Exploring the lived experiences of mothers caring for children with complex needs at home.

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Background

• Doctoral study
• Registered Children’s nurse
• All Ireland study
The study

• **Phenomenon of interest**

Mothers’ experiences of caring for a child with complex needs at home in Ireland within a contemporary health care environment.
Context

- Increasing numbers of children with “life-limiting” illnesses*
- Increasing emphasis on service provision and community care
- Care by parents /mothers*
Aim

• To explore the mothers’ life-worlds and from this to develop a greater understanding of their experiences (and to identify potential interventions that may support mothers)

• To describe, analyse and explain in order to illuminate this phenomenon*.

• Focus was to investigate understanding and interpret the text in which understanding is reported (Gadamer, 1979).
Research framework

• Phenomenology based on the work of Heidegger and Gadamer
• An interpretivist approach in which the perspective of the other, as well as the researcher, is important.

• Three beliefs
• Reality is complex and based on subjective experiences
• I am not separate from the research*
• Truth is best achieved by conducting the research process openly with subjects in their natural environments and without prior theorising (Lincoln and Guba, 1985)
Recruitment

• Via gatekeepers* – 60 mothers invited to contribute
• 17 participated
• Written consent with ongoing confirmation and information
Data collection

- Unstructured in-depth multiple interviews (3)
- Diaries (3) – a good day, a bad day and a normal day
- 48 interviews
- 11 sets of diaries
- Researcher diaries, field notes, memos*
The children

- Aged under 1-19*
- Identified by service providers
- *Children had rare disorders, some of which were progressive
- Metabolic, neurological & genetic disorders, rare syndromes, no diagnosis*
The mothers

- 17 (10 RoI; 7 NI)
  - 14 had one child with complex needs
  - 3 had more than one child with complex needs
  - *Young adults with complex needs (unrelated)
  - *Experiences of death of children
The findings

• Different to the literature...stress/coping etc

• Different mothering experience
• Confronted by complex, unremitting care-giving
• Three worlds
• Eight dimensions
Three worlds

- Inside world
- Mothers’ experiences
- Outside world
- Going-between world
Dimensions

• Care-giving*
• Paperwork and administration
• Constant instability
• Constant observation
• A no-choice situation
• Knowingness
• Unknowingness
• Constant communication*
Mothers' experiences

- Care-giving
- Paperwork and administration
- Constant instability
- Constant observation
- No choice situation
- Knowingness
- Unknowingness
- Constant communication
Summary

- Mother’s experiences occur in 3 worlds
- They include many dimensions that need to be understood in their totality.
Thank you

• To the mothers who contributed,
• The organisations used in recruitment.

• Any questions
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