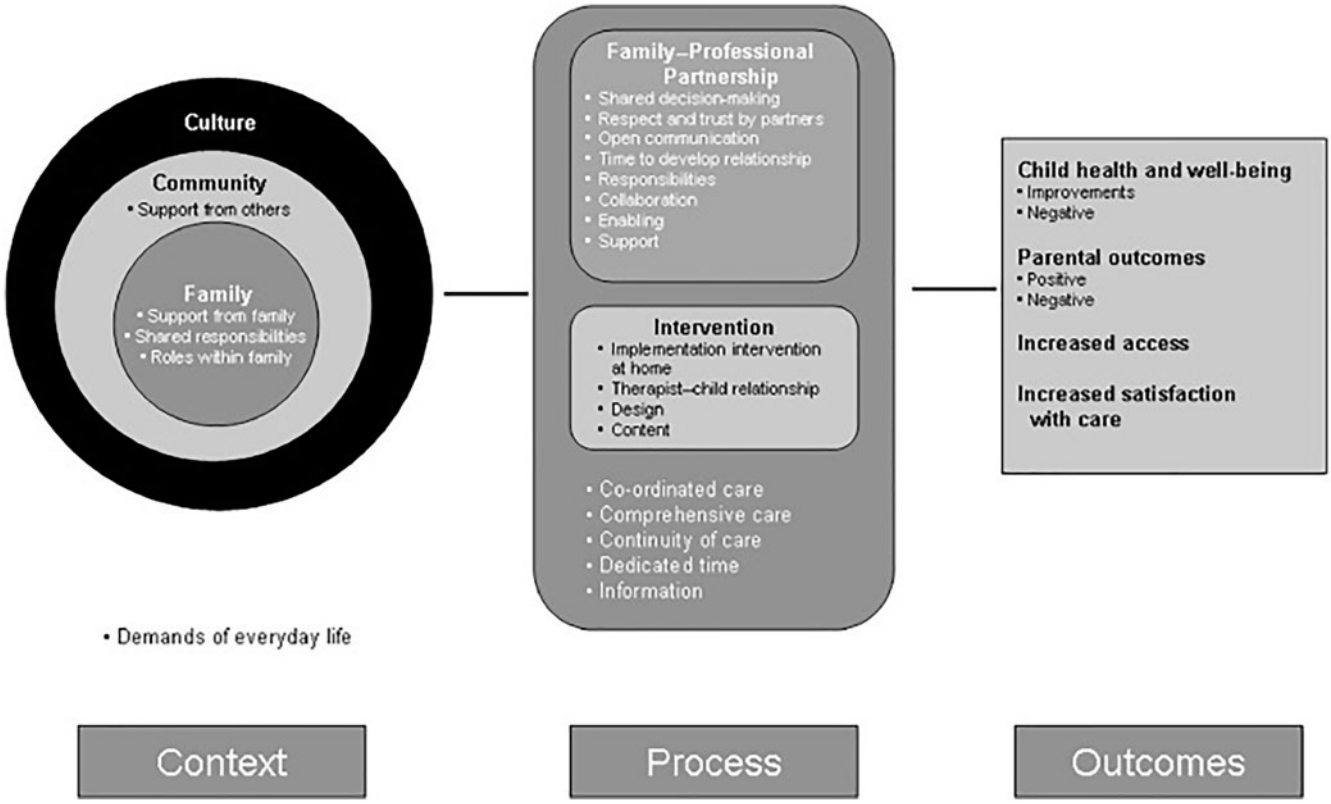

Figure 2. Experiences of parents of children with CP with their child's physical and occupational therapy [19]. Reproduced with permission from Journal Child: Care, Health and Development, Vol. 40, Page 793, Copyright© 2013 by John Wiley and Sons.

intervention. Additional process factors are coordinated care, comprehensive care, continuity of care, dedicated time, and receiving information [19]. We recognise the aforementioned process-related factors as contributors to therapy being a possible stressor, affecting whether and to what extent parents experience therapy-related parental stress as an outcome.

