One, two, three, towards autonomy?!

Supporting parental self-management within paediatric rehabilitation services

Ruud Wong Chung

ONE, TWO, THREE, TOWARDS AUTONOMY?!
SUPPORTING PARENTAL SELF-MANAGEMENT WITHIN PAEDIATRIC REHABILITATION SERVICES

Ruud Wong Chung

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	prof.dr. P.J. van der Wees

- Without equality no partnerships -

Contents

1

General introduction

'... It is undeniable that people in our current network and information society are more outspoken and independent than in the past. Combined with the need to reduce the government deficit, this is gradually transforming the classic welfare state into a participatory society. Everyone who can, is asked to take responsibility for their own life and surrounding ...'
(Speech from the Throne 2013,
King Willem-Alexander of the Netherlands) *

'... The participation paradox: An appeal for participation particularly comes into its own when everyone can take part. However, it can have the opposite effect if opportunities are unequally distributed, and capabilities are limited ...'
(Inaugural speech Prof. Dr. F.A. Hindriks,
University of Groningen, 2015) **

'... This focus on 'the participation society', 'parents' own responsibility', 'self-management'. What really worries me is that it will lead to several of our parents falling between two stools ...'
(Child healthcare professional, 2016) ***

This dissertation investigates perspectives, attitudes, experiences, motivations, and associated factors, of both parents and child healthcare professionals, regarding parental self-management support in the care of children with chronic conditions. Building on the insights from the initial two studies, two tools were developed that may enhance the support provided by child healthcare professionals to parents, empowering them in managing their child's care.

* Retrieved from: https://www.koninklijkhuis.nl/documenten/toespraken/2013/09/17/troonrede-2013.
** Retrieved from: https://www.rug.nl/staff/f.a.hindriks/oratie-frank-hindriks.pdf.
*** Retrieved from: Qualitative dataset PhD research project R.W. Wong Chung.

INTRODUCTION

In recent decades the concept of self-management has gained prominence across various societal domains. Today, it constitutes a crucial element of governmental strategic health policies, encouraging citizens to take responsibility for coping with chronic health issues and enhancing quality of life, as well as contributing to the manageability of limited (financial) resources in future health support and care (Australian Health Ministers' Advisory Council [AHMAC], 2017; Nolte et al., 2018). In the Netherlands this commitment is confirmed in the policy agenda of the Dutch Ministry of Health, Welfare and Sport (2023), referring to the 'Healthy and Active Life Agreement' between government, healthcare organisations and healthcare insurances that highlights the integral role of self-management in achieving optimal health outcomes. However, stimulating and supporting self-management may have different meanings and require different approaches and actions for different health conditions, such as children with chronic conditions and their parents.

Despite the prominent role of self-management and its support in current healthcare, there is no consensus definition, nor a shared understanding of what self-management exactly entails. The World Health Organisation [WHO] (2022) characterises self-management as a fundamental aspect of daily life, empowering individuals, families, and communities, to promote and maintain health, prevent health issues, and manage illness and disability, with or without the support of a healthcare professional. Self-management of chronic conditions was originally associated with managing medication intake for conditions such as diabetes or asthma. It is, however, nowadays also used in a wider range of behaviours and chronic conditions (van Staa et al., 2021). In paediatric rehabilitation services, chronic conditions self-management is primarily linked to managing daily life functioning in children with early-onset disabilities, such as cerebral palsy (CP), developmental coordination disorder (DCD), spina bifida, or neuromuscular disorders. These disabilities often involve motor-sensory impairments, frequently accompanied by intellectual disabilities and/or emotional or behavioural issues (Pangalila et al., 2015). In Australia, a nation with an established tradition of self-management policies due to its demographic and topographic characteristics, supporting chronic condition self-management involves empowering individuals for active engagement in managing their chronic condition in daily life. For some of the key-aspects of self-management support, see Table 1.1.

Table 1.1 Principles of self-management support (Australian Health Ministers' Advisory Council, 2017)

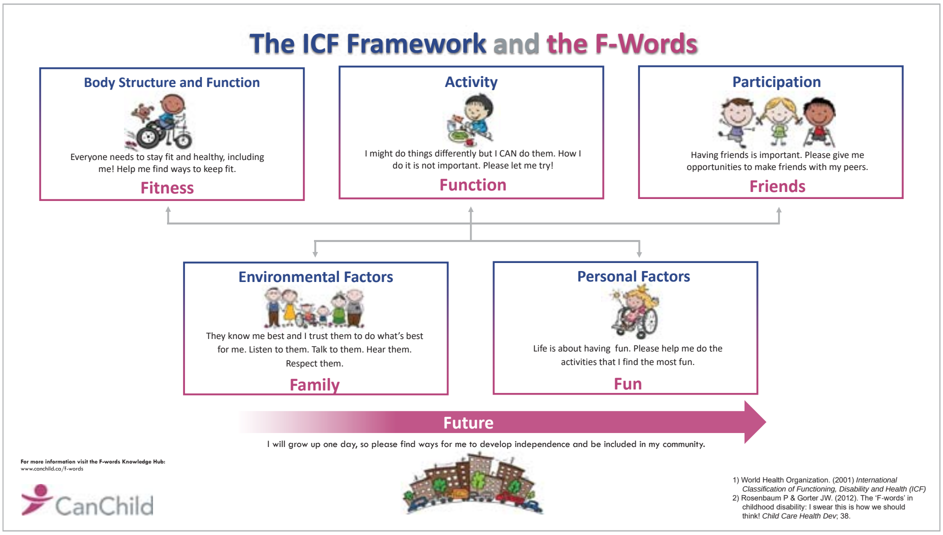
Improving knowledge of the chronic condition
Goal setting appropriate to health, and social needs and values
Shared decision-making in partnership with healthcare providers
Involvement of caregivers and family in care planning as appropriate
Discussing treatment preferences
Setting individual quality of life goals
Enabling access to resources and information to better navigate the health system
Improving proficiency in the use of digital technology and e-health

Global rise of chronic conditions among children

The burden of chronic health conditions is growing worldwide, affecting approximately 25% of children and youth in Europe and the United States (van Cleave et al., 2010; van Hal et al., 2019). In the Netherlands, approximately 6.8% of children in the age 2 to 12 experience limited daily activities due to a long-term health condition (CBS, 2023). Consequently, paediatric rehabilitation services have incorporated self-management support to enhance functioning and participation, of children and youth with chronic disabilities (FMS, 2017; WHO, 2023).

Engagement of parents

In child healthcare interventions parents play a crucial role, holding responsibility for the decisions regarding their child's treatment. According to Dutch legislation regarding 'therapeutic treatment agreement' (Dutch Ministry of Health, Welfare, and Sport, 2024) for children up to age 12, parents have full responsibility for any decision taken in the context of the treatment of their child. If children are between 12 and 16 years old, parents need to co-authorise every decision. Family-centred services, recognising parents as pivotal in their child's life, have become a guiding principle in child healthcare. The WHO's International Classification of Functioning, Disability and Health, Children and Youth version [ICF-CY] (2017) highlights this central role of parents classifying them as the immediate family in a child's environment. The F-words model (Rosenbaum & Gorter, 2012) can be considered as a broadening and deepening of the ICF-CY framework and is inspired by six words starting with an 'F': Functioning, Family, Friends, Fitness, Fun, and Future. The F-words model acquires growing popularity within the field of paediatric rehabilitation services, and like the ICF-CY itself, it very clearly depicts parents as a critical factor in the child's environment. Having a child with a chronic condition may increasingly be challenging for parents when the child grows older, both physically and mentally. Engaging parents and collaborating with them in partnership therefore are seen as key to family-centred services. For a representation of the ICF and F-words model combined, see Figure 1.1.



Everyone needs to stay fit and healthy, including me! Help me find ways to keep fit.

I might do things differently but I CAN do them. How I do it is not important. Please let me try!

Having friends is important. Please give me opportunities to make friends with my peers.

They know me best and I trust them to do what's best for me. Listen to them. Talk to them. Hear them. Respect them.

Life is about having fun. Please help me do the activities that I find the most fun.

I will grow up one day, so please find ways for me to develop independence and be included in my community.

For more information visit the F-words Knowledge Hub:
www.canchild.ca/f-words

1) World Health Organization. (2001) *International Classification of Functioning, Disability and Health (ICF)*
2) Rosenbaum P & Gorter JW. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child Care Health Dev*; 38.

Figure 1.1 Combination of the ICF and the F-Words model. Used with permission, retrieved from www.canchild.ca.

Supporting parental self-management

The essential role of parents in the life of children with chronic conditions draws attention to the needs that parents may have in self-management of their child's daily care. These needs may vary along differences in for example socio-economic status, gender, education, ethnicity, cultural backgrounds, family composition, and attitudes. Not all parents wish to, or are consistently able to actively participate in their child's treatment process (Siebes et al., 2006). This may especially apply to parents of children with complex care needs and high demands for healthcare services. Offering self-management support services to parents, while holding fixed expectations about their responsibility, commitment, and service use can risk alienating those parents, or label them as disengaged (Lawn et al., 2011). Consequently, parental self-management supportive skills that enable professionals to support parents with differing perspectives are becoming indispensable in the toolbox of any child healthcare professional.

Motivation to support parental self-management

Equipping healthcare professionals with the necessary skills-set to attune to the variety of parental perspectives, is not an automatic process. Development of such expertise and the willingness to use those skills, may require adaptations in attitude and behaviour.

Two theories that are focused on explaining underlying processes that are critical to changes in people's behaviour are the Self-Determination Theory [SDT] (Ryan & Deci, 2000; Ryan et al., 2008) and Ajzen's Theory of Planned Behaviour [TPB] (1991; 2012). Both SDT and TPB suggest that an individual's intention to engage in, and adhere to, a particular behaviour—such as supporting parental self-management by child healthcare professionals—is influenced by their underlying motivations for adopting that approach.

Since SDT and TPB are closely related theories, they are often used concurrently. Hagger and Chaztisarantis (2009) found significant correlations between key-aspects of SDT and TPB. 'Perceived autonomy support' was strongly associated with autonomous motivation (also labelled as intrinsic motivation), consistent with SDT. Autonomous motivation in turn, was indicated to have significant effect on attitudes and self-efficacy, which according to TPB are the most proximal associated factors for intention and adherence to new (planned) behaviour. Motivating child healthcare professionals to support parents by increasing the professionals' perceived support of autonomy, alongside bolstering their attitudes and confidence, therefore appears paramount for fostering supportive behaviour towards parental self-management.

Improving parental self-management support

A growing body of literature acknowledges the value of parental self-management support (Harniess et al., 2022; Olij et al., 2021). An important next step is therefore to understand the underlying perspectives and associated factors pertaining to parental self-management and its support (Jeglinski et al., 2011; Palisano et al., 2009). Particularly, exploring the viewpoints of parents and child healthcare professionals is pivotal, as their perspectives on health, illness, and treatment can significantly differ (Darrah et al., 2010), thereby influencing therapy goals and approaches (Wiart et al., 2010).

Parents of children with chronic conditions harbour a wide spectrum of beliefs, desires, and needs (Alsem et al., 2014; Siebes et al., 2012; Terwiel et al., 2017), leading to varying meanings, values, and expectations associated with self-management support. What may constitute an optimal approach for one individual may be less suitable for another (Trappenburg et al., 2013). This range of perceptions and conceptions may hinder child healthcare professionals from recognising problems and providing adequate support to parents. A deeper understanding of parental perspectives can empower professionals to tailor their approach to individual preferences and needs, thereby enhancing engagement between healthcare services and families (Pennarola et al., 2012). Lawn et al. (2011) advocate for further reflection on how professionals interpret self-management support, emphasising its importance in delivering appropriate services. Given the diversity of needs, desires, and expectations of parents, it is also important to consider what child healthcare professionals need for effectively supporting parents' self-management.

In contemporary healthcare, it is suggested that digital communication tools can contribute to the interaction between parents and professionals, particularly in information exchange, disease monitoring, treatment, and self-management and support (Gulmans et al., 2012; Marziniak et al., 2018). When developing such digital tools, it is recommended to consider the patients' views (Cerdan et al., 2017), as well as the real-life settings in which the tools will be used (Mohr et al., 2018), as those experiences can positively add to the functionality of such applications and identify risk factors that may impede its future use.

Reflective practice

Reflection is a powerful tool for lifelong learning, influencing personal and professional development. It creates awareness and enables a person to act and adapt in various contexts (Colomer et al., 2020). Child healthcare professionals who reflect on their perspectives, motivations, and attitudes regarding the support of parental self-management might be able to enhance their collaborative work with parents (Coyne, 2015). The development of reflective skills can help to deepen understanding of roles and to better adapt to the diversity of parental preferences. Availability of instruments that can facilitate healthcare professionals in their processes of reflection therefore would be recommendable.

REFLEXIVITY

The drive behind this PhD trajectory stems from a desire to empower parents for self-management in their child's daily care and to strengthen their position in the web of healthcare professionals surrounding them. The author's engagement with parents in his daily practice as a child healthcare professional at a paediatric rehabilitation institute, served as a key motivation for pursuing this research. However, this involvement sometimes also posed challenges in maintaining the necessary scientific distance. Ongoing reflection and regular discussion within the research project group, as well as methodological procedures for trustworthiness, helped ensure an appropriate balance. While scientific approach may lean towards pragmatism, the underlying philosophy is rooted in a critical emancipatory worldview. This holds that research in healthcare should contribute to understanding of assumptions and beliefs underlying social conditions and inequity, promoting equality particularly by acknowledging and empowering those in disadvantaged positions, ultimately striving for a more equitable and sustainable world (Hankivsky & Christoffersen, 2008; Kincheloe & Maclaren, 2005; Meekosha & Shuttleworth, 2009). This dissertation endeavours to represent a step in that direction.

AIMS AND OUTLINE OF THE DISSERTATION

This dissertation describes four studies. Two mixed-methods studies were aimed at investigating parents' and child healthcare professionals' perspectives, experiences, attitudes, motivations, and associated factors regarding parental self-management and its support. To address the absence of a free available validated instrument in the Netherlands for child healthcare professionals to reflect on their attitudes and behaviour towards the support of parental self-management, the third study subsequently aimed to develop and validate such a tool. Lastly, the purpose of the fourth study was to develop and implement a digital media platform to enhance interaction between parents and child healthcare professionals.

Chapter 2 focusses on parents and provides the outcomes of a cross-sectional survey used to explore correlations between parental self-management, motivation and perceived autonomy support. Additionally, semi-structured interviews were conducted to acquire more in-dept comprehension of parents' views. Chapter 3 focusses on child healthcare professionals and describes the motivations of paediatric rehabilitation professionals to support parental self-management. Correlations between motivation and beliefs regarding parental self-management support were investigated, as well as associations with sex, age, and years of working experience. Subsequent interviews explored the perceptions of professionals. In Chapter 4 the value of reflection is emphasised. The chapter presents the development and validation of a reflective tool for child healthcare professionals regarding the support of parental self-management. The psychometric quality of the S-scan - PS was investigated in accordance with the COSMIN checklist, consensus-based standards for the selection of health status measurement instruments, described by Mokkink et al. (2010). Chapter 5 describes how theoretical insights in user-led development of services that might support parental self-management, were put into practice. Informed by the findings described in Chapter 2 and 3, an interactive digital media platform was co-created together with representatives of all relevant stakeholders aspiring to bolster child healthcare professional - parent communication and tuning in the context of the child's treatment. Participatory action research inspired the process of analysis, design, development, implementation and evaluation. Chapter 6 contains the general discussion, reflecting on the main findings in this dissertation, including methodological considerations, implications for practice, and suggestions for future research.

REFERENCES

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, *50*, 179-211.

Ajzen, I. (2012). The theory of planned behavior. In P. A. M. van Lange, A. W. Kruglanski, & E. T. Higgins (Eds.), *Handbook of theories of social psychology* (pp. 438-460). Sage.

Alsem, M. W., Siebes, R. C., Gorter, J. W., Jongmans, M. J., Nijhuis, B. G. J., & Ketelaar, M. (2014). Assessment of family needs in children with physical disabilities: Development of a family needs inventory. *Child: Care, Health and Development*, *40*(4), 498-506. https://doi.org/10.1111/cch.12093

Australian Health Ministers' Advisory Council. (2017). *National strategic framework for chronic conditions. Canberra: Australian Government*. Retrieved April 20, 2018, from: http://www.health.gov.au/internet/main/publishing.nsf/content/nsfcc

CBS [Statistics Netherlands]. (2023). *Statline - Ervaren gezondheid, zorggebruiken leefstijl bij kinderen tot 12 jaar*. Retrieved August 25, 2024, from https://opendata.cbs.nl/statline/#/CBS/nl/dataset/83716ned/table?fromstatweb

Cerdan, J., Catlan-Matamoros, D., & Warny Berg, S. (2017). Online communication in a rehabilitation setting: Experiences of patients with chronic conditions using a web portal in Denmark. *Patient Education and Counseling*, *100*(12), 2283-2289. https://doi.org/10.1016/j.pec.2017.06.023

Colomer, J., Serra, T., Canabate, D., & Bubnys, R. (2020). Reflective learning in higher education: Active methodologies for transformative practices. *Sustainability*, *12*(9), 3827. https://doi.org/10.3390/su12093827

Coyne, I. (2015). Families and health-care professionals' perspectives and expectations of family-centred care: Hidden expectations and unclear roles. *Health Expectations*, *18*, 769-808. https://doi.org/10.1111/hex.12104

Darrah, J., Wiart, L., Magill-Evans, J., Ray, L., & Andersen, J. (2010). Are family-centered principles, functional goal setting and transition planning evident in therapy services for children with cerebral palsy? *Child: Care, Health and Development*, *38*(1), 41-47. https://doi.org/10.1111/j.1365-2214.2010.01160.x

Dutch Ministry of Health, Welfare and Sport. (2024). *Wet inzake geneeskundige behandelovereenkomst (WGBO) [Law on medical treatment agreement]*. Burgerlijk Wetboek 7, afd.5, art. 446-468. Overheid. Retrieved October 18, 2024, from https://wetten.overheid.nl/BWBR0005290/2024-0101/#Boek7_Titeldeel7_Afdeling5

Dutch Ministry of Health, Welfare and Sport (2023). *Rijksbegroting 2024 – XVI Volksgezondheid, welzijn en sport. Tweede Kamer, vergaderjaar 2022-2023*. Retrieved August 25, 2024, from https://www.rijksoverheid.nl/documenten/begrotingen/2023/09/19/xvi-volksgezondheid-welzijn-en-sport-rijksbegroting-2024

FMS [Federation medical specialists]. (2017). *Medical specialist 2025. Ambition, trust, cooperation*. Retrieved August 25, 2024, from https://demedischspecialist.nl/sites/default/files/FMS_visiedoc_MS2025%28eng%29_2017_PL_v02%28lr%29.pdf

Gulmans, J., Vollenbroek-Hutten, M., Van Gemert-Pijnen, L., & Van Harten, W. (2012). A web-based communication system for integrated care in cerebral palsy: Experienced contribution to parent-professional communication. *International Journal of Integrated Care*, *12*, e9. https://doi.org/10.5334/ijic.672

Hagger, M. S., & Chaztisarantis, N. L. D. (2009). Integrating the theory of planned behaviour and self-determination theory in health behaviour: A meta-analysis. *British Journal of Health Psychology*, *14*, 275-302. https://doi.org/10.1348/135910708X373959

Harniess, P. A., Gibbs, D., Bezemer, J., & Purna Basu, A. (2022). Parental engagement in early intervention for infants with cerebral palsy - A realist synthesis. *Child: Care, Health and Development*, *48*(3), 359-377. https://doi.org/10.1111/cch.12916

Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health*, *18*(3), 271-283. https://doi.org/10.1080/09581590802294296

Jeglinsky, I., Autti-Rämö, I., & Brogren Carlberg, E. (2011). Two sides of the mirror: Parents' and service providers' view on the family-centeredness of care for children with cerebral palsy. *Child: Care, Health and Development*, *38*(1), 79-86. https://doi.org/10.1111/j.1365-2214.2011.01305.x

Kincheloe, J. L., & McLaren, P. (2005) Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (3rd ed., pp. 303-342). Sage.

Lawn, S., McMillan, J., & Pulvirenti, M. (2011). Chronic condition self-management: Expectations of responsibility. *Patient Education Counsil*, *84*(2), e5-e8. https://doi.org/10.1016/j.pec.2010.07.008

Marziniak, M., Brichetto, G., Feys, P., Meyding-Lamadé, U., Vernon, K., & Meuth, S. G. (2018). The use of digital and remote communication technologies as a tool for multiple sclerosis management: Narrative review. *Journal of Medical Internet Research - Rehabilitation and Assistive Technologies*, *5*(1), e5. https://doi.org/10.2196/rehab.7805

Meekosha H., & Shuttleworth, R. P. (2009). What's so critical about critical disability studies? *Australian Journal of Human Rights*, *15*(1), 47-75. https://doi.org/10.1080/1323238X.2009.11910861

Mohr, D. C., Riper, H., & Schueller, S. M. (2018). A solution-focused research approach to achieve an implementable revolution in digital mental health. *JAMA Psychiatry*, *75*(2), 113-114. https://doi.org/10.1001/jamapsychiatry.2017.3838

Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. L., ... De Vet, H. C. (2010). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: An international Delphi study. *Quality of Life Research*, *19*(4), 539-549. https://doi.org/10.1007/s11136-010-9606-8

Nolte, E., McKee, M., & Knai, C. (2008). *Managing chronic conditions: An introduction to the experiences in eight countries*. In E. Nolte, C. Knai, & M. McKee (Eds.), Managing chronic conditions: Experiences in eight countries (pp. 1-15). European Observatory on Health Systems and Policies, WHO. Retrieved February 23, 2018, from http://apps.who.int/iris/bitstream/10665/107920/1/E92058.pdf?ua=1

Olij, C., Vos, M., Van Oostrum, N., Van Etten-Jamaludin, F., & Maaskant, J. (2021). Effective interventions to support self-management for parents of children with a chronic condition: A systematic review. *Maternal and Child Health Journal*, *25*(12), 1842-1865. https://doi.org/10.1007/s10995-021-03244-x

Palisano, R. J., Almarsi, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2009). Family needs of parents of children and youth with cerebral palsy. *Child: Care Health and Development*, *36*(1), 85-92. https://doi.org/10.1111/j.1365-2214.2009.01030.x

Pangalila, R., Becher, J., & Maathuis, K. (2015). Kinderrevalidatie in Nederland [Paediatric rehabilitation in the Netherlands]. In M. Hadders-Algra, K. Maathuis, & R. Pangalila (Eds.), *Kinderrevalidatie* (5th rev. ed., pp. 5-27). Koninklijke Van Gorcum BV.

Pennarola B. W., Rodday, A. M., Mayer D. K. (2012). Factors associated with parental activation in pediatric hematopoietic stem cell transplant. *Medical Care Research and Review*, *69*(2), 194-214. https://doi.org/10.1177/1077558711431460

Rosenbaum, P., & Gorter, J. W. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child: Care, Health & Development*, *38*(4), 457-463. https://doi.org/10.1111/j.1365-2214.2011.01338.x

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*(1), 68-78. https://doi.org/10.1037/0003-066X.55.1.68

Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *The European Health Psychologist*, *10*, 2-5.

Siebes, R. C., Ketelaar M., Gorter J. W., Alsem, M., & Jongmans, M. J. (2012). Needs of families with children who have a physical disability: A literature review. *Critical Reviews in Physical and Rehabilitation Medicine*, *24*(1-2), 85-108. https://doi.org/10.1615/CritRevPhysRehabilMed.2013006542

Siebes, R. C., Wijnroks, L., Ketelaar, M., Van Schie, P. E. M., Gorter, J. W., & Vermeer, A. (2006). Parent participation in paediatric rehabilitation treatment centres in the Netherlands: A parents' viewpoint. *Child: Care, Health and Development*, *33*(2), 196-205. https://doi-org.vu-nl.idm.oclc.org/10.1111/j.1365-2214.2006.00636.x

Terwiel, M., Alsem, M. W., Siebes, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred service: differences in what parents of children with cerebral palsy rate important. *Child: Care, Health and Development*, *43*(5), 663-669. https://doi.org/10.1111/cch.12460

Trappenburg, J., Jaarsma, T., Van Os-Medendorp, H., Kort, H., De Wit, N., Hoes, A., & Schuurmans, M. (2013). Self-management: One size does not fit all. *Patient Education and Counseling*, *92*(1), 134-137. https://doi.org/10.1016/j.pec.2013.02.009

van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *Journal of the American Medical Association*, *303*(7), 623-630. https://doi.org/10.1001/jama.2010.104

van Hal, L., Tierolf, B., Van Rooijen, M., & Van der Hoff, M. (2019). *Een actueel perspectief op kinderen en jongeren met een chronische aandoening in Nederland: Omvang, samenstelling en participatie*. [A current perspective on children and youth with a chronic condition in the Netherlands: Scope, composition and participation]. Utrecht: Verweij-Jonker Institute. Retrieved August 25, 2024, from https://www.verwey-jonker.nl/wp-content/uploads/2020/07/217026_actueel_perspectief_op_kinderen_en_WEB-1.pdf van Staa, A., Hilberink, S. R., & Sattoe, J. N. T. (2021). Self-management of young people with Chronic conditions. An overview and introduction. In J. N. T. Sattoe, A. van Staa, & S. R. Hilberink (Eds.), *Self-management of young people with chronic conditions* (pp. 1-14). Springer Nature Switzerland AG. https://doi.org/10.1007/978-3-030-64293-8

Wiart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability and Rehabilitation*, *32*(3), 248-258. https://doi.org/10.3109/09638280903095890

World Health Organisation [WHO]. (2017). *International classification of functioning, disability and health, children and youth version [ICF-CY]*. Retrieved August 25, 2024, from https://www.whofic.nl/en/node/901

World Health Organisation [WHO]. (2022). *WHO guideline on self-care interventions for health and well-being*. Retrieved August 25, 2024, from https://app.magicapp.org/#/guideline/Lr21gL

World Health Organisation [WHO]. (2023). *Rehabilitation*. Retrieved August 25, 2024, from https://www.who.int/news-room/fact-sheets/detail/rehabilitation

2

Managing oneself or managing together? Parents' perspectives on chronic condition self-management in Dutch paediatric rehabilitation

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ABSTRACT

Purpose: With the growing attention in paediatric rehabilitation services for supporting self-management, the need increases for more shared understanding of the concept. The aim of this study was to explore parent activation, associated factors of, and underlying perceptions on parental self-management of parents of children with chronic conditions.

Materials and methods: Using a mixed-methods strategy, first variations in self-management behaviours, motivation and perceived autonomy support were assessed with a cross-sectional survey among parents of children with chronic conditions ($N = 239$). Statistical analysis involved descriptive statistics and univariate analysis of variance. The survey was followed by 18 in-depth interviews with parents. Thematic analysis was used to recognise relevant topics in the qualitative data.

Results: In the survey most parents reported being active self-managers. Nevertheless, only one third persisted in self-management when under stress. Autonomous motivation was strongly associated with parental self-management. In the interviews, parents mentioned attuning with professionals and finding balance as important aspects of self-management. To facilitate self-management, professionals were expected to have expert knowledge, be engaged and empathic.

Conclusion: From the perspective of parents, self-management should be viewed as a collaborative effort in which they are supported by professionals, rather than having to manage it 'by themselves'.

Keywords: parental self-management; motivation; parents' expectations; parent-professional interaction; communication; partnership

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Implications for rehabilitation:

- To facilitate self-management, parents expect professionals to have expert knowledge and additionally show interpersonal competences as openness, engagement and empathy.
- Motivating parents may facilitate their level of self-management regarding the care for their child with a chronic disorder.
- Good communication and collaboration with professionals appear to be key aspects of parental self-management.
- Parents expect paediatric rehabilitation teams to tune their services to the needs, desires and expectations of parents to support them in 'self-managing' the care for their child.

INTRODUCTION

Self-management has emerged as an important theme in the ongoing development of paediatric rehabilitation. These services provide interdisciplinary treatment to children and adolescents experiencing problems in their activities and participation due to an illness or health condition with consequential impairments, mostly also in motor functions (Pangalila et al., 2015). Chronic conditions self-management appears in governmental policy plans as a strategic target to foster autonomy of persons with chronic conditions, both for organising as well as defraying various forms of support and care (Nolte et al., 2008; Zwar et al., 2006). Policies aiming to promote autonomy and individualise treatment stem largely from humanitarian and/or emancipatory ideals. Equality, individual freedom, and self-determination are acknowledged as fundamental human rights (United Nations, 1976) that may be compromised for citizens facing chronic conditions due to the way care is delivered. Additionally, chronic conditions have grown in numbers worldwide due to changes in lifestyle and increased survival despite health risks. Chronic health issues nowadays affect approximately 25% of the group of children and youth, represented in for instance asthma, obesity, attention-(hyper)activity disorder, and concomitants of prematurity or congenital syndromes due to improved treatment and pre-/neonatal care like cerebral palsy and Down syndrome (van Cleave et al., 2010). As such, chronic conditions have become one of the major threats to public health and a growing economic burden on society. Curbing these threats is considered a collective responsibility, where primary care systems need to adopt and support self-management of these health issues (Nolte et al., 2008; WHO, 2002).

In healthcare for paediatric populations, parents play a central and crucial role. Studies on family-centred care, in which children and their parents are a central intervention focus, suggest that services need to be tuned to both parents' and children's needs and expectations (Jeglinsky et al., 2012; McDowell et al., 2015; Palisano et al., 2009). Essential for effective support is therefore to understand their conception of self-management (Pennarola et al., 2012).

Conceptions of self-management

Health policies already feature a diversity of conceptions of self-management (Lawn et al., 2011). People with chronic conditions need continuous access to healthcare providers and deal with a broad range of professionals over prolonged periods of time. Self-management places persons with a chronic condition and their families at the centre of their own health care, optimising their ability for participation in their health process. Effective self-management empowers people through knowledge acquisition about their conditions. It actively engages them in shared goal setting with professionals, in discussion of treatment preferences and planning of daily care, in alignment with their abilities, social needs, values, and other priorities in life (Australian Health Ministers' Advisory Council, 2017). The General Self-Management Model developed in the Netherlands by the Dutch Institute for Health Care Improvement (CBO, 2011) emphasises communication, partnership, trust, and respect between professionals and people with illnesses or disorders.

Parental self-management, applied to parents of children with chronic conditions, would be reflected in the competences of parents in terms of their knowledge, skills and confidence to actively participate in the healthcare processes concerning their child's development, health and well-being. Rehabilitation professionals should empower parents and their children for such engagement, taking differences in individual needs, desires and possibilities into account (Pulvirenti et al., 2014).

Motivation and self-management

In the light of the shifting views and expectations regarding disability and healthcare (Huber, 2011), researchers such as Shogren and Turnbull (2006) have focused on processes in which self-determination of children with disabilities and their families are emphasised. Self-Determination Theory (SDT) as described by Ryan and Deci (2000) in general offers an explanation how external factors, such as an illness or chronic condition, are likely to diminish well-being. According to SDT, when people perceive that adapting to such condition contributes to the satisfaction of their basic psychological needs for autonomy, relatedness, and competence, this can lead to a long-term increase of their well-being (Deci & Ryan, 2008; Ryan et al., 2008). Research on self-determination-oriented healthcare interventions fostering positive health behaviours, such as physical activity or smoking cessation, showed more success if people were *autonomous motivated* and if professionals were perceived as *autonomy supportive* (Farholm et al., 2016; Münster Halvari et al., 2010; Ryan et al., 2009; Williams & Deci, 2001). Although the research evidence is still limited, theoretical and empirical arguments suggest that also for parents, perceived autonomy supportive paediatric rehabilitation and concomitant autonomous motivation are associated with stronger self-management. Besides SDT, also another theoretical framework, the *Theory of Planned Behaviour* [TPB], argues that the adherence to a certain behaviour is influenced by one's motivation (Ajzen, 1991; Ajzen, 2002; Javadi et al., 2013). Studies on TPB-based self-management practices emphasise the impact of attitudes to self-management behaviour (Hagger et al., 2016) and of social context, including family, friends and community (Lee et al., 2017) on a person's motivation for self-management.

There is growing attention for chronic condition self-management within the field of paediatric rehabilitation. However, the concept of parental self-management remains relatively underexplored, especially the views of parents, and how they perceive their participation and relations in the rehabilitation processes regarding their child (Almasri & Palisano, 2018; Lindsay et al., 2013). Positive associations between parent involvement and self-management were reported in recent studies on parental support and self-management in adolescents with diabetes (Dashiff et al., 2013). Barlow et al. (2008) underlined the positive effects of a focus on self-management for parents of children with a chronic condition in coping with consequences of those conditions on their lives, such as stress, social isolation, insufficient time or lack of comprehension and compassion by others.

Parents of children with chronic conditions express a wide range of desires, needs and expectations (Alsem et al., 2014; Siebes et al., 2012; Terwiel et al., 2017), so the meaning, experiences and values linked to self-management can vary as well. Conceptions of self-management may affect therapy goals and approaches (Wiart et al., 2009). What is an optimal approach for one individual, may well be insufficient or overdone for the other (Trappenburg et al., 2013). Thorough consideration of parents' role and how exactly they facilitate their child's autonomy, is therefore suggested (Lindsay et al., 2013). Increased insight in parental perspective can help to tune-in to their individual needs and preferences, improving engagement between families with complex needs and healthcare services (Pennarola et al., 2012). This study adds to the existing literature by focusing on the meaning and value of self-management to parents, their motivations and their expectations of healthcare professionals.

The purpose of the current study was to quantitatively and qualitatively describe the various perceptions on parental self-management of parents of children with chronic conditions using paediatric rehabilitation services. Associations were explored between different self-management experiences, perceived autonomy support and motivation, and demographic factors as age, gender, education, family structure and family income suggested in literature (Hernandez et al., 2014; Neylon et al., 2013; Protheroe et al., 2017; Wilski et al., 2015).

The following research questions were addressed:

1. (1) To what extent do parents of children with chronic conditions report active forms of self-management?
2. (2) Are perceived autonomy support, autonomous motivation for self-management and self-reported activity regarding self-management interrelated?
3. (3) Are demographic factors (parental age, gender, education, family income, relationship status and illness severity associated with parents' self-reported activity regarding self-management?
4. (4) What are the views, expectations, perceived barriers and facilitators of parents concerning self-management?

