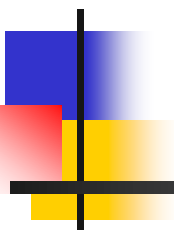


# Mothers' experiences of caring for a child with severe brain injury while living in a disadvantaged community in the Cape Flats



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# Background

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- I work with children with severe TBI in rehab phase
- Mothers participate in therapy
- Concern: focus on child and his/her functional impairment and not enough on the mother
- MDT research 2007
- Need for further research for health professionals' better understanding of mothers' lived experiences



# Definition of terms

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- Traumatic Brain Injury (TBI) (1)
- Disability (2)
- Disadvantaged Community (3)



# Research problem

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- Minimal information on lived experiences of mothers with children with severe TBI living in disadvantaged communities in Cape Flats. (4)



# Purpose of study

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- For OT to get better understanding of context and experiences of mothers living in disadvantaged communities while caring for their children with severe TBI.
- To provide contextually relevant OT services.



# Objectives of the study

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- Luborsky and Lysack (5)
- 4 important aspects of the lived experience to explore in a phenomenological study:
  - Lived space
  - Lived body
  - Lived time
  - Lived social relationships and social networks



# Objectives derived and adapted

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- the lived space of mothers who care for their children with severe TBI while living in a disadvantaged community
- the lived body of mothers, including their roles and occupational configurations
- mothers' lived time
- mothers' lived social relationships and social networks



# Study design

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- 2 interviews with 4 mothers
- Audiotaped
- Verbatim transcriptions





# Phenomenology

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- Qualitative methodology

Seeks to understand what certain experiences are like for people, to understand and describe their contexts and to learn from their subjective experience and the meaning they develop from those experiences. (6,7)



# Phenomenology cont.

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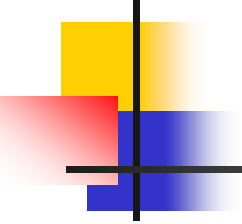
- Moustakas' empirical phenomenological approach: (8)
- To explore people's lived experiences and to describe these experiences in detail in order to provide a foundation for researcher to analyze the experiences reflectively.

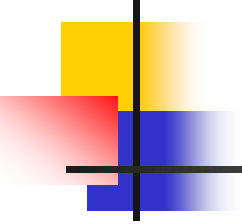


# Results

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- **Theme 1: Personal burden of care**
  - “hy moet at all times in my oë wees”
- Constant worry
- No time for self
- Daily struggles
- Small reliefs

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- **Theme 2: Living a different life with a different child – “Ek het nie beplan om vir haar so groot te maak nie”**
  - Changed parenting style
  - Mothering response

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- **Theme 3: Holding onto faith and hope – “Bid, dis al wat gaan help. En glo”**
  - Seeking answers
  - Remaining optimistic
  - Trusting in God’s will



# Discussion of results

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- **1. Lived space**
  - Living in disadvantage (9)
  - Unsafe physical environment
  - Living arrangements
  - Lack of appropriate facilities



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- **2. Lived body**

- Experience of stress
- Identity
- Meaning of occupation
- Changed roles
- Need to relax
- Spirituality



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### **3. Lived social relationships and social networks**

- Isolation
- Friendships
- Expectations of family





# Implications for practice

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- Intervention with mothers to identify supports and barriers. Help mothers to utilize resources
- Case manager
- Support group



# Acknowledgements

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  - Hilary Beeton
- Participants



# References

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1. Lebbby PC & Asbell SJ. The Source for Traumatic Brain Injury Children and Adolescents. East Moline, Illinois: LinguiSystems Inc; 2007. pp.40 - 65.
2. World Health Organization. International Classification of Functioning, Disability and Health Short Version. Geneva: WHO Library Cataloguing-in Publication Data; 2001. p. 190.
3. Rashid A, Seedat M, van Niekerk A & Bulbulia S. Discerning community resilience in disadvantaged communities in the context of violence and injury prevention. South African Journal of Psychology 2004;34(3):386 – 408.
4. Oosthuizen D. Families of Children with Traumatic Brain Injuries: Stressors and needs in the South African context. [unpublished honours dissertation]. Department of Psychology, University of Cape Town; 2007.



# References cont.

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5. Luborsky MR & Lysack C. Overview of Qualitative Research. In Kielhofner G, editor. Research in Occupational Therapy: Methods of Inquiry for Enhancing Practice. Philadelphia: FA Davis Company; 2006. pp. 326 – 340.
6. Carpenter C & Suto M, editors. Qualitative research for occupational and physical therapists. A practical guide. Oxford, Iowa: Blackwell Publishing; 2008. pp.21 – 39, 60 – 76.
7. Cook JV, editor. Qualitative Research in Occupational Therapy. Australia: Delmar; 2001. pp.3 – 9, 24 – 51.
8. Moustakas C, editor. Phenomenological research methods. Thousand Oaks: Sage Publications, Inc; 1994.
9. Elwan A. Poverty and Disability: A Survey of the Literature. Social Protection Discussion Paper Series No. 9932. Social Protection Unit, Human Development Network, The World Bank. [Online] December 1999.



# Thank you

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- Questions?
- Comments?