Therapy-related parental stress

Therapy-related parental stress is a distinctive component of parental stress, with therapy being the particular stressor of interest. Parent-delivered therapy and exercise at home is generally valued by professionals, but also requires a task-oriented approach and high dose (i.e., many hours) to be effective [4], and therapy adherence may lead to parental sacrifices with a negative impact on daily life, family relations, and well-being [6,7]. As a consequence, therapy may result in stress and have impact on the functioning and health of parents. Thus, the proposed definition of therapy-related parental stress is "the subjective stress and subsequent changes of functioning and health experienced by a parent of a child with a physical disability in response to paramedical therapies (i.e., physical, occupational, and/or speech and language therapy)". Therapies vary in content and design parameters and differ with regard to parental engagement, ranging from parents getting advice to performing an intensive home-based programme with their child themselves. The concept of therapy-related parental stress applies to all kinds of therapies, although its relevance may be positively correlated with parental engagement in therapy.

In accordance with this definition, we propose a theoretical model for the process of therapy-related parental stress (Figure 3). Preceding its development, a focus group discussion with mothers of children with CP confirmed the relevance of the therapy-related parental stress concept and revealed its main contributors. These parents have had experience with various therapeutic interventions for their child and were involved, in a "co-thinker" role, in a related research project [20,21]. The three above-mentioned models of De Brock, Raina et al., and Kruijsen-Terpstra et al. were used to build the model. Additionally, the results of the focus group were used to add contributing factors that did not emerge from these sources.

In the proposed model, the process of therapy-related parental stress is visualised by a lemniscate (i.e., infinity symbol). This represents the constant influence of the perception and impact of therapy on the implementation of subsequent interventions during the many years of rehabilitation of a child. The phases are continuous rather than intermittent.

Therapy is the focus of attention as the potential stressor. The enlarged steering wheel shaped figure visualises five distinctive contributors to the course of therapy: content and design of the therapy, family–professional partnership, family factors, child factors, and parent factors. The former two are represented in the process domain of Kruijsen-Terpstra et al.'s model [19]. The first contributor, the *content and design of the therapy,* contains the treatment modality, frequency of appointments, implementation of therapy and related exercises at home (including adaptations to daily routines and parent–child interaction), etc. *Family-professional partnership* comprises therapist–child and therapist–parent(s) relationship. Elements considered important in family-centred care, like shared decision-making and open communication between professional and family, which are also incorporated in Kruijsen-Terpstra et al.'s model [19], are of interest for this contributor. Although Kruijsen-Terpstra et al. consider the family subdomain as part of the context, the proposed model acknowledges *family factors* as a central element in the course of therapies. This contributor mainly includes roles and