MATERIALS AND METHODS

Design

In this study a mixed-methods design was used. According to a sequential explanatory strategy (Creswell, 2009) parents' activation regarding self-management and possible associated factors were quantitatively explored in Phase A with a cross-sectional survey. In Phase B semi-structured interviews were conducted with parents scoring over the full range of the spectrum, using qualitative analysis to obtain deeper understanding of the underlying views, expectations, perceived barriers and facilitators that might relate to their activation regarding self-management. Data integration has been performed as described by Fetters and colleagues (Fetters et al., 2013). On the methods level, quantitative data were linked to the qualitative data in the sampling frame through *connectin*g in which interview participants were selected based on their scores in the survey. On the report level, a *contiguous approach* was followed describing the quantitative and qualitative results in two separate sections. The qualitative results were reported as a *narrative*. In the Discussion section, the findings from quantitative and qualitative analyses were synthesised.

The context of the investigation regarded two Dutch centres for rehabilitation where parents and their children with a chronic condition received rehabilitation services over longer periods of time, provided by professionals from nine paediatric rehabilitation teams.

Sample and procedures

Phase A

In total 608 parents of children receiving treatment from participating paediatric rehabilitation institutes, were invited by post to participate in an online survey on parental self-management. Parents were also offered the possibility to fill out the questionnaire paper-based, or by face-to-face interview. Included were parents with a child aged 0–12, with a chronic condition according to the description of Mokkink et al. (2008). Excluded were parents with children not receiving any actual interdisciplinary treatment at the time of the investigation. A cut off at age 12 was chosen because until this age, according to Dutch legislation regarding 'Medical Treatment Agreement' (Dutch Ministry of Health, Welfare and Sport, 2017), parents have full right of decision about the intervention.

Phase B

All parents participating in the survey were asked for permission to approach them again during the second phase of the study for a 45–60-minute semi-structured interview on their perceptions of self-management. Ultimate selection of the interviewees was based on maximum variation purposeful sampling (Palinkas et al., 2015). Depending on their scores on the Parent-PAM, parents over the full available spectrum of levels of activity regarding self-management were included. To broaden the diversity of opinions, individual information of participants on motivation, perceived autonomy support, and demographic variables like gender, age, income, education and relationship status, retrieved from the survey were also considered during the inclusion process. Invitation for the interviews was performed stepwise by telephone in an iterative process of data collection and data analysis, until saturation was achieved from qualitative coding of the content. Most parents were interviewed at home. Some chose to be interviewed at the rehabilitation centre where their child received treatment. Each interview initially focused on several basic questions but could explore different aspects of self-management depending on the responses of the interviewee. All dialogues were audio recorded and transcribed verbatim immediately afterwards.

Ethical considerations

Reflexivity This study has been conducted from a *critical emancipatory paradigm* for health care research (Tijmstra & Boeije, 2009). The investigators aimed to contribute to the empowerment of parents for self-management in accordance with their preferences and abilities, and to strengthen their position as partners of the rehabilitation professionals involved with their child. They belief that for partnership comprehension of parents' perspectives by professionals is essential. This contributed to their choice for a mixed methods approach and to actually give parents voice through the narrative presentation of the qualitative data extracts.

According to the researchers' view people can be their own agent of change. For this reason, the study has been conceptualised within the theoretical framework of SDT. As SDT emphasises on support of basic needs to become motivated for self-management, the interviews also focused on experiences and expectations of parents regarding the support of professionals. The main researcher is a paediatric rehabilitation professional who in his clinical work experiences how both professionals and parents can struggle with their roles regarding self-management (support). To promote trustworthiness, a second researcher without a clinical role was involved in the iterative process of data collection and extraction. Integration and presentation of the quantitative and qualitative findings were characterised by ongoing reflective discussion within the research group.

All parents were asked for informed consent, for the survey as well as for the interviews. Confidentiality of all information retrieved from the study and anonymity in relation to any future reports were guaranteed. The study was accepted by the Scientific Quality Committee of Amsterdam Public Health research institute and the Scientific and Ethical Review Committee of Vrije Universiteit Amsterdam, and by the boards of the involved rehabilitation centers.

Instruments

Phase A

Parent activation regarding self-management

The self-reported activation of parents regarding self-management, expressed in their knowledge skills and confidence, was measured with use of the Parent-Patient Activation Measure [Parent-PAM] (©Insignia Health 2013). The Parent-PAM is an adapted version of the Patient Activation Measure [PAM-13] developed by Hibbard et al. (Hibbard et al., 2005), which is a 13-item, Gutman like, 0–100 incremental scale, measuring self-management of one's health or chronic condition. A Dutch validation study of the PAM-13 supported convergent validity of the PAM-13NL with the SBSQ-D, an instrument for measuring health literacy (Rademakers et al., 2012).

The Parent-PAM was previously used in a study on parental activation in hematopoietic stem cell transplant demonstrating sufficient internal consistency reliability (α = .85), in line with the Dutch PAM-13 (α = .88). That investigation also reported sufficient agreement between PAM-13 and Parent-PAM regarding the distributions of the four levels: belief in an active role; confidence and knowledge to take action; taking action; and staying the course under stress (Pennarola et al., 2012).

Motivation

The Treatment Self-Regulation Questionnaire [TSRQ] assessed types of motivation for parents to engage in self-management. This instrument was developed by Williams et al. (1996) and used in a population of adults with obesity to measure their motivation to follow a weight-loss and maintenance program at a community hospital in the USA. Their study identified two subscales: controlled, externally regulated reasons and intrinsic, autonomous reasons. The TSRQ has been modified for use in various studies about the motivation for health behaviours. A more recent validation study across three health behaviours, namely smoking, diet and physical exercise, among 2731 adult participants at four universities in de United States, showed acceptable internal consistency reliabilities (α = .73 to .93) (Levesque et al., 2007). The TSRQ has different versions varying from 9 up to 19 questions. Some versions also include a subscale amotivation. In this study, a 12-item version of the TSRQ was used with subscales controlled motivation and autonomous motivation.

Perceived autonomy support

Perceived support for self-management from paediatric rehabilitation professionals like the physician, physiotherapist, occupational therapist, speech and language therapist, social worker or psychologist working with their child, was measured with the Healthcare Climate Questionnaire [HCCQ]. The instrument has 15 items and uses a 7-point Likert scale. The HCCQ was developed and tested in the same study as the TRSQ, and high internal consistency was found (α = .96) (Williams et al., 1996). Research testing Self-Determination Theory in oral-selfcare, also reported good internal consistency and validity of the HCCQ (Münster Halvari et al., 2010).

Not all questionnaires used in the survey were available in Dutch language and none of the questionnaires were used before in the same population as this investigation. Therefore, translation of the instruments and slight rephrasing of some items took place to improve suitability. The translation and/or adaptation process followed international guidelines delineated by Beaton et al. (2000) and the World Health Organisation (WHO) (n.d.). The steps included translation of the instrument from English to Dutch, synthesis within the project group, back translation to English by a native speaker with expert knowledge of the Dutch Language, testing in an expert panel together with cognitive interviewing, and final adaptations to the questionnaires.

For each of the instruments used in this study, internal consistencies of scale and subscales were computed, expressed in Cronbach's α. Reliability of the translated and adapted HCCQ, TSRQ and Parent-PAM in this study was adequate (Table 2.1).

Table 2.1 Internal consistency reliabilities of the adapted instruments

Instrument		Cronbach's α
Parent-Patient Activation Measure [Parent-PAM]	13 items	.80
Health Care Climate Questionnaire [HCCQ]	15 items	.95
Treatment Self-Regulation Questionnaire [TSRQ]		
Autonomous Motivation	6 items	.87
Controlled Motivation	6 items	.73

To investigate the factor structure, a confirmatory factor Analysis (CFA) was conducted using Mplus. The model fit was evaluated by four fit indices. Chi-square, RSMEA, CFI and TLI (Schreiber et al., 2006). Values suggested a reasonable fit for HCCQ (one domain) and TSRQ (two factors). Additional Rasch analysis of the Parent-PAM confirmed a one factor structure, justifying its use in the Dutch setting. Given the adequate internal consistency reliability scores, the original scale structures of the instruments were retained.

Phase B

To explore the perceptions of parents regarding self-management, a semi-structured interview was developed with seven main questions (Table 2.2). The questions were formulated by the researcher and discussed with members of the research group. Subsequently these were adapted, piloted with three parents, and using parents' feedback finalised for use in the interviews.

Table 2.2 Basic interview questions

What does self-management mean to you?
How important is self-management in your own situation?
To what degree do you conduct self-management yourself?
What do you expect of professionals regarding self-management support?
How do you experience the support by professionals?
Which facilitating factors do you experience regarding self-management?
Which barriers do you experience regarding self-management?

Data analysis

Phase A

Descriptive group statistics were computed in SPSS 24. Distributions, skewness and kurtosis, missing values and outliers were investigated. Pearson correlations were computed between the three relevant constructs autonomy support, motivation and self-management. (significant at $p < 0.05$). Associations between demographic factors and self-management were tested by General Linear Model Univariate Analysis of Variance.

Phase B

Qualitative analysis of the semi-structured interviews was performed following a cyclic scheme, involving repeated coding and recoding of earlier and next interviews. Data were analysed by means of coding, categorisation and theme identification, with use of NVIVO 11 (© QSR International Pty Ltd). This method resembled the open coding and axial coding process often described in grounded theory (Boeije, 2012). To enhance the credibility of the qualitative analysis, each transcript was summarised and sent to corresponding participants for member checking. All analysed transcripts were reviewed by a second researcher who commented on the findings and proposed new topics and codes, or a rephrasing of existing codes. Based on the discussions between both researchers, adjustments and/or additions were made. A third investigator was asked for peer feedback on a regular basis, for suggestions and to evaluate whether data were appropriately interpreted, and procedures were respected.

RESULTS

Phase A

In total 239 of 608 parents took part in the survey (response rate 39%). The two most frequent reasons for non-participation were, I am too busy, and I already participate in other research. Characteristics of the samples of the survey and the interviews can be found in Table 2.3.

Table 2.3 Characteristics of the samples

	Survey *N* = 239 *n* (%) / *M* (*SD*)	Interviews *N* = 18 *n* / % / *M* (*SD*)
Parent characteristics		
Age (min–max)	21–62 / 39.4 (6.4)	26–55 / 37.7 (6.7)
Gender (female)	206 (86.2%)	17 (94.4%)
Nationality (Dutch)	227 (95%)	17 (94.4%)
Education		
Low (primary school / lower vocational education)	28 (11.7%)	4 (22.2%)
Middle (middle vocational education)	90 (37.7%)	6 (33.3%)
High (higher vocational education / university)	117 (49.0%)	8 (44.4%)
Relationship status (living with a partner)	202 (84.5%)	16 (88.9%)
Family characteristics		
Family income		
< 1x average*	16 (6.7%)	1 (5.6%)
1-2x average	72 (30.1%)	3 (16.7%)
> 2x average	142 (59.4%)	13 (72.2%)
* Gross average income € 37.000 /y		
Child characteristics		
Age (min–max))	0–12 / 6.4 (3.2)	1–10 / 5.24 (3.1)
Gender (boy)	138 (58.7%)	13 (72.2%)
Characteristics of the condition (*during the last year*)		
Visit to doctor	176 (73.6%)	13 (72.2%)
Admitted in hospital	77 (32.2%)	4 (22.2%)
Surgery	49 (20.5%)	2 (11.1%)
Irregular course of illness	42 (17.6%)	2 (11.1%)
Medication	115 (48.1%)	7 (38%)
Use of helping aids	144 (60.3%)	13 (72.2%)
Diet	44 (18%)	4 (22.2%)
Hearing limitations	22 (9.2%)	2 (11.1%)
Visual limitations	56 (23.4%)	8 (44.4%)
Visible malformations	123 (51.5%)	11 (61.1%)
Communication problems	96 (40.2%)	14 (77.8%)
Behavioural problems	65 (27.2%)	7 (38.9%)
Learning problems	84 (35.1%)	6 (33.3%)
Epilepsy	38 (15.9%)	2 (11.1%)

Parent activation, motivation and perceived autonomy support for self-management

Regarding the first research question how parents report concerning their active self-management, 12.6% of the parents believed an active role is important (Parent-PAM level 1) and 9.6% thought they also had confidence and knowledge to become active (Parent-PAM level 2). According to the Parent-PAM both level one and two were not really active self-managers though; 39.7% of the parents actually took action (level 3), but only 30.5% of all parents took action and could also maintain this under stress (level 4), Figure 2.1.

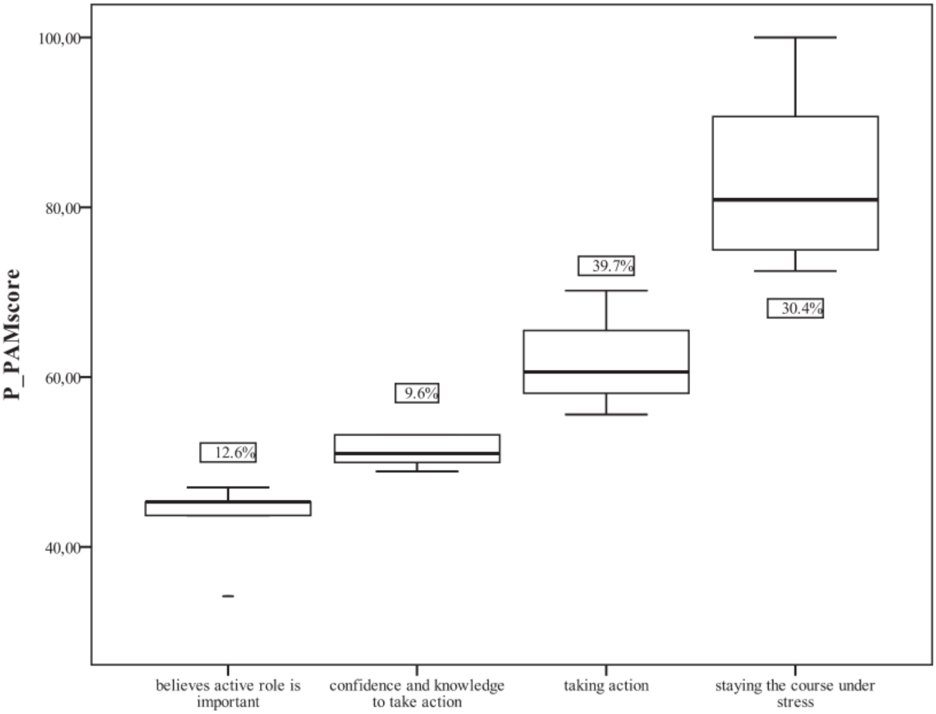

Figure 2.1 Boxplot, level of parent engagement regarding self-management.

The scores of parents on the Parent-PAM had a mean of approximately 65 on a 0–100 scale, indicating that on average parents perceived themselves as active, but had difficulties to continue this during stressful periods. For descriptive statistics of the Parent-PAM, the TSRQ and the HCCQ (Table 2.4).

Table 2.4 Descriptive statistics of the Parent-PAM, TSRQ, and HCCQ

	Mean	St. deviation	Skewness	Min–Max
Parent-Patient Activation Measure [Parent-PAM]	65.12	14.73	.47	34.20–100
Treatment Self-Regulation Questionnaire [TSRQ]				
Autonomous (intrinsic) motivation	5.88	.95	-.98	1.83–7
Controlled (extrinsic) Motivation	2.8	1.08	.38	1–6
Healthcare Climate Questionnaire [HCCQ]	5.84	.83	-.97	2.47–7

The mean scores of parents on their motivation for self-management and of their perceived autonomy support, were measured on a 1–7 Likert scale. Based on the means of the TSRQ, parents reported to be highly autonomous (intrinsic) motivated and less influenced by extrinsic factors. Also, the relatively high HCCQ mean score suggested that parents perceived professionals as fairly autonomy supportive.

Associated factors of parental self-management

With respect to the second and third research question, perceived autonomy support was weakly positively associated with autonomous motivation ($r = .14, p = .037$) Autonomous motivation was strongly associated with self-reported parental activation ($r = .51, p = .000$). Neither perceived autonomy support nor controlled motivation was associated with parental activation ($p = .052$ and $p = .715$, respectively). However, perceived autonomy support appeared to be weakly negatively associated with illness severity of the child ($r = -.15, p = .022$).

Univariate variance analyses showed that demographic factors (parental gender, education level, income, relationship status) and illness severity jointly explained 6% of the variance in parental activation ($F(8,197) = 1.59; p = .129$) and no individual factor was significantly related to self-reported parental activation, except for parental age which was associated with higher levels of activation ($ß = .01; F(1, 206) = 6.17, p = .014$).

Phase B

The fourth research question addressed the underlying perceptions of parents regarding self-management. In total 18 parents were interviewed. The age of the parents varied between 26 and 55 years with an average age of 37.7. During the qualitative analytic process, the interviews could be structured around four general topics. Several themes were identified (Table 2.5).

Table 2.5 General topics and identified themes

General topics	Themes
Attitudes towards self-management *How parents feel and think about self-management*	Views on self-management Making own decisions Being engaged Governmental policy Partnership / collaboration Value of self-management Competence Adequate knowledge Learning process Self-efficacy
Expectations regarding self-management support *What parents expect of professionals*	Relationship with professionals Feeling acknowledged Trust in professional Personal traits of professional Expertise of professionals State-of-the-art knowledge Interpersonal skills Attitude of professionals Openness Empathy Engagement Clarity and guidance Attitude towards child
Factors influencing self-management *What parents experience as barriers or facilitators*	Obstructing factors Planning problems Bureaucracy Lack of coordination Supporting factors Communication Continuity Flexibility Parent-to-parent contact
Degree of self-management *The extent to which parents are active self-managers*	Acceptance Taking initiative Finding balance Between support and self-management With partner and/or family

The variety of parent opinions is reflected in the narrative overview of themes and topics, with accompanying quotes. After each quote some demographic information on the respondent is added, Sex (M/F); Age parent (years); Living with or without partner (Partner/No-Partner - P/NP); Age child (years).

The perspectives of parents underlying their motivations for self-management were expressed in their attitudes towards self-management, the expectations they had of professionals, and the external factors that influenced their self-management processes.

Attitudes towards self-management

The attitudes of parents could be categorised in terms of their views, values, and competences regarding self-management. Parents gave a broad variety of 'views' on the general concept of self-management in relation to the care for their child. Some parents articulated that self-management involves 'making one's own decisions': *That you are the one deciding in what way your child will develop. That you decide what happens with your child, which therapies it gets (F;27;NP;3).* For other parents, self-management meant having more possibilities to 'become engaged' in the treatment process of their child: *That the professional would take me seriously as 'manager' of the care for my child (F;39; P;10).* Although all parents agreed that a focus on promoting self-management and autonomy of citizens in 'governmental policy' in principle is a good development, there also were major concerns: *It is good to look what people can do themselves, but then they for instance say about my child, can't a neighbour just help out? But that is not possible, not with his background. To work with him you really need specific training (F;44;NP;6).* While some parents saw self-management as a process in which they are in the lead, for others the professional should be the one to give direction. Nevertheless, all parents emphasised that for self-management, though not experienced by everybody as a free choice, 'partnership' and 'collaboration' with professionals are essential, as one parent concluded: *That name self-management. It is a bit misleading: 'Self', it actually should be called: together-management (F;30;P;2).*

Parents specifically endorsed the 'value' of self-management, with as main reason that they are the ones ultimately responsible for the care for their child and therefore need to be in the lead: *Do you have another choice? I would almost say. For me it goes without saying. If doctors take over and I as a parent lose authority, it will not work. This is about ownership (M;31;P;1).*

With regard to their 'competence' for self-management, most of the interviewed parents stated that it is important to obtain 'adequate knowledge' about the condition of their child. Parents described parental self-management as a continuous 'learning process'. They often felt insecure especially during the first years, but by learning becoming more confident and skilled over the course of time, developing 'self-efficacy': *To be thrown into the deep, some will manage, but others probably will not at all. I myself had to* *learn this through the years. I totally wasn't a person who would persevere in something. I really had to learn that (F;33;P;8).*

Expectations regarding self-management support

The assumptions of parents concerning the support for self-management by professionals could be divided into three groups. In the 'relationship with professionals' it was essential for parents to 'feel acknowledged' and be able to 'trust' the professional. If those lacked, working together would be difficult. Parents furthermore pointed out that their relationship with the professional was influenced by his or her "personal traits" such as age, experience, and character: *It is more about the person himself. My current physiotherapist and I, we really get along well together. So, you make contact much more easily (F;39;P;10).*

Concerning the 'expertise of professionals', parents first and foremost expected professionals to have 'state-of-the-art knowledge' about the problems of their child. Nevertheless, parents also expected more general 'interpersonal skills' of professionals. The ability to tune-in was considered essential. With other professionals, but also tuning-in to the differences between parents: *She does that very well with those differences between me and my partner. She manoeuvres exactly in between, taking both of us seriously (F;51;P;8).* Most expectations of parents were actually related to the 'attitude of professionals.' 'Openness', 'empathy', and 'engagement' were important themes to parents. Engagement went beyond a more academic involvement, as formulated by one of the parents: *Well, besides my child getting what she needs, the only thing I really expect of professionals, is 'love'. If you work with children with disabilities you really need to have your heart in what you do (F;27;NP;3*). 'Clarity and guidance' were also considered critical aspects of professional attitude, positive, or negative when lacking: *They are all trying to help, but in the end, you are the one who must decide... It is such a difficult process in which I would have liked a bit more guidance (F;48;P;10).* Some parents specifically mentioned the professional's 'attitude towards their child', for instance whether there was a click or not: *With his current therapist, he doesn't have that connection, which means he does other things, misbehaves (F;32;P;5).*

In summary, though parents had a wide diversity of expectations of self-management support, they most of all expected support that fitted their own individual situation the best, as one parent stated: *I really believe their commitment is sincere, but it is the difference between a professional who knows how to push the right buttons and the one who does not (F;42;P;5).*

Factors influencing self-management

Parents experienced several external factors that supported or impeded their self-management processes. In the category 'obstructing factors', 'planning problems' often appeared a recurrent nuisance for many parents: *…only the planning, really! They for instance plan a therapy session on Friday half past two in the afternoon. Then my child behaves badly every week and messes things up, which could be expected since it is end of the week (F;32;P;5).* Also, the accessibility of the planning office was indicated by many parents as frustrating: *They are only reachable in the mornings. I work at those hours and when I have a moment, I get the answering machine: you must call between eight and twelve, and I think: But I'm calling between eight and twelve (F;30;P;6)?!*

Another impediment was 'bureaucracy', especially in relation to procedures concerning helping aids: *So, we needed a new wheelchair. I notice this and bring it up to the rehabilitation team. They conclude the same. But then local government also must come, and another independent professional must have a look. Meanwhile several months have passed and I still have no wheelchair for my child (F;38;P;6).* Last, 'lack of coordination' was regularly mentioned as an obstructing factor, for instance related to appointments for team-meetings with professionals. Coordination could also be related to the therapy frequencies of children: *It is quite a lot that my child receives, physiotherapy, occupational therapy, speech and language therapy, which is too much for him (F;48;P;10).*

'Communication' was indicated most often as 'supporting factor' of self-management. Parents emphasised the importance of short lines of communication. Among professionals themselves, but also referring to parent-professional contact: *That you can say what is on your mind, even without having an appointment (F;35;P;10).* If physical communication was not possible, indirect contact for instance through email or a communication notebook was valued too. 'Continuity' of professionals was described by several parents as a supporting factor as well: *I appreciate that my child works with some therapists who are there over such a long period of time, that they get to know him very well (F;48;P;10).* 'Flexibility' was another theme that arose: *Then it becomes a tailor-made approach. That you look which parent is up to it and which parent is not. Parents who are not able to self-manage, please keep investing in them (F;39;P;10).*

Finally, 'parent-to-parent contact' was reported repeatedly in the interviews: *I think parent meetings could help. Parents who exchange their experiences, I really think it could help (F;42;P;5).*

Degree of self-management

When asked to elaborate on the extent to which they considered themselves active self-managers, some parents stated that to become a self-manager, 'acceptance' of the situation was necessary, which obviously was not that easy, as expressed by a mother who said: *You take up everything you think is possible. Though in the end nothing really fitted. I just wanted too much at the same time, which cost me a lot of energy (F;48;P;10).* Several parents emphasised the necessity of 'taking initiative'. Furthermore, 'finding balance' for instance between self-managing and asking for support was a dilemma for many parents: *I find it very difficult. On one hand, you want to take the lead, but on the other hand personally I would be happy if somebody would take over, or partially (F;30;P;2).* Balancing self-management with the needs of the partner or the rest of the family also was a recurring issue: *It is sometimes quite difficult because you are in a family with two other children as well. They also ask a lot of energy (F;44;P;3).* …. When a balance was found though, this created space for positive development: *In a way, we now have the feeling that everything makes sense. We are all happy and we can combine the situations well. We have gotten a totally new way of life (F;40;P;2).*

DISCUSSION

Perspectives on and experiences with self-management varied widely among parents of children with chronic conditions using paediatric rehabilitation services. Nevertheless, synthesis of the quantitative and qualitative data revealed several noteworthy relations between the level of activity regarding self-management reported by parents in the survey and the underlying views and experiences mentioned during the interviews.

The impact of stress on parental self-management

Although in the survey according to their scores on the Parent-PAM about two-thirds of the parents reported to be active self-managers in the care for their child, more than half of those parents could not sustain this in stress situations. Approximately one-fifth of all parents reported not to be active at all. Thus, while paediatric rehabilitation has embraced parental involvement as a guiding principle (Cross et al., 2015; Ketelaar et al., 2017; Rosenbaum & Gorter, 2012) to enhance outcomes for children (Kratz et al., 2009; Schwartz & Axelrad, 2015), active parental self-management cannot be presumed for all parents, all the time. During the succeeding interviews, almost all parents reported that balancing between self-management and support, within the family, with a partner, and/or with work remained a continuous challenge. Given the fact that parents of children with chronic conditions are prone to high levels of anxiety and stress (Kratz et al., 2009; Lach et al., 2009; Parkes et al., 2011), the strength of active self-management is a relevant concern for professionals supporting parents. Disbalance in the functioning of parents or family situation may be associated with both mental as physical health of children with chronic conditions (Leeman et al., 2016) and should therefore continuously be considered.

The role of motivation and perceived support

The survey showed that parents considered themselves autonomously motivated for parental self-management and not very much influenced by extrinsic factors. Additionally, autonomous motivation went along with active parental self-management. Consistent with Self-Determination Theory and in line with other findings in the health field (Koponen et al., 2017; Patrick & Williams, 2012; Shigaki et al., 2010), parents' perceived autonomy support from professionals was positively associated with their autonomous motivation. Even though no causal conclusions can be drawn, this suggests a potential pathway for professional conduct that contributes to parental autonomous motivation and in turn to parental self-management (Kratz et al., 2009; Haskard Zolnierek & Dimatteo, 2009). Furthermore, illness severity of the child was negatively associated with the autonomy support perceived by parents, which might indirectly influence their motivation for self-management. Professionals should therefore be attentive to the increasing risk of alienation in their relationship with parents, depending on the severity of the condition of the child (Lawn et al., 2011).

Adequate communication was mentioned in the interviews as one of the most important supporting factors of parental self-management, corroborated in studies on parent engagement (King et al., 2015; Alsem et al., 2017). The flip side was that if the communication process was flawed, this also immediately had a negative impact on parents' perceptions. Such statements of parents endorse the possible association between supportive professional behaviour and parents' motivations for active engagement in self-management.

Age and the learning process

The association of age with parental activation in the survey parallels remarks made by parents in the interviews when they described self-management as a learning process in which they gradually, as their child became older and their own experience grew, felt more confident and competent 'self-managers'. Parental self-management as a learning process that becomes easier with age and experience, is reaffirmed by Alsem et al. (2016) and Kratz et al. (2009) in studies about parents' perspectives and chronic illness management. This dynamical character of self-management implies that professionals should be continuously attentive to the changing context of individual parents and children from the start throughout the full course of treatment (Dashiff et al., 2013; Orell-Valente & Cabana, 2008; van Houtum et al., 2015).

Self-management support – a personalised process

There were considerable differences in the reported levels of parental self-management during the survey, as well as in the desired amount and form of involvement in the management process of their children expressed in the interviews. Still, all consulted parents underscored that self-management is a way to take responsibility for one's own child. However, parents also acknowledged that self-management may not always be feasible for every parent. Therefore, subsidiary, tailor-made self-management support for all parents delivered by professionals remains important (Fordham et al., 2012; Rosenbaum & Gorter, 2012). Such focused support may address the most important impediments to effective self-management according to the parents, which were related to therapy planning, availability of the planning office, and bureaucratic procedures. Similar organisational issues were previously delineated by Kratz et al. (2009) in a study on childhood chronic illness management.

Need for additional skills of professionals

Parent's expectations in relation to self-management support went beyond 'state of the art' knowledge of professionals about the chronic condition. Both, parents scoring high and low on active parental self-management in the survey, indicated that they also expected interpersonal skills and attitudes of professionals, like openness, empathy and engagement. Van Houtum et al. (2015) argued, based on a nationwide study on chronic disease self-management in the Netherlands, that perceived needs related to self-management tasks and support are more often general rather than specific to the occurring chronic condition at hand. Studies on parent and child engagement in mental healthcare confirm that professionals should possess discipline transcending competences to be able to tune-in to each specific child and parents, to be sensitive and responsive to their context, and to induce trust and engagement by listening, empathy, emotional attendance and use of relational skills (King et al., 2014).

LIMITATIONS

Although parents with a minority cultural background and low education were represented in both the survey as well as the interview study, their number was lower than found in the general population (CBS, 2018a; 2018b). Furthermore, the current study does not include children's and adolescents' own perspectives on self-management, which are relevant as well (Schwartz & Axelrad, 2015). The cross-sectional, single-informant, self-report design of the study makes the findings inconclusive regarding causal direction, although the relevance of presented associations is underscored by the qualitative results. The 39% response to the survey should be taken into account before the findings are generalised beyond the investigated samples.

IMPLICATIONS FOR PRACTICE AND FURTHER RESEARCH

Parents who are adapting to self-management may recognise their individual struggles and dilemmas within the diversity of perceptions and reflections reported in this study. This diversity accentuates the need for professionals to address strength of active self-management in individual parents as well as variation within parents across time. Since autonomous motivation was identified as a significant factor associated with parental activation for self-management and perceived autonomy support correlated positively with motivation, interpersonal skills in scaffolding parents' personal growth in this area of life is an important competence domain for professionals. The organisational barriers to self-management identified by the parents in this study should trigger rehabilitation institutes to make their services more parent-friendly, lower the level of stress, and thereby improve the support of self-management. In implementing these changes, attention may be necessary towards the perceptions, attitudes and types of motivation of paediatric rehabilitation professionals themselves towards self-management support.

CONCLUSION

The findings in this study confirm existing literature (Barlett et al., 2017; Battersby et al., 2010; Kratz et al., 2009; Palisano et al., 2012) explaining chronic conditions self-management as a process in which collaboration and partnership with professionals are essential. If there is one lesson that could be drawn from this study, it would be that from the perspective of parents the concept of self-management in the care for their child with a chronic condition, is considered more a matter of together-management rather than managing it 'by themselves'.

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REFERENCES

Ajzen, I. (1991). The theory of planned behaviour. *Organizational Behavior and Human Decision Processes, 50*, 179-211.

Ajzen, I. (2002). Perceived behavioural control, self-efficacy, locus of control, and the theory of planned behaviour. *Journal of Applied Social Psychology, 32*(4), 665-683. https://doi.org/10.1111/j.1559-1816.2002.tb00236.x

Almasri, N., An, M., & Palisano, R. J. (2018). Parents' perception of receiving family-centered care for their children with physical disabilities: A meta-analysis. *Physical & Occupational Therapy in Pediatrics, 38*(4), 427-443. https://doi.org/10.1080/01942638.2017.1337664

Alsem, M. W., Ausems, F., Verhoef, M., Jongmans, M. J., Meily-Visser, J. M., & Ketelaar, M. (2017). Information seeking by parents of children with physical disabilities: An exploratory qualitative study. *Research in Developmental Disabilities, 60*, 125-134. https://doi.org/10.1016/j.ridd.2016.11.015

Alsem, M. W., Siebes, R. C., Gorter, J. W., Jongmans, M. J., Nijhuis, B. G. J., & Ketelaar, M. (2014). Assessment of family needs in children with physical disabilities: Development of a family needs inventory. *Child: Care, Health and Development, 40*(4), 498-506. https://doi.org/10.1111/cch.12093

Alsem, M. W., Verhoef, M., Gorter, J. W., Langezaal, L. C., Visser-Meily, J. M., & Ketelaar, M. (2016). Parents' perceptions of the services provided to children with cerebral palsy in the transition from preschool rehabilitation to school-based services. *Child: Care, Health and Development*, *42*(4), 455-463. https://doi.org/10.1111/cch.12341

Australian Health Ministers' Advisory Council. (2017). *National strategic framework for chronic conditions*. Canberra: Australian Government. Retrieved April 20, 2018, from http://www.health.gov.au/internet/main/publishing.nsf/content/nsfcc

Barlow, J., Swaby, L., & Turner, A. (2008). Perspectives of parents and tutors to a self-management program for parents/guardians of children with long-term and life-limiting conditions: A life raft we can sail along with. *Journal of Community Psychology, 36*(7), 871-884. https://doi.org/10.1002/jcop.20258

Bartlett, D., Chiarello, L. A., Hjorngaard, T., & Sieck Taylor, B. (2017). Moving from parent "consultant" to parent "collaborator": One pediatric research team's experience. *Disability and Rehabilitation, 39*(21), 2228-2235. https://doi.org/10.1080/09638288.2016.1219402

Battersby, M., von Korff, M., Schaefer, J., Davis, C., Ludman, E., Greene, S. M., Parkerton, M., & Wagner, E. H. (2010). Twelve evidence-based principles for implementing self-management support in primary care. *Joint Commission Journal on Quality and Patient Safety, 36*(12), 561-570. https://doi.org/10.1016/s1553-7250(10)36084-3

Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine, 25*(24), 3186-3191. https://doi.org/10.1097/00007632-200012150-00014

Boeije, H. (2012). Methoden en technieken van kwalitatieve analyse [Methods and techniques of qualitative analysis]. In H. Boeije (Ed.), *Analyseren in kwalitatief onderzoek* [Analysing in qualitative research] (pp. 84-121). Boom Lemma.

CBO [Dutch Institute for Health Care Improvement]. (2011). *Kort & Krachtig: Generiek model zelfmanagement [General Model Self-management]*. Retrieved December 3, 2024, from https://www.zorgvoorbeter.nl/kennisbundel-zelfmanagement/zelfmanagementondersteuning-is-teamwerk

CBS [Statistics Netherlands]. (2018a). Bevolkingsontwikkeling; migratieachtergrond en generatie [Population growth; migration background and generation]. Retrieved April 16, 2018, from https://opendata.cbs.nl/statline/#/CBS/nl/dataset/70751ned/table?ts=1523914608251

CBS [Statistics Netherlands]. (2018b). Sociale monitor, welvaart en welzijn in de Nederlandse samenleving [Social monitor, welfare and well-being in the Dutch Society]. Retrieved April 16, 2018, from https://opendata.cbs.nl/statline/#/CBS/nl/dataset/81573NED/table?ts=1523915290217

Creswell, J. W. (2009). Mixed methods procedures. In *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed., pp. 203-223). Sage Publications.

