




**THE POLITICS OF DISABLEMENT
SUMMER SCHOOL 25 AND 26 AUGUST 2022**

The lifeworld of parents caring for children with PIMD
Images and metaphors expressed by Dutch parents

THE HAGUE
UNIVERSITY OF
APPLIED SCIENCES

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- Introduction research concern
 - Presentation: Images and metaphors expressed by Dutch parents (caring for children with PIMD)
 - Dialogue and participation

PhD Research: Experiences of parents caring for children with PIMD (1)

Experiences of parents caring for children with PIMD

Key question: In what ways do parents who are caring for children with PIMD thrive?

How good care is perceived, provided and evaluated

Insider perspective

PhD Research: Experiences of parents caring for children with PIMD (2)

Children/persons with PIMD →

- Combination of profound cognitive, neuromotor and sensory impairments
- Children with medical complexity (CMC)(such as gastrointestinal, respiratory and feeding difficulties, epilepsy, spasticity and scoliosis)
- Communication usually happens through nonverbal expressions, sounds and muscle tensions
- Associated with: chromosomal deviations, brain formation, metabolic diseases or acquired brain damage (accidents or near drowning)
- Dependent on others for many aspects of their lives
- Shorter life expectancy or a high risk of an unpredictable life-threatening complication
- Healthcare technology (medical devices and assistive technology)

(ICPCN, 2022; Nakken & Vlaskamp, 2007; Van der Putten et al., 2017)

PhD Research: Experiences of parents caring for children with PIMD (3)

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Research groups: Technology for Health & Participatory Health Research

Perspective as a mother

Exploring the parents' experiences

Literature review & blogs written by Dutch parents

Interviews with 25 Dutch parents (at home)

In-depth interviews → open and nondirective phenomenological style (Dahlberg et al., 2008)

Images and metaphors in parents' stories

Relevant → access to an additional source of experimental meaning

The lifeworld of parents caring for children with PIMD

This study →

Aim: Contribute to the comprehension of parents' experiences and vulnerabilities by examining the images and metaphors used by (Dutch) parents → the deeper layers of what parents express through use of language

Social imaginary (Taylor) → to reflect on the sociocultural or collective dimension of parents' linguistic choices

Alternative imaginaries

Methods used

Mixed group of parents

Systematic metaphor analysis (Schmitt, 2005)

Metaphorical concepts

Discussion & triangulation

Parents participated in member reflections (23)

Findings

Broad spectrum of expressions → six metaphorical concepts

- *Stagnation*
- *Labyrinth*
- *Battle*
- *Transition*
- *Medal (coin)*
- *Parallel worlds*

Stagnation

“Life continues but ours took a turn somewhere”

- Stagnated ideas and dreams in various domains of life
- Contrast with “normal” (family and personal) development
- Professional careers and connections with peers
- Death of the child
- Overcoming stagnation → going through grief, mobilizing help, acceptance or integration

Labyrinth

“It was such a search for possibilities”

- Parenting children with PIMD → images of navigating a labyrinth (disorientation and being lost in a confusing situation)
- Difficulties in being provided with the correct information and complex service systems
- Medical decision making → dilemmas about treatment and quality of life and death
- Not knowing the future (short and long term)
- Regaining control over family thriving

Battle

“We had to fight for everything”

- *Battling, struggling, manning the barricades, negotiating, battered, affronted, pushed aside, etc.*
- Matters: resources needed to manage as a family (quality of life of the child and family) → unwanted dependency on procedures and protocols
- Discourse of battling in reference to the child’s vulnerable health

Transition

*“We must keep changing expectations
and continuously adapt to circumstances”*

- Constantly evolving challenges to integrate care needs into everyday family life and changing attitudes and circumstances
- Growth and transformation → the child's best expert and learning to raise their voices
- Continuous challenges to integrate care needs in day-to-day family life and changing views and circumstances

Medal (or coin)

“Everything has two sides”

- Demanding yet enriching
- Contradictions in dealing with emergencies
- Contrasting emotions evoked by anticipating the child’s future and uncertain life expectancy
- Unanticipated positive discoveries

Parallel worlds

“I was brutally pushed into a parallel world”

- Two separate worlds → parent alternates between the two
 - Solitude; lack of understanding of those nearest
 - Friction with the outer world; exclusion
 - Creating an aligned reality in which the child could do well
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- Fellow parents
 - Social support

Interplay with social imaginaries

Deeper layers in parents' figurative linguistic choices (Taylor, 2004; Sartre, 2004)

Social imaginaries: common understandings and values within certain sociocultural groups → communicated in language and other forms of cultural and artistic expressions

Interpretation of sociocultural and collective dimension of vulnerabilities
→ larger context of beliefs and values incorporated in such imaginaries clarifies how experiences and vulnerabilities were shaped

Practices associated with the social imaginary of health and normality, autonomy and responsibility and of what lives are worth living →

Three considerations

- Society promotes strong values of health and disability
- Feelings of not meeting expectations and of not fitting in
- Taylor → ability to talk and remember as the foundation of people's individuality and possibility to relate to others
- Healthcare systems often not aligned with family needs → lack of priority
- Taylor → modern imaginary of the human and self (childcare ultimately assumed an individual challenge)
- Families can be autonomous and thriving only if they are recognized by the wider political context
- Meaning making → new positions towards collective ideals (imaginary regarding relationship with the child, family life and career paths)

Conclusion and implications

What parenting a child with PIMD *means* and *does* is created by an social imaginary (“vulnerabilities”)

Imaginaries may be transformed to frames that are more inclusive to families with children with PIMD

Placing autonomy and accountability within a relational perspective

Humane healthcare services

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Dialogue



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