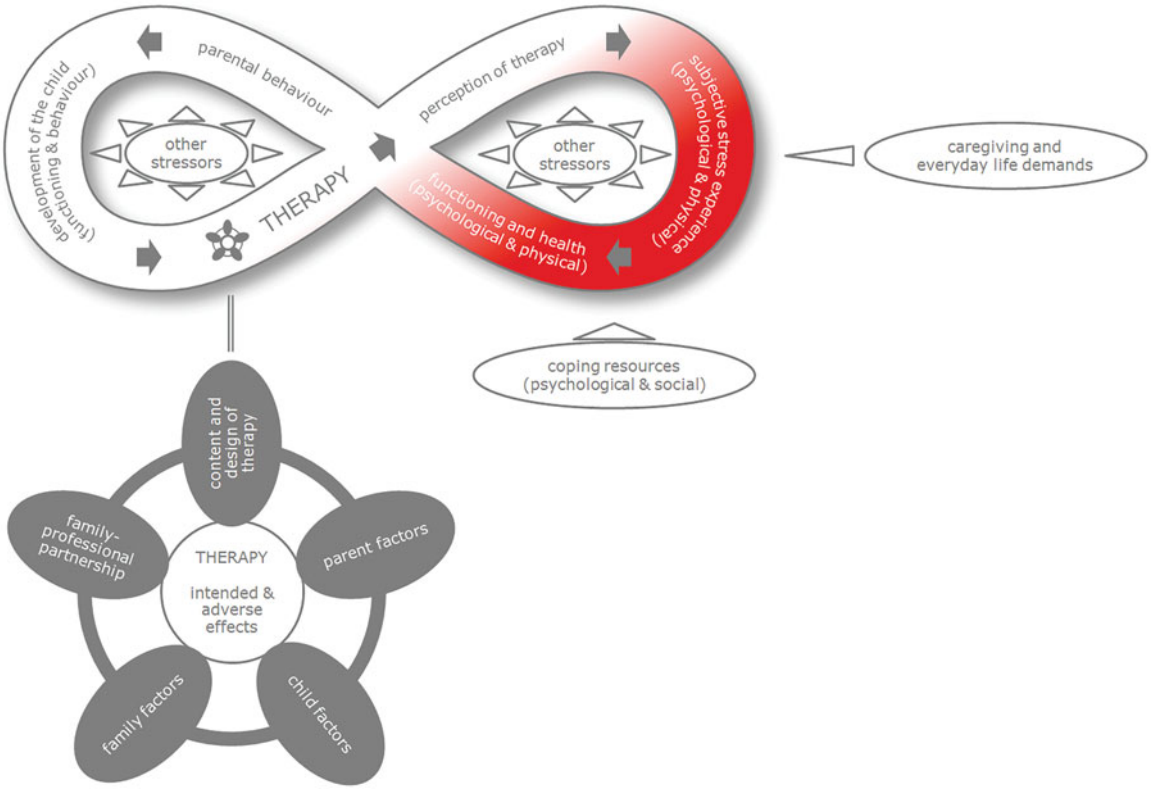

Figure 3. Model of therapy-related parental stress.

responsibilities within the family, family planning, and interactions between the child with a physical disability, parents, and siblings. The previously described contributors and examples were confirmed to contribute to the course of therapy by the parents in the aforementioned focus group discussion. Furthermore, child factors and parent factors were derived from the focus group as separate contributors. The child's character (e.g., being stubborn), feelings and emotions (e.g., frustration), behaviour (e.g., rebellion), mental and physical condition (e.g., fatigue), and motivation are recognised as *child factors* affecting the course of therapy. Similarly, the parent's feelings (e.g., disappointment), mental and physical condition (e.g., fatigue), and motivation constitute the *parent factors*. All five contributors are assumed to interact with each other and together result in *intended and adverse effects of the therapy*. Intended effects are for instance improved performance of activities. Adverse effects can vary from mild reactions to major events, like frustration and increase of spasticity, respectively.

All aforementioned contributors, together with the intended and adverse effects, determine the *perception of therapy* by the parent. This is in line with Raina et al. [17,18], who acknowledge perception of formal care in relation to caregiver strain. In accordance with De Brock [12], the subsequent components of the process of therapy-related parental stress are subjective stress experience by the parent, functioning and health of the parent, parental behaviour, and development of the child, respectively. Since the development of the child may influence the course of therapy, the process is regarded cyclic. The perception of therapy results in the *subjective stress experience*, which can be psychological and/or physical, as described by De Brock [12]. The subjective stress experience, i.e., primary stress response, influences the secondary stress response, which includes the *functioning and health* of the parent (again psychological and/or physical). Health is included on the basis of Raina et al.'s model [17,18]. Together, the subjective stress experience and the change of functioning and health of the parent constitute the therapy-related parental stress. This successively affects *parental behaviour*, and *development of the child* (functioning and behaviour).