Cross, A., Rosenbaum, P., Grahovac, D., & Gorter, J. W. (2015). Knowledge mobilization to spread awareness of the “F-words” in childhood disability: Lessons from a family researcher partnership. *Child: Care, Health and Development, 41*(6), 947-953. https://doi.org/10.1111/cch.12249

Dashiff, C., Suzuki-Crumly, J., Kracke, B., Britton, L., & Moreland, E. (2013). Cystic fibrosis-related diabetes in older adolescents: Parental support and self-management. *Journal for Specialists in Pediatric Nursing*, *18*(1), 42-53. https://doi.org/10.1111/jspn.12010

Deci, E. L., & Ryan, R. M. (2008). Self-determination theory: A macrotheory of human motivation, development, and health. *Canadian Psychology, 49*(3), 182-185. https://doi.org/10.1037/a0012801

Dutch Ministry of Health, Welfare and Sport. (2017). *Wet inzake Geneeskundige Behandelovereenkomst (WGBO) [Law on Medical Treatment Agreement]*. Burgerlijk Wetboek 7, afd.5, art. 446-468. Overheid. Retrieved March 10, 2018, from http://wetten.overheid.nl/BWBR0005290/2017-10-10#Boek7_Titeldeel7_Afdeling5

Farholm, A., Halvari, H., Niemiec, C. P., Williams, G. C., & Deci, E. L. (2016). Changes in return to work among patients in vocational rehabilitation: A self-determination theory perspective. *Disability and Rehabilitation*, *39*(20), 2039-2046. https://doi.org/10.1080/09638288.2016.1215559

Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving integration in mixed methods designs - Principles and practices. *Health Services Research, 48*(6), 2134-2156. https://doi.org/10.1111/1475-6773.12117

Fordham, L., Gibson, F., & Bowes, J. (2012). Information and professional support: Key factors in the provision of family-centred early childhood intervention services. *Child: Care, Health and Development*, *38*(5), 647-653. https://doi.org/10.1111/j.1365-2214.2011.01324.x

Goethals, E. R., Oris, L., Soenens, B., Berg, C. A., Prikken, S., van Broeck, N., Weets, I., Casteels, K., & Luyckx, K. (2017). Parenting and treatment adherence in type 1 diabetes throughout adolescence and emerging adulthood. *Journal of Pediatric Psychology*, *42*(9), 922-932. https://doi.org/10.1093/jpepsy/jsx053

Hagger, M. S., Hardcastle, S. J., Hingley, C., Strickland, E., Pang, J., & Watts, G. F. (2016). Predicting self-management behaviors in familial hypercholesterolemia using an integrated theoretical model: The impact of beliefs about illnesses and beliefs about behaviors. *International Journal of Behavioral Medicine*, *23*(3), 282-294. https://doi.org/10.1007/s12529-015-9531-x

Haskard Zolnierek, K. B., & Dimatteo, M. R. (2009). Physician communication and patient adherence to treatment: A meta-analysis. *Medical Care, 47*(8), 826-834. https://doi.org/10.1097/MLR.0b013e31819a5acc

Hernandez, R., Ruggiero, L., Riley, B. B., Wang, Y., Chavez, N., Quinn, L. T., Gerber, B. S., & Choi, Y. K. (2014). Correlates of self-care in low-income African American and Latino patients with diabetes. *Health Psychology*, *33*(7), 597-607. https://doi.org/10.1037/hea0000043

Hibbard, J. H., Mahony, E., Stockard, J., & Tusler. M. (2005). Development and testing of a short form of the Patient Activation Measure. *Health Services Research, 40*(6), 1918-1930. https://doi.org/10.1111/j.1475-6773.2005.00438.x

Huber, M. (2011). How should we define health? *BMJ, 343*, d4163. https://doi.org/10.1136/bmj.d4163

Javadi, M., Kadkhodaee, M., Yaghoubi, M., Maroufi, M., & Shams, A. (2013). Applying theory of planned behavior in predicting of patient safety behaviors of nurses. *Materia Socio-medica*, *25*(1), 52-55. https://doi.org/10.5455/msm.2013.25.52-55

Jeglinsky, I., Autti-Rämö, I., & Brogren Carlberg, E. (2012). Two sides of the mirror: Parents' and service providers' view on the family-centeredness of care for children with cerebral palsy. *Child: Care, Health and Development, 38*(1), 79-86. https://doi-org.vu-nl.idm.oclc.org/10.1111/j.1365-2214.2011.01305.x

Ketelaar, M., Bogossian, A., Saini, M., Visser-Meily, A., & Lach, L. (2017). Assessment of the family environment in pediatric neurodisability: A state-of-the-art review. *Developmental Medicine & Child Neurology, 59*, 259-269. https://doi.org/10.1111/dmcn.13325

King, G., Currie, M., & Petersen, P. (2014). Child and parent engagement in the mental health intervention process: A motivational framework. *Child and Adolescent Mental Health, 19*(1), 2-8. https://doi.org/10.1111/camh.12015

King, G., Desmarais, C., Lindsay, S., Piérart, G., & Tétreault, S. (2015). The roles of effective communication and client engagement in delivering culturally sensitive care to immigrant parents of children with disabilities. *Disability and Rehabilitation, 37*(15), 1372-1381. https://doi.org/10.3109/09638288.2014.972580

Koponen, A. M., Simonsen, N., & Suominen, S. (2017). Quality of primary health care and autonomous motivation for effective diabetes self-management among patients with type 2 diabetes. *Health Psychology Open, 4*(1), 1-9. https://doi.org/10.1177/2055102917707181

Kratz, L., Uding, N., Trahms, C. M., Villareale, N., & Kieckhefer, G. M. (2009). Managing childhood chronic illness: Parent perspectives and implications for parent-provider relationships. *Families, Systems, & Health, 27*(4), 303-313. https://doi.org/10.1037/a0018114

Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., & Rosenbaum, P. L. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability and Rehabilitation, 31*(8), 607-618. https://doi.org/10.1080/09638280802242163

Lawn, S., McMillan, J., & Pulvirenti, M. (2011). Chronic condition self-management: Expectations of responsibility. *Patient Education and Counseling, 84*, e5-e8. https://doi.org/10.1016/j.pec.2010.07.008

Lee, L. T., Bowen, P. G., Mosley, M. K., & Turner, C. C. (2017). Theory of planned behavior: Social support and diabetes self-management. *Journal of Nurse Practitioners, 13*(4), 265-270. https://doi.org/10.1016/j.nurpra.2016.07.013

Leeman, J., Crandell, J. L., Lee, A., Bai, J., Sandelowski, M., & Knafl, K. (2016). Family-functioning and the well-being of children with chronic conditions: A meta-analysis. *Research in Nursing & Health, 39*(4), 229-243. https://doi.org/10.1002/nur.21725

Levesque, C. S., Williams, G. C., Elliot, D., Pickering, M. A., Bodenhamer, B., & Finley, P. J. (2007). Validating the theoretical structure of the Treatment Self-Regulation Questionnaire (TSRQ) across three different health behaviours. *Health Education Research, 22*(5), 691-702. https://doi.org/10.1093/her/cyl148

Lindsay, S., Kingsnorth, S., Mcdougall, C., & Keating, H. (2013). A systematic review of self-management interventions for children and youth with physical disabilities. *Disability and Rehabilitation*, *36*(4), 276-288. https://doi.org/10.3109/09638288.2013.785605

McDowell, B. C., Duffy, C., & Parkes, J. (2015). Service use and family-centred care in young people with severe cerebral palsy: A population based, cross-sectional clinical survey. *Disability and Rehabilitation, 37*(25), 2324-2329. https://doi.org/10.3109/09638288.2015.1019649

Mokkink, L. B., van der Lee, J. H., Grootenhuis, M. A., Offringa, M., Heymans, H. S., & Dutch National Consensus Committee Chronic Diseases and Health Conditions in Childhood (2008). Defining chronic diseases and health conditions in childhood (0-18 years of age): National consensus in the Netherlands. *European Journal of Pediatrics*, *167*(12), 1441-1447. https://doi.org/10.1007/s00431-008-0697-y

Münster Halvari, A. E., Halvari, H., Bjornebekk, G., & Deci, E. L. (2010). Motivation and anxiety for dental treatment: Testing a self-determination theory model of oral self-care behaviour and dental clinic attendance. *Motivation and Emotion, 34*, 15-33. https://doi.org/10.1007/s11031-010-9154-0

Neylon, O. M., O'Connell, M. A., Skinner, T. C., & Cameron, F. J. (2013). Demographic and personal factors associated with metabolic control and self-care in youth with type 1 diabetes: a systematic review. *Diabetes/Metabolism Research and Reviews*, *29*(4), 257-272. https://doi.org/10.1002/dmrr.2392

Nolte, E., McKee, M., & Knai, C. (2008). Managing chronic conditions: An introduction to the experiences in eight countries. In E. Nolte, C. Knai, & M. McKee (Eds.), *Managing chronic conditions: Experiences in eight countries* (pp. 1-15). European Observatory on Health Systems and Policies, WHO. Retrieved February 23, 2018, from http://apps.who.int/iris/bitstream/10665/107920/1/E92058.pdf?ua=1

Orrell-Valente, J. K., & Cabana, M. D. (2008). 'The apple doesn't fall far from the tree': The role of parents in chronic disease self-management. *Current Opinion in Pediatrics, 20*(6), 703-704. https://doi.org/10.1097/MOP.0b013e328319bad1

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research, 42*, 533-544. https://doi.org/10.1007/s10488-013-0528-y

Palisano, R. J., Almarsi, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2009). Family needs of parents of children and youth with cerebral palsy. *Child: Care, Health and Development, 36*(1), 85-92. https://doi.org/10.1111/j.1365-2214.2009.01030.x

Palisano, R. J., Chiarello, L. A., King, G. A., Novak, I., Stoner, T., & Fiss, A. (2012). Participation-based therapy for children with physical disabilities. *Disability and Rehabilitation, 34*(12), 1041-1052. https://doi.org/10.3109/09638288.2011.628740

Pangalila, R., Becher, J., Maathuis, K., Hadders-Algra, M., & Pangalila, R. (2015). Kinderrevalidatie in Nederland [Paediatric rehabilitation in the Netherlands]. In M. Hadders-Algra, K. Maathuis, & R. Pangalila (Eds.), *Kinderrevalidatie* (5th revised ed., pp. 5-27). Koninklijke Van Gorcum BV.

Parkes, J., Caravalle, B., Marcelli, M., Franco, F., & Colver, A. (2011). Parenting stress and children with cerebral palsy: A European cross-sectional survey. *Developmental Medicine & Child Neurology, 53*(9), 815-821. https://doi.org/10.1111/j.1469-8749.2011.04014.x

Patrick, H., & Williams, G. C. (2012). Self-determination theory: Its application to health behavior and complementarity with motivational interviewing. *International Journal of Behavioral Nutrition and Physical Activity, 9*, 18. https://doi.org/10.1186/1479-5868-9-18

Pennarola, B. W., Rodday, A. M., Mayer, D. K., et al. (2012). Factors associated with parental activation in pediatric hematopoietic stem cell transplant. *Medical Care Research and Review, 69*(2), 194-214. https://doi.org/10.1177/1077558711431460

Protheroe, J., Whittle, R., Bartlam, B., Estacio, E. V., Clark, L., & Kurth, J. (2017). Health literacy, associated lifestyle and demographic factors in adult population of an English city: a cross-sectional survey. *Health Expectations*, *20*(1), 112-119. https://doi.org/10.1111/hex.12440

Pulvirenti, M., McMillan, J., & Lawn, S. (2014). Empowerment, patient centred care and self-management. *Health Expectations, 17*, 303-310. https://doi.org/10.1111/j.1369-7625.2011.00757.x

Rademakers, J., Nijman, J., van der Hoek, L., Heijmans, M., & Rijken, M. (2012). Measuring patient activation in the Netherlands: Translation and validation of the American short form Patient Activation Measure (PAM13). *BMC Public Health, 12*, 577. https://doi.org/10.1186/1471-2458-12-577

Rosenbaum, P., & Gorter, J. W. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child: Care, Health and Development, 38*(4), 457-463. https://doi.org/10.1111/j.1365-2214.2011.01338.x

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68-78. https://doi.org/10.1037/0003-066X.55.1.68

Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *European Health Psychologist*, *10*(1), 2-5.

Ryan, R. M., Williams, G. C., Patrick, H., & Deci, E. L. (2009). Self-determination theory and physical activity: The dynamics of motivation in development and wellness. *Hellenic Journal of Psychology, 6(2)*, 107-124.

Schreiber, J. B., Nora, A., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *Journal of Educational Research, 99*(6), 323-338. https://doi.org/10.3200/JOER.99.6.323-338

Schwartz, D. D., & Axelrad, M. E. (2015). The role of parents. In *Healthcare partnerships for pediatric adherence: Promoting collaborative management for pediatric chronic illness care* (pp. 91-101). SpringerBriefs in Public Health. https://doi.org/10.1007/978-3-319-15591-4_

Shigaki, C., Kruse, R. L., Mehr, D., Sheldon, K. M., Ge, B., Moore, C., & Lemaster, J. (2010). Motivation and diabetes self-management. *Chronic Illness, 6*(3), 202-214. https://doi.org/10.1177/1742395310375630

Shogren, K. A., & Turnbull, A. P. (2006). Promoting self-determination in young children with disabilities: The critical role of families. *Infants and Young Children, 19*(4), 338-352. https://doi-org.vu-nl.idm.oclc.org/10.1097/00001163-200610000-00006

Siebes, R. C., Ketelaar, M., Gorter, J. W., Alsem, M., & Jongmans, M. J. (2012). Needs of families with children who have a physical disability: A literature review. *Critical Reviews in Physical and Rehabilitation Medicine, 24*(1-2), 85-108. https://doi.org/10.1615/CritRevPhysRehabilMed.2013006542

Terwiel, M., Alsem, M. W., Siebes, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred service: differences in what parents of children with cerebral palsy rate important. *Child: Care, Health and Development*, *43*(5), 663-669. https://doi.org/10.1111/cch.12460

Tijmstra, J., & Boeije, H. (2009). Benaderingen van onderzoek [Approaches to research]. In H. Boeije, H. 't Hart, & J. Hox (Eds.), *Onderzoeksmethoden, 8ste geheel herziene druk [Research Methods, 8th fully revised edition],* (pp. 64-101). Boom Lemma.

Trappenburg, J., Jonkman, N., Jaarsma, T., van Os-Medendorp, H., Kort, H., de Wit, N., Hoes, A., & Schuurmans, M. (2013). Self-management: One size does not fit all. *Patient Education and Counseling*, *92*(1), 134-137. https://doi.org/10.1016/j.pec.2013.02.009

United Nations. (1976). *International covenant on civil and political rights*. Retrieved March 1, 2019, from http://www.ohchr.org/Documents/ProfessionalInterest/ccpr.pdf

United Nations. (n.d.). *Universal declaration of human rights*. Retrieved March 1, 2018, from http://www.un.org/en/universal-declaration-human-rights/

van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *JAMA, 303*(7), 623-630. https://doi.org/10.1001/jama.2010.104

van Houtum, L., Rijken, M., & Groenewegen, P. (2015). Do everyday problems of people with chronic illness interfere with their disease management? *BMC Public Health, 15*(1), 1000. https://doi.org/10.1186/s12889-015-2303-3

van Houtum, L., Rijken, M., Heijmans, M., & Groenewegen, P. (2015). Perceptions of self-management tasks and support needs of people with chronic illness: Generic or disease-specific? *Annals of Behavioral Medicine, 49*(2), 221-229. https://doi.org/10.1007/s12160-014-9649-0

Wiart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2009). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability and Rehabilitation*, *32*(3), 248-258. https://doi.org/10.3109/09638280903095890

Williams, G. C., & Deci, E. L. (2001). Activating patients for smoking cessation through physician autonomy support. *Medical Care, 39*(8), 813-823. https://doi.org/10.1097/00005650-200108000-00007

Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, E. L. (1996). Motivational predictors of weight loss and weight-loss maintenance. *Journal of Personality and Social Psychology, 70*(1), 115-126. https://doi.org/10.1037/0022-3514.70.1.115

Wilski, M., Tasiemski, T., & Kocur, P. (2015). Demographic, socioeconomic and clinical correlates of self-management in multiple sclerosis. *Disability and Rehabilitation*, *37*(21), 1970-1975. https://doi.org/10.3109/09638288.2014.993435

World Health Organization. (2002). *Innovative care for chronic conditions: Building blocks for action*. Retrieved March 1, 2018, from http://www.who.int/chp/knowledge/publications/icccreport/en/

World Health Organization. (n.d.). *Process of translation and adaptation of instruments*. Retrieved March 1, 2018, from http://www.who.int/substance_abuse/research_tools/translation/en/

Zwar, N., Harris, M., Griffiths, R., Roland, M., Dennis, S., Powell Davies, G., & Hasan, I. (2006). A systematic review of chronic disease management. Research Centre for Primary Health Care and Equity, School of Public Health and Community Medicine, UNSW. Retrieved February 23, 2018, from https://doi.org/10.26190/unsworks/384

3

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 ten percent 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 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

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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 recognise the organisational preconditions for supporting parental self-management.

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.

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 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, 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. (2010), 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.

METHODS

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*, the Results section 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 the Discussion section. 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).

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.

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 specialised 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 optimise 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.

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. (2006) 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., 2006). 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 Appendix 3.1.

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 Gutman 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 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 3.1).

Table 3.1 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

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 3.2. Before use the interview questions were piloted, discussed, and adapted by the research group.

Table 3.2 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?

Data analysis

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 y; 11–20 y; > 20 y) were tested by General Linear Model Multivariate Analysis of Variance.

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.

RESULTS

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 3.3).

Table 3.3 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	

For descriptive statistics of the TSRQ and the CS-PAM, see Table 3.4. 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.

Table 3.4 Descriptive statistics of the TSRQ and the CS-PAM NL

	n	Min[a]	Max[a]	Mean	*SD*	Skew	*SE*	Kurtosis	*SE*
TSRQ									
Autonomous motivation	175	4.00	7.00	5.82	.61	-.26	.18	.05	.37
Controlled motivation	175	1.00	5.00	3.34	.94	-.16	.18	-.39	.37
CS-PAM									
Beliefs regarding the importance of parental self-management	172[b]	42.00	100.00	63.06	11.52	1.30	.19	2.18	.37

Abbreviations: CS-PAM, Clinicians-Patient Activation Measure; SD, standard deviation; SE, standard error; TSRQ, Treatment Self-Regulation Questionnaire.

[a] Possible range TSRQ (1–7), CS-PAM (0–100).

[b] Data of 3 respondents were excluded because of invalid responses according to scoring instructions.

On the accumulating 4-stage scale of the CS-PAM (Figure 3.1), 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 recognised the importance of parents ‘having knowledge and behaviour to prevent symptoms related to their child’s health condition’.

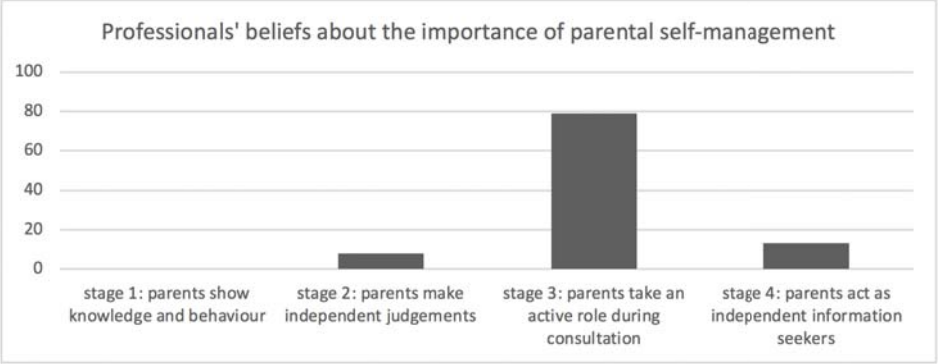

Figure 3.1 Scores of professionals reflected on the accumulating four-stage ordinal scale of the Clinicians-Patient Activation Measure (CS-PAM) NL.

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 ($r = .06$, $p = .44$).

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 ($r = .14$, $p = .070$).

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 ($F(2.168) = 3.05$; $p = .050$; $R^2 = 0.60$) 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.

Phase 2: Qualitative results

The interviews addressed the underlying views of professionals on parental support. In total 16 professionals were interviewed, see Table 3.5.

Table 3.5 Characteristics of the interviewed professionals (*n* = 16)

	n	%	*M* (*SD*)
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	

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 3.6.

Table 3.6 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 & trust	- Self-management support is about mutual trust in each other and respect for each other's 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 instead 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 & 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.

Table 3.6 continues on next page.

Table 3.6 ***Continued***

Themes	Subthemes	Example quotations of professionals
	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 & organisational 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.
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.

Table 3.6 continues on next page.

Table 3.6 ***Continued***

Themes	Subthemes	Example quotations of professionals
	Family functioning	- Is there a situation that these parents, for what reason ever, cannot 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		
Themes		Example quotations of professionals
Developing process		- 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.
Additional skills		- 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.

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.

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 organisation to ensure the preconditions for self-management support, ‘scheduling constraints’, and experienced ‘financial and organisational 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.

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’.

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.

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., 2020). Nevertheless, given the diversity of professionals' underlying perspectives on what exactly parental engagement in self-management incorporates, also seen in literature (Darrah et al., 2010), 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).

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., 2020). 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).

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 et al., 2010; Nguyen et al., 2016).

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 centered service, reporting that professionals at older age with more working experience tended to perceive self-management as more important.

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., 2015). 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 utilising 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).

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. Generalisation 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 organisational 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.

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 Hooft 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.

REFERENCES

Australian Health Ministers' Advisory Council. (2017). *National strategic framework for chronic conditions*. Canberra: Australian Government. Retrieved April 20, 2018, from: http://www.health.gov.au/internet/main/publishing.nsf/content/nsfcc

Beaton, D. E., Bombardier, C., Guillemin, F., & Bosi Ferraz, M. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *SPINE, 25*(24), 3186-3191. https://doi.org/10.1097/00007632-200012150-00014

Bos-Touwen, I. D., Trappenburg, J. C. A., van der Wulp, I., Schuurmans, M. J., & De Wit, N. J. (2017). Patient factors that influence clinicians' decision making in self-management support: A clinical vignette study. *PLoS ONE, 12*(2), e0171251. https://doi.org/10.1371/journal.pone.0171251

Coyne, I. (2015). Families and health-care professionals' perspectives and expectations of family-centred care: Hidden expectations and unclear roles. *Health Expectations, 18,* 769-808. https://doi.org/10.1111/hex.12104

Coventry, P. A., Fisher, L., Kenning, C., Bee, P., & Bower, P. (2014). The effectiveness of interventions to enhance self-management support competencies in the nursing profession: A systematic review. *Journal of Advanced Nursing 73*(8), 1807-1824. https://doi.org/10.1111/jan.13249

Creswell, J. W. (2009). *Research design. qualitative, quantitative and mixed methods approaches* (3rd ed.). Sage Publications.

Dall'Oglio, I., Di Furia, M., Tiozzo, E., Gawronski, O., Biagioli, V., Di Ciommo, V. M., Paoletti, S., Bianchi, N., Celesti, L., Raponi, M., OPBG Nursing and Allied Health Professionals Research Group, Antonielli, G., Baronio, B., Bergami, A., Cianchi, D., Ciliento, G., Vittoria Di Toppa, M., Fabbiani, A., Fagioli, D., Frillici, C., … Ventura, M. (2018). Practices and perceptions of family centered care among healthcare providers: A cross-sectional study in a pediatric hospital. *Journal of Pediatric Nursing*, *43*, e18-e25. https://doi.org/10.1016/j.pedn.2018.07.015

Darrah, J., Wiart, L., Magill-Evans, J., Ray, L., & Andersen, J. (2012). Are family-centered principles, functional goal setting and transition planning evident in therapy services for children with cerebral palsy? *Child: Care, Health and Development*, *38*(1), 41-47. https://doi.org/10.1111/j.1365-2214.2010.01160.x

Deci, E. L. & Ryan, R. M. (2008). Self-determination theory: A macrotheory of human motivation, development, and health. *Canadian Psychology, 49*(3), 82-185. https://doi.org/10.1037/a0012801

Duprez, V., Vandecasteele, T., Verhaeghe, S., Beeckman, D., & van Hecke, A. (2017). The effectiveness of interventions to enhance self-management support competencies in the nursing profession: A systematic review. *Journal of Advanced Nursing 73*(8), 1807-1824. https://doi.org/10.1111/jan.13249

Dutch Ministry of Health, Welfare and Sport. (2017). *Wet inzake Geneeskundige Behandelovereenkomst (WGBO) [Law on Medical Treatment Agreement]*. Burgerlijk Wetboek 7, afd.5, art. 446-468. Overheid. Retrieved March 10, 2018, from http://wetten.overheid.nl/BWBR0005290/2017-10-10#Boek7_Titeldeel7_Afdeling5

Dwarsaard, J., & van de Bovenkamp, H. (2015). Self-management support: A qualitative study of ethical dilemmas experienced by nurses. *Patient Education and Counseling, 98,* 1131-1136. https://doi.org/10.1016/j.pec.2015.05.017

Feeg, V. D., Paraszczuk, A. M., Çavosoglu, H., Shields, L., Pars, H., & Al Mamum, A. (2016). How is family centered care perceived by healthcare providers from different countries? An international comparison study. *Journal of Pediatric Nursing, 31,* 267-276. https://doi.org/10.1016/j.pedn.2015.11.007

Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving integration in mixed methods designs - principles and practices. *Health Services Research, 48*(6), 2134-2156. https://doi.org/10.1111/1475-6773.12117

Fordham, L., Gibson, F., & Bowes, J. (2011). Information and professional support: Key factors in the provision of family-centred early childhood intervention services. *Child: Care, Health and Development, 38*(5), 647-653. https://doi.org/10.1111/j.1365-2214.2011.01324.x

Franklin, M., Lewis, S., Willis, K., Bourke-Taylor, H., & Smith, L. (2018). Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. *Chronic Illness, 14*(2), 79-103. https://doi.org/10.1177/1742395317710082

Geense, W. W., van Gaal, B. G. I., Knoll, J. L., Cornelissen, E. A. M., & van Achterberg, T. (2017). The support needs of parents having a child with a chronic kidney disease: A focus group study. *Child: Care, Health and Development, 43*(6), 831-838. https://doi.org/10.1111/cch.12476

Javadi, M., Kadkhoodaee, M., Yaghoubi, M., Maroufi, M., & Shams, A. (2013). Applying theory of planned behaviour in predicting of patient safety behaviours of nurses. *Materia Socio Medica, 25*(1), 52-55. https://doi.org/10.5455/msm.2013.25.52-55

Harris M. F., Williams, A. M., Dennis, S. M., Zwar, N. A., & Powell-Davies, G. (2008). Chronic disease self-management: Implementation with and within Australian general practice. *Medical Journal of Australia, 189*(10), 17-20. https://doi.org/10.5694/j.1326-5377.2008.tb02204.x

Hibbard, J. H., Collins, P. A., Mahony, E., & Baker, L. H. (2009). The development and testing of a measure assessing clinician beliefs about patient self-management. *Health Expectations,13,* 65-72. https://doi.org/10.1111/j.1369-7625.2009.00571.x

Hsieh, H. F., & Shannon, S. E. (2006). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. https://doi.org/10.1177/1049732305276687

Khairnar, R., Kamal, K. M., Giannetti, V., Dwibedi, N., & McConoha, J. (2019). Primary care physician perspectives on barriers and facilitators to self-management of type 2 diabetes. *Journal of Pharmaceutical Health Services Research, 10,* 117-123. https://doi.org/10.1111/jphs.12280

King, G., Currie, M., & Petersen, P. (2014). Child and parent engagement in the mental health intervention process: A motivational framework. *Child and Adolescent Mental Health, 19*(1), 2-8. https://doi.org/10.1111/camh.12015

King, G., Chiarello, L. A., Ideishi, R, D'Arrigo, R., Smart, E., Ziviani, J., & Pinto, M. (2019). The nature, value, and experience of engagement in pediatric rehabilitation: Perspectives of youth, caregivers, and service providers. *Developmental Neurorehabilitation*, *23*(1), 18-30. https://doi.org/10.1080/17518423.2019.1604580

Kirk, S., Beatty, S., Callery, P., Gellatly, J., Milnes, L., & Pryjmachuk, S. (2012). The effectiveness of self-care support interventions for children and young people with long-term conditions: A systematic review. *Child: Care, Health and Development, 39*(3), 305-324. https://doi.org/10.1111/j.1365-2214.2012.01395.x

Kosmala-Anderson, J. P., Wallace, L. M., & Turner, A. (2010). Confidence matters: A self determination theory study of factors determining engagement in self-management support practices of UK clinicians. *Psychology, Health & Medicine, 15*(4), 478-491. https://doi.org/10.1080/13548506.2010.487104

Levesque, C. S., Williams, G. C., Elliot, D., Pickering, M. A., Bodenhamer, M., & Finley, P. J. (2007). Validating the theoretical structure of the treatment self-regulation questionnaire (TSRQ) across three different health behaviours. *Health Education Research*, *22*(5), 691-702. https://doi.org/10.1093/her/cyl148

Morgan, H. M., Entwistle, V. A., Cribb, A., Christmas, S., Owens, J., Skea, Z. C., & Watt, I. S. (2016). We need to talk about purpose: A critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expectations, 20,* 243-259. https://doi.org/10.1111/hex.12453

Nam, S., Chesla, C., Stotts, N. A., Kroon, L., & Janson, S. L. (2011). Barriers to diabetes management: Patient and provider factors. *Diabetes Research and Clinical Practice, 93,* 1-9. https://doi.org/10.1016/j.diabres.2011.02.002

Nguyen, T., Henderson, D., Stewart, D., Hlyva, O., Punthakee, Z., & Gorter, J. W. (2016). You never transition alone! Exploring the experiences of youth with chronic health conditions, parents and healthcare providers on self-management. *Child: Care, Health and Development, 42*(4), 464-472. https://doi.org/10.1111/cch.12334

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health, 42,* 533-544. https://doi.org/10.1007/s10488-013-0528-y

Rademakers, J., Jansen, D., Van der Hoek, L., & Heijmans, M., (2015). Clinicians' beliefs and attitudes toward patient self-management in the Netherlands: Translation and testing of the American clinician support for patient activation measure (CS-PAM). *BMC Health Services Research, 15*(138), 1-7. https://doi.org/10.1186/s12913-015-0799-y

Rosenbaum P., &. Gorter, J. W. (2011). The 'F-words' in childhood disability: I swear this is how we should think! *Child: Care, Health and Development, 38*(4), 457-463. https://doi.org/10.1111/j.1365-2214.2011.01338.x

Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *The European Health Psychologist, 10*, 2-5.

Schwartz, D. D., & Axelrad, M. E. (2015). *Healthcare partnerships for pediatric adherence: Promoting collaborative management for pediatric chronic illness care.* Springer.

Terwiel, M., Alsem, M. W., Siebes, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred services: Differences in what parents of children with cerebral palsy rate important. *Child: Care Health and Development*, *43*(5), 663-669. https://doi.org/10.1111/cch.12460

Tijmstra, J., & Boeije, H. (2009). Benaderingen van onderzoek [Approaches to research]. In H. Boeije, H. 't Hart, & J. Hox (Eds.), *Onderzoeksmethoden, 8ste geheel herziene druk [Research Methods, 8th fully revised edition]* (pp. 64-101). Boom Lemma.

Vallis, M. (2015). Are behavioural interventions doomed to fail? Challenges to self- management support in chronic diseases. *Canadian Journal of Diabetes, 39,* 30-34. https://doi.org/10.1016/j.jcjd.2015.01.002

Van Hooft, S. M., Dwarswaard, J., Jedeloo, S., Bal, R., Van Staa, A. (2015). Four perspectives on self-management support by nurses for people with chronic conditions: A Q-methodological study. *International Journal of Nursing Studies, 52,* 157-166. https://doi.org/10.1016/j.ijnurstu.2014.07.004

Van Houtum, L., Rijken, M., Heijmans, M., & Groenewegen, P. (2015). Perceptions of self-management tasks and support needs of people with chronic Illness: Generic or disease specific? *Annals of Behavioral Medicine, 49*(2), 221-229. https://doi.org/10.1007/s12160-014-9649-0

Williams, G. C., Grow, V. M., Freedman, Z. R., Ryan, R. M., & Deci, L. E. (1996). Motivational predictors of weight loss and weight-loss maintenance. *Journal of Personality and Social Psychology, 70*(1), 115-126. https://doi.org/10.1037//0022-3514.70.1.115

Wong Chung, R. W., Willemen, A. M., Voorman, J. M., Ketelaar, M., Becher, J. G., Verheijden, J. M. A., & Schuengel, C. (2020). Managing oneself or managing together? Parents' perspectives on chronic condition self-management in Dutch pediatric rehabilitation services. *Disability and Rehabilitation, 42*(23), 3348-3358. https://doi.org/10.1080/09638288.2019.1594396

Young, H. M. L., Apps, L. D., Harrison, S. L., Johnson-Warrington, V. L., Hudson, N., & Singh, S. J. (2015). Important, misunderstood, and challenging: A qualitative study of nurses' and allied health professionals' perceptions of implementing self-management for patients with COPD. *International Journal of COPD, 10*(3), 1043-1052. https://doi.org/10.2147/COPD.S78670

Zwar, N., Harris, M., Griffiths, R., Roland, M., Dennis, S., Powell Davies, G., & Hasan, I. (2006). *A systematic review of chronic disease management*. Research Centre for Primary Health Care and Equity, School of Public Health and Community Medicine, UNSW. Retrieved February 23, 2018, from https://doi.org/10.26190/unsworks/384

APPENDIX 3.1. 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 why 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
Not at all true			Somewhat true			Very true

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.

4

The development and validation of the S-scan - parental self-management support (S-scan - PS): A self-reflection tool for child healthcare professionals

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ABSTRACT

Background: Professionals providing self-management support to parents regarding the care for their child with a chronic condition nowadays is an important aspect of child healthcare. This requires professionals to orient themselves towards partnership and collaboration with parents. The aims of the current study were the development and validation of the S-Scan - Parental self-management Support (S-scan - PS) as a tool for healthcare professionals to reflect on their attitude and practices regarding the support for parental self-management.

