UNDERSTANDING BURNOUT AMONG PARENTS OF CHILDREN WITH COMPLEX CARE NEEDS: A SCOPING REVIEW INFORMED BY A STAKEHOLDER CONSULTATION

PROJECT “OUDERS IN EVENWICHT - DOORGAAN ALS DE KINDEREN VOOR GAAN”

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Abstract

Parents of children with complex care needs (CCN) are faced with tremendous demands and challenges (Lindström et al. 2010; Woodgate et al. 2015), in addition to the normative tasks of parenting. Parenting-related strain due to caring for a child with CCN may have negative physical and psychological effects on wellbeing. Parents of children with CCN have been reported to experience increased stress, feelings of hopelessness, anxiety, and/or depression (Woodgate et al. 2015; van Oers et al. 2014; Miodrag et al. 2015).

To contribute to the understanding of the nature and origins of parenting-related strain, some in the field have referred to the concept of ‘parental burnout’, described as a three dimensional syndrome characterised by (1) emotional exhaustion related to one’s parental role, (2) emotional distancing from one’s child, (3) and lack of personal accomplishment in the parental role (Roskam, Raes & Mikolajczak 2017). Parental burnout has been associated with an increase in escape and suicidal ideations, addiction, partner estrangement and conflicts (Mikolajczak et al. 2018), sleep problems, somatic complaints (Mikolajczak et al. 2018; Sarrionandia-Pena 2019), and neglectful and violent behaviour towards the child (Hubert et al. 2018; Mikolajczak et al. 2018).

Considering the challenges that parents of children with CCN face, these parents are particularly vulnerable to parental burnout. Due to the detrimental consequences of parental burnout, it is important to investigate to what extent research has addressed burnout among these parents as well as the social validity of the concept, before identifying and developing strategies for alleviation and prevention.
Open Science efforts

Free accessible
This research has been planned to be published in an open access journal (Child: Care, Health and Development). Furthermore, the initial study protocol is available for the public on OSF.

Transparency/Reproducible
In September 2020, the research protocol of the scoping review was made publically available on OSF. The research protocol is also publically available on Researchgate. Furthermore, an updated version of the research design will be published in December 2020 on OSF. The data gathered from the literature and anonymous transcripts from the stakeholder consultation is available upon request.

Dissemination
In addition to the open access publication and the research protocol on OSF and Researchgate, a co-created public version of the article will be published in Dutch. The co-created public version will be made available through patient organizations or on websites such as, schouders.nl. Furthermore, we also plan to present the research findings at the conference European Academy Of Childhood Disability, in May 2021. To increase visibility of our research and Ouders in Evenwicht we have planned to create a Twitter account to share the aforementioned research material.

Collaboration
Ouders in Evenwicht is a collaborative project with parents of children with CCN, healthcare professionals working with families/parents of children with CCN, and researchers. The project was instigated by parents of children with CCN by creating a Research Agenda for Childhood Rehabilitation containing research topics needing urgent attention. Using the Research Agenda for Childhood Rehabilitation, an experience expert parent presented one of the research ideas during a “Broedplaatsbijeenkomst”, a platform where researchers, professionals, clients and their parents come together to share ideas and knowledge. The research question ‘how can we prevent distress and burnout in parents of children with CCN?’ was presented. The research question was well-received and resulted in the experienced expert parent composing a research team: four researchers with different backgrounds, a healthcare professional, and another experience expert parent. Then five research questions were drafted, together with two parents of children with CCN for a scoping review to map and synthesize literature on burnout among parents of children with CCN and a stakeholder consultation with the aim to gain social validity, guide the interpretation of the data, and to give direction to further research and a research proposal. Based on the research questions, the experience expert parent and one researcher started conducting the review. The data from the literature was gathered in a spreadsheet, analyzed, and translated into Dutch. The translated analysis was then presented at a stakeholder consultation consisting of a group of parents, healthcare professionals, and researchers who were asked to reflect on the analysis from their own experiences. The research proposal is planned to be written in the first quarter of 2021 in the same multidisciplinary setting, with the possibility to modify the project group to fit the research proposal.
To ensure that every project member could engage in a manner according to their wishes and strengths, the Involvement Matrix (www.participatiematrix.nl) was used throughout the research.

**Impact, successes and failures**

Parents of children with CCN have been advocating for increasing attention in research towards the risk of prolonged parenting-related strain, parental burnout, and potential mitigating factors. This was the base for the research questions formulated for this study. Consequently, as the research questions are directly derived from parents of children with CCN, we expect this study to have a societal impact as well as an individual impact on those parents and professionals who participated in the stakeholder consultation. Stakeholders expressed that they were happy to contribute to the research as it provides the opportunity to contribute and help parents in the future.

Choosing to focus on specific research questions while trying to incorporate ideas from both the project group and parents appeared challenging. This resulted in many research questions rather than a few specific ones. However, we believe that the effort of having research questions composed by a diverse group of people with various perspectives, makes this research unique.

Furthermore, we noticed that despite providing weekly written updates to the project group, it appeared that this was not sufficient and some project members felt that they were not properly engaged in the research. Therefore, the project team decided to also arrange monthly meetings to ensure the engagement of each project member. In addition, we also made greater effort to use the Involvement Matrix to promote and shape collaboration. We believe that the collaboration within this is an unique example of how co-creation in research can be successful.

**Open Science Resources**

Scoping review protocol: https://osf.io/v5gpj/

**References**

The final results are not yet available.