Aspects other than the therapy can influence the subjectively experienced stress. Raina et al.'s model [17,18] indicates that caregiving demands have consequences for the experienced burden of parents of children with a physical disability. In addition, Kruijsen-Terpstra et al. [19] imply that the demands of everyday life impact parents' experiences with therapy. Hence, *caregiving and everyday life demands* are incorporated as interacting factors for the subjective stress experience. *Coping resources* can also act as a mediator between the primary and secondary stress response, as stated through the models of De Brock, Raina et al., and Kruijsen-Terpstra et al. [12,17–19]. In conformity with these models, we differentiate psychological and social resources as moderating factors for subjective stress experience affecting functioning and health of the parent. Psychological coping resources are, for example, self-esteem and stress management. Social resources include family function and social support (e.g., from extended family). Coping resources cohere with the previously described parent factors as contributor of the therapy. Notwithstanding, the parent factors are variable over time and directly related to the course of therapy, whereas coping resources are more stable personality characteristics. The same applies to other related elements, for example, the contributor family factors and family function as part of social resources. Other stressors, both related and unrelated to caregiving, can intervene with the therapy-related parental stress process at any stage. Although contextual factors like culture and socio-economic status have been described to influence both general parental stress and stress unique to parenting and caring for a child with a physical

disability [17–19], based on the focus group discussion these are expected to be less relevant for therapy-related parental stress. Since a more parsimonious model is preferred over a more complex model, these factors are not included in the proposed model.

Evaluating parental stress

As was pointed out in the introduction to this article, it is crucial to acknowledge paramedical therapies as a potential stressor for parents in clinical practice and research. Therefore, this section reflects on the assessment of therapy-related parental stress.

General parental stress: Several questionnaires are available to measure the amount of general stress parents may perceive, of which the Parenting Stress Index (PSI) is probably the most used [22]. It focuses on stressors that are unique to the parent–child relationship. Such generic parental stress questionnaires, however, do not focus particularly on parents of children with a physical disability. As a consequence, they may not be able to differentiate stressors significant to parenting and caring for a child with a physical disability. In spite of that, they are frequently used in this population to investigate the occurrence of stress and the effect of interventions [6,23].

Stress unique to parenting and caring for a child with a physical disability: For this purpose instruments like the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS), and Distress Thermometer for Parents (DT-P) are likely more appropriate, since they include domains such as overprotection or dependency [24,25]. Also, the Measure of Processes of Care (MPOC) evaluates the perception of formal care, i.e., parents' perceptions of the extent to which the health services their child receives are family centred [26].

Therapy-related parental stress: The latter measures are more population specific than generic parental stress questionnaires and an association may be expected between their concepts and therapy-related parental stress. Still, the items of such questionnaires will most likely not be valid to capture the stress parents experience related to therapy their child receives, nor sufficiently responsive to pick up relevant changes in parental stress during an intervention programme. This will result in an inadequate evaluation of the degree of therapy-related parental stress and thus a probable underestimation of the adverse effect of therapies, both in clinical practice and intervention research. Likewise, information regarding particular sources of stress should be assessed to guide efforts or interventions to reduce therapy-related parental stress. Therefore, a questionnaire that specifically measures the concept of therapy-related parental stress is required.

We hypothesise that the perceived therapy-related parental stress may fluctuate during the course of a therapeutic intervention. For example, while experiencing a high-stress level during the startup of a new therapy, this may diminish if parents feel more empowered to deliver the therapy, or increase if the child does not benefit from the therapy as expected. These kinds of processes require repeated measurements of therapy-related parental stress before, during, and after the therapy instead of a single retrospective assessment. Also, in our opinion, both effectiveness and adverse effects of therapeutic interventions should always be assessed, comparable to the standard use of measures like number needed to treat and number needed to harm in drug interventions [27].

Discussion

This article provides a first definition of therapy-related parental stress and a theoretical model to visualise the processes with regard to its concept. The proposed model can facilitate health professionals to comprehend this phenomenon in relation to the potential influence of their therapy programmes, both positive and negative. Furthermore, the need for measures to evaluate this particular type of parental stress is emphasised.