Methods: An existing instrument was adapted together with field experts for professionals to self-evaluate their support for self-management of parents. The resulting 36-item self-report questionnaire was filled in by healthcare professionals in the Netherlands working with children and their parents. Cognitive interviews, exploratory and confirmatory factor analysis, and test-retest reliability analysis were part of the development and validation process.

Results: In total, 434 professionals, including physicians, physiotherapists, occupational therapists, and nurses, from thirteen rehabilitation institutes and five medical centres participated. The cognitive interviews with child healthcare professionals indicated adequate face and content validity. The S-scan - PS scale had acceptable internal consistency ($.71 \leq \alpha \leq .91$) for the total score as well as the domain scores. Confirmatory factor analysis (CFA) showed acceptable root mean square error of approximation (RMSEA) model fit (.066), though not on other tested goodness-of-fit indices. Test-retest reliability of the instrument was moderate with an average intraclass correlation coefficient (ICC) = .61.

Conclusion: The S-scan - PS fulfils important psychometric criteria for use by child healthcare professionals to reflect on parental self-management support. Such self-reflection might help to improve their approach towards supporting self-management of parents in the care for their child with a chronic condition. Further research is needed into the construct validity and test-retest reliability of the instrument.

Keywords: child healthcare; parental self-management; professionals' attitude; self-management support; self-reflection; validity

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Key messages:

- The S-scan - PS may be useful for professionals to reflect on their attitudes and behaviours regarding the support of parental self-management.
- The S-scan - PS can help professionals to identify areas of parental self-management support where they can improve on.
- The S-scan - PS shows acceptable reliability and validity.

INTRODUCTION

Professionals supporting self-management of patients with chronic conditions is currently recognised as a key aspect of healthcare (Morgan et al., 2017). This includes encouraging patients to be actively engaged in shared decision-making in partnership and collaboration with professionals, discussing treatment preferences and planning of daily care, in alignment with their abilities, social needs, values, and other priorities in life (Australian Health Ministers' Advisory Council, 2017). Commensurate with children's age, parents are directly involved and in the lead in the management of care (Modi et al., 2012; Schwartz & Axelrad, 2015). Therefore, self-management support in child healthcare to a large extent involves supporting parents in their self-management regarding the daily care for their child (Olij et al., 2021; Saxby et al., 2020) and promoting their engagement and competence (Harniess et al., 2022; King et al., 2020). Nevertheless, existing literature suggests that self-management support of professionals to parents, remains a challenging process (Mitchell et al., 2020). To facilitate a partnership-based, parental self-management supportive approach in child healthcare (Wong Chung et al., 2020), the current study developed and validated a tool that professionals may use to self-assess their own attitudes and behaviours with respect to parental self-management support and reflect on the outcomes.

A self-reflective stance by health care professionals may be particularly important to be able to accommodate to differences among parents in engagement in the care for their child (Siebes et al., 2007). While some parents confidently take the lead in decisions concerning the care for their child, other parents rely more on professionals to take decisions on their behalf (Jackson et al. 2008; Mackean et al., 2005). Underlying these differences appears to be a common expectation from parents that healthcare professionals have an open attitude towards the level of self-management and are supportive in any case (Wong Chung et al., 2020). Also, healthcare professionals vary in opinions on parental self-management and the preferred degree of involvement of parents (Darrah et al, 2010; Wong Chung et al, 2021). This might affect their decisions to the actual support of self-management (Bos-Touwen et al., 2017).

Healthcare professionals in the Netherlands already have access to the Self-management-scan (S-scan) that is a Dutch questionnaire for healthcare professionals to reflect on their self-management supportive behaviours towards patients with chronic conditions. This instrument was originally developed by Zwier within the National Action Program Self-management in the Netherlands (CBO, 2012). The S-scan was conceptualised on basis of the Chronic Care Model (CCM) as described by Wagner and colleagues (Hughes et al., 2020; Verhoef, 2013; Wagner et al., 1999). The CCM conceptualises self-management as the ability to cope with symptoms, treatment, physical and social consequences, and adaptations in lifestyle that are inherent to living with a chronic condition. Self-management in this model is interpreted as a dynamic process between the individual with a chronic condition and the healthcare professional, supported by policies and resources from society, and a supportive and informative healthcare system. The dynamic process is directed on empowering patients to take control of their care process, including treatment goals and plan. The psychometric properties of the S-scan are unknown, however. Also, no such instrument exists that focuses on the support for self-management of parents regarding the care for their child with a chronic condition.

In the current investigation, therefore, an adapted version of S-scan was developed, the S- scan - Parental self-management Support (S-scan - PS), as a tool for professionals to reflect on their support of parental self-management. The study had two goals. Firstly, to develop the S-scan - PS as a self-reflection tool for professionals and secondly, its validation in a sample of child healthcare professionals.

METHODS

Research framework

Development and validation were conducted in two consecutive phases. In phase 1, a first version of the S-scan - PS was developed: the S-scan - PS.1, an adapted version of the S-scan, by means of exploring its face and content validity, as well as its factor structure. In phase 2, the last version of the S-scan - PS.1 was validated with testing of construct validity, internal consistency, and test-retest validity. At the end of phase 2, all results of the study were discussed once more and some final textual adaptations were made. This process ultimately resulted in the S-scan - PS. Investigation of the psychometric quality of the S-scan - PS followed the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) checklist (Mokkink et al., 2010).

Sample and procedures

Pilot study

At the start of the research project, an expert group consisting of six researchers and child healthcare clinicians with different backgrounds discussed the results of a pilot study they previously conducted to explore the structure and reliability of the original S-scan and its potential for use in a population of professionals supporting self-management of parents within rehabilitation institutes. Supplement 4.1 describes methods and results from this pilot.

Phase 1 and 2

Cognitive interviewing took place with other child healthcare professionals to evaluate the appropriateness and clearness of wording used in the original S-scan. Possible participants were approached within the network of the expert group through purposeful sampling, striving for variety in discipline, age, and working experience.

Based on the findings, modifications were made to the instrument. This process led to the S-scan - PS.1, which was then digitally administered by study ambassadors to a sample of healthcare professionals in the Netherlands.

Child healthcare professionals working in the Netherlands were included if they frequently were in contact with parents of children with chronic conditions, like, physicians, physiotherapists, psychologists, social workers, nurses, and speech and language therapists. To optimise the response rate to the survey, oral presentations were conducted at network meetings to inform healthcare professionals about the study and recruit them to become ambassadors of the study, encourage participation, and distribute the digital survey within their own organisations.

Healthcare professionals received an email from the ambassadors in their organisation, with a link to an online media platform where they could anonymously respond to what extent on a six-point Likert scale, they agreed with statements about parental self-management support. Upon opening the survey, before being redirected to the questionnaire itself, potential respondents were informed about the aims and procedures of the study, its voluntary nature, and privacy protection. All participants were given the possibility to receive personal feedback regarding their scores on the questionnaire. To enable later assessment of test-retest reliability, a question was included in the survey asking respondents whether they would be willing to participate in the test-retest investigation. For data analyses in phase 1 and phase 2, respondents were randomly allocated to one of two subsamples. The retest questionnaire was distributed via personally addressed online links to those participants who had responded positively to the request to take part in the reliability survey. The collected data were anonymised with codes, stored on a secured server, and only shared in password-protected files.

Instrument

The original S-scan as developed by Zwier (CBO, 2012), records attitudes of professionals regarding self-management, and the support they provide their adult patients with self-management. It consists of two parts. Part I contains 36 statements, divided into two subscales and seven domains, with scores on a 4-point Likert scale: (1) totally disagree - never; (2) partly disagree - sometimes; (3) partly agree - often; (4) totally agree - always. Subscale one focuses on the professional's view on self-management and consists of the following domains: A. Vision and attitude, B. Transfer of knowledge, C. Coaching, and D. Guidance of facilities and resources. Subscale two assesses their self-management support and includes the following domains: E. Self-management in consultation, F. Policy and organisation, and G. Environmental factors and conditions. Part II of the S-scan provides a 'cobweb-like' diagram with an average score on each domain, based on the responses to the statements in Part I. Figure 4.1 depicts this diagram that functions as a score display, helping the healthcare professional to identify domains of support for self-management that could be improved.

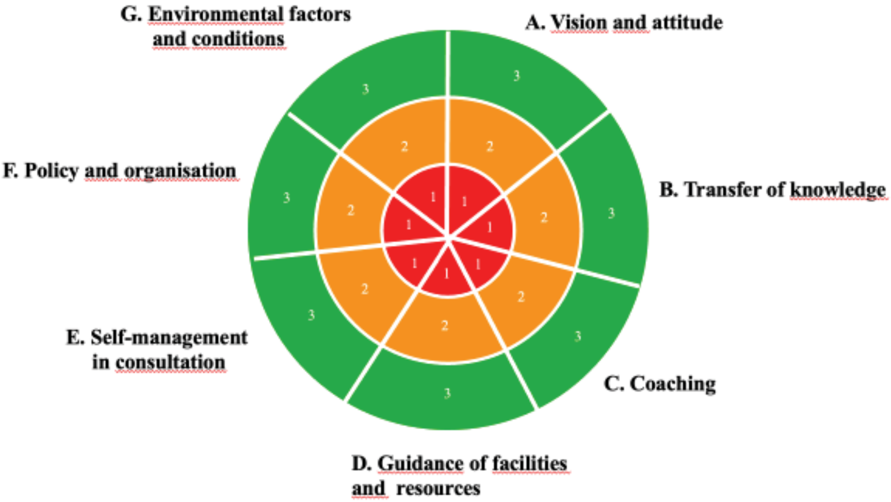

Figure 4.1 Cobweb-like diagram of the S-scan.

Data analyses

Statistical data analyses were conducted with SPSS 23.0 (IBM corporation, 2015) and Mplus, version 8 (Muthén & Muthén, 1998–2017). The dataset was split into two subsamples by randomly assigning participants to one dataset for exploration of the factor structure in phase 1 and one dataset for the psychometric validation in phase 2. Independent-samples *t*-tests were calculated to compare the age and years of working experience for participants who were placed in both datasets. A Chi-square test of independence was calculated to compare both datasets on gender. *P*-values of < .05 (two-tailed) were regarded as statistically significant.

Phase 1

To explore face and content validity, responses to the cognitive interviews were discussed in the expert group. Decisions regarding adaptations to the instrument were based on consensus among all experts.

To assess construct validity of the S-scan - PS.1, exploratory factor analysis (EFA) was conducted on the phase 1 subsample. The correlation matrix was used as matrix of associations. Factors were extracted using principal axis factoring (PAF). Two methods were used to determine the number of factors: the eigenvalue > 1 rule and Cattel's scree test. To decide which rotation method to use, first an oblique rotation (promax) was requested. When most of the correlations in the factor correlation matrix appeared below .32, orthogonal rotation (varimax) would be performed as suggested by Tabachnick et al. (2007). Additional EFAs were carried out and analysed (Watkins, 2018) using no fixed factors, two, and six fixed factors. Cronbach's alphas were calculated to investigate the internal consistency of the domains of the S-Scan - PS.1. Cronbach's alpha above .70 was considered acceptable (Field, 2009). All results of phase 1 were discussed in the expert group to arrive at a modified structure of the S-scan - PS.1 to be tested in Phase 2. A priori power calculations indicated that a minimum of 180 participants were needed for EFA and internal consistency analysis on a 36-item questionnaire (Bujang et al., 2018; Osborne & Costello., 2004).

Phase 2

The adapted structure of the S-scan - PS.1 was subject to confirmatory factor analysis (CFA). In accordance with Brown (2006), this involved the specification and estimation of factor-structure models, indicating a set of latent variables (factors) that account for covariances among observed variables. A factor model was fitted to examine how well the domains as identified during phase 1 represented the data. To estimate the parameters of the CFA models, diagonally weighted least squares (WLSMV) was considered most appropriate, because the S-scan - PS.1 uses Likert scales. Various goodness-of-fit indices were used to evaluate model fit, including Chi-square (χ^2), comparative fit index (CFI), Tucker Lewis index (TLI), root-mean-square error of approximation (RMSEA), and standardized root-mean-square residual (SRMR). In general, CFI and TLI values were expected to be ≥ .95, RMSEA values < .08 and SRMR values ≤ .05 for excellent model fit, suggested by Brown (2006), Hu and Bentler (1999), and Muthén and Muthén (1998–2017). Cronbach's alphas were used to evaluate internal consistency of the full S-scan - PS.1, and of its domains. Finally, intraclass correlation coefficients (ICC) were computed for each item, to investigate test-retest reliability and agreement. ICC estimates and their 95% confident intervals were analysed with use of a two-way mixed effects model of absolute agreement, using average measure ICC. As Indicated by Koo and Li (2016), coefficients were classified as: excellent (≥ .91), good (.75–.9), moderate (.51–.74) or poor (≤ .5). For CFA analyses, a sample size of $n > 200$ is needed, when factor loadings and interim correlations are high, and the number of factors is limited (Wolf et al., 2013). Kennedy (2022) suggests a minimum of 100 respondents for calculating ICC.

RESULTS

Participants

In total, 446 healthcare professionals responded, from 13 rehabilitation centres and five medical centres. Some respondents indicated that they were employed in a school for children with special (educational) needs due to their disability or in an institute for children with profound intellectual and multiple disabilities. Twelve respondents expressed they did not want to participate in the study and were excluded from the analyses, resulting in a dataset of $n = 434$ without any missing data. Table 4.1 shows the demographic characteristics of the final sample. The two randomly split, equally sized datasets for phase 1 and 2, each with $n = 217$ participants, did not show significant differences in age, gender and years of working experience ($p > .16$).

Table 4.1 Characteristics of the sample (*n* = 434)

	n	%
Age (min–max), in years*	20–65	
Gender (female)	388	90
Years of working experience		
0–10 years	127	29
11–20 years	156	36
> 20 years	151	35
Work setting		
Rehabilitation centre	297	68
Medical centre	115	27
Other	22	5
Profession		
Medical specialist	54	12
Physiotherapist	94	22
Occupational therapist	84	19
Speech and language therapist	38	9
Nurse	60	14
Social worker	19	4
Psychologist	37	9
Other profession	48	11

* (*M* = 43.15, *SD* = 10.49).

Phase 1

Cognitive interviewing took place with 15 child healthcare professionals. Respondents consisted of occupational therapists, physiotherapists, physicians, nurses, and a social worker. Their age varied from 30 to 60 years, and their working experience from seven to 40 years. The interviews indicated that the phrasing of the statements was clear and well understood. The content of the questionnaire was considered an appropriate representation of the topic, and feasible in terms of the time needed to respond to the items.

Based on the discussions in the expert group about the results of the pilot study and the interviews, the word ‘parents’ replaced ‘patient’ in every item. Because of this, the formulation of several items was slightly altered. Items that in the pilot study did not load on its corresponding domain were adapted so they would better fit in the domain. In the pilot, EFA conducted with seven fixed factors, explained 39% of the variance. In that model all 11 items of the domains: F. Policy and organisation and G. Environmental factors and conditions, described in the original S-scan, loaded on the same factor (.28–.70). It was therefore decided to merge both domains into one domain formulated as follows: F. Policy and organisation of self-management within the institution, which left the S-scan - PS.1 with six instead of seven domains. Because specifically these items were considered relevant for team-discussions among professionals, it was agreed to keep all 11 items. The wording of items 1, 10 and 34 was altered to improve clarity. In item 2 and item 24 specific words were underlined to emphasize their importance. The 4-point Likert scale of the original S-scan was changed in a 6-point Likert scale giving participants more opportunity to discriminate in their response to the statements but not providing so many scale anchors that answering was expected to become experienced as too time consuming. Additionally, the scale values (disagree-agree versus never-always) were adapted to the nature of every item.

Exploratory factor analysis

Several EFAs were conducted to explore the structure of the S-Scan - PS.1. First, an EFA using oblique rotation (promax) was performed. As most correlations in the factor correlation matrix were below .32, a subsequent EFA with orthogonal rotation (varimax) was conducted on the 36 items. The Kaiser–Meyer–Olkin measure of sampling adequacy (KMO) was .85 and Bartlett's test of sphericity was significant (χ^2 (630) = 2999.31, $p < .001$). This suggested that performing factor analyses on the data was justified. All following factor analyses therefore were conducted with orthogonal rotation (varimax). An EFA with no fixed factors, showed nine factors according to the eigenvalue > 1 rule. This model explained 48% of the explained variance. Five factors explained 41% of the variance and seven factors explained 46% of the variance. A second EFA, with two fixed factors, showed that a two-factor model explained 29 % of the variance. The pattern matrix revealed that most items loaded on their corresponding factor, that is subscale 1 or 2. This was not the case for items 22 to 25 (the entire domain E. Self-management in consultation), which loaded on the wrong factor. Items 1 and 9 had low loadings. A third EFA with six fixed factors explained 42% of the variance. The items of the domain A. Vision and attitude all loaded on one factor. Also, all 11 items of domain F. Policy and organisation of self-management within the institution loaded on the same factor. The domains: B. Transfer of knowledge, C. Coaching, D. Guidance of facilities and resources, and E. Self-management in consultation on the other hand, loaded on more than one factor. Supplement 4.2a, contains a table with the pattern matrix for exploratory factor analysis with six fixed factors.

Table 4.2 shows the internal consistency coefficients of the S-scan - PS.1 with six domains. The Cronbach's alpha coefficient was .90 for the entire questionnaire, .85 for subscale 1, and .88 for subscale 2. The Cronbach's alphas for the separate domains were in the acceptable range. The alpha for domain E. Self-management in consultation was the lowest. Item removal did not lead to a higher Cronbach's alpha for this domain.

Table 4.2 Internal consistency coefficients of the six S-scan - PS.1 domains

Domain	Number of items	Cronbach's alpha
Subscale 1		
A. Vision and attitude	6	.69
B. Transfer of knowledge	6	.66
C. Coaching	5	.75
D. Guidance of facilities and resources	4	.77
Subscale 2		
E. Self-management in consultation	4	.61
F. Policy and organisation within the institution	11	.87

The results of the EFAs and the internal consistency analysis in phase 1 were used to make further adaptations tot the structure of the S-scan - PS.1. Item 9 from domain B. Transfer of knowledge, loaded differently than the other items in this domain. This could be explained by the content of the item, 'Patients with much knowledge about their disease can live better with their disease than patients with less knowledge', which refers to knowledge but not to knowledge transfer per se. Therefore, item 9 was removed, and remaining items renumbered. Elimination of item 9 led to a higher Cronbach's alpha. Item 14 from domain C. Coaching loaded on the factor A. Vision and attitude. The nature of this statement also was considered suitable for that domain. Therefore item 14 was moved to domain Vision and attitude, as item 7. Items 30 and 31 loaded on factor E. Self-management in consultation. These two items were therefore assigned to that domain, and renumbered as item 25 and 26. Finally, based on the low explained variance of the two-factor model, and because the two subscales did not fully correspondent with the domains they represented, the overarching structure with two subscales was dropped, focusing instead on the structure of the tool with six domains.

Phase 2

Confirmatory factor analysis

Based on the results of phase 1, CFA was conducted on the six-factor model that reflected the six domains of the S-scan - PS.1. The goodness-of-fit statistics of the model showed adequate fit on the RMSEA, but not on the other indices, see Table 4.3.

Table 4.3 CFA, goodness-of-fit indices for the model

	χ^2	df	*p*	RMSEA	CFI	TLI	SRMR
Model Six factors	1060.51	545	< .001	0.066	0.896	0.886	0.076

The CFA factor loadings were high on the a priori factors for all the items in the model, varying from 0.48 to 0.85, except for item six (0.31). Internal consistency reliability was indicated by Cronbach's alpha of .91 for the complete S-scan - PS and sufficient Cronbach's alphas (.71–.86) for every domain. Supplement 4.2b shows the factor loadings for confirmatory factor analysis with six factors, and internal consistency coefficient.

Test-retest reliability

In total 73 professionals took part in the test-retest investigation. Participants in the retest survey did not differ on gender χ^2 (1) = 2.28, *p* = .131, age *t*(431) = 0.77, *p* = .441, and years of working experience *t*(432) = 0.85, *p* = .395 from participants in the test survey. After removal and exclusion from further analysis of four outliers (above and below +2 and -2 *SD*) related to the number of days between filling in the questionnaire the first and the second time, the test-retest period ranged from 21 to 67 days (*M* = 39.10, *SD* = 10.97). The removal of the outliers finally led to a sample of *n* = 69. There were no missing data. On average over the 35 items, ICC (.61) indicated moderate test-retest reliability of the S-scan - PS.1. Items 3, 4, 5, 6, 11, 12, 23 and 25 showed poor test-retest reliability (≤ .5), 18 items had moderate reliability (.51–.74) and nine items showed good reliability, from .75 to .81. See Supplement 4.2c for a table with test-retest intraclass correlation coefficients.

Final adaptations

Ultimately, all results obtained in phase 1 and phase 2 were once more considered within the expert group. Since in the EFA in phase 1, item 23 (i.e., item 22 in the final instrument) had a factor loading < .32 and thus was considered insufficient according to Costello and Osborne (2005), this item was slightly reformulated to improve its suitability with the domain Self-management in consultation: 'Parents make decisions regarding establishing and adjusting treatment after consultation / advice from me' was reformulated as 'Parents make decisions regarding establishing and adjusting treatment in consultation with me'. This last minimal change then finally led to the S-scan - PS. See Appendix 4A for an overview of the items and domains.

Part II of the original S-scan with the cobweb-like diagram remained preserved but was adapted to the structure of the S-scan - PS, with six domains and the 6-point Likert scale. The full S-scan - PS can be found in Supplement 4.3 (Dutch version) and Supplement 4.4 (English version - not validated, added for the benefit of the reader).

DISCUSSION

The aim of this study was to develop and to validate the S-scan - PS as a tool for child healthcare professionals, measuring self-reported perceptions regarding support for self-management of parents having children with chronic conditions. Cognitive interviewing indicated adequate face and content validity. Interviewed professionals perceived the items as understandable and considered the instrument to be an appropriate tool to reflect on one's own attitudes and behaviours towards parental self-management support.

After the final adjustments, there was evidence that supported acceptable internal consistency of the entire S-scan - PS and its domains. However, some caution should be regarded concerning this interpretation, as Cronbach's alpha tends to increase with the number of items. Given the relatively large number of 35 items of the S-scan - PS, future investigations regarding the construct validity should also consider possible item redundancy (Taber, 2018).

It should be noted that model fit of the final structure with six domains was not optimal for the data. The EFA revealed several items with high cross-loadings across domains, showing that assigning such items to one domain would reduce explained variance. Further refinement of item formulations may be needed to improve domain-specificity, which may increase the value of the S-scan - PS for self-reflection by healthcare professionals.

The test-retest reliability analyses showed moderate to strong reliability of the items. This indicates that the S-scan - PS captures reasonably stable attitudes and practices, which is important if the tool is to support enduring change in professionals. The relatively small number of respondents who participated in the retest might have affected test-retest reliability though.

The purpose of the S-scan - PS as a mirror to one's own ideas, attitudes and behaviours specifically also applies to Part II of the tool. The cobweb-like diagram, providing a visual overview of the average score on each domain, indicates those areas of parental self-management support that professionals might consider developing further. Domain F of the S-scan - PS contains questions about how professionals perceive the organisational policies regarding parental self-management support within their institution. According to the Chronic Care Model, embedding support for chronic condition self-management within comprehensive policies of the healthcare organisation, is an essential precondition for success (Wagner et al., 2001, Zwar et al., 2006). Perceived barriers to self-management support that professionals experience within their organisation, may well hamper their actual support to parental self-management (Khairnar et al., 2019). The S-scan - PS therefore may be also of interest to healthcare organisations seeking to review their services (Bamm & Rosenbaum, 2008; Kuo et al., 2012).

The development of the S-scan - PS has taken place in an era when family-centered approach has been adopted as ‘best-practice’ in child healthcare (Gerlach & Varcoe, 2021; Moore et al., 2009). The S-scan - PS as a tool for self-reflection of child healthcare professionals is highly relevant, as this could facilitate the improvement of their self-management supportive skills (van Hooft et al., 2015). An important question would nevertheless be whether stronger support for parents’ self-management contributes to child and family functioning, as has been suggested in literature (Ginsburg et al., 2005; Monaghan et al., 2011).

LIMITATIONS AND PRACTICAL IMPLICATIONS

The current research has some limitations that should be considered when interpreting the results. First, ‘ambassadors’ working at healthcare organisations, most probably contributed positively to the recruitment of participants for the survey. Despite the anonymous nature of the survey, their involvement for data-collection among direct colleagues might also have induced social desirability, and selection bias for professionals with an interest in the topic. Furthermore, the results of Phase 1 gave suggestion to the need of reformulation of some of the items in the S-scan - PS.1 prior to Phase 2. This was not possible though, because the data of Phases 1 and 2 were collected on basis of the same version of the questionnaire. Another limitation was related to the sample sizes used for CFA and test-retest reliability. The factor loadings were relatively low, and the number of factors was high, which limited the power of the CFA. This might have affected the fit indices (Kyriazos, 2018). Also, with 69 respondents, the retest sample was below the minimum of 100 for test-retest reliability analysis as is suggested by Kennedy (2022). Additionally, there was a large variation in time intervals between filling in the questionnaire for the first and the second time, which could have affected the test-retest reliability results (Marx et al., 2003). Finally, findings may also give rise to future reconsideration of the conceptual background of the S-scan - PS, evaluating the CCM first described by Wagner et al. (1999) in the light of current views on parental self-management parental. This also implies that participation of parents should be sought in the further development of the tool (Mills et al., 2017).

CONCLUSION

In this study, construct validity, and test-retest reliability could not fully be established, indicating that further research into the construct validity and reliability would be recommendable. Nevertheless, the findings do suggest that the S-scan - PS may be used to support reflective practice in child healthcare. Such reflection can help healthcare professionals to become aware of areas of strengths and limitations in their support for parental self-management that they may want to change, considering the diversity of parents' perspectives regarding such support (Mitchell et al., 2020). The S-scan - PS should preferably be integrated within more extensive policies of healthcare institutes seeking to improve the delivery of family-centred services. Importantly, such organisation-wide strategies need to address the variety of expectations among the families they serve (Wong Chung et al., 2021).

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

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.

ETHICS STATEMENT

The study was approved by the scientific committee of the Amsterdam Public Health research institute. Regulatory criteria regarding privacy and data protection were met.

REFERENCES

Australian Health Ministers' Advisory Council. (2017). *National strategic framework for chronic conditions*. Canberra: Australian Government. Retrieved April 20, 2018, from: http://www.health.gov.au/internet/main/publishing.nsf/content/nsfcc

Bos-Touwen, I. D., Trappenburg, J. C. A., van der Wulp, I., Schuurmans, M. J., & De Wit, N. J. (2017). Patient factors that influence clinicians' decision making in self-management support: A clinical vignette study. *PLoS ONE, 12*(2), e0171251. https://doi.org/10.1371/journal.pone.0171251

Brown, T. A. (2006). *Confirmatory factor analysis for applied research*. Guilford Publications.

Bujang, M. A., Omar, E. D., & Baharum, N. A. (2018). A review on sample size determination for Cronbach's alpha test: A simple guide for researchers. *The Malaysian Journal of Medical Science, 25*(6), 85-99. https://doi.org/10.21315/mjms2018.25.6.9

CBO (2012). *Z-scan-self diagnostic instrument for self-management support professionals.* Retrieved April 10, 2020, from https://zel.nl/files/a_-Z-scan-Professionals-deel-2-11-april-2017.pdf

Costello, A. B., & Osborne, J. (2005). Best practices in exploratory factor analysis: four recommendations for getting the most from your analysis. *Practical Assessment Research & Evaluation, 10*(7), 1-9.

Darrah, J., Wiart, L., Magill-Evans, J., Ray, L., & Andersen, J. (2012). Are family-centred principles, functional goal setting and transition planning evident in therapy services for children with cerebral palsy? *Child: Care, Health and Development*, *38*(1), 41-47. https://doi.org/10.1111/j.1365-2214.2010.01160.x

Field, A. (2009). *Discovering Statistics Using SPSS* (3rd ed.) Ltd., Sage Publications.

Gerlach, A., & Varcoe, C. (2021). Orientating child- and family-centered care towards equity. *Journal of Child Health Care, 25*(3),457-467. https://doi.org/10.1177/1367493520953354

Ginsburg, K. R., Howe, C. J., Jawad, A. F., Buzby, M., Ayala, J. M., Tuttle, A., & Murphy, K. (2005). Parents' perceptions of factors that affect successful diabetes management for their children. *Pediatrics*, *116*(5), 1095-1104. https://doi.org/10.1542/peds.2004-1981

Harniess, P. A., Gibbs, D., Bezemer, J., & Purna Basu, A. (2022). Parental engagement in early intervention for infants with cerebral palsy - A realist synthesis. *Child, Care, Health and Development, 48*, 359-377. https://doi.org/10.1111/cch.12916

Hu, L. T., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, *6*(1), 1-55. https://doi.org/10.1080/10705519909540118

Hughes, G., Shaw, S. E., & Greenhalgh, T. (2020). Rethinking integrated care: A systematic hermeneutic review of the literature on integrated care strategies and concepts. *The Milbank Quarterly, 98*(2), 446-492. https://doi.org/10.1111/1468-0009.12459

IBM Corporation. (2015). *IBM SPSS Statistics for Machintosh, Version 23.0.* Armonk, NY: IBM Corporation.

Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, *11*(3), 232-251. https://doi.org/10.1111/j.1369-7625.2008.00496.x

Kennedy, I. (2022), Sample size determination in test-retest and Cronbach alpha reliability estimates. *British Journal of Contemporary Education, 2*(1), 17-29. http://doi.org/10.52589/BJCE-FY266HK9

Khairnar, R., Kamal, K. M., Giannetti, V., Dwibedi, N., & McConoha, J. (2019). Primary care physician perspectives on barriers and facilitators to self-management of type 2 diabetes. *Journal of Pharmaceutical Health Services Research, 10*(1), 117-123. https://doi.org/10.1111/jphs.12280

King, G., Chiarello, L. A., Ideishi, R, D'Arrigo, R., Smart, E., Ziviani, J., & Pinto, M. (2020). The nature, value, and experience of engagement in pediatric rehabilitation: Perspectives of youth, caregivers, and service providers. *Developmental Neurorehabilitation, 23*(1), 18-30. https://doi.org/10.1080/17518423.2019.1604580

Koo, T. K., & Li, M. Y. (2016). A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *Journal of Chiropractic Medicine*, *15*(2), 155-163. https://doi.org/10.1016/j.jcm.2016.02.012

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal Child and Health Journal, 16*(2), 297-305. https://doi.org/10.1007/s10995-011-0751-7

Kyriazos, T. A. (2018). Applied Psychometrics: Sample size and Sample power considerations in factor analysis (EFA, CFA) and SEM in general. *Psychology, 9*(8), 2207-2230. https://doi.org/10.4236/psych.2018.98126

Marx, R. G., Menezes, A., Horovitz, L., Jones, E. C., & Warren, R. F. (2003). A comparison of two time intervals for test-retest reliability of health status instruments. *Journal of Clinical Epidemiology*, *56*(8), 730-735. https://doi.org/10.1016/s0895-4356(03)00084-2

Mills, S. L., Brady, T. J., Jayanthan, J., Ziabakhsh, S., & Sargious, P. M. (2017). Toward consensus on self-management support: the international chronic condition self- management support framework. *Health Promotion International. 32*(6), 942-952. https://doi.org/10.1093/heapro/daw030

Mitchell, A. E., Morawska, A., & Mihelic, M. (2020). A systematic review of parenting interventions for child chronic health conditions. *Journal of Child Health Care, 24*(4), 603-628. https://doi.org/10.1177/1367493519882850

Modi, A. C., Pai, A. L., Hommel, K. A., Hood, K. K., Cortina, S., Hilliard, M. E., Guilfoyle, S. M., Gray, W. N., & Drotar, D. (2012). Pediatric self-management: A framework for research, practice, and policy. *Pediatrics*, *129*(2), e473-e485. https://doi.org/10.1542/peds.2011-1635

Mokkink, L. B., Terwee, C. B., Patrick, D. L., Alonso, J., Stratford, P. W., Knol, D. L., Bouter, L. M., & de Vet, H. C. (2010). The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Quality of Life Research, 19*(4), 539-549. https://doi.org/10.1007/s11136-010-9606-8

Monaghan, M., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2011). Supporting parents of very young children with type 1 diabetes: Results from a pilot study. *Patient Education and Counseling*, *82*(2), 271-274. https://doi.org/10.1016/j.pec.2010.04.007

Moore, M. H., Mah, J. K., & Trute, B. (2009). Family-centred care and health-related quality of life of patients in paediatric neurosciences. *Child: Care, Health and Development*, *35*(4), 454-461. https://doi.org/10.1111/j.1365-2214.2008.00902.x

Morgan, H. M., Entwistle, V. A., Cribb, A., Christmas, S., Owens, J., Skea, Z. C., & Watt, I. S. (2017). We need to talk about purpose: A critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expectations, 20*(2), 243-259. https://doi.org/10.1111/hex.12453

Muthén, L. K., & Muthén, B. O. (1998–2017*). Mplus User's Guide* (8th ed.). Muthén & Muthén.

Olij, C., Vos, M., van Oostrum, N., Van Etten-Jamaludin, F., & Maaskant, J. (2021). Effective interventions to support self-management for parents of children with a chronic condition: A systematic review. *Maternal and Child Health Journal. 25*(12), 1842-1865. https://doi.org/10.1007/s10995-021-03244-x

Osborne, J. W., & Costello, A. B. (2004). Sample size and subject to item ratio in principal components analysis. *Practical Assessment, Research, and Evaluation*, *9*(1), 11. https://doi.org/10.7275/ktzq-jq66

Saxby, N., Ford, K., Beggs, S., Battersby, S., & Lawn, S. (2020). Developmentally appropriate supported self-management for children and young people with chronic conditions: A consensus. *Patient Education and Counseling*, *103*(3), 571-581. https://doi.org/10.1016/j.pec.2019.09.029

Schwartz, D. D., & Axelrad, M. E. (2015). *Healthcare partnerships for pediatric adherence: Promoting collaborative management for pediatric chronic illness care*. Houston, TX: Springer.

Siebes, R. C., Wijnroks, L., Ketelaar, M., Van Schie, P. E., Gorter, J. W., & Vermeer, A. (2007). Parent participation in paediatric rehabilitation treatment institutes in the Netherlands: A parents' viewpoint. *Child: Care, Health and Development*, *33*(2), 196-205. https://doi.org/10.1111/j.1365-2214.2006.00636.x

Tabachnick, B. G., & Fidell, L. S., & Ullman, J.B. (2007). *Using multivariate statistics (5th ed.)*. Pearson.

