Barriers and Facilitators to Movement in Paediatric Palliative Care

A Qualitative Multi-Perspective Study

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Introduction

- Paediatric palliative care (PPC) aims to improve children's quality of life, and the Dutch PPC guideline recommends daily movement.[1]
- In practice, PPC predominantly focuses on caregiving and symptom management, with limited attention to movement and physical activity.
- This study aims to identify and explore barriers and facilitators to movement in PPC from the perspectives of children, parents, paediatric therapists, and other stakeholders.

Method

- Semi-structured generative interviews with children (n=4), parents (n=11) and paediatric physical and occupational therapists (n=9), and two focus groups (n=11) with nurses, pedagogical staff, managers, teachers and volunteers.
- Inductive thematic analysis.[2]

Preliminary results

"WE REALIZED THAT THIS CARE JOURNEY IS A MARATHON, NOT A SPRINT."
(FATHER OF GIRL 13Y, CP GMFCS-V)

"MOVEMENT GIVES HIM CHOICES, AND THEREFORE FREEDOM".
(FATHER OF NON-AMBULANT BOY 2Y, COMPLEX GENETIC DISEASE)





CHILD FACTORS

Barriers

- Medical complexity & vulnerability
- Limited energy & endurance
- Dependency & participation restrictions

Facilitators

- Enjoyment & intrinsic motivation
- Autonomy & active participation
- Physical ability & potential for improvement
- Energy, sleep & well-being

"WHEN I PLAY SOCCER I FORGET ABOUT EVERYTHING FOR A WHILE".
(GIRL, 14Y, METABOLIC DISEASE)



PARENTAL AND FAMILY FACTORS

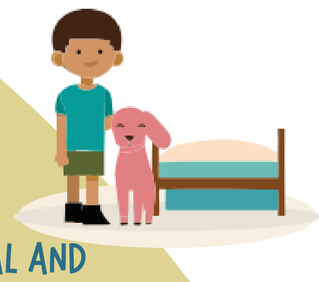
Barriers

- Time, energy & caregiving burden
- Safety concerns
- Limited support
- Shame
- Knowledge & awareness gaps

Facilitators

- Parental capacity & commitment
- Activity-oriented parenting
- Family & social support
- Adaptive problem-solving

"I DON'T KNOW HOW ON EARTH I'M GOING TO MANAGE THAT"
(MOTHER OF AMBULANT GIRL 8Y, GENETIC DISEASE)



ORGANISATIONAL AND HEALTHCARE CONTEXT

Barriers

- Low priority for physical activity
- Limited knowledge (exchange)
- Limited access to assistive devices
- Time & reimbursement constraints
- Communication & continuity challenges

Facilitators

- Physical activity as an integral part of care
- Integration into care plans
- Consultation & collaboration structures
- Availability of resources

"THIRTY MINUTES OF THERAPY A WEEK WILL NOT MAKE A DIFFERENCE"
(PAEDIATRIC PHYSICAL THERAPIST)

PROFESSIONAL FACTORS

Barriers

- Unclear roles & responsibilities
- Limited therapist confidence
- Expectations exceed caregiver capacity
- Limited coordination & communication
- Insufficient recognition of care needs

Facilitators

- Creativity & flexibility
- Meaningful, child-centred activities
- Recognising & using movement opportunities
- Face-to-face contact
- Multidisciplinary collaboration
- Shared goals & clear communication



PHYSICAL AND SOCIAL ENVIRONMENT

Barriers

- Transportation barriers
- Limited space & facilities
- Limited storage for assistive devices
- Weather constraints

Facilitators

- Inclusive movement opportunities
- Accessible space & environment
- Appropriate assistive devices & equipment
- Social & workplace support

"SMALL STEPS MATTER"
(VOLUNTEER)

"WHEN WE ALL WORK TOGETHER, WE CAN CREATE SO MANY MORE POSSIBILITIES FOR THE CHILD."
(PAEDIATRIC OCCUPATIONAL THERAPIST)



Discussion

- "PPC is not about me", stakeholders do not identify with the term paediatric palliative care.
- Highly diverse population
- Movement can take many forms and can be understood in different ways

Conclusion

- Barriers and facilitators to movement occur across multiple and interacting levels.
- This highlights the need for a systemic and context-sensitive approach to promoting movement, centred on collaboration, a shared vision on movement, face-to-face contact, and recognising and using opportunities for movement in the child's daily life, however small.



Take-home message

- Small movements matter too
- Integrating meaningful movement into daily life is a team effort

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Moving for Quality of Life

Regieorgaan SIA

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