In previous research, some authors noticed parental stress associated with therapy [7]. Therapy-related parental stress has not been acknowledged as a separate concept, though. This conceptual description of therapy-related parental stress is the first attempt to draw attention to a highly important, but under-considered, topic and to clarify the current state of knowledge.

Family-centred approaches are considered best practice for formal care [1]. One of the six main concepts of family-centred care is "encouraging the development of true collaborative relationships between families and health-care providers, and partnership" [28]. Notwithstanding, a study comparing families and health professionals' perspectives on family-centred care has identified that the collaborative processes are often not sufficiently implemented when family-centred care is operationalised [28]. Particularly the decision of the parents' role in the treatment of their child is frequently not made collaboratively, considering the wishes and abilities of the parents at the particular point in time. Instead, health-care providers delegate responsibilities to the parents, irrespectively of their needs and resources [28,29]. This reverses the potential of family-centred care to reduce the risk of therapy-related parental stress. The field of tension between the parents' perspective and evidence-based requirements of training principles and doses may account for this paradox.

Limitations

Several limitations of this study should be recognised. The limited frameworks available and the single focus group did not allow for a completely saturated therapy-related parental stress model. The main weakness of this study is that the proposed model is purely theoretical and, as most models, is a simplified representation of reality. In addition, the available models as well as the focus group mainly targeted parents of children with CP, which is the most common physical disability in childhood. Since CP is an early-onset, non-progressive disability primarily affecting movement and posture and a variety of possible comorbidities, generalisation of the proposed model to parents of children with physical disabilities with other characteristics may be limited.

Implications and recommendations

This conceptual description has several important implications and recommendations. In addition to child-related measures, we advocate that therapy-related parental stress should be an outcome of interest in both formal care and research projects in order to evaluate the effect of therapies on the family level. This will avoid overvaluation of the effectiveness of a therapy, as it does not solely take the beneficial effect on the functioning of the child into account. After all, even a therapy that effectively increases, for instance, motor performance of the child, can also create therapy-related parental stress as an adverse effect.

Future studies are required to establish to what extent therapy-related parental stress is an issue for families and to unravel its complexity. Empirical testing of the presented components

and their mutual associations is needed to confirm or improve the proposed model. To allow evaluation of therapy-related parental stress, psychometrically sound instruments must be developed. In the long term, these efforts should lead to well-founded recommendations and guidelines for clinical practice.

Preventing therapy-related parental stress, evaluating both the experienced level of stress and supportive/hindering factors throughout interventions, and incorporating remediating methods in therapy programmes to reduce the effect of stress provoking factors should become standard procedures in the clinical treatment. To accomplish this, interdisciplinary collaboration among therapists, social workers, remedial educationalists, and parents will be necessary. Awaiting validated questionnaires, we recommend clinicians to include therapy-related parental stress in their conversations with parents.

The issue of therapy-related parental stress requires further attention in order to advance paediatric rehabilitation and its evidence base. This is supported by a recent editorial of Zebracki [30], advocating to treat paediatric patients within the context of the family system, and to consider the well-being of the caregiver. One of the aims of this article is to stimulate awareness of the phenomenon of therapy-related parental stress. We invite the field to debate about an accurate definition, to determine the position of therapy-related parental stress in relation to other scopes of parental stress, and advance the proposed model, to guide paediatric rehabilitation practice and research.

Conclusion

This study provided a conceptual description of the phenomenon of therapy-related stress in parents of children with a physical disability. A definition and theoretical model are proposed, and a reflection on the measurement and evaluation of therapy-related parental stress is provided. This article has argued that it is highly important to consider therapy-related parental stress in practice and research. However, greater efforts are needed to enable monitoring, prevention, and reduction of therapy-related parental stress.

Disclosure statement

The authors report no conflicts of interest.

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