Taber, K. S. (2018). The use of Cronbach's alpha when developing and reporting research instruments in science education. *Research in Science Education, 48*, 1273-1296. https://doi.org/10.1007/s11165-016-9602-2

van Hooft, S. M., Dwarswaard, J., Jedeloo, S., Bal, R., Van Staa, A. (2015). Four perspectives on self-management support by nurses for people with chronic conditions: A Q-methodological study. *International Journal of Nursing Studies, 52*(1), 157-166. https://doi.org/10.1016/j.ijnurstu.2014.07.004

Verhoef, J. (2013). *Eigen regie versterken: Geen zaak van de patiënt alleen. Programmatische aanpak zelfmanagement en zelfmanagementondersteuning door co-creatie [Strengthening autonomy: not a case of the patient alone. Programmatic approach self-management and self-management support through co-creation]*. Inaugural speech. Hogeschool Leiden.

Wagner, E. H., Davis, C., Schaefer, J., Von Korff, M., & Austin, B. (1999). A survey of leading chronic disease management programs: Are they consistent with the literature? *Managed Care Quarterly*, *7*(3), 56-66.

Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J., & Bonomi, A. (2001). Improving chronic illness care: Translating evidence into action. *Health Affairs, 20*(6), 64-78. https://doi.org/10.1377/hlthaff.20.6.64

Watkins, M. W. (2018). Exploratory Factor Analysis: A guide to best practice. *Journal of Black Psychology, 44*(3), 219-246. https://doi.org/10.1177/0095798418771807

Wolf, E. J., Harrington, K. M., Clark, S. L., & Miller, M. W. (2013). Sample size requirements for structural equation models: An evaluation of power, bias, and solution propriety. *Educational and Psychological Measurement, 76*(6), 913-934. https://doi.org/10.1177/0013164413495237

Wong Chung, R. W., Willemen, A. M., Voorman, J. M., Ketelaar, M., Becher, J. G., Verheijden, J. M. A., & Schuengel, C. (2020). Managing oneself or managing together? Parents' perspectives on chronic condition self-management in Dutch paediatric rehabilitation services. *Disability and Rehabilitation*, *42*(23), 3348-3358. https://doi.org/10.1080/09638288.2019.1594396

Wong Chung, R. W., Willemen, A. M., Voorman, J. M., Ketelaar, M., Becher, J. G., & Schuengel, C. (2021). Professionals' motivation to support parental self-management regarding children with physical disability in Dutch rehabilitation services: 'Please mind your gap'. *Child: Care, Health and Development*, *47*(5), 685-696. https://doi.org/10.1111/cch.12883

Zwar, N., Harris, M., Griffiths, R., Roland, M., Dennis, S., Powell Davies, G., & Hasan, I. (2006). *A systematic review of chronic disease management*. Research Centre for Primary Health Care and Equity, School of Public Health and Community Medicine, UNSW. Retrieved February 23, 2018, from https://doi.org/10.26190/unsworks/384

APPENDIX 4A

Table A4A Overview of the items and domains of the S-scan - PS

Item	Domain
	A. Vision and attitude
1	I think it is important that parents themselves choose how the care made available to them is utilized;
2	I always start out from what parents want and are also able to do;
3	Building a trusting relationship with parents is for me the basis on which to support self-management;
4	I think it is important to provide care that fits within with the values, views and culture of parents;
5	I respect and appreciate the experiential expertise of parents;
6	I think it is important that parents are able to cope with their child's disease as well as its consequences on their daily lives;
7	Even if the goals are not directly medical, I support them if parents think that they are important;
	B. Transfer of knowledge
8	I teach parents what to pay attention to with regard to complaints and symptoms;
9	I teach parents to recognize the connection between the disease and the symptoms;
10	I explain difficult and/or complex information in a manner that is more suited for parents;
11	I think it is important to identify what knowledge the parents have about the disease;
12	I think it is important that parents know where they can go when they have questions;
	C. Coaching
13	I adjust my treatment to the wishes and needs of parents;
14	I help parents set feasible goals (15);
15	I encourage parents to explore different options in order to reach their goal(s);
16	I help parents choose activities that their child can handle well;
	D. Guidance of facilities and resources
17	I collect reliable information about facilities/resources and share this with parents;
18	I refer parents to persons and/or organizations who can help/support them in living with the disease;
19	Together with parents, I look for facilities/resources that suit them and their child's preferences, affinities and environment;
20	I do a decent job in guiding parents through the care process;
	E. Self-management in consultation
21	In our practice parents can take part in the care process in a way that suits them;
22	Parents make decisions regarding establishing and adjusting treatment in consultation with me;
23	When I provide information, I ensure to align with what the parents want to know about the illness and/or treatment of their child;
24	In every consultation I ask parents what goes well in their lives with regards to the disease, as well as what problems they experience;
25	I let parents determine how much autonomy they wish to have;
26	I search for interventions that support optimal autonomy of parents;
	F. Policy and organisation of self-management within the institution
27	We have formulated a vision concerning self-management in our team;
28	There are sufficient competencies in our team to support and encourage the self-management of parents;
29	Within my practice it is clear for everyone who does what in order to support the self-management of parents;

Table A4A continues on next page.

Table A4A ***Continued***

Item	Domain
30	Every child in my practice has a plan of care that includes his/her wishes and needs, as well as those of the parents;
31	In my practice there are sufficient IT possibilities to support the self-management of parents;
32	Supporting the self-management of parents is a priority in our quality of care;
33	In our practice we have an extensive overview (social map) with options to support parents;
34	I offer parents the opportunity to have intermediary contact intended for feedback and/or questions concerning self-management;
35	Parental self-management support is a set portion of all our care protocols.

The full S-scan - PS is available in Supplement 4.3 (Dutch) and 4.4 (English).

The English translation of the Dutch instrument: 'Z-scan OvO, Zelfmanagement Ondersteuning van Ouders: Zelfreflectie instrument voor Zorgprofessionals', has not been validated but is added for the benefit of the readers.

No part of S-scan - PS may be altered without the explicit written permission of the authors. The instrument may be used freely for clinical and/or research purposes, provided the source is appropriately cited.

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SUPPLEMENT 4.1: PILOT STUDY

Pilot study

Prior to the development of the S-scan - PS a pilot study was conducted to assess the potential of the original S-scan for adaptation into a new instrument aiming to support child healthcare professionals in reflecting on parental self-management support.

METHODS

Sample and procedures

In the pilot study a project group consisting of researchers and child healthcare professionals discussed the appropriateness of using the S-scan in the context of parental self-management support. First, cognitive interviewing was conducted with six child healthcare professionals to investigate face and content validity. The instructions were evaluated, the feasibility of filling in the questionnaire, as well as the suitability and clarity of phrasing of each item. Subsequently, the questionnaires were filled in by healthcare professionals in the Netherlands working with children with chronic conditions and their parents.

Data analysis

Data analyses were performed with computer programs SPSS 23.0 (IBM corporation, 2015). Data from all 175 participants were used, as there were no missing data. Exploratory Factor Analyses (EFAs) were conducted to assess structure of the S-scan. Cronbach's alphas were computed to assess the internal consistency of the whole questionnaire, of subscale 1 and 2, and of the seven subdomains.

RESULTS

The questionnaire was filled in by 175 professionals working in two paediatric rehabilitation centres in the Netherlands (response rate 82%). For characteristics of the sample, see Table S4.1.1.

Table S4.1.1 Characteristics of the sample (*n* = 175)

	Min–Max	%
Age (min–max)*	22–64	
Gender (female)		92
Years of working experience		
0–10 years		32
11–20 years		37
> 20 years		31
Work setting		
Rehab centre		100
Profession		8
Medical specialist		23
Physiotherapist		19
Occupational therapist		11
Speech and language therapist		10
Therapeutic group worker		5
Social worker		10
Psychologist		15
Other profession		

* (*M* = 42.93, *SD* = 10.72).

Exploring the properties of the S-scan

Cognitive interviewing revealed that in general the items of the S-scan (Table S4.1.2) were sufficiently understood, when used in the context of parental self-management support.

Table S4.1.2 Overview of the S-scan items, domains, and subscales

Item	S-scan
	Subscale 1
	A. Vision and attitude
1	I think it is important that patients themselves choose how the available care is utilized;
2	I always start out from what patients want and are also able to do;
3	Building a trusting relationship with every patient is for important to me
4	I think it is important to provide care that fits within with the values, views and culture of the patient;
5	I respect and appreciate the experiential expertise of my patients;
6	I think it is important my patients are able to cope with well/have a good live with their disease;
	B. Transfer of knowledge
7	I teach my patients what to pay attention to with regard to complaints and symptoms;
8	I teach my patients to recognize the connection between the disease and the symptoms;

Table S4.1.2 continues on next page.

Table S4.1.2 ***Continued***

Item	S-scan
9	Patients with much knowledge about their disease can live better with their disease than patients with less knowledge;
10	I can explain difficult and/or complex information in a simple way;
11	I think it is important to identify what knowledge the patient has about the disease;
12	I think it is important that patients can come to me with all their questions;
	C. Coaching
13	I ask patients what they want to achieve with the treatment
14	I support the goals of the patient, also if they are not directly medical;
15	I help the patient to set feasible goals;
16	I encourage the patient to explore different options in order to achieve his goal;
17	I help the patient choose activities that he/she can handle well;
	D. Guidance to facilities and resources
18	I collect reliable information about facilities/resources and share this with my patients;
19	I refer the patient to persons and/or organizations the patient who can help/support in living with the disease;
20	Together with the patient, I look for facilities/resources that suits his/her preferences, affinities and environment;
21	I do a decent job in guiding my patients through the care process;
	Subscale 2
	E. Self-management in consultation
22	In our practice every patient can take part in the care process in a way that suits him/her;
23	The patient makes decisions regarding establishing and adjusting treatment after consultation / advice from me;
24	When I provide information, I ensure to align with what the patient want sto know about his/her disease and/or treatment;
25	In every consultation I ask my patients what goes well in their lives with regards to the disease, as well as what problems they experience;
	F. Policy and organisation
26	We have formulated a vision concerning self-management in our team;
27	There are sufficient competencies in our team to support and encourage the self-management of patients;
28	Within my practice it is clear for everyone who does what in order to support the self-management of the patients;
29	Every patient with a chronic disease in my practice has an individual plan of care;
30	I let my patients determine how much autonomy they wish to have;
31	I search for interventions that support optimal autonomy of parents;
	G. Environmental factors and conditions
32	In my practice there are sufficient IT possibilities to support the self-management of patients;
33	Supporting the self-management is a priority in our quality of care;
34	In our practice we have an extensive overview (social map) with options to support patients;
35	I offer my patients the opportunity to have intermediary contact intended for feedback and/or questions concerning self-management;
36	Self-management support is a set portion of all our care protocols.

Although most items contained the word 'patient', it appeared clear to the interviewees that wherever it was written 'patient', 'parent' was meant. The results of the interviews were discussed within the project group, after which it was decided that the formulation of the items would not be altered. Nevertheless, it was explicitly stated in the preface of the instrument that when items mentioned 'patient', this should be read as 'parent'.

Table S4.1.3 Descriptive statistics S-scan (mean, *SD*, range)

Item	Mean	*SD*	Range (theoretical range 1–4)
Item 1	2.97	.57	2–4
Item 2	3.29	.54	2–4
Item 3	3.71	.49	2–4
Item 4	3.35	.61	2–4
Item 5	3.52	.53	2–4
Item 6	3.85	.36	3–4
Item 7	3.26	.65	2–4
Item 8	3.17	.64	1–4
Item 9	2.67	.64	2–4
Item 10	2.99	.53	2–4
Item 11	3.34	.58	2–4
Item 12	3.52	.63	2–4
Item 13	3.34	.66	1–4
Item 14	3.07	.53	2–4
Item 15	3.28	.61	1–4
Item 16	3.01	.66	1–4
Item 17	3.07	.60	1–4
Item 18	2.75	.85	1–4
Item 19	2.57	.74	1–4
Item 20	2.84	.86	1–4
Item 21	2.54	.60	1–4
Item 22	2.93	.54	2–4
Item 23	2.67	.75	1–4
Item 24	2.98	.63	1–4
Item 25	2.90	.80	1–4
Item 26	2.69	.81	1–4
Item 27	3.27	.67	1–4
Item 28	2.54	.73	1–4
Item 29	3.63	.60	2–4
Item 30	2.81	.64	1–4
Item 31	3.14	.66	1–4
Item 32	2.60	.88	1–4
Item 33	2.91	.77	1–4
Item 34	2.77	.75	1–4
Item 35	3.07	.88	1–4
Item 36	2.53	.76	1–4

Table S4.1.3. displays the descriptive statistics for the items of the S-scan. Means appeared generally high. EFA was primarily conducted with oblique rotation (promax), showing most correlations in the factor correlation matrix below .32. Subsequently, the following analyses were carried out using orthogonal rotation (varimax) on the 36 items. The Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy was .78, which was above the recommended value of .5 recommended by Field (2009). Bartlett's test of sphericity was significant ($\chi^2(630) = 1939.65$, $p < .001$). According to Young and Pearce (2013) these outcomes indicated that it was appropriate to use factor analyses on the current data. The first EFA, without fixed factors, revealed 12 factors according to the eigenvalue > 1 rule, and explained 49% of the variance. The scree plot, however, indicated around 5–7 factors, with five factors explaining 36% and seven factors explaining 41% of the variance, see Figure S4.1.1.

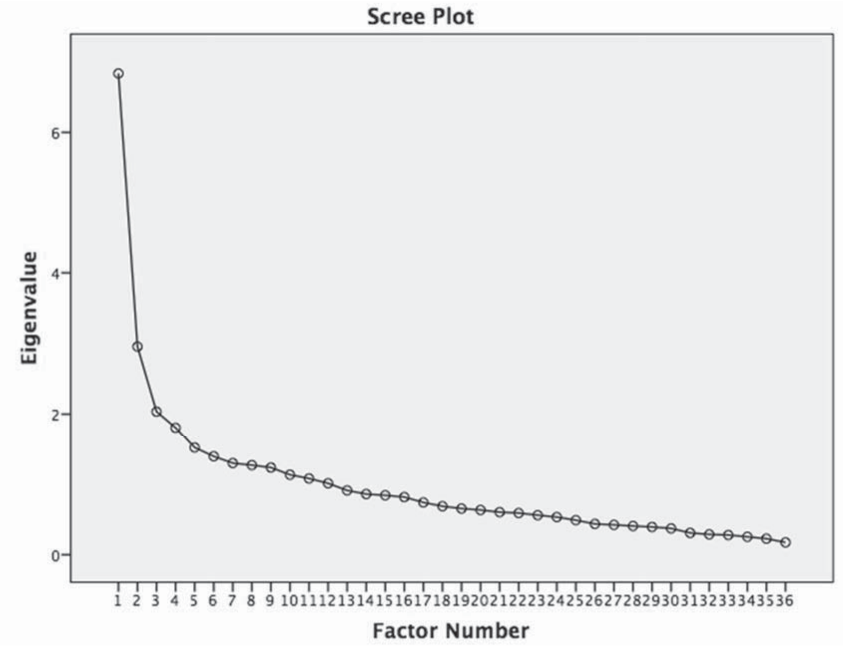

Figure S4.1.1 Scree Plot, EFA no fixed factors

A second EFA, with two fixed factors, explained 23% of the variance. The factor and pattern matrix did not clearly show a two-factor model though. A third EFA, using seven fixed factors, showed a seven-factor model explaining 39% of the variance. For the factor loadings of the third EFA, see Table S.4.1.4. Regarding the domain 'Vision and attitude' 4 of 6 items loaded on factor three. 3 of 6 items of 'Transfer of knowledge' loaded primarily on factor five. 3 of 5 of the items of the domain 'Coaching' loaded on factor four. All items of ‘Guidance of facilities and resources’ loaded on factor two. Finally, all items of the domains ‘Policy and organisation’ and ‘Environmental factors and conditions’ loaded on factor one.

Table S4.1.4 EFA with seven fixed factors, pattern matrix

		Factor						
Domain		1	2	3	4	5	6	7
Vision and attitude	Item 1	.04	.11	**.51**	.07	.08	.14	.08
	Item 2	.14	.13	**.43**	.05	.09	-.07	.09
	Item 3	.10	.22	.23	.04	.02	-.02	**.51**
	Item 4	.11	.09	**.62**	.02	.10	.03	.16
	Item 5	.07	.23	**.49**	.18	.13	-.02	.17
	Item 6	-.88	.04	.29	.02	.06	.27	**.31**
Transfer of knowledge	Item 7	.07	.14	.21	.16	**.59**	.23	.03
	Item 8	.18	.12	.16	.20	**.94**	.05	.03
	Item 9	.05	-.08	.03	**.27**	.21	-.08	.12
	Item 10	.05	.19	.18	.07	**.19**	.16	.15
	Item 11	.04	-.01	.13	.25	.20	.19	**.30**
	Item 12	.02	-.02	.30	-.19	-.09	.19	**.30**
Coaching	Item 13	-.02	.20	.28	.24	.17	**.46**	-.02
	Item 14	-.03	-.03	**.59**	.13	.04	.10	-.06
	Item 15	.19	.18	.01	**.59**	.02	.16	.11
	Item 16	.21	.21	.13	**.67**	.15	.16	-.16
	Item 17	.07	.24	.19	**.53**	.20	.04	.12
Guidance of facilities and resources	Item 18	.12	**.84**	.02	.13	.04	-.06	.24
	Item 19	.06	**.51**	.29	.10	.09	.14	-.14
	Item 20	.12	**.73**	.05	.12	.01	.10	.08
	Item 21	.03	**.60**	.16	.05	.15	.21	-.01
Self-management in consultation	Item 22	**.35**	-.05	.21	.22	-.05	.29	.14
	Item 23	.12	.28	.29	.05	-.03	**.35**	-.04
	Item 24	**.27**	.07	.19	.07	.15	.08	.08
	Item 25	.04	.15	-.07	.06	.11	**.43**	.15
Policy and organisation	Item 26	**.68**	.09	.20	.01	.08	-.09	-.05
	Item 27	**.53**	-.11	-.04	.22	-.07	.05	.33
	Item 28	**.65**	.01	.07	.21	.15	.10	.07
	Item 29	**.28**	.07	-.07	-.02	.-03	.08	.06
	Item 30	**.43**	-.01	.30	.23	.06	.16	.08
	Item 31	**.42**	.15	.21	.29	.09	.12	-.09
Environmental factors and conditions	Item 32	**.38**	-.11	-.06	.14	-.02	-.03	.03
	Item 33	**.54**	.12	.10	.06	.11	-.16	-.08
	Item 34	**.43**	.24	.08	.03	-.02	.09	-.02
	Item 35	**.49**	.00	-.02	-.01	.06	.37	-.02
	Item 36	**.70**	.12	.03	-.09	.07	-.11	.00

In Table S4.1.5 Cronbach's alphas of the S-scan domains are displayed. The Cronbach's alpha coefficient for the full questionnaire was .87, and for subscale 1 and 2 respectively .83 and .80. As according to Field (2009) Cronbach's alpha above .70 generally should be considered acceptable, most domains had acceptable or close to acceptable Cronbach's alphas. The Cronbach's alphas of the domains 'Transfer of knowledge' and 'Self-management in consultation' were insufficient though. Removing item 12 from 'Transfer of knowledge' would increase the Cronbach's alpha to .62 and excluding item 25 from 'Self-management in consultation' to Cronbach's alpha .50, which were both still not sufficient.

Table S4.1.5 Internal consistency of the seven S-scan domains

Domain	Number of items	Cronbach's alpha
Subscale 1		
A. Vision and attitude	6	.68
B. Transfer of knowledge	6	.57
C. Coaching	5	.70
D. Guidance of facilities and resources	4	.79
Subscale 2		
E. Self-management in consultation	4	.44
F. Policy and organisation within the institution	6	.71
G. Environmental factors and conditions	5	.64

CONCLUSION

After evaluation of the results of the pilot study, it was concluded that the S-scan had potential for use in the context of parental self-management support. Although the text of questionnaire appeared to be sufficiently understood, it was considered necessary to optimise the structure of the instrument as well as the wordings in the statements. It was therefore decided to continue with the development of the S-scan - PS.

REFERENCES

Field, A. (2009). *Discovering statistics Using SPSS. 3rd Edition*. Ltd., London: Sage Publications.

IBM Corporation (2015). *IBM SPSS statistics for Machintosh, Version 23.0*. Armonk, NY: IBM Corporation.

Yong, A. G., & Pearce, S. (2013). A beginner's guide to factor analysis: Focusing on exploratory factor analysis. *Tutorials in Quantitative Methods for Psychology*, *9*(2), 79-94. https://doi.org/10.20982/tqmp.09.2.p079

SUPPLEMENT 4.2

Table S4.2a Pattern matrix for exploratory factor analysis with six fixed factors

		Factor					
Domain	Item	1	2	3	4	5	6
A. Vision and attitude	Item 1	.12	**.61**	.00	.00	-.17	.13
	Item 2	.20	**.57**	.12	.13	.15	-.05
	Item 3	.07	**.41**	.28	.07	.07	.12
	Item 4	.06	**.47**	-.04	.05	.15	.07
	Item 5	-.01	**.47**	.15	.06	.16	-.18
	Item 6	.07	**.48**	.03	.09	-.08	.29
B. Knowledge transfer	Item 7	.11	.03	**.78**	.07	.06	.07
	Item 8	.09	.04	**.79**	.09	.04	.06
	Item 9	-.03	.11	**.16**	.00	.08	**.33**
	Item 10	.03	.12	**.49**	.12	.15	.08
	Item 11	-.01	.12	**.41**	.06	.14	.38
	Item 12	.05	**.33**	.15	.17	.11	.10
C. Coaching	Item 13	.06	**.53**	.06	.20	.27	-.14
	Item 14	.06	**.44**	-.08	.10	.38	.12
	Item 15	.15	.15	.42	**.42**	.22	-.02
	Item 16	.29	.15	**.39**	.37	.36	-.04
	Item 17	.24	.25	.34	**.45**	.20	-.17
D. Guidance of facilities and resources	Item 18	.14	.16	.13	**.78**	.06	-.06
	Item 19	.24	.10	.20	.35	**.46**	.20
	Item 20	.16	.16	.04	**.79**	.08	.17
	Item 21	.26	.18	.18	.24	**.44**	.11
E. Self-management in consultation	Item 22	.30	.17	.19	.02	**.48**	.00
	Item 23	**.27**	.23	.17	.23	.03	-.04
	Item 24	.10	**.35**	.28	.12	.31	-.27
	Item 25	.31	.14	.31	.13	**.46**	.14
F. Policy and organisation of self-management within the institution	Item 26	**.72**	.10	.05	.03	.17	.10
	Item 27	**.60**	.14	.10	.03	.24	.00
	Item 28	**.70**	-.05	.11	.08	.25	-.06
	Item 29	**.47**	.11	-.00	.24	-.01	-.16
	Item 30	**.43**	.31	.25	-.08	.17	-.13
	Item 31	**.50**	.22	.20	-.03	.40	-.09
	Item 32	**.54**	-.07	-.01	.02	.12	.02
	Item 33	**.71**	.09	.05	.13	.05	-.03
	Item 34	**.61**	.09	-.06	.17	-.03	.15
	Item 35	**.47**	.28	.11	.10	.07	.06
	Item 36	**.74**	.06	.11	.16	-.02	-.08

Table S4.2b Factor loadings for confirmatory factor analysis with six factors and internal

Domain	A. Vision and attitude	B. Transfer of knowledge	C. Coaching	D. Guidance of facilities and resources	E. Self-management in consultation	F. Policy and organisation of self-management within the institution
Item						
Item 1	0.48	-	-	-	-	-
Item 2	0.71	-	-	-	-	-
Item 3	0.65	-	-	-	-	-
Item 4	0.65	-	-	-	-	-
Item 5	0.57	-	-	-	-	-
Item 6	0.31	-	-	-	-	-
Item 7	0.66	-	-	-	-	-
Item 8	-	0.79	-	-	-	-
Item 9	-	0.85	-	-	-	-
Item 10	-	0.62	-	-	-	-
Item 11	-	0.56	-	-	-	-
Item 12	-	0.61	-	-	-	-
Item 13	-	-	0.60	-	-	-
Item 14	-	-	0.78	-	-	-
Item 15	-	-	0.80	-	-	-
Item 16	-	-	0.74	-	-	-
Item 17	-	-	-	0.67	-	-
Item 18	-	-	-	0.85	-	-
Item 19	-	-	-	0.80	-	-
Item 20	-	-	-	0.74	-	-
Item 21	-	-	-	-	0.62	-
Item 22	-	-	-	-	0.53	-
Item 23	-	-	-	-	0.65	-
Item 24	-	-	-	-	0.51	-
Item 25	-	-	-	-	0.70	-
Item 26	-	-	-	-	0.79	-
Item 27	-	-	-	-	-	0.59
Item 28	-	-	-	-	-	0.67
Item 29	-	-	-	-	-	0.77
Item 30	-	-	-	-	-	0.52
Item 31	-	-	-	-	-	0.49
Item 32	-	-	-	-	-	0.67
Item 33	-	-	-	-	-	0.62
Item 34	-	-	-	-	-	0.60
Item 35	-	-	-	-	-	0.77
Cronbach's alpha	.71	.71	.76	.77	.74	.86

Table S4.2c Test-retest intraclass correlation coefficients

Item	ICC	95% confidence interval
Item 1	.65	.44–.78
Item 2	.68	.49–.80
Item 3	.21	-.26–.51
Item 4	.46	.14–.67
Item 5	.49	.18–.68
Item 6	.36	-.03–.61
Item 7	.71	.53–.82
Item 8	.74	.57–.84
Item 9	.80	.68–.88
Item 10	.59	.34–.75
Item 11	.41	.05–.64
Item 12	-.20	-.91–.25
Item 13	.76	.61–.85
Item 14	.64	.42–.76
Item 15	.70	.51–.81
Item 16	.61	.36–.76
Item 17	.81	.69–.88
Item 18	.76	.61–.85
Item 19	.75	.60–.85
Item 20	.80	.67–.87
Item 21	.58	.32–.74
Item 22	.62	.38–.77
Item 23	.45	.12–.65
Item 24	.73	.57–.83
Item 25	.42	.07–.64
Item 26	.54	.27–.72
Item 27	.77	.57–.87
Item 28	.77	.64–.86
Item 29	.80	.67–.87
Item 30	.69	.50–.81
Item 31	.61	.36–.76
Item 32	.69	.50–.81
Item 33	.56	.30–.73
Item 34	.69	.49–.81
Item 35	.62	.40–.77

SUPPLEMENT 4.3

De Z-scan - Zelfmanagement ondersteuning van ouders (Z-scan - OvO); een zelfreflectie instrument voor zorgprofessionals

123 NAAR EIGEN REGIE…
ZELFMANAGEMENT ONDERSTEUNING VAN OUDERS IN DE ZORG VOOR HUN KIND MET EEN CHRONISCHE CONDITIE

Z-Scan - OvO
Zelfmanagement Ondersteuning van Ouders; een zelfreflectie instrument voor zorgprofessionals

Amsterdam Public Health

merem
MEDISCHE REVALIDATIE

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De studie die heeft geleid tot de 'Z-scan OvO is gepubliceerd in Child, Care, Health & Development, 2023: '**The development and validation of the S-scan - Parental self-management Support (S-scan - PS): A self-reflection tool for child healthcare professionals**'

Z-scan - OvO: Zelfmanagement Ondersteuning van Ouders - zelfreflectie instrument voor zorgprofessionals

Het doel van dit zelfreflectie instrument is het geven van handvatten om zelfmanagementondersteuning van ouders van kinderen met een chronische aandoening/beperking, in uw eigen praktijk te verbeteren. De zelfreflectie is te gebruiken door zowel individuele zorgverleners als door een team van zorgverleners. De Z-scan - OvO is opgebouwd uit twee delen.

Deel I bestaat uit een aantal stellingen over de mate waarin u als zorgprofessional, op dit moment, aandacht besteedt aan het stimuleren of verbeteren van zelfmanagement van ouders binnen uw huidige praktijk.
Onder zelfmanagementondersteuning wordt hierbij verstaan, de *empowerment* van ouders voor actieve betrokkenheid in het management van de chronische aandoening/beperkingen van hun kind, in overeenstemming met hun interesses en mogelijkheden. Hierbij hoort onder meer het vergroten van kennis; het stellen van doelen in partnerschap tussen ouder en zorgprofessionals en in lijn met behoeftes, waarden en gewenste kwaliteit van leven; inclusie van verzorgers en familie in de planning van zorg (Australian Health Ministers' Advisory Counsil, 2017) *.

In **Deel II** worden uw antwoorden per domein gerangschikt in een spinnenwebdiagram. U kunt zo in één oogopslag zien op welke onderdelen u mogelijk doelen zou kunnen stellen om zelfmanagementondersteuning van ouders in uw praktijk te verbeteren.

De stellingen die in Deel I worden bevraagd zijn ondergebracht in **6 domeinen**. De vragen in domein A t/m E gaan over uw visie en wat u in uw dagelijkse praktijk aan zelfmanagementondersteuning doet. De vragen in domein F gaan over de ondersteuning van zelfmanagement binnen de organisatie waar u werkt.

A. Visie en attitude
B. Kennisoverdracht
C. Coaching
D. Wegwijzen voorzieningen
E. Zelfmanagement in het consult
F. Beleid en organisatie van zelfmanagement in de instelling

De Z-scan - OvO is gebaseerd op de Z-scan (CBO - M. Zwier, 2012). Deze werd ontwikkeld in het Landelijk Actieprogramma Zelfmanagement (LAZ), gericht op de zelfmanagement-ondersteuning van volwassen patiënten met een chronische ziekte.
De Z-scan - OvO is tot stand gekomen met financiële ondersteuning vanuit het onderzoeks-programma: Quality of Care van het Amsterdam Public Health research institute (APH). Het instrument is ontwikkeld en gevalideerd als onderdeel van het PhD project "123 towards Autonomy?! Parental self-management support in paediatric rehabilitation services" (R.W. Wong Chung, Amsterdam Public Health, Vrije Universiteit van Amsterdam, Faculteit der Gedrags- en Bewegingswetenschappen).

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* Australian Health Ministers' Advisory Council. (2017). *National strategic framework for chronic conditions.* Canberra: Australian Government.

DEEL I - Stellingen zelfmanagementondersteuning

Invul instructie
Hieronder staan 35 stellingen die betrekking hebben op het ondersteunen van zelfmanagement van ouders in relatie tot de zorg voor hun kind met een chronische aandoening/beperking. Geef aan of u het eens bent met de volgende stellingen door de antwoordoptie aan te kruisen die voor u als zorgprofessional op dit moment het meest van toepassing is.

