



# 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



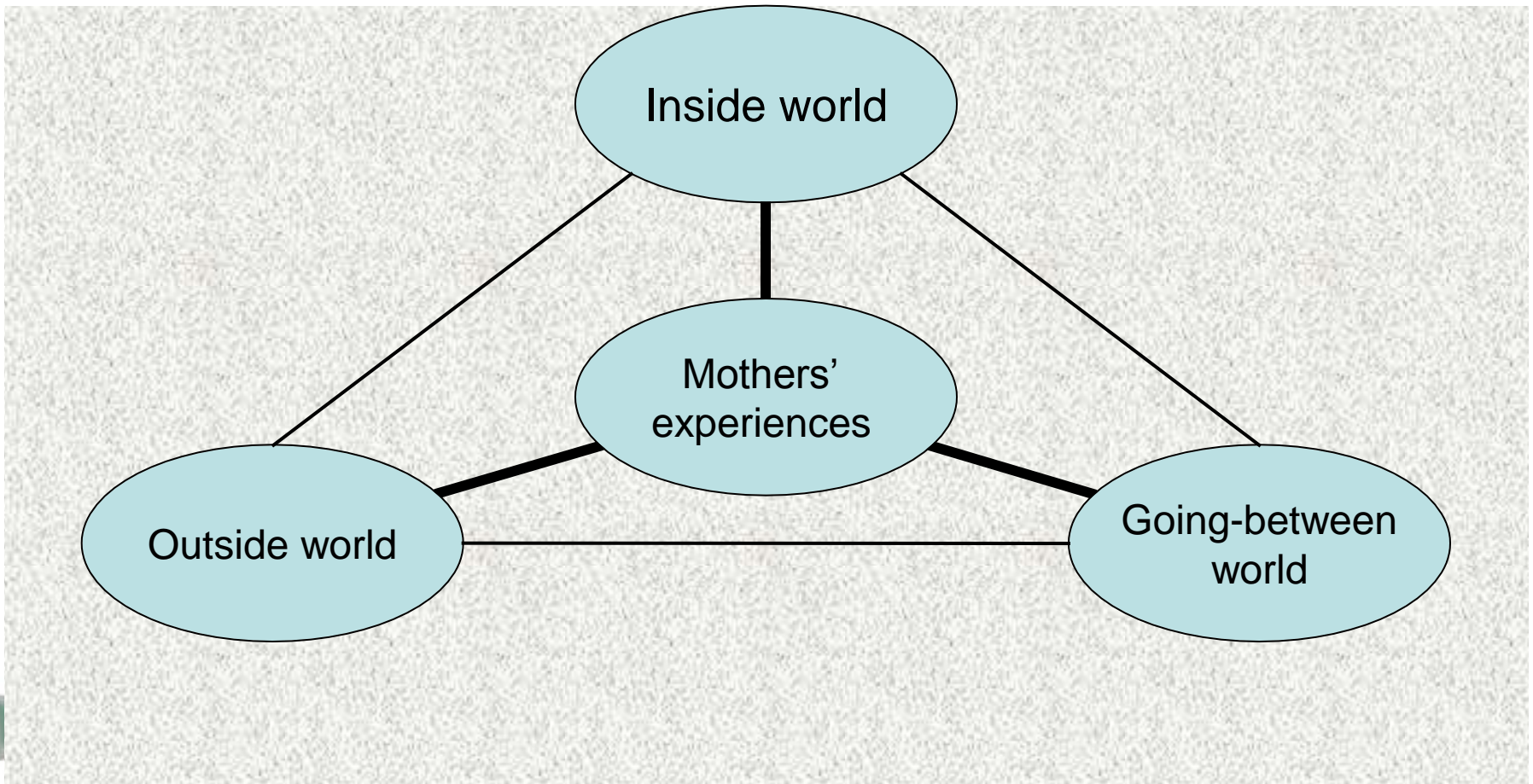


# The findings

- *Different to the literature..stress/coping etc*
- Different mothering experience
- Confronted by complex, unremitting care-giving
- Three worlds
- Eight dimensions



# Three worlds





# 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.
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- Any questions
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