U kunt kiezen uit 6 antwoordopties, lopend van **helemaal mee oneens/nooit** tot **helemaal mee eens/altijd**

A. Visie en attitude		
1	Ik vind het belangrijk dat ouders zelf kiezen hoe de voor hen beschikbare zorg wordt ingezet;	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○
2	Ik ga altijd uit van wat ouders willen en kunnen;	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○
3	Het opbouwen van een vertrouwensrelatie met ouders is voor mij de basis om zelfmanagement te ondersteunen;	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○
4	Ik vind het belangrijk zorg aan te bieden die past bij de waarden, opvattingen en cultuur van ouders;	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○
5	Ik respecteer en waardeer de ervaringsdeskundigheid van ouders;	nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6) ○ ○ ○ ○ ○ ○
6	Ik vind het belangrijk dat ouders kunnen omgaan met de ziekte van hun kind en de consequenties daarvan op hun	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○

<table>
<tr><td></td><td>dagelijkse leven;</td><td></td></tr>
<tr><td>7</td><td>Ook als de doelen niet direct medisch zijn, ondersteun ik deze als ouders ze belangrijk vinden;</td><td>nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6)
○ ○ ○ ○ ○ ○</td></tr>
</table>

<table>
<tr><th colspan="3">B. Kennisoverdracht</th></tr>
<tr><td>8</td><td>Ik leer ouders waar ze op moeten letten ten aanzien van klachten en symptomen;</td><td>helemaal een beetje een beetje helemaal
mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6)
○ ○ ○ ○ ○ ○</td></tr>
<tr><td>9</td><td>Ik leer ouders de samenhang tussen de ziekte en de symptomen te zien;</td><td>nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6)
○ ○ ○ ○ ○ ○</td></tr>
<tr><td>10</td><td>Moeilijke of ingewikkelde informatie leg ik op een voor ouders passende manier uit;</td><td>nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6)
○ ○ ○ ○ ○ ○</td></tr>
<tr><td>11</td><td>Ik vind het belangrijk om te weten welke kennis ouders hebben over de ziekte;</td><td>helemaal een beetje een beetje helemaal
mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6)
○ ○ ○ ○ ○ ○</td></tr>
<tr><td>12</td><td>Ik vind het belangrijk dat ouders weten waar zij terecht kunnen met vragen;</td><td>helemaal een beetje een beetje helemaal
mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6)
○ ○ ○ ○ ○ ○</td></tr>
</table>

<table>
<tr><th colspan="3">C. Coaching</th></tr>
<tr><td>13</td><td>Ik stem mijn behandeling af op de wensen en behoeften van ouders;</td><td>nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6)
○ ○ ○ ○ ○ ○</td></tr>
<tr><td>14</td><td>Ik help ouders haalbare doelen te stellen;</td><td>nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6)
○ ○ ○ ○ ○ ○</td></tr>
<tr><td>15</td><td>Ik stimuleer ouders verschillende mogelijkheden te</td><td>nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6)
○ ○ ○ ○ ○ ○</td></tr>
</table>

	verkennen om hun doel te bereiken;						
16	Ik help ouders activiteiten te kiezen die hun kind goed aankan;	nooit(1) ○	. bijna nooit(2) ○	soms(3). ○	. meestal(4) ○	bijna altijd(5). ○	altijd(6) ○

D. Wegwijzen voorzieningen

17	Ik verzamel betrouwbare informatie over voorzieningen en deel dit met ouders;	nooit(1) ○	. bijna nooit(2) ○	soms(3). ○	. meestal(4) ○	bijna altijd(5). ○	altijd(6) ○
18	Ik wijs ouders op personen of organisaties die kunnen helpen/ ondersteunen in het leven met de ziekte;	nooit(1) ○	. bijna nooit(2) ○	soms(3). ○	. meestal(4) ○	bijna altijd(5). ○	altijd(6) ○
19	Ik zoek samen met ouders naar voorzieningen die passen bij de voorkeur, affiniteit en leefwereld van hen en hun kind;	nooit(1) ○	. bijna nooit(2) ○	soms(3). ○	. meestal(4) ○	bijna altijd(5). ○	altijd(6) ○
20	Ik kan ouders goed wegwijs maken in de zorg;	helemaal mee oneens(1) ○	mee oneens(2) ○	een beetje mee oneens(3) ○	een beetje mee eens(4) ○	mee eens(5) ○	helemaal mee eens(6) ○

E. Zelfmanagement in het consult

21	In onze praktijk kunnen ouders op een voor hen passende manier een eigen aandeel in de zorg nemen;	helemaal mee oneens(1) ○	mee oneens(2) ○	een beetje mee oneens(3) ○	een beetje mee eens(4) ○	mee eens(5) ○	helemaal mee eens(6) ○
22	Ouders beslissen over het instellen en aanpassen van de	nooit(1) ○	. bijna nooit(2) ○	soms(3). ○	. meestal(4) ○	bijna altijd(5). ○	altijd(6) ○

	behandeling in overleg met mij;						
23	Als ik informatie geef, sluit ik aan bij wat ouders willen weten over de ziekte en/of behandeling van hun kind;	nooit(1) ○	bijna nooit(2) ○	soms(3). ○	meestal(4) ○	bijna altijd(5). ○	altijd(6) ○
24	In elk consult vraag ik ouders wat hen goed afgaat in het leven met de ziekte en welke problemen zij ervaren;	nooit(1) ○	bijna nooit(2) ○	soms(3). ○	meestal(4) ○	bijna altijd(5). ○	altijd(6) ○
25	Ik laat ouders bepalen hoeveel eigen regie zij wensen;	nooit(1) ○	bijna nooit(2) ○	soms(3). ○	meestal(4) ○	bijna altijd(5). ○	altijd(6) ○
26	Ik zoek naar interventies die de voor ouders optimale eigen regie ondersteunen;	nooit(1) ○	bijna nooit(2) ○	soms(3). ○	meestal(4) ○	bijna altijd(5). ○	altijd(6) ○

F. Beleid en organisatie van zelfmanagement in de instelling

27	Wij hebben een visie geformuleerd over zelfmanagement in ons team;	helemaal mee oneens(1) ○	mee oneens(2) ○	een beetje mee oneens(3) ○	een beetje mee eens(4) ○	mee eens(5) ○	helemaal mee eens(6) ○
28	In ons team zijn voldoende competenties aanwezig om zelfmanagement van ouders te ondersteunen en te stimuleren;	helemaal mee oneens(1) ○	mee oneens(2) ○	een beetje mee oneens(3) ○	een beetje mee eens(4) ○	mee eens(5) ○	helemaal mee eens(6) ○
29	In mijn praktijk is voor iedereen duidelijk wie wat doet om zelfmanagement van	helemaal mee oneens(1) ○	mee oneens(2) ○	een beetje mee oneens(3) ○	een beetje mee eens(4) ○	mee eens(5) ○	helemaal mee eens(6) ○

	ouders te ondersteunen;	
30	Elk kind in mijn praktijk heeft een zorgplan waarin zijn/haar wensen en behoeften, en die van ouders, zijn meegenomen;	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○
31	In mijn praktijk zijn er voldoende ICT mogelijkheden om zelf-management van ouders te ondersteunen;	nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6) ○ ○ ○ ○ ○ ○
32	Zelfmanagement van ouders ondersteunen is een speerpunt in onze kwaliteitszorg;	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○
33	Wij hebben in onze praktijk een uitgebreid overzicht (sociale kaart) met mogelijkheden ter ondersteuning van ouders;	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○
34	Ik bied ouders de mogelijkheid tussentijds contact te hebben voor feedback of vragen over zelfmanagement;	nooit(1) |. bijna nooit(2) | soms(3). |. meestal(4) | bijna altijd(5). | altijd(6) ○ ○ ○ ○ ○ ○
35	Zelfmanagement ondersteuning van ouders is een vast onderdeel van al onze zorgprotocollen.	helemaal een beetje een beetje helemaal mee oneens(1) | mee oneens(2) | mee oneens(3) | mee eens(4) | mee eens(5) | mee eens(6) ○ ○ ○ ○ ○ ○

Voor het berekenen van de scores kunt u de volgende procedure aanhouden:

$$\text{Totaalscore} = \frac{\text{het totaal aantal gescoorde punten op de Z-scan OvO}}{35}$$

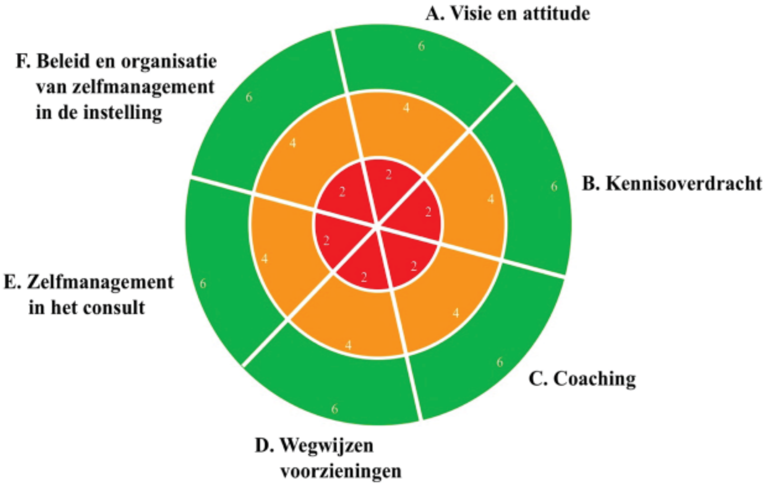
$$\text{Domeinscore} = \frac{\text{het totaal aantal gescoorde punten binnen het betreffende domein}}{\text{Het aantal vragen in het domein}}$$

DEEL II - Spinnenwebdiagram

Hieronder kunt u de resultaten invullen van de zelfreflectie in de vorm van een spinnenweb diagram. Vul hiervoor de gemiddelde score in per domein (Domeinscore)

$$\text{Domeinscore} = \frac{\text{het totaal aantal gescoorde punten binnen het betreffende domein}}{\text{Het aantal vragen in het domein}}$$

De domeinen waarop u in het groen gekleurde deel van het diagram scoort, zijn in principe voldoende. De domeinscores die in het spinnenweb diagram zijn weergegeven met de kleuren oranje of rood, zijn domeinen waarop verbetering kan worden behaald.



SUPPLEMENT 4.4

The S-scan - Parental self-management support (S-scan - PS); a self-reflection tool for child healthcare professionals.

123 TOWARDS AUTONOMY…
SELF-MANAGEMENT SUPPORT FOR PARENTS REGARDING THE CARE FOR THEIR CHILD WITH A CHRONIC CONDITION

S-scan - PS
Parental self-management Support; a self-reflection tool for child healthcare professionals

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This English translation of the Dutch instrument: ‘Z-scan OvO, Zelfmanagement Ondersteuning van Ouders: Zelfreflectie instrument voor Zorgprofessionals’ has not been validated but has been made available for the benefit of the readers of the article: **‘The development and validation of the S-scan - Parental self-management Support (S-scan - PS): A self-reflection tool for child healthcare professionals’,** published in Child, Care, Health & Development, 2023.

S-scan - PS: Parental self-management Support - Self-reflection tool for child healthcare professionals

The purpose of this self-reflection tool is to provide, within your own practice, ways for improving the self-management support for parents of children with a chronic disorder/disability. The self-reflection can be utilized by both individual professionals and teams. The S-scan - PS is comprised of two parts.

Part I consists of a number of statements regarding the extent to which you, the child healthcare provider, are paying attention to the stimulation of improving the self-management of parents within your current practice.
Parental self-management support is understood to signify the empowerment of parents with regard to active involvement within the management of the chronic condition/disability of their child, in accordance with the child's interests and abilities. This includes the enhancement of knowledge; the setting of goals done in partnership between parent(s) and healthcare professionals which are in line with the needs, values, and desired quality of life; the inclusion of caregivers and/or family in the planning of care (Australian Health Ministers' Advisory Council, 2017) *.
In **Part II**, your answers are ordered per domain in a cobweb diagram. This makes it possible to see 'at a glance' for which specific domains you could set goals in order to improve in your practice the support of self-management of parents regarding the care for their child.

The statements that are questioned in Part I are placed in **6 domains**. The questions contained in domains A through E concern your vision/standpoint as well as what you do with regards to self-management support in your daily practice. The questions in domain F are about the support/backing of self-management within the institution where you work.

A. Vision and attitude
B. Transfer of knowledge
C. Coaching
D. Guidance of facilities and resources
E. Self-management in consultation
F. Policy and organization of self-management within the institution

The S-scan - PS (Dutch: Z-scan OvO) is based on the Z-scan (CBO - M. Zwier, 2012). The Z-scan was developed in the National Self-Management Action Program Self-management (Landelijk Actieprogramma Zelfmanagement / LAZ), aimed at the self-management support of adult patients with a chronic disease. The Z-scan - OvO has been developed and validated as part of the PhD project "123 towards Autonomy?! Parental self-management support in pediatric rehabilitation services" (R.W. Wong Chung, Amsterdam Public Health, Vrije Universiteit Amsterdam, Faculty of Behavioral and Movement Sciences).

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*Australian Health Ministers' Advisory Council. (2017). *National strategic framework for chronic conditions.* Canberra: Australian Government.

PART I - Self-management support statements

Instructions
Below are 35 statements pertaining to the support of self-management of parents in relation to the care of their child with a chronic disorder/disability. Please indicate whether you agree with the following statements by marking the option that is the most currently applicable to you as a healthcare provider.

You can choose from 6 answer choices, ranging from **completely disagree/never** to **completely agree/always**

A. Vision and attitude

1	I think it is important that parents themselves choose how the care made available to them is utilized;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
2	I always start out from what parents want and are also able to do;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
3	Building a trusting relationship with parents is for me the basis on which to support self-management;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
4	I think it is important to provide care that fits within with the values, views and culture of parents;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
5	I respect and appreciate the experiential expertise of parents;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
6	I think it is important that parents are able to cope with their child's disease as well as its consequences on their daily lives;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
7	Even if the goals are not directly medical, I support them if parents think that they are important;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○

B. Transfer of knowledge

8	I teach parents what to pay attention to with regard to complaints and symptoms;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○

9	I teach parents to recognize the connection between the disease and the symptoms;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
10	I explain difficult and/or complex information in a manner that is more suited for parents;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
11	I think it is important to identify what knowledge the parents have about the disease;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
12	I think it is important that parents know where they can go when they have questions;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○

C. Coaching

13	I adjust my treatment to the wishes and needs of parents;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
14	I help parents set feasible goals;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
15	I encourage parents to explore different options in order to reach their goal(s);	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
16	I help parents choose activities that their child can handle well;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○

D. Guidance of facilities and resources

17	I collect reliable information about facilities/resources and share this with parents;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○

18	I refer parents to persons and/or organizations who can help/support them in living with the disease;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
19	Together with parents, I look for facilities/resources that suit them and their child's preferences, affinities and environment;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
20	I do a decent job in guiding parents through the care process;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○

E.	**Self-management in consultation**						
21	In our practice parents can take part in the care process in a way that suits them;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
22	Parents make decisions regarding establishing and adjusting treatment in consultation with me;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
23	When I provide information, I ensure to align with what the parents <u>want</u> to know about the disease and/or treatment of their child;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
24	In every consultation I ask parents what goes well in their lives with regards to the disease, as well as what problems they experience;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
25	I let parents determine how much autonomy they wish to have;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
26	I search for interventions that support optimal autonomy of parents;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○

F. Policy and organization of self-management within the institution

27	We have formulated a vision concerning self-management in our team;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
28	There are sufficient competencies in our team to support and encourage the self-management of parents;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
29	Within my practice it is clear for everyone who does what in order to support the self-management of parents;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
30	Every child in my practice has a plan of care that includes his/her wishes and needs, as well as those of the parents;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
31	In my practice there are sufficient IT possibilities to support the self-management of parents;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
32	Supporting the self-management of parents is a priority in our quality of care;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
33	In our practice we have an extensive overview (social map) with options to support parents;	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○
34	I offer parents the opportunity to have intermediary contact intended for feedback and/or questions concerning self-management;	never(1) ○	almost never(2) ○	sometimes(3) ○	mostly(4) ○	almost always(5) ○	always(6) ○
35	Parental self-management support is a set portion of all our care protocols.	completely disagree(1) ○	disagree(2) ○	slightly disagree(3) ○	slightly agree(4) ○	agree(5) ○	completely agree(6) ○

You can utilize the following formulas to calculate the scores:

$$\text{Total score} = \frac{\text{the total number of points scored in the S-scan PS}}{35}$$

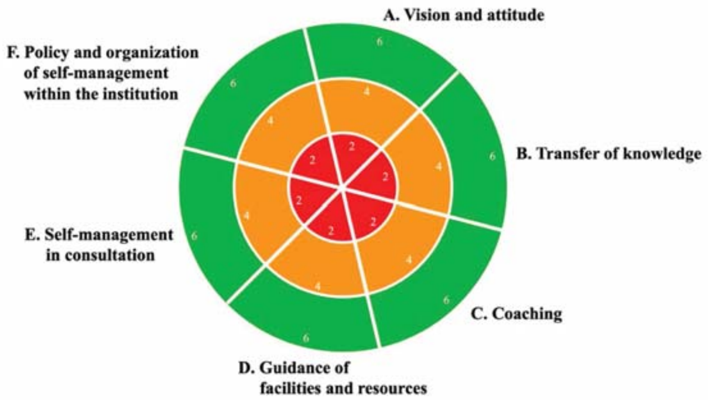
$$\text{Domain score} = \frac{\text{the total number of points scored within the domain in question}}{\text{the number statements within the specific domain}}$$

PART II – Cobweb-like diagram

Below you can enter the results of the self-diagnosis in the form of a cobweb diagram. To do this, enter the average score per domain (Domain score)

$$\text{Domain score} = \frac{\text{the total number of points scored within the domain in question}}{\text{the number of questions within the specific domain}}$$

The domains in which you scored in the green-colored sections of the diagram are generally sufficient. Orange and red scores in the cobweb diagram indicate domains where improvement can still be achieved.



5

Shared decision-making 2.0! Co-creating an interactive media platform for shared decision making in paediatric rehabilitation services together with parents

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ABSTRACT

The global impact of the COVID-19 pandemic has underscored the integral role of eHealth and digital communication in the future of rehabilitation services.

Since 2019, at Merem Medical Rehabilitation an interactive media platform has been developed aimed at enhancing partnership, communication, and shared decision-making between parents of children with chronic disabilities and healthcare professionals. The creation of this innovation presented both opportunities and challenges. Shared decision-making, involving stakeholders throughout all phases, appeared as a critical success factor during the platform's development and implementation. This article reflects on the experiences of the project, contributing insights to a knowledge base for similar innovative rehabilitation initiatives.

INTRODUCTION

Family-centred care, where parents and healthcare professionals collaborate in the treatment of children with a chronic disability, has been accepted as the standard in child healthcare (Almasri et al., 2018; Gerlach & Varcoe, 2021). Empowering parents in autonomy, participation, and self-management is integral to this approach (Kratz et al., 2009; Olij et al., 2021; Phoenix et al., 2019). Children with chronic disabilities often follow a lengthy rehabilitation treatment process spanning several years. Therefore, effective collaboration between parents, as experts on their child, and healthcare professionals is crucial. Aligning treatment with the perspectives and expectations of the home environment is likely to enhance its effectiveness and overall experience.

Over the past decades, digital resources have gained recognition for facilitating parent-healthcare professional communication (Cerdan et al., 2017; Gulmans et al., 2012). An interactive digital media platform, in addition to face-to-face therapy, enables communication through photos, videos, and text. Such 'hybrid' treatment brings the context of child and parent, and that of the professional closer together. A media platform offers professionals insights into the home situation, aiding in tailoring therapy to the specific needs of parents and children. Parents in turn, get a better idea and more control regarding the treatment processes within the rehabilitation centre. Seeing what is performed during therapy may help parents transfer aspects of the treatment into their home situation. As such, it might indirectly foster a child's learning in the context of its own environment. However, strict rules and legislation regarding privacy and security in healthcare result in major challenges when using existing digital channels, like WhatsApp or YouTube, which often fall short of required electronic safety standards.

Preliminary investigation

The PhD trajectory 'One, two, three, towards autonomy?! Supporting parental self-management in paediatric rehabilitation services', by Ruud Wong Chung at the Faculty of Behavioural and Human Movement Sciences of the Vrije Universiteit Amsterdam aims to support autonomy and self-management of parents of children with chronic disabilities in child healthcare. The first phase of the traject investigated motivation and underlying perceptions of both parents and healthcare professionals in paediatric rehabilitation. Autonomy support, short lines of communication, and shared decision-making emerged as vital conditions for effective collaboration and parental self-management. Professionals expressed limitations in contact with parents, also because they perceived their available treatment time as increasingly limited. Several professionals indicated the need for additional training to assume a 'coaching role' towards parents. Parents for their side expected expert knowledge, engagement, and empathy of professionals (Wong Chung et al., 2020; Wong Chung et al., 2021).

Co-creation of the interactive media platform

The project, conducted at Merem Medical Rehabilitation, aimed to create a media platform for digital interaction, enhancing communication and tuning between parents and healthcare professionals, Figure 5.1. The methodological approach was inspired by participatory research, involving all relevant stakeholders from the outset, co-creating and co-deciding in all phases of the project (Chevalier & Buckles, 2013). A project group, comprising parents, professionals, management, planning, IT-department, software supplier, and researchers, collaborated to shape the project. Shared decision-making guided the development and implementation of desired functionalities within the media platform.

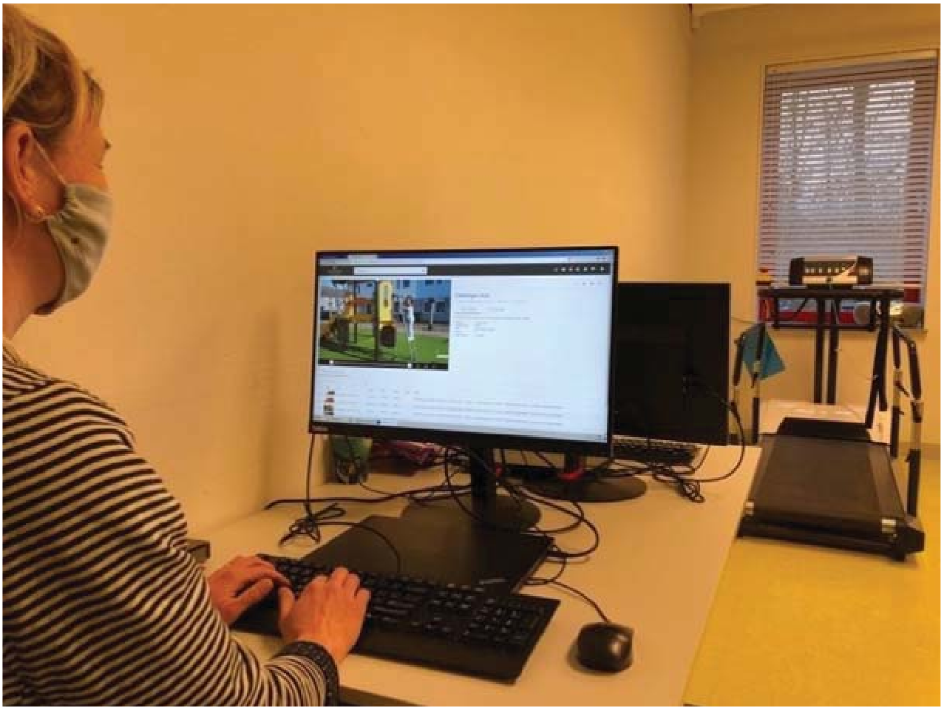


Figure 5.1 Interactive media platform.

The project framework (Figure 5.2) included two overlapping pilots in two children's teams at different locations of Merem. In total 58 parents (RR 67.4%) and 63 professionals (RR 87.5%) agreed to participate in the project.

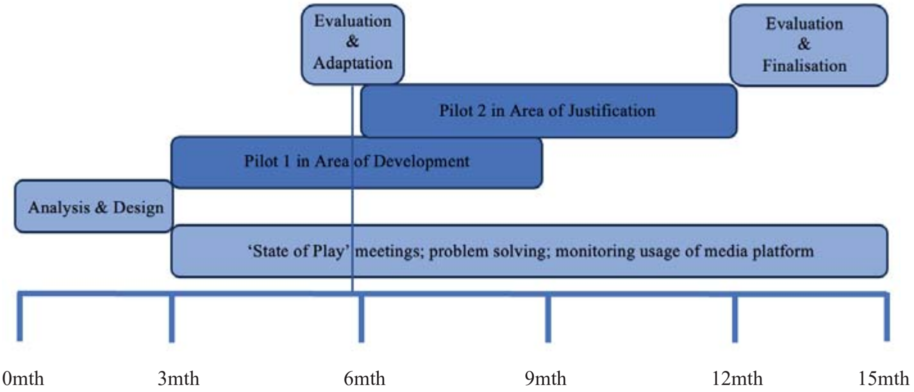


Figure 5.2 Project framework for creation of the media platform.

The ADDIE model, encompassing five overlapping phases: analysis, design, development, implementation, and evaluation, steered the iterative innovation process (Gustafson & Branch, 2007), see Figure 5.3. In the 'Analyse' and 'Design' phases, the findings of the preliminary investigation were discussed, the framework of the project set, and preconditions and structure of the media platform realised. An existing digital media platform, arQive, was chosen for further development and implementation.

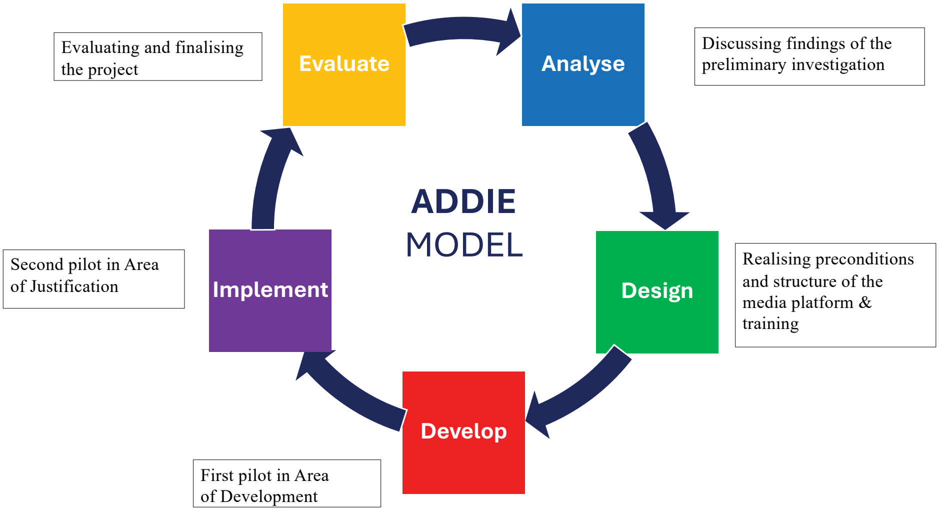
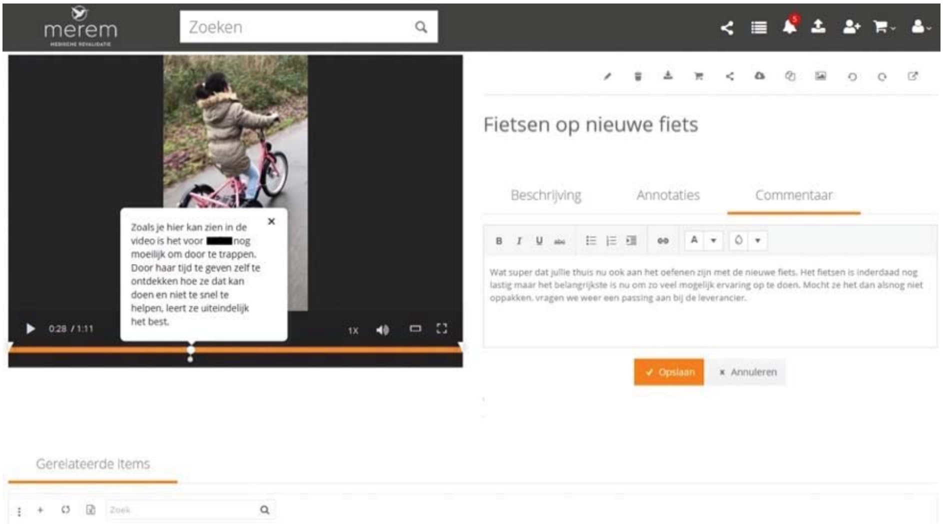


Figure 5.3 The ADDIE-model.

The opportunity to exchange images was an explicit desire. The point of departure was that all professionals and parents should be able to upload and edit media files in the platform. Feedback should be directly linked to the visual material via annotations and comments, see Figure 5.4. The system had to be fully integrated within Merem's Electronic Patients File. Additional collaboration took place with the software supplier regarding their 'arQive Camera App', making it possible to upload videos and photos directly into the platform without storage on the media carrier itself. All aspects of the innovation had to be compliant with existing privacy and safety standards. The 'Develop' phase consisted of the first pilot, serving as a so-called 'Area of Development'. Halfway through pilot 1, just before the start of pilot 2, time was reserved for mid-term evaluation and adaptation. In the 'Implement' phase the pilot was repeated in a children's team at a different site of Merem to observe whether the media platform would also hold in another environment, thus constituting an 'Area of Justification'. Lastly, the project was evaluated and finalised in the 'Evaluate' phase. Stakeholders in the project group were asked to reflect on the project with use of the MIDI - Measurement Instrument for Determinants of Innovation (Fleuren et al., 2014) and two focus group interviews.



Zoals je hier kan zien in de video is het voor [redacted] nog moeilijk om door te trappen. Door haar tijd te geven zelf te ontdekken hoe ze dat kan doen en niet te snel te helpen, leert ze uiteindelijk het best.

Fietsen op nieuwe fiets

Wat super dat jullie thuis nu ook aan het oefenen zijn met de nieuwe fiets. Het fietsen is inderdaad nog lastig maar het belangrijkste is nu om zo veel mogelijk ervaring op te doen. Mocht ze het dan alsnog niet oppakken. vragen we weer een passing aan bij de leverancier.

Figure 5.4 Annotations in the interactive media platform.

Throughout all ADDIE-phases the project group met on a regular basis to discuss the state of play and solve urgent issues. End users were intermittently asked for verbal feedback by project group members. Usage of the media platform additionally was monitored by a functional application manager.

To optimise acceptance and usage of the media platform, an 'education development group' prepared a specific training for professionals, to be conducted at the start and halfway each pilot. The training aimed to increase the actual use of the media platform through technical instruction, showing good practice, and exchanging experiences. Additionally, the training sought to enhance the motivation, attitude, knowledge, and skills, of professionals regarding an autonomy supportive, coaching, treatment approach. As with the development of the media platform itself, the process was steered by shared decision-making together with parents. Parents, as experts by experience, also took an explicit role in providing the training.

Impact of the COVID-19 pandemic

In March 2020, just before the start of the second pilot, the Netherlands went into lockdown due to Covid-19. This had huge implications for the original project framework and design. Face-to-face treatment became nearly impossible, posing unforeseen challenges and opportunities. Professionals in general felt overloaded by the impact of Covid-19, influencing their motivation towards the project. Several parents who had agreed to participate in the project suddenly more or less disappeared out of sight. The additional trainings had to be partially cancelled and conducted online.

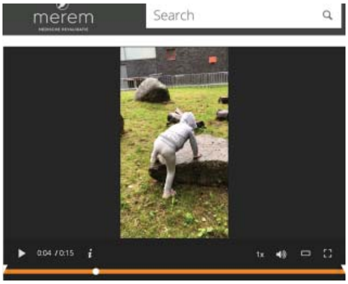
On the other hand, several professionals and parents, initially reluctant to be involved in the project, experienced a 'sense of urgency' as the media platform offered the opportunity for remote treatment. General technical preconditions were prioritised facilitating easier realisation. At top-level management it was decided to make the platform immediately available to the entire organisation. For new teams however, a roll-out was chosen as 'lean' as possible, with minimal technical instruction and support, and without the accompanying training.

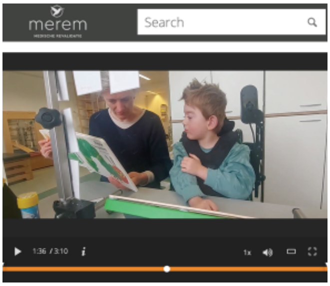
RESULTS AND CHALLENGES

The project resulted in an interactive media platform that has been fully integrated in Merem's Electronic Patient File, meeting the obligatory standards for electronic safety and privacy, and suitable for parents and healthcare professionals to interact in the context of treatment. See Figure 5.5 for some examples.

- Parents have questions about their child's behaviour during eating. They upload a video, and the remedial educationalist thinks along.

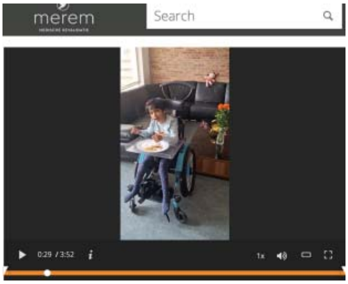
- The physiotherapist uploads a video of a child climbing onto obstacles in the schoolyard and gives tips in the video regarding guidance. Inspired by the video, parents take their child to the playground in their own neighbourhood.





- The speech and language therapist reads a book with a child, incorporating the use of a communication device, and records the session. This provides parents with a practical example of how they can read with their child at home.

- Parents feel that their child’s position in the wheelchair is not optimal and wonder whether the chair has become too small. They film their child sitting in her adapted chair. The occupational therapist organises a fitting for the chair and makes a step-by step instruction for parents how to position the child optimally in the chair. A home visit is not necessary because of the video.



- A therapeutic group worker places photos on the media platform of an activity in the context of the current group theme. Grandpa and grandma really enjoy watching the pictures together with parents of the child.

- The rehabilitation physician watches the videos uploaded by parents and professionals before a consultation. At the start of the conversation, she watches one of the uploaded videos together with parents. Parents are visibly proud of what their child shows at home.

Figure 5.5 Examples of parent-healthcare professional interaction within the media platform.

Challenges during the project included organisational and technical issues. The IT-department had difficulty guaranteeing WIFI-network strength, sufficient electronic devices, and technical support. Changes in management, and employee resistance posed complications. Several project group members expressed that at top-level management they experienced lack of (financial) guarantee for the embedment of the digital media platform within the organisation. Additionally, involvement of MarCom (Marketing and Communication) to raise awareness in the organisation about the added value of the media platform, was missed.

Despite positive ideas about the project's objectives, several professionals expressed fear that the media platform in future could lead to imposed reduction of face-to-face contact with their patients. Others felt too overloaded to start using the media platform. Although many participating parents were positive about the opportunity to communicate via the media platform, there were also parents who considered it too time-consuming in practice. Additionally, concerns were raised about the user-friendliness of especially the accompanying arQive Camera App.

FOLLOWING SITUATION

In the spring of 2021, some months after the project had finished, the interactive arQive media platform, with functionalities developed in the project, was available to all treatment teams across all locations of Merem Medical Rehabilitation. Further optimisation of the functionalities, user-friendliness, and technical support remained necessary. User reactions from the initially participating teams were nevertheless generally positive. However, monitoring of the arQive media platform, revealed that it was mainly used in the teams that fully participated in the project, had been offered the opportunity to contribute ideas, co-decided on content and conditions, and received additional trainings. In the other teams, where the platform was made available at the start of the first COVID-19 lockdown, with minimal support and without additional training, the platform was sparsely used. Individual professionals from those teams were generally more hesitant to embrace the innovation as part of their treatment toolbox.

CONCLUSION

This project aimed to create an interactive digital media platform fostering short communication lines and tuning between parents and healthcare professionals, in the treatment for children with chronic disabilities. Despite the challenges imposed by the COVID-19 pandemic, shared decision-making involving all stakeholders from the project's inception appeared crucial for a successful innovation process, as suggested by Edwards et al. (2021). Additional training focusing on the motivation, expectations and attitude of individual professionals, and the vision of treatment teams, supported the actual use of the media platform. Healthcare organisations should provide structural financial and technical support that meet the end users' expectations, to ensure continued intention for use and further development of digital innovations (Ammenwerth, 2019; Venkatesh et al., 2003). Further investigation into determinants of successful end user engagement and the effectiveness of digital parent-healthcare professional interaction is recommended.

POSTSCRIPT

The original project to create the interactive media platform was designed as a research framework with structurally planned moments of data collection in each of the pilots (T0, T1, T2) among the end users—parents and healthcare professionals—on their views and experiences regarding the media platform. The outbreak of COVID-19 unfortunately tampered the original research project plan, making scientific evaluation of the usage of the media platform impossible. Nevertheless, the authors believe that the information shared in this article about the process of co-creating the media platform together with representatives of all stakeholders, can serve as an example of a development - implementation process, informed by the findings regarding the support of parental self-management as described in chapter two and three of this PhD-dissertation. Accordingly, it might contribute to the recognition of stakeholder involvement throughout all phases of an innovation project.

REFERENCES

Almasri, N. A., An, M., & Palisano, R. J. (2018). Parents' perception of receiving family-centered care for their children with physical disabilities: A meta-analysis. *Physical & Occupational Therapy in Pediatrics, 38*(4), 427-443. https://doi.org/10.1080/01942638.2017.1337664

Ammenwerth, E. (2019). Technology acceptance models in health informatics: TAM and UTAUT. *Studies in Health Technology and Informatics*, *263*, 64-71. https://doi.org/10.3233/shti190111

Cerdan, J., Catalan-Matamoros, D., & Warny Berg, S. (2017). Online communication in a rehabilitation setting: Experiences of patients with chronic conditions using a web portal in Denmark. *Patient Education and Counseling, 100*(12), 2283-2289. https://doi.org/10.1016/j.pec.2017.06.023

Chevalier, J., & Buckles, D. *Participatory Action Research*. Routledge; 2013.

Edwards, J., Waite-Jones, J., Schwarz, T., & Swallow, V. (2021). Digital technologies for children and parents sharing self-management in childhood chronic or long-term conditions: A scoping review. *Children*, *8*(12),1203. https://doi.org/10.3390/children8121203

Gerlach, A., & Varcoe, E. (2021). Orienting child- and family-centered care toward equity. *Journal of Child Health Care, 25*(3), 457-467. https://doi.org/10.1177/1367493520953354

Gulmans, J., Vollenbroek-Hutten, M., Van Gemert-Pijnen, L., & Van Harten, W. (2012). A web-based communication system for integrated care in cerebral palsy: Experienced contribution to parent-professional communication. *International Journal of Integrated Care, 12,* e9. https://doi.org/10.5334/ijic.672

Gustafson, K. L., & Branch, R. M. (2007). *What is instructional design?* In R. A. Reiser & J. V. Dempsey (Eds.), *Trends and issues in instructional design and technology* (pp. 10-17). Pearson Education.

Fleuren, M. A. H., Paulussen, T. G. W. M., Van Dommelen, P., & Van Buuren, S. (2014). Towards a measurement instrument for determinants of innovations. *International Journal for Quality in Health Care, 26*(5), 501-510. https://doi.org/10.1093/intqhc/mzu060

Kratz, L., Uding, N., Trahms, C. N., Villareale, N., & Kieckhefer, G. M. (2009). Managing childhood chronic illness: parent perspectives and implications for parent-provider relationships. *Family, Systems, & Health*, *27*(4), 303-313. https://doi.org/10.1037/a0018114

Olij, C., Vos, M., Van Oostrum, N., Van Etten-Jamaludin, F., & Maaskant, J. (2021). Effective interventions to support self-management for parents of children with a chronic condition: A systematic review. *Maternal and Child Health Journal*, *25*(12), 1842-1865. https://doi.org/10.1007/s10995-021-03244-x

Phoenix, M., Jack, S. M., Rosenbaum, P. L., & Missiuna, C. (2019). A grounded theory of parents' attendance, participation and engagement in children's developmental rehabilitation services: Part 2. The journey to child health and happiness. *Disability and Rehabilitation*, *42*(15), 2151-2160. https://doi.org/10.1080/09638288.2018.1555618

Venkatesh, V., Morris, M., Davis, G., & Davis, F. (2003). User acceptance of information technology: Toward a unified view. *MIS Quarterly*, *27*(3),425-478. https://ssrn.com/abstract=3375136

Wong Chung, R. W., Willemen, A. M., Voorman, J. M., Ketelaar, M., Becher, J. G., Verheijden, J. M. A., & Schuengel, C. (2020). Managing oneself or managing together? Parents' perspectives on chronic condition self-management in Dutch paediatric rehabilitation services. *Disability and Rehabilitation*. *42*(23), 3348-3358. https://doi.org/10.1080/09638288.2019.1594396

Wong Chung, R. W., Willemen, A. M., Voorman, J. M., Ketelaar, M., Becher, J. G., & Schuengel, C. (2021). Professionals' motivation to support parental self-management regarding children with physical disability in Dutch rehabilitation services: 'Please mind your gap'. *Child: Care, Health and Development, 47*(5), 685-696. https://doi.org/10.1111/cch.12883

6

General discussion

INTRODUCTION

This dissertation investigated perspectives, attitudes, experiences, motivations, and associated factors, of both parents and child healthcare professionals, regarding parental self-management support in the care of children with chronic conditions. Building on this, two tools were developed that potentially enhance the support provided by child healthcare professionals to parents, empowering them in managing their child's care. One tool was an instrument for child healthcare professionals in the Netherlands to facilitate self-reflection on their attitudes and behaviour towards supporting parental self-management. The other tool was a digital media platform aimed at fostering interaction between parents and child healthcare professionals within the context of the child's treatment.

This chapter will discuss the main findings and methodological considerations of the four studies conducted within the scope of this dissertation, articulate implications for practice, and present recommendations for future research.

MAIN FINDINGS

Perspectives on parental self-management and support

Chapter 2 described differences among parents in their self-reported level of self-management based on interviews about their views on parental self-management and support. While on the survey most parents of children with chronic conditions considered themselves active self-managers, only 30% of responding parents felt confident in maintaining this role during times of stress related to their child's care. Approximately 20% of parents reported not being actively involved in self-management at all. Although self-management was valued by most parents, being a self-manager can be challenging, particularly when stress is involved, which is in line with earlier research (Leeman et al., 2016; Parkes et al., 2011). This insight is relevant to child healthcare professionals, as engaging parents is considered a critical component of self-management-oriented interventions for children with chronic conditions, particularly when the children are young.

However, involving parents in chronic condition intervention programs for children can be inherently complicated (Mitchell et al., 2020). The interviews with parents revealed a variety of perspectives regarding the precise meaning of parental self-management. Some preferred to take the lead in organising their child's care, whereas other parents were inclined to give a more prominent role to professionals. Balancing self-management with other daily responsibilities—such as work, a partner, or other family members—was mentioned by parents as a strenuous process. Furthermore, many parents described themselves as struggling to ask for help when needed, often attempting to handle everything on their own. These findings are important for healthcare professionals to consider, as prolonged exposure to the stress of balancing multiple responsibilities—especially when parents find it difficult to ask for help, while trying to uphold an appearance of control—can leave parents vulnerable to overload, exhaustion, or even burnout (Patty et al., 2024).

Several factors emerged from the interviews with parents that could potentially facilitate parental self-management. Consistent with existing literature on the interaction between parents and healthcare professionals (Phoenix et al, 2019; Terwiel et al., 2017), parents viewed effective and open communication between them and child healthcare professionals as crucial for successful parental self-management. Moreover, they experienced the interaction with professionals as a highly personal process, in which parental self-management could only be effectively supported in a relationship with professionals that was characterised by mutual respect and trust. Parents expected professionals to be experts in their field, while also possessing strong interpersonal skills, including listening, empathy, emotional availability, and relational abilities. These findings align with growing attention in literature for a coaching role of healthcare professionals, emphasising a need for cross-disciplinary coaching skills (King et al., 2024; Pozniak et al., 2024; Schwellnus et al., 2019).

Ultimately, several parents participating in the study described in Chapter 2, characterised parental self-management to be more a collaborative effort than ‘managing by oneself’, emphasising partnership and shared decision-making. This is in accordance with literature in which shared decision-making in partnership with parents is increasingly recommended as the preferred approach in paediatric healthcare (Boland et al., 2019; Mackenzie et al., 2023). Parents identified, however, several factors that could complicate parental self-management within partnership-based collaboration and shared decision-making with child healthcare professionals. For instance, they mentioned differences in personal beliefs and attitudes regarding the level of involvement they desired as parents, or organisational challenges like time constraints, due to the need to balance multiple tasks and responsibilities with the care for their child with chronic conditions.

Chapter 3 focused on the perspectives and motivations of child healthcare professionals and showed that, like parents, most child healthcare professionals recognised the value of parental self-management. In line with van Hooft's study (2015) on perspectives on self-management support, this research also revealed that professionals hold diverse interpretations of what parental self-management and its support entail. In the survey professionals expressed varying assumptions about the level of parental engagement. More than 90% of the respondents expected parents to play an active role regarding self-management. Nevertheless, only 13% of that group believed that parents should also be independent information seekers, taking the initiative in the rehabilitation process. In the interviews following the survey, healthcare professionals reported that they regularly experienced dilemmas in balancing the support they provided to parents with their perceived professional responsibility towards the child. Furthermore, professionals mentioned time constraints, and feelings of overload, to have negative influence on their support of parents. In line with parents' expectations about the necessary professional competences, professionals themselves recognised the importance of possessing additional coaching skills to engage with the diversity of parents and expressed a need for extra training to develop these interpersonal skills.

The role of motivation

In both the findings of Chapter 2 and Chapter 3, autonomous motivation of parents and child healthcare professionals was statistically significantly associated with parental self-management (supportive) behaviour. According to Self-Determination Theory (SDT), the satisfaction of three basic psychological needs leads to motivation becoming self-sustaining, and for desired behaviours to be long-lasting (Ryan et al., 2008; Ryan et al., 2009). Firstly, perceived support of autonomy in making decisions for oneself regarding a course of action is required. Secondly, there must be a sense of relatedness towards others involved in the actions. Thirdly, individuals must feel competent to perform those actions. Parents in the study indicated that having responsibility and the opportunity to be involved in decisions were important to perceive that their autonomy was supported. Professionals emphasised that making autonomous decisions in how they conducted their work, alongside sufficient organisational backing and teamwork, was crucial for supporting parental self-management. Both professionals and parents considered engagement, trust, and respect towards each other as pivotal aspects of relatedness. Finally, parents saw the development of their own self-management competences as a time-related process shaped by daily experiences, while professionals expressed a desire for additional training to enhance their own self-management supportive competences.

The research findings in this dissertation support the idea that, as theorised in SDT, motivation and the underlying interrelated basic needs—perceived autonomy support, relatedness, and competence—may play an important role in promoting and facilitating approaches that support parental self-management. This is relevant for individual child healthcare professionals in their interaction with parents, but also for healthcare institutes aiming to implement parental self-management supporting policies.

The value of reflection and co-creation

Chapter 4 describes the development and validation of the S-scan - Parental self-management Support (S-scan - PS). The findings in Chapter 2 and 3 suggested that supporting parental self-management requires child healthcare professionals to attune to the individual needs and preferences of parents, to be aware of and adapt to their specific circumstances, while reflecting on their own views, motivations, and actual behaviours. The S-scan - PS would provide a tool for child healthcare professionals to reflect as individuals and as a team on their attitudes and behaviours towards supporting parental self-management.

The investigation into the psychometric properties of the instrument ultimately led to a structure comprising two parts. Part I consists of 35 items divided across six domains: Vision and attitude, Transfer of knowledge, Coaching, Guidance of facilities and resources, Self-management in consultation, and Policy and organisation of self-management within the institution. This Part I would enable child healthcare professionals to reflect on their attitudes and behaviours in relation to these areas. Part II presents all six domains in a cobweb-like diagram, which would provide an immediate visual representation of the average scores across each domain. As such, Part II would highlight potential strengths and weaknesses in the professional's attitude and behaviour. The study reported that the S-scan - PS meets key psychometric criteria as a reflective tool, with acceptable internal consistencies ($0.71 \leq \alpha \leq 0.91$) for the total and domain scores, acceptable root mean square error of approximation (RMSEA) model fit (0.066), and moderate test–retest reliability with an average intra class correlation coefficient (ICC = 0.61). However, further investigation into its construct validity and test- retest reliability is needed since, beside RMSEA, confirmatory factor analysis did not meet the other goodness-of-fit indices, and the number of respondents participating in the test-retest reliability study was relatively small. Based on the findings, the researchers suggested that the S-scan - PS could serve as a valuable tool for child healthcare professionals to reflect on how they support parental self-management.

Reflective practice can be a powerful catalyst for continuous learning, adaptive behaviour, and professional development (Colomer et al., 2020; Ng et al., 2022; van Hooft et al., 2015). Such an approach could not only benefit individual professionals but also enhance the quality of care provided by interprofessional child healthcare teams (Parrott et al., 2023). Consequently, the S-scan - PS might be a useful addition to the toolbox of professionals working with children and their parents, promoting self-awareness and encouraging lasting behavioural change.

Chapter 5 provides an example of an innovation project aimed at enhancing communication and tuning between parents and child healthcare professionals, delineated in the findings within this dissertation as important potential facilitators of parental self-management and its support. The study described in this chapter highlights the critical role of stakeholder involvement throughout all phases of development of such innovation. Through collaboration involving all relevant stakeholders a digital media platform was co-created, compliant with safety and privacy standards, and seamlessly integrated into the healthcare institute's Electronic Patient File. The media platform that was developed and piloted, enables parents and healthcare professionals to communicate with each other in the context of the child's treatment, by sharing comments, documents, audio files, and videos. Questions, feedback, and/or instructions can be exchanged, also through annotations pinned directly into the videos. As such, the media platform may help bridging the gap between the child's functioning at home and the treatment they receive at the healthcare centre, by bringing these two contexts closer together.

The study's findings align with the growing consensus in literature that successful use of digital applications requires involving the intended end-users from the outset (Cerdan et al., 2017; Gammon et al., 2014; Mohr et al., 2018). Theories on the acceptance and use of information technology, such as the Technical Acceptance Model [TAM] and the Unified Theory of Acceptance and Use of Technology [UTAUT], suggest that the actual use of digital applications depends on factors such as end-users' expectations regarding the application's performance and the effort required to use it. Both performance and effort expectancy are believed to influence the end-users' attitudes and intentions to use digital technology (Ammenwerth, 2019; Dwivedi et al., 2019). Ultimately, months after the media platform's roll out, it was primarily used by teams that were fully involved in all phases of the project and had received additional training focused on professionals' motivations, attitudes and perspectives regarding the digital platform's added value. This underpins the importance of early stakeholder engagement, emphasising not only the development of the application itself but also pivotal factors for actual use, such as motivation, attitude, and knowledge.

METHODOLOGICAL CONSIDERATIONS

Sample

Several factors necessitate caution when generalising the findings in Chapter 2 and Chapter 3 beyond the investigated samples. Both studies were conducted in two rehabilitation centres located in a central region of the Netherlands. Performing the study at different locations or settings might also have led to different outcomes. Moreover, 95% of the parents and 99% of the professionals who participated in the studies were of Dutch nationality. Although parents with low level of education and those from minority cultural backgrounds participated in both the survey and the semi-structured interviews, their representation was lower compared to the general population. Additionally, there was a 39% response rate among parents in the first study in comparison to an 85% response rate among professionals in the second study. Parents who provided reasons for not participating, primarily cited time constraints or involvement in different research as the most important reasons. Full reasons for the relative lower response remained unclear, and cultural or language barriers may have contributed. Furthermore, it is not clear to what extent selection bias may have been present, due to parents who have difficulties in self-managing their child's care declining participation because of time constraints. Only parents of children aged 0–12 were included in the study due to their legal responsibility for making decisions regarding their child's treatment in the Netherlands. Parents of adolescents and young adults were not approached. Their perspectives on self-management and parental engagement, are also important to know. When children grow up to adolescence and adulthood, parents become involved into a transition of healthcare responsibilities from themselves to their child, as well as in a transitional process of relocation of healthcare services from paediatric services to adult oriented service providers. These interrelated transitional processes dynamically influence roles, responsibilities, and interactions between parents and healthcare professionals, and therefore are aspects of attention for child healthcare professionals (Shaw et al., 2021).

In the study described in Chapter 4, the sample size of 217 respondents used for confirmatory factor analysis was narrowly sufficient for this purpose, and the 69 participants for test-retest reliability analysis were below the recommended minimum of 100 respondents (Kennedy, 2022). Additionally, while “ambassadors” at the participating healthcare institutes likely positively influenced recruitment, this may have introduced selection bias, favouring professionals with an interest in the topic and potentially leading to social desirability in responses. The sample in Chapter 5 was severely impacted by the COVID-19 pandemic, which made it impossible to collect data within the original research framework on the views and experiences of parents and professionals as end-users of the developed media platform.

Instruments

The instruments used in the surveys of the studies in Chapter 2 and 3—the Parent-Patient Activation Measure [Parent-PAM], the Clinicians-Patient Activation Measure [CS-PAM], the Treatment Self-Regulation Questionnaire [TSRQ], and the Healthcare Climate Questionnaire [HCCQ]—had not been previously employed in the field of Dutch paediatric rehabilitation, and some were not available in Dutch language. Before the investigation, the instruments were translated into Dutch and/or adapted following international standards, including translation, back-translation, piloting and finalisation. Some items were slightly rephrased for suitability. Results of the analysis, involving Exploratory Factor Analysis (EFA), Confirmatory Factor Analysis (CFA), internal consistency reliability analysis, and Rasch-analysis, supported the use of these instruments for the studies. However, generalisation of the results beyond the study population of parents of children with chronic conditions receiving treatment within paediatric rehabilitation services, as well as the healthcare professionals involved in the children’s treatment, needs to be done with caution.

Design and analyses

The studies on the perspectives of parents and child healthcare professionals had a cross-sectional, single-informant, self-reporting design. This restricts the certainty around causal interpretation of the associations found in both studies. Data in the S-scan - PS development and validation study were collected through a cross-sectional survey, with the sample randomly split for EFA and CFA to increase validity. Because all data were collected using the same version of the questionnaire, it was not possible to adjust the phrasing of some S-scan - PS items based on EFA results before conducting the CFA. The S-scan - PS was developed in close adherence to the pre-existing structure and formulations of the original S-scan, which was created in 2012 based on the Chronic Care model for managing chronic illnesses introduced in the late 1990s (Wagner et al., 1999). Since then, the healthcare field has undergone transformation, with changing circumstances and paradigms, particularly regarding the conceptualisation of self-management and parental engagement. This may have reduced alignment of items and wordings in the questionnaire with the current understanding of parental self-management, potentially influencing the responses of the professionals participating in this study. Finally, no parents of children with chronic conditions were involved in the project group conducting the S-scan - PS research. As a result, the wording of the instruments and the interpretation of findings may be limited in fully capturing the parents' perspective.

IMPLICATIONS FOR PRACTICE

The studies presented in this dissertation suggest several important implications for practice of child healthcare professionals working alongside parents. Chapter 2 and Chapter 3 described research into the perspectives of both parents and professionals on parental self-management. The considerable differences within parents' views and experiences underpin the need for child healthcare professionals to recognise and address parents' diverse and evolving needs and desires, which seems crucial for empowering parents and enhancing their ability to engage in active self-management. In this process professionals must continuously balance their approach by considering parents' preferences and expectations, while also reflecting on their own personal and professional values, beliefs, and competencies.

Autonomous motivation was associated with both parental self-management and healthcare professionals' beliefs about supporting parental self-management. Additionally, perceived autonomy support was positively associated with parents' autonomous motivation. Both findings underline why it is important that policies and measures stimulate parents' self-management, and respect and support the autonomy of both parents and child healthcare professionals. Next to autonomy support, satisfying the sense of competence is essential to increasing motivation according to Self-Determination Theory. Providing specific training focused on self-management support attitudes and abilities, including coaching skills, might enhance professionals' feeling of competence, and in turn, their motivation to support parental self-management. As suggested in Chapter 4, such training should ideally also encourage the integration of reflection into professionals' clinical practice.

Based on SDT, relatedness between parents and healthcare professionals might be helpful to support autonomous motivation for self-management support. Both parents and child healthcare professionals identified several organisational barriers to parental self-management and its support. These included issues with scheduling appointments with parents in the context of their child's treatment and limited dedicated time for professionals to engage with parents. Rehabilitation institutes should develop policies and allocate financial resources to minimise these barriers and assure the organisational preconditions for structural improvement of the support for parental self-management, for instance by offering additional ways of communication, like digital media applications, to safely exchange information, photos, and videos.

Partnership-based collaboration and communication between child healthcare professionals and parents was highlighted as a crucial aspect of parental self-management and its support in Chapter 2 and 3. Additionally, Chapter 5 emphasised the importance of involving both parents and professionals as key stakeholders in the creation of a digital media platform. This aligns with the "nothing about us without us" principle, which is increasingly recognised in healthcare (Jackson & Moorley, 2022), particularly also in Dutch rehabilitation services (VRA, 2018). Partnership based shared decision-making, not only in the context of treatment but also throughout all phases of innovation projects, might be a critical factor for success. For those professionals involved in research or innovation projects, such as the development of the S-scan - PS and the digital media platform within this dissertation, the 'Involvement matrix' (Ketelaar et al., 2020; Smits et al., 2020) can be a useful tool for initiating and/or retrospectively reflecting on innovative projects with various stakeholders. It helps guiding design, and discussions with stakeholders, including parents, about their actual or desired level of involvement.

For professionals working with parents in clinical settings, familiarity with the four-step shared decision-making approach described by Stiggelbout et al. (2015) could be beneficial. This approach involves: (1) informing parents that their opinion on a certain decision is valued; (2) explaining the positive and negative aspects of the decision; (3) discussing together with parents their preferences and supporting them in their consideration; (4) discussing parents' desired role in the decision-making process, making or postponing the decision, and deliberate about follow-up.

Finally, the field of healthcare is undergoing significant transitions, driven by societal developments and challenges, such as the rise in chronic diseases, increasing costs, and a shortage of healthcare workers. The focus is shifting from chronic condition management towards health management and from treatment towards prevention.

In Dutch healthcare the dynamic concept of health described by Huber et al. (2016) has gained acceptance, placing adaptability and self-management at the centre of its definition. Governmental health policies, reflected in the Health and Active Life Agreement, emphasise this dynamic health concept, with a wide focus on health and promotion of health incorporating the delivery of appropriate care, as well as the promotion of individual autonomy and self-management (Dutch Ministry of Health, Welfare and Sport, 2023). This approach is also featured in the Vision document 2025 of the Federation of Medical Specialists (FMS, 2017), and the Policy plan 2025 of the Dutch Society of Rehabilitation Medicine (VRA, 2018). This underlines the notion that, both healthcare institutions and individual child healthcare professionals must be aware of these transitional developments, adapt their policies and strategies, as well as their personal competencies accordingly, as transition into such future healthcare will not automatically take place.

RECOMMENDATIONS FOR FUTURE RESEARCH

Parental self-management and its support

The importance of parental self-management in the daily care of children with chronic disabilities, is increasingly acknowledged in research (Olij et al., 2021). The cross-sectional studies in this dissertation give promising insights in factors that are associated with parental self-management and the support required by child healthcare professionals. Future research should include longitudinal studies investigating parental self-management support needs over time. Furthermore, more robust research designs are necessary, with well documented experimental trials that investigate associations between enhanced parental self-management and child functioning. While our research focused on parents of children, age 0–12, it is also important to consider the views of parents with older children and adolescents, as well as the views of these children and adolescents themselves. Our research revealed an underrepresentation of parents from minority cultural backgrounds. Given the multicultural nature of modern society, especially in urban areas, it is crucial to explore these parents' perspectives on self-management, their support preferences, and the key factors involved in a culturally sensitive approach. Structural increasing the representation of parents from minority cultural background in future research asks for overarching multilevel policies. Nevertheless, on a researchers' level, identifying and actively approaching parents as representative of minority cultural groups to be involved in early phases of research projects or to be ambassadors during the execution phase of an investigation, can be contributing factors for enhancing their participation (Gill & Redwood, 2013; Thakur et al., 2021).

Both parents and professionals in our studies highlighted the need for healthcare professionals to enhance their interpersonal skills. This is particularly important while those skills are often needed in the interaction with parents who are in stressful situations, at times affecting their own communication. Future research could focus on the development and impact of specific training programs aimed at enhancing professionals' abilities to support parental self-management, including reflective practices and essential coaching skills. Since self-management is described as a collaborative process, involving partnership, respect, and trust as vital aspects, further research into shared decision-making with parents would be highly beneficial, both in clinical interventions and throughout all phases of innovation or research projects.

Digital communication

The future of communication is undeniably digital. Information technology, electronic applications, and media platforms will increasingly influence interactions between healthcare professionals and parents. Investigations into factors that contribute to successful end-user engagement with digital technology are crucial, like in the present study the expectations of parents and healthcare professionals about the functionalities offered within the media platform. Additionally, research is needed into expectations concerning the effort that using the platform will cost. Parents who already feel overloaded will likely be prone to not using the application if they expect that it will be complex and time consuming. Lastly, research into the effectiveness of electronic interactions between parents and healthcare professionals, is also important. Without research, there is a high risk that many digital applications will be developed and offered for use in parent-professional interactions but will fail to be effectively integrated into clinical practice.

Leadership for change

We live in a rapidly changing, complex, and disrupting world that presents significant societal challenges, including within healthcare (United Nations, 2020). Professionals in child healthcare can attest to the palpable demand for substantial transitions. Some healthcare professionals experience this period as a dynamic opportunity for structural improvement of the services they deliver. However, for others, it is a time marked by stress, insecurity, and, at times, resistance to change (Amarantou et al., 2017).

This dissertation found that most child healthcare professionals recognise the importance of supporting parental self-management, the necessity of additional skills to attune and collaborate with parents, and the need for changes in their own attitudes and behaviours to achieve this. However, several barriers were identified, such as the absence of structured self-management policies within institutions and financial or organisational instability. Addressing the numerous barriers and challenges in current healthcare requires the development of new policies and leadership competencies at every level of the organisation that is adaptive to complexity and open to change (Kaplan, 2020; Hall et al., 2024; Underwood, 2024), while simultaneously helping to prevent burnout and reduce attrition of staff (Bosak et al., 2021). Drawing on the findings of this dissertation, such leadership should include empowering professionals with greater autonomy, fostering new competencies through self-reflection, enhancing relatedness by actively listening to professionals' expectations, needs, and concerns, and involving all relevant stakeholders – including parents and patients – in shaping policies for change from the outset. These measures can also serve as a guiding force through the necessary transitions towards a sustainable, accessible, and future-proof healthcare system. Ideally, this transformative leadership approach should be informed by thorough research into its principles and components.

REFERENCES

Amarantou, V., Kazakopoulou, S., Chatzoudes, D., & Chatzoglou, P. (2018). Resistance to change: An empirical investigation of its antecedents. *Journal of Organisational Change Management*, *31*(2), 426-450. https://doi.org/10.1108/JOCM-05-2017-0196

Ammenwerth, E. (2019). Technology acceptance models in health informatics: TAM and UTAUT. In P. Scott et al. (Eds.), *Applied interdisciplinary theory in health informatics* (pp. 64-71). IOS Press. https://www.iospress.com/catalog/books/applied-interdisciplinary-theory-in-health-informatics

Boland, L., Graham, I. D., Legare, F., Lewis, K., Jull, J., Shepard, A., Lawson, M. L., Davis, A., Yameogo, A., & Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: A systematic review. *Implementation Science*, *14*(7), 1-25. https://doi.org/10.1186/s13012-018-0851-5

Bosak, J., Kilroy, S., Chenevert, D., & Flood, P. C. (2021). Examining the role of transformational leadership and mission valence on burnout among hospital staff. *Journal of Organisational Effectiveness: People and Performance*, *8*(2), 208-227. https://doi.org/10.1108/JOEPP-08-2020-0151

Cerdan, J., Catalan-Matamoros, D., & Warny Berg, S. (2017). Online communication in a rehabilitation setting: Experiences of patients with chronic conditions using a web portal in Denmark. *Patient Education and Counseling*, *100*(12), 2283-2289. https://doi.org/10.1016/j.pec.2017.06.023

Colomer, J., Serra, T., Canabate, D., & Bubnys, R. (2020). Reflective learning in higher education: Active methodologies for transformative practices. *Sustainability*, *12*(9), 3827. https://doi.org/10.3390/su12093827

Dutch Ministry of Health, Welfare and Sport (2023). *Rijksbegroting 2024 – XVI Volksgezondheid, welzijn en sport. Tweede Kamer, vergaderjaar 2022-2023*. Retrieved August 25, 2024, from https://www.rijksoverheid.nl/documenten/begrotingen/2023/09/19/xvi-volksgezondheid-welzijn-en-sport-rijksbegroting-2024

Dwivedi, Y. K., Rana, N. P., Jeyaraj, A., Clement, M., & Williams, M. D. (2019). Re-examining the unified theory of acceptance and use of technology (UTAUT): Towards a revised theoretical model. *Information Systems Frontiers*, *21*(3), 719-734. https://doi.org/10.1007/s10796-017-9774-y

FMS [Federation medical specialists]. (2017). *Medical specialist 2025. Ambition, trust, cooperation*. Retrieved august 25, 2024, from https://demedischspecialist.nl/sites/default/files/FMS_visiedoc_MS2025%28eng%29_2017_PL_v02%28lr%29.pdf

Gammon, D., Strand, M., & Eng, L. S. (2014). Service users' perspectives in the design of an online tool for assisted self-help in mental health: A case study of implications. *International Journal of Mental Health Systems*, *8*(2), 1-8. https://doi.org/10.1186/1752-4458-8-2

Gill, P. S., & Redwood, S. (2013). Under-representation of minority ethnic groups in research - Call for action. *British Journal of General Practice*, *63*(612), 342-343. https://doi.org/10.3399/bjgp13X668456

Hall, K., Bardier, C., Greer, D., Clayton, A., & Poblete, R. (2024). Unleashing leadership potential in unprecedented times: Lessons learned from an evaluation of a virtual cohort based adaptive leadership program for public health executives. *Public Health in Practice*, *8*(4), 100532. https://doi.org/10.1016/j.puhip.2024.100532

Huber, M. Van Vliet, M., Giezenberg, M., Winkens, B., Heerkens, Y., Dagnelie, P. C., & Knottnerus, J. A. (2016). Towards a 'patient-centred' operationalisation of the new dynamic concept of health: A mixed methods study. *British Medical Journal Open*, *6*(1), e010091. https://doi.org/10.1136/bmjopen-2015-010091

Jackson, D., & Moorley, C. (2022). 'Nothing about us without us': Embedding participation in peer review processes. *Journal of Advanced Nursing*, *78*(5), e75-e76. https://doi.org/10.1111/jan.15122

Kaplan, G. S. (2020). Defining a new leadership model to stay relevant in healthcare. *Frontiers of Health Services Management*, *36*(3), 12-20. https://doi.org/10.1097/HAP.0000000000000077

Kennedy, I. (2022). Sample size determination in test-retest and Cronbach alpha reliability estimates. *British Journal of Contemporary Education*, *2*(1), 17-29. https://doi.org/10.52589/BJCE-FY266HK9

Ketelaar, M., Smits, D. W., van Meeteren, K., Klem, M., & Alsem, M. W. (2020). Involvement of young people and families in all stages of research: What, why and how? In C. Imms & D. Green (Eds), *Participation: optimising outcomes in childhood-onset neurodisability* (pp. 105-117). MacKeith Press.

King, G., Graham, F., & Ziegler, S. A. (2024). (2024) Comparing three coaching approaches in pediatric rehabilitation: Contexts, outcomes, and mechanisms. *Disability and Rehabilitation*, *46*(12), 2708-2719. https://doi.org/10.1080/09638288.2023.2229731

Leeman, J., Crandell, J. L., Lee, A., Bai, J., Sandelowski, M., & Knafl, K. (2016). Family-functioning and the well-being of children with chronic conditions: A meta-analysis. *Research in Nursing & Health*, *39*(4), 229-243. https://doi.org/10.1002/nur.21725

Mackenzie, N. E., Tutelman, P. R., Chambers, C. T., Parker, J. A., Boland, L., Lipstein, E. A. Jordan, I., Jordan, Z., Finley, G. A., April, K. T., Witteman, H. O., & Birnie, K. A. (2023). Can sharing improve caring? A call to prioritize shared decision making in pediatric pain management. *Clinical Practice in Pediatric Psychology*, *11*(3), 253-261. https://doi.org/10.1037/cpp0000488

Mitchell, A. E., Morawska, A., & Mihelic, M. (2020). A systematic review of parenting interventions for child chronic health conditions. *Journal of Child Health Care*, *24*(4), 603-628. https://doi.org/10.1177/1367493519882850

Mohr, D. C., Riper, H., & Schueller, S. M. (2018). A solution-focused research approach to achieve an implementable revolution in digital mental health. *JAMA Psychiatry*, *75*(2), 113-114. https://doi.org/10.1001/jamapsychiatry.2017.3838

Ng, S. L., Forsey, J., Boyd, V. A., Friesen, F., Langlois, S., Ladonna, K., Mylopoulos, M., & Steenhof, N. (2022). Combining adaptive expertise and (critically) reflective practice to support the development of knowledge, skill, and society. *Advances in Health Sciences Education*, *27*(1), 1265-1281. https://doi.org/10.1007/s10459-022-10178-8

Olij, C., Vos, M., Van Oostrum, N., Van Etten-Jamaludin, F., & Maaskant, J. (2021). Effective interventions to support self-management for parents of children with a chronic condition: A systematic review. *Maternal and Child Health Journal*, *25*(7), 1842-1865. https://doi.org/10.1007/s10995-021-03244-x

Parkes, J., Caravale, B., Marcelli, M., Franco, F., & Colver, A. (2011). Parenting stress and children with cerebral palsy: a European cross-sectional survey. *Developmental Medicine & Child Neurology*, *53*(9), 815-821. https://doi.org/10.1111/j.1469-8749.2011.04014.x

Parrott, J., Speerhas, T., Klick, B. D., Vasifedan, T., & Guins, T. (2023). Interprofessional reflective practice to improve pediatric healthcare outcomes. *Reflective Practice*, *24*(5), 680-691. https://doi.org/10.1080/14623943.2023.2235585

Patty, N. J. S., Van Meeteren, K. M., Verdonk, M., Ketelaar, M., Schuengel, C., & Willemen, A. M. (2024). Conceptualizing burnout from the perspective of parents of children with complex care needs. *PEC Innovations*, *5*, 100325. https://doi.org/10.1016/j.pecinn.2024.100325

Phoenix, M., Jack, S. M., Rosenbaum, P. L., & Missiuna, C. (2019). A grounded theory of parents' attendance, participation and engagement in children's developmental rehabilitation services: Part 2. The journey to child health and happiness. *Disability and Rehabilitation*, *42*(15), 2151-2160. https://doi.org/10.1080/09638288.2018.1555618

Pozniak, K., King, G., Chambers, E., Martens, R., Earl, S., de Camargo, O. K., McCauley, D., Teplicky, R., & Rosenbaum, P., (2024). What do parents want from healthcare services? Reports of parents' experiences with pediatric service delivery for their children with disabilities. *Disability and Rehabilitation*, *46*(12), 2670-2683. https://doi.org/10.1080/09638288.2023.2229733

Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *The European Health Psychologist*, *10*, 2-5.

Ryan, R. M., Williams, G. C,. Patrick, H., & Deci, E. L. (2009). Self-determination theory and physical activity: The dynamics of motivation in development and wellness. *Hellenic Journal of Psychology*, *6*, 107-124.

Schwellnus, H., Seko, Y., King, G., Baldwin, P., & Servais, M. (2019). Solution-focused coaching in pediatric rehabilitation: Perceived therapist impact. *Physical & Occupational Therapy in Pediatrics*, *40*(3), 1-16. https://doi.org/10.1080/01942638.2019.1675846

Shaw, K. L., Heath, G., & Farre, A. (2021). Transition to adulthood: Shifting roles between young people with chronic conditions and their parents. In J. N. T. Sattoe, A. van Staa, & S. R. Hilberink (Eds.), *Self-management of young people with chronic conditions* (pp. 107-134). Springer Nature Switzerland AG.

Smits, D. W., van Meeteren, K., Klem, M., Alsem, M., & Ketelaar, M., (2020). Designing a tool to support patient and public involvement in research projects: The involvement matrix. *Research Involvement and Engagement*, *6*(30), 1-7. https://doi.org/10.1186/s40900-020-00188-4

Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. J. M. (2015). Shared decision making: Concepts, evidence, and practice. *Patient Education and Counseling*, *98*(10), 1172-1179. http://dx.doi.org/10.1016/j.pec.2015.06.022

Thakur, N., Lovinsky-Desir, S., Apell, D., Bime, C., Castro, L., Celedón, J. C., Ferreira, J., George, M., Mageto, Y., Mainous III, A. G., Pakhale, S., Riekert, K. A., Roman, J., Ruvalcaba, E., Sharma, S., Shete, P., Wisnivesky, J. P., & Holguin, F. (2021). Enhancing recruitment and retention of minority populations for clinical research in pulmonary, critical care, and sleep medicine - An official American thoracic society research statement. *American Journal of Respiratory and Critical Care Medicine*, *204*(3), 26-50. https://doi.org/10.1164/rccm.202105-1210ST

Terwiel, M., Alsem, M. W., Siebes, R. C., Bieleman, K., Verhoef, M., & Ketelaar, M. (2017). Family-centred services: Differences in what parents of children with cerebral palsy rate important. *Child: Care Health and Development*, *43*(5), 663-669. https://doi.org/10.1111/cch.12460

United Nations. (2020). *World social Report: Inequality in a rapidly changing world. Department of economic and social affairs.* United nations publications. Retrieved October 19, 2024, from https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2020/02/World-Social-Report2020-FullReport.pdf

Underwood, S. (2024). Redefining leadership within the NHS' complex adaptive system. *Future Healthcare Journal*, *11*(1), 100015. https://doi.org/10.1016/j.fhj.2024.100015

van Hooft, S. M., Dwarswaard, J., Jedeloo, S., Bal, R., & van Staa, A. (2015). Four perspectives on self-management support by nurses for people with chronic conditions: A Q-methodological study. *International Journal of Nursing Studies*, *52*(1), 157-166. https://doi.org/10.1016/j.ijnurstu.2014.07.004

VRA [Dutch Society of Rehabilitation Medicine]. (2018). *Revalidatiegeneeskunde 2025: Beleidsplan* [Rehabilitation medicine 2025: Policy plan]. Retrieved August 25, 2024 from https://www.revalidatie.nl/wp-content/uploads/2022/09/beleidsplan_revalidatiegeneeskunde_2025.pdf

Wagner, E. H., Davis, C., Schaefer, J., & Von Korff, M. (1999). A survey of leading chronic disease management programs: Are they consistent with the literature? *Managed Care Quarterly*, *7*(3), 56-66.

Summary
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SUMMARY

The purpose of this dissertation was to investigate perspectives, attitudes, experiences, motivations, and associated factors, of both parents and child healthcare professionals, regarding parental self-management support in the care of children with chronic conditions. Building on these insights, two tools were developed that have potential to enhance child healthcare professionals' support to parents, empowering them in managing their child's care.

There is growing interest in self-management within society, healthcare, and research, particularly for individuals, families, and communities to promote and maintain health, prevent illness or disability, and manage daily life. Self-management can be challenging for individuals, especially when dealing with chronic health issues.

For children with chronic conditions, particularly younger ones, parents play a crucial role and bear significant responsibility. Their involvement in daily care management is recognised as vital for the child's functioning and well-being, as well is the support provided to parents by child healthcare professionals. Despite the increasing focus on self-management in healthcare, including parental self-management and the support it requires, there is no universal agreement on the concept of chronic condition self-management, parental engagement, nor what the support from child healthcare professionals should entail. Parents and professionals often have varying perspectives on parental self-management and the support that is needed, both within their groups and in relation to each other, as well as over time.

Chapter 1 introduces the central theme of this dissertation: supporting parental self-management in the care for a child with a chronic condition. It highlights key aspects of chronic condition self-management, parental engagement, the support provided by child healthcare professionals, and the role of motivation in parental self-management support. This chapter also outlines the aims and structure of the dissertation, as well as personal reflexivity.

Chapter 2 discusses parents' perspectives on managing chronic conditions in their children. As interest in supporting self-management within paediatric rehabilitation services increases, there is a growing need for a shared understanding of the concept. The study investigated parental activation, factors associated with it, and parents' perceptions of self-management regarding the care for their children with chronic conditions. A mixed-methods approach was employed, starting with a cross-sectional

survey of parents of children with chronic conditions. The data-analyses comprised descriptive statistics and univariate analysis of variance. The survey was followed by in-depth interviews with parents, using thematic analysis to identify relevant themes. The survey results indicated that most parents considered themselves active in self-management, although only one third maintained this under stress. Autonomous motivation was closely associated with parental self-management. In the qualitative interviews, parents emphasised the importance of aligning with professionals and finding a balance as key aspects of self-management. They expected professionals to have expert knowledge, be engaged, really listen, and demonstrate empathy to support self-management effectively. It was concluded that from the parents' viewpoint, self-management should be seen as a partnership-based, collaborative effort, supported by professionals, rather than something they are expected to manage primarily on their own.

Chapter 3 explores the motivation of rehabilitation professionals to support parental self-management for children with physical disabilities, along with their beliefs about parental self-management and the perceptions that underpin their motivation. Child healthcare professionals increasingly value self-management support within paediatric rehabilitation services for children with physical disabilities. However, their views on the role of parents and their own role in supporting these parents, are less well understood. A mixed-methods approach was used, beginning with a survey of rehabilitation professionals, followed by semi-structured interviews. The associations between autonomous (intrinsic) versus controlled (extrinsic) motivation and beliefs about parental self-management were examined, followed by directed content analysis to explore key themes in the qualitative data for a deeper understanding of the professionals' motivation. The results showed that professionals mostly reported autonomous motivation for supporting parental self-management. Autonomous motivation was associated with beliefs about the importance of parental self-management. While a large majority of professionals believed that parents should play an active role, only few professionals thought it was important for parents to act independently and take initiative in the rehabilitation process. Subsequent interviewing indicated that professionals often struggled to balance maintaining control with 'handing over responsibility' to parents. A 'professional-like' attitude was expected from parents, with 'involvement' and 'commitment' seen as crucial prerequisites. Professionals also expressed a need for further coaching skills to improve their support of parental self-management. While professionals appeared primarily autonomously motivated to support parental self-management, their challenges in balancing responsibility-sharing within the partnership with parents may hinder their ability to effectively empower parents. Furthermore, professionals reported several aspects, as for instance time constraints, and feelings of overload, to have negative influence on their support of parents. Reflecting on potential discrepancies between professionals' motivation, beliefs, and actual behaviour may be key to enhancing support of parental self-management.

The studies presented in Chapter 4 and 5 build on the findings of the previous chapters.

The study described in **Chapter 4** aimed to develop and validate a tool for child healthcare professionals, the S-scan Parental self-management Support (S-scan - PS), to reflect on their attitudes and behaviour towards supporting parental self-management, due to the lack of a freely available validated instrument in the Netherlands for such a purpose. An existing instrument was adapted in collaboration with field experts to enable professionals to self-assess their support of parental self-management. The resulting 36-item self-report questionnaire was completed by healthcare professionals in the Netherlands working with children and their parents. The development and validation process included cognitive interviews, exploratory and confirmatory factor analysis and test-retest reliability analysis. The results, which included participation from child healthcare professionals such as physicians, physiotherapists, occupational therapists, and nurses, from 18 institutions, indicated satisfactory face and content validity as well as internal consistency and test-retest reliability, though not all criteria for construct validity were met. Further investigation into construct validity and reliability was recommended. Nevertheless, it was concluded that the S-scan - PS can be used by child healthcare professionals to reflect on their support of parental self-management.

Chapter 5 presents an example of translating research into practice. Informed by the results of the first two studies in this dissertation, an interactive digital media platform was developed and piloted aiming to enhance communication and attuning between child healthcare professionals and parents in the context of treating children with chronic conditions. The methodological approach was inspired by participatory research principles, involving representatives of relevant stakeholders—professionals, parents, management, planning, IT-department, software supplier, and researchers—in a co-creation and shared decision-making process throughout all project phases. Although the research process was seriously hampered by the COVID-19 pandemic, the project illustrates the value of early stakeholder involvement and shared decision-making in innovation projects. Several risk factors for actual use of the media platform were indicated, such as the need for structural financial and adequate technical end-user support. Additional training focusing on the views, expectations, attitude, and motivation, of individual professionals and treatment teams was recommended. Suggestions were also made for future research into the determinants of successful end-user engagement, and the added value of digital professional-parent communication.

Chapter 6 the general discussion, recapitulates and discusses the main findings of the dissertation, along with methodological considerations, implications for practice, and recommendations for future research. The wide perspectives of both child healthcare professionals as parents on parental self-management and its support are highlighted, as well as the role of motivation in professionals' self-management supportive behaviour and the importance of partnership-based shared decision-making in the collaborative process between parents and professionals. Several methodological considerations are noted, related to sampling, the instruments used in the studies, and the research design and data analyses. Recommendations for future research include longitudinal studies on parents' needs and expectations regarding parental self-management and support over time, as well as experimental trials investigating associations between enhanced parental self-management and child functioning in daily life. Further research into the critical factors of successful digital parent-professional interaction is also suggested. Lastly, a need for research is emphasised into new, transformative, leadership that is adaptable to complexity and open to change within healthcare. Such leadership aims to empower child healthcare professionals and guide them and their organisations through the fundamental transitions required to create a sustainable and accessible future of healthcare, one that also supports parental self-management.

SAMENVATTING (SUMMARY IN DUTCH)

Het doel van dit proefschrift was het onderzoeken van perspectieven, attitudes, ervaringen, motivaties en geassocieerde factoren, van zowel ouders als gezondheidszorgprofessionals, met betrekking tot zelfmanagementondersteuning van ouders bij de zorg voor kinderen met chronische condities. Gebaseerd op de inzichten van de eerste twee studies, zijn er twee tools ontwikkeld die mogelijk kunnen bijdragen aan de steun door professionals die ouders empowert voor zelfmanagement in de dagelijkse zorg voor hun kind.

Er is toenemende belangstelling binnen de samenleving, de gezondheidszorg en het onderzoek voor zelfmanagement van individuen, gezinnen en (leef)gemeenschappen om gezondheid te bevorderen en/of te behouden, ziekte of beperkingen te voorkomen, en voor het managen van het dagelijks leven. Zelfmanagement kan daarbij met name een uitdaging zijn wanneer het gaat om chronische condities.

Bij kinderen met een of meer chronische condities, vooral als ze nog jong zijn, hebben ouders een essentiële rol en dragen zij grote verantwoordelijkheid bij het nemen van beslissingen. De betrokkenheid van ouders bij de dagelijkse zorg wordt algemeen erkend als essentieel voor het functioneren en het welzijn van kinderen, net als de steun die hen door zorgprofessionals wordt geboden. Ondanks deze toenemende aandacht voor zelfmanagement in de zorg, inclusief zelfmanagement van ouders en de ondersteuning door professionals die daarvoor nodig is, bestaat er geen algemene consensus over de definitie van zelfmanagement, de betrokkenheid van ouders, of wat ondersteuning door zorgprofessionals precies zou moeten inhouden. Ouders en professionals hebben vaak verschillende perspectieven ten aanzien van zelfmanagement en de ondersteuning daarvan, zowel binnen hun eigen groep, als in relatie tot elkaar, maar ook in de loop van de tijd.

Hoofdstuk 1 introduceert het centrale thema van dit proefschrift: het ondersteunen van zelfmanagement van ouders in de zorg voor hun kind met een chronische conditie. Het hoofdstuk belicht de belangrijkste aspecten van zelfmanagement, de betrokkenheid van ouders, de ondersteuning die wordt geboden door zorgprofessionals en de rol van motivatie bij de ondersteuning van zelfmanagement door ouders. Dit hoofdstuk beschrijft ook de doelstellingen en opbouw van het proefschrift, evenals persoonlijke reflexiviteit.

Hoofdstuk 2 bespreekt de perspectieven van ouders op het omgaan met de consequenties van chronische condities bij hun kinderen. Naarmate de belangstelling voor het ondersteunen van zelfmanagement binnen de kinderrevalidatie toeneemt, groeit ook de behoefte aan een gezamenlijk gedragen begrip van het concept. De studie die in hoofdstuk 2 wordt beschreven, onderzocht de activatie van ouders met betrekking tot zelfmanagement, de factoren die daarmee samenhangen, en de perceptie van ouders op zelfmanagement in de zorg voor hun kind. Er werd voor het onderzoek gebruikgemaakt van een mixed-methods benadering. Hierbij werd gestart met een cross-sectionele survey onder ouders van kinderen met een chronische conditie. De data-analyse omvatte beschrijvende statistiek en univariate variantieanalyse. De survey werd gevolgd door diepte-interviews met ouders, waarbij gebruik werd gemaakt van kwalitatieve thematische analyse om relevante thema's te identificeren. Uit de onderzoeksresultaten bleek dat de meeste ouders zichzelf als actieve zelfmanagers beschouwden, hoewel slechts een derde van hen dit volhield in situaties van stress. Autonome (intrinsieke) motivatie was nauw geassocieerd met zelfmanagement van ouders. In de interviews benadrukten ouders het belang van goede afstemming met zorgprofessionals en de uitdaging van 'balanceren' tussen werk, partner, gezin en zorg voor het kind als sleutelfactoren van zelfmanagement. Voor effectieve ondersteuning van zelfmanagement verwachtten ouders van professionals dat zij onder andere over 'state-of-the-art' vakkennis beschikken, betrokken zijn, echt kunnen luisteren en empathie tonen. Er werd geconcludeerd dat vanuit het standpunt van de ouders, zelfmanagement moet worden gezien als een gezamenlijke inspanning, in partnerschap en samenwerking met professionals, en niet als iets dat ze voornamelijk 'zelf' moeten doen.

Hoofdstuk 3 onderzoekt de motivatie van kinderrevalidatieprofessionals voor het ondersteunen van zelfmanagement van ouders voor hun kind met een chronische conditie, hun percepties ten aanzien van zelfmanagement van ouders, en de opvattingen die ten grondslag liggen aan hun motivatie. Professionals in de kinderrevalidatie hechten steeds meer waarde aan zelfmanagementondersteuning van kinderen met chronische condities. Hun opvattingen over de betrokkenheid van ouders en hun eigen rol bij het ondersteunen van deze ouders zijn echter minder bekend. Ook in dit onderzoek werd gebruik gemaakt van een mixed-methods methode, waarbij eerst een vragenlijst onder kinderrevalidatieprofessionals werd afgenomen, gevolgd door semigestructureerde interviews. Associaties tussen de motivaties van professionals en hun opvattingen over het ondersteunen van zelfmanagement van ouders werden onderzocht, gevolgd door thematische analyse van de kwalitatieve data voor een diepgaander begrip van de perspectieven van de professionals. Uit de resultaten bleek dat verreweg de meeste professionals aangaven autonoom gemotiveerd te zijn voor het ondersteunen van zelfmanagement van ouders. Autonome motivatie bleek geassocieerd met hun visie op het belang van zelfmanagement van ouders. Terwijl een grote meerderheid van de professionals van mening was dat ouders een actieve rol zouden moeten spelen, vonden maar weinig professionals het belangrijk dat ouders onafhankelijk handelen en het initiatief nemen in het revalidatieproces. Uit de interviews bleek dat professionals vaak moeite hadden om een balans te vinden tussen het 'houden van controle' en het 'geven van verantwoordelijkheid' aan ouders. Van ouders werd een 'professionele' houding verwacht, waarbij 'betrokkenheid' en 'het nakomen van afspraken' als cruciale randvoorwaarden werden gezien. Professionals gaven ook aan behoefte te hebben aan de verdere ontwikkeling van coachingvaardigheden om zelfmanagement van ouders beter te kunnen ondersteunen. Hoewel professionals vooral autonoom gemotiveerd leken om zelfmanagement van ouders te ondersteunen, kunnen de uitdagingen bij het zoeken naar balans in de verdeling van verantwoordelijkheid binnen het partnerschap met ouders hun vermogen om ouders effectief te ondersteunen belemmeren. Professionals noemden verder verschillende aspecten, zoals te weinig tijd, of gevoelens van overbelasting, die een negatieve invloed konden hebben op het ondersteunen van zelfmanagement van ouders. Reflectie door professionals op de mogelijke discrepanties tussen hun motivatie, opvattingen en daadwerkelijk gedrag, kan van cruciaal belang zijn om de ondersteuning van zelfmanagement van ouders te verbeteren.

De studies die worden gepresenteerd in Hoofdstuk 4 en 5 bouwen verder op de bevindingen uit de voorgaande hoofdstukken.

Het onderzoek dat wordt beschreven in **Hoofdstuk 4** had tot doel een instrument voor professionals in de kindergezondheidszorg te ontwikkelen en te valideren, de 'Z-scan OvO - zelfmanagementondersteuning van ouders in de zorg voor hun kind met een chronische conditie' (S-scan Parental self-management Support / S-scan - PS), voor zorgprofessionals om te kunnen reflecteren op hun eigen houding en gedrag ten aanzien van het ondersteunen van zelfmanagement van ouders. Dit vanwege het ontbreken van een vrij verkrijgbaar gevalideerd instrument in Nederland voor een dergelijk doel. In samenwerking met experts uit het veld werd een bestaand instrument aangepast om professionals in staat te stellen zelf hun ondersteuning van zelfmanagement van ouders te evalueren. De 36-item vragenlijst werd binnen het onderzoek ingevuld door zorgprofessionals in Nederland die met kinderen en hun ouders werken. Het ontwikkelings- en validatieproces omvatte cognitieve interviews, exploratieve en confirmatieve factoranalyse, en test-hertestbetrouwbaarheidsanalyse. Aan het onderzoek namen professionals uit de kindergezondheidszorg deel, waaronder artsen, fysiotherapeuten, ergotherapeuten en verpleegkundigen uit 18 verschillende instellingen. De resultaten van het onderzoek wezen op voldoende 'face' en 'content' validiteit, interne consistentie en test-hertestbetrouwbaarheid, hoewel niet aan alle criteria van constructvaliditeit werd voldaan. Verder onderzoek naar de constructvaliditeit en betrouwbaarheid werd aanbevolen. Niettemin werd geconcludeerd dat de S-scan - PS door professionals in de kindergezondheidszorg kan worden gebruikt om te reflecteren op ondersteuning van zelfmanagement van ouders.

Hoofdstuk 5 presenteert een voorbeeld van de vertaling van onderzoek naar de praktijk. Op basis van de resultaten van de eerste twee onderzoeken in dit proefschrift werd een interactief digitaal mediaplatform ontwikkeld en getest, met als doel de communicatie en afstemming tussen professionals en ouders te verbeteren in de context van de behandeling van kinderen met een chronische conditie. De onderzoeksmethode was geïnspireerd op de principes van participatief onderzoek, waarbij vertegenwoordigers van de relevante stakeholders—professionals, ouders, management, planning, IT-afdeling, softwareleverancier en onderzoekers—betrokken waren bij het proces van co-creatie en shared decision-making tijdens alle fasen van het project. Hoewel het onderzoeksproces ernstig werd belemmerd door de COVID-19-pandemie, illustreert het project de waarde van vroegtijdige betrokkenheid van stakeholders en gezamenlijke besluitvorming bij innovatieprojecten. Er werden verschillende risicofactoren voor het daadwerkelijke gebruik van het mediaplatform benoemd, zoals de noodzaak van structurele financiële projectondersteuning en adequate technische ondersteuning van eindgebruikers. Aanvullende training gericht op de opvattingen, de verwachtingen, attitude en motivatie van individuele professionals en behandelteams werd aanbevolen. Er werden ten slotte ook aanbevelingen gedaan voor toekomstig onderzoek naar de determinanten van succesvolle betrokkenheid van eindgebruikers en de toegevoegde waarde van digitale communicatie tussen professionals en ouders.

Hoofdstuk 6, de algemene discussie, bespreekt de belangrijkste bevindingen van het proefschrift, samen met methodologische overwegingen, praktische implicaties en aanbevelingen voor toekomstig onderzoek. De brede variatie in de perspectieven van zowel zorgprofessionals als ouders op zelfmanagement en de ondersteuning daarvan worden benadrukt, evenals de rol die motivatie speelt bij het zelfmanagement ondersteunende gedrag van professionals en het belang van het op partnerschap gebaseerde proces van shared decision-making tussen ouders en professionals. Er worden verschillende methodologische overwegingen genoemd die verband houden met de studiepopulatie, de instrumenten die in de onderzoeken worden gebruikt, de onderzoeksopzet en de data-analyses. Aanbevelingen voor toekomstig onderzoek omvatten robuuster onderzoek naar de behoeften en verwachtingen van ouders met betrekking tot hun eigen zelfmanagement en de ondersteuning daarvan, evenals onderzoek naar het verband tussen toegenomen zelfmanagement van ouders en het functioneren van het kind. Er wordt ook verder onderzoek aanbevolen naar de determinanten van succesvolle digitale interactie tussen ouders en zorgprofessionals. Ten slotte wordt de noodzaak benadrukt van onderzoek naar nieuw, transformatief leiderschap in de gezondheidszorg, om zorgprofessionals te begeleiden en te empoweren bij de fundamentele transities die nodig zijn voor een duurzame en toegankelijke toekomstige gezondheidszorg, die ook de ondersteuning van zelfmanagement van ouders zal omvatten.

ABOUT THE AUTHOR

Ruud Wong Chung was born on 20 January 1961 in Nijmegen, the Netherlands. He obtained his VWO-B diploma in 1979 at Elshof College in Nijmegen. In the early 1980s, he studied cultural anthropology and social geography at the Catholic University of Nijmegen, while also travelling and participating actively in the extra-parliamentary movement of the time. In 1987, he began his physiotherapy studies at the University of Applied Sciences in Amsterdam, where he graduated cum laude in 1991. From 1999 to 2001, he specialised in paediatric physiotherapy at Avans+ University of Applied Sciences in Breda. In 2010, Ruud began an international Master of Science in Health Professions Education at the Faculty of Health, Medicine and Life Sciences of Maastricht University, graduating cum laude in 2012.

Since 1991, he has worked with children and their parents as a physiotherapist at Merem Medical Rehabilitation (formerly RC de Trappenberg) in Huizen, Hilversum, and Almere, with a one-year period at Rijndam Rehabilitation in Rotterdam in 1993. Also beginning in 1991, Ruud became involved in teaching in Higher Education, working with institutions in the Netherlands such as the European School of Physiotherapy (ESP) at the University of Applied Sciences Amsterdam and the Association of Teachers in Paediatric Neurorehabilitation (VDKNR) at the Radboudumc Health Academy (RHA). Over the years, he has also taught internationally in numerous healthcare projects, including in China, Palestine, and especially Ukraine, where he has been involved in interprofessional, family-centered, healthcare training since 2003.

Ruud is currently an educational supervisor in a government-funded project with Netherlands4Ukraine, Healthcare4Ukraine, and the Superhumans Foundation in Lviv, which aims to enhance rehabilitation services in Ukraine, particularly in response to the needs of war victims. From 2024 to 2026, this project will provide interprofessional training in the Netherlands to several Ukrainian rehabilitation teams, with Dutch rehabilitation specialists from centres such as Basalt, MRC Aerdenburg, and Heliomare.

Additionally, Ruud served on the National Steering Committee for Developmental Coordination Disorder from 2002 to 2023. He currently chairs the VDKNR board and has been a board member of the Dutch Academy of Childhood-onset Disability (DACD) since 2012.

Ruud is married to Krista Bongers. They live in Amsterdam and have two sons, Luka and Jona, and a beautiful dog, Moon. Whenever they find the time they are outdoors, hiking and (wild) camping, in the mountains or backcountry.

PUBLICATIONS

International publications

Wong Chung, R. W., Willemen, A. M., Voorman, J. M., Ketelaar, M., Becher, J. G., Verheijden, J. M. A., & Schuengel, C. (2019). Managing oneself or managing together? Parents' perspectives on chronic condition self-management in Dutch paediatric rehabilitation services. *Disability and Rehabilitation*, *42*(23), 3348-3358. https://doi.org/10.1080/09638288.2019.1594396

Wong Chung, R. W., Willemen, A. M., Voorman, J. M., Ketelaar, M., Becher, J. G., & Schuengel, C. (2021). Professionals' motivation to support parental self-management regarding children with physical disability in Dutch rehabilitation services: 'Please mind your gap'. *Child: Care, Health and Development*, *47*(5), 685-696. https://doi.org/10.1111/cch.12883

Wong Chung, R. W, Willemen, A. M., Bakker, A., Maaskant, J. M., Voorman, J. M, Becher, J. G., Schuengel, C., & Alsem, M. W. (2024). The development and validation of the S-scan parental self-management support (S-scan - PS): A self-reflection tool for child healthcare professionals. *Child: Care, Health and Development*, *50*(1), e13223 https://doi.org/10.1111/cch.13223

Dutch publications

Alsem, M. W., Wong Chung, R. W., Rentinck, I. C. M., Reinders-Messelink, H. A., Willemen, A. M., & Ketelaar, M. (2021). Gezin en Samenleving. In M. Hadders-Algra, R. Pangalila, J. G. Becher, J. van der Burg, T. Hielkema, & J. de Moor (Eds.), *Kinderrevalidatie* (6th ed., pp. 307-323). Koninklijke van Gorcum.

Wong Chung, R. W., Voorman, J. M., Kreuter, I., & Willemen, A. M. (2021). Samen beslissen 2.0! De implementatie van een interactief mediaplatform voor ouders en professionals. *NTR*, *43*(2), 12-15.

International presentations

Wong Chung, R. W., Voorman, J. M., Willemen, A. M., Ketelaar, M., Becher, J. G., & Schuengel. C. (2016, June 1-4). *One, two, three, towards self-responsibility?! Exploring intentions for self-management of parents of children with a chronic condition and rehabilitation professionals*. Poster presentation, 28th Annual Meeting European Association of Childhood-onset Disability (EACD); Challenge the Boundaries. Stockholm, Sweden.

Wong Chung, R. W., Voorman, J. M., Willemen, A. M., Ketelaar, M., Becher, J. G., & Schuengel. C. (2016, November 10-12). *One, two, three, towards self-responsibility?! Exploring intentions for self-management of parents of children with a chronic condition and rehabilitation professionals*. Poster presentation, Dutch Congress of Rehabilitation Medicine (DCRM); Valued based medicine: is it about money, values, or ethics? Maastricht, The Netherlands. Awarded best poster.

Wong Chung, R. W., Voorman, J. M., Willemen, A. M., Ketelaar, M, Becher, J. G., & Schuengel. C. (2017, May 17-20). *One, two, three, towards autonomy?! Views of parents of children with a chronic condition and rehabilitation professionals on parental self-management*. Oral presentation, 29th Annual Meeting European Association of Childhood-onset Disability (EACD); Steps into the future. Amsterdam, the Netherlands.

Wong Chung, R. W. (2018, September 6-8). *One, two, three, towards autonomy?! Views on parental self-management of rehabilitation professionals and of parents of children with a chronic condition; a mixed-methods investigation*. Oral presentation, European Bobath Tutor Association (EBTA); Ages and stages. Brighton, United Kingdom.

Wong Chung, R. W. (2018, October 10-12). *One two, three, towards autonomy?! Views of parents and rehabilitation professionals on parental self-management*. Oral presentation, EarlyAid Conference; Early Childhood Intervention: changing paradigms through participatory practices with families, professionals and society. Kharkiv, Ukraine.

Wong Chung, R. W, Willemen, A. M., Voorman, J. M., Ketelaar, M., Verheijden, J. M. A., Becher, J. G., & Schuengel, C. (2019, May 23-25). *One, two, three, towards autonomy; improving partnership, communication and tuning between parents and professionals through participatory action research [PAR]*. Poster presentation, 31st Annual Meeting European Association of Childhood-onset Disability (EACD); Participation through innovation. Paris, France.

Dutch presentations

Wong Chung, R. W. (2015, March 17). *Zelfmanagement in de kinderrevalidatie*. Presentatie, Regionale Refereeravond RC de Trappenberg. Huizen, the Netherlands.

Wong Chung, R. W. (2018, July 10). *1, 2, 3 naar eigen regie; Spreekt zelfmanagement voor zich?* Presentatie, Symposium Eigen regie en betrokkenheid van ouders in de zorg en onderzoek: waar staan we en wat kunnen we (nog) beter doen? Utrecht, the Netherlands.

Wong Chung, R. W. (2018, November 28). *1, 2, 3 naar eigen regie; Spreekt zelfmanagement voor zich?* Presentatie, CP-netwerkdag; Participatie in het zorgproces. Utrecht, the Netherlands.

Wong Chung, R. W. (2019, December 13). *1, 2, 3 naar eigen regie?! Is zelfmanagement vanzelfsprekend?* Presentatie, Ronald McDonald Kinderfonds symposium; Empower de Ouder. Amersfoort, the Netherlands.

Wong Chung R. W. (2023, March 14). *Eigen Regie 2.0; Ontwikkeling van een digitaal mediaplatform ter versterking van partnerschap, communicatie en samen beslissen*. Presentatie, Merem kennis en innovatie event. Hilversum, the Netherlands.

International trainings & workshops

Verheijden, J. M. A., Voorman, J. M., Willemen, A. M., Schuengel, C., Wong Chung, R. W., & Ketelaar, M. (2017, May 17). *Family focused interventions*. Preconference symposium, 29th Annual Meeting European Association of Childhood-onset Disability (EACD); Steps into the future. Amsterdam, the Netherlands.

Reinders-Messelink, H. A., Van den Berg-Emons, H. J. G., Verheijden, J. M. A., Van Wely, L., & Wong Chung, R. W. (2017, May 17-20). *Self-management support in paediatric rehabilitation: From therapist to coach*. Instructional course, 29th Annual Meeting European Association of Childhood-onset Disability (EACD); Steps into the future. Amsterdam, the Netherlands.

Alsem M. W., Wong Chung, R. W., Ketelaar, M., & Verheijden, J. M. A. (2017, November 9-10). *Parental participation and engagement: Needs, wishes, and opportunities*. Workshop, Dutch Congress of Rehabilitation Medicine (DCRM). Maastricht, the Netherlands.

Wong Chung, R. W., & Khvorostenko, O. (2018, November 10-12). *Engaging parents in pediatric rehabilitation; From (physical) therapist to coach*. Workshop, EarlyAid Conference; Early childhood intervention: Changing paradigms through participatory practices with families, professionals and society. Kharkiv, Ukraine.

Wong Chung, R. W. (2023, January 20-23). *Parental engagement: From therapist to coach*. Training, Ukrainian Catholic University Lviv, Interdisciplinary approach to (war-related) traumatic brain injury (TBI) in children. Lviv, Ukraine.

Dutch trainings & workshops

Wong Chung, R. W., Van Wely, L., Verheijden, J., Van den Berg, R., Westendorp-Haverdings, M., & Reinders-Messelink, H. (2017). *E-learning Zelfmanagement in de kinderrevalidatie*. https://free-learning.nl/modules/zelfmanagement/start.html

Wong Chung, R. W. (2018, April 3). *1, 2, 3 naar eigen regie?! Betrokkenheid en zelfmanagement(ondersteuning) van ouders van een kind met (ernstige) meervoudige beperkingen: Wensen, uitdagingen en kansen*. Workshop, Nederlandse Vereniging van Fysiotherapie voor Verstandelijk Gehandicapten (NVFVG), De (Kinder)fysiotherapeut in de VG, van alle markten thuis. Nijkerk, the Netherlands.

Wong Chung, R. W., Willemen, A. M., Kreuter, I., & Zeevenhooven, E. Z. (2019, December 13). *1, 2, 3 naar eigen regie?! Ouderbetrokkenheid, ondersteuning en partnerschap. En hoe dan?* Workshop, Ronald McDonald Kinderfonds symposium; Empower de ouder. Amersfoort, the Netherlands.

Wong Chung, R. W., Kreuter, I., & Zeevenhooven, E. Z. (2020, October 8). *1, 2, 3 naar eigen regie?! Ouderbetrokkenheid, ondersteuning en partnerschap. En hoe dan?* RC Heliomare, online.

Wong Chung, R. W. (2024, June 18). *Eigen regie 2.0: Ontwikkeling en validatie van de Z-scan - OVO, zelfmanagement ondersteuning van ouders*. Presentatie, Onderwijs en opleidingsregio medisch specialisten - Noord West Nederland (OORNWN), online.

AUTHOR CONTRIBUTIONS

Chapter 2 Managing oneself or managing together? Parents' perspectives on chronic condition self-management in Dutch pediatric rehabilitation services

Author	Conception	Design	Data collection	Analysis	Interpretation	Initial draft	Critical review and revision	Final manuscript
Ruud Wong Chung	X	X	X	X	X	X	X	X
Agnes Willemen	X	X	X	X	X		X	X
Jeanine Voorman	X	X	X	X	X		X	X
Marjolein Ketelaar	X	X			X		X	X
Jules Becher	X	X			X		X	X
Johannes Verheijden	X						X	X
Carlo Schuengel	X	X			X		X	X

Chapter 3 Professionals' motivation to support parental self-management regarding children with physical disability in Dutch rehabilitation services: 'Please mind your gap'

Author	Conception	Design	Data collection	Analysis	Interpretation	Initial draft	Critical review and revision	Final manuscript
Ruud Wong Chung	X	X	X	X	X	X	X	X
Agnes Willemen	X	X	X	X	X		X	X
Jeanine Voorman	X	X	X	X	X		X	X
Marjolein Ketelaar	X	X			X		X	X
Jules Becher	X	X			X		X	X
Carlo Schuengel	X	X			X		X	X

Chapter 4 The development and validation of the S-scan - parental self-management support (S-scan - PS): A self-reflection tool for child healthcare professionals

Author	Conception	Design	Data collection	Analysis	Interpretation	Initial draft	Critical review and revision	Final manuscript
Ruud Wong Chung	X	X	X	X	X	X	X	X
Agnes Willemen	X	X	X	X	X		X	X
Amber Bakker	X	X	X	X	X		X	X
Jolanda Maaskant			X		X		X	X
Jeanine Voorman	X	X			X		X	X
Jules Becher					X		X	X
Carlo Schuengel					X		X	X
Mattijs Alsem		X	X		X		X	X

Chapter 5 Shared decision-making 2.0! Co-creating an interactive media platform for shared decision-making with parents in paediatric rehabilitation services

Author	Conception	Design	Data collection	Analysis	Interpretation	Initial draft	Critical review and revision	Final manuscript
Ruud Wong Chung	X	X	X	X	X	X	X	X
Jeanine Voorman	X	X	X		X		X	X
Ines Kreuter	X	X					X	X
Agnes Willemen	X	X	X	X	X		X	X

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However, two factors played a decisive role in me continuing and ultimately completing this journey. The first was the realisation that, as with any path in life, my PhD project was not primarily about the destination, but particularly about the journey itself. This understanding helped me regain motivation to persevere in moments of doubt, enabling me to enjoy the learning opportunities and special encounters the process offered, rather than solely focusing on the end goal. The second crucial factor in successfully completing this project was the continuous support of those who accompanied me on this adventure. Without them, I would not have reached the point where I stand today.

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There is increasing attention on parental self-management in the daily care for their children with chronic conditions. However, self-management can be challenging, and there is no consensus on what parental self-management and its support should specifically involve. In this dissertation, we explored the views, attitudes, experiences, motivations, and associated factors of both parents and child healthcare professionals, regarding parental self-management and the support it entails. Drawing on these insights, we developed two tools that may help to enhance the support provided by professionals to parents in managing their child's care.

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