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FAM-WEST. West Syndrom: building knowledge and singularity of the families experiences

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FAM-WEST

West Syndrom: building knowledge and singularity of the families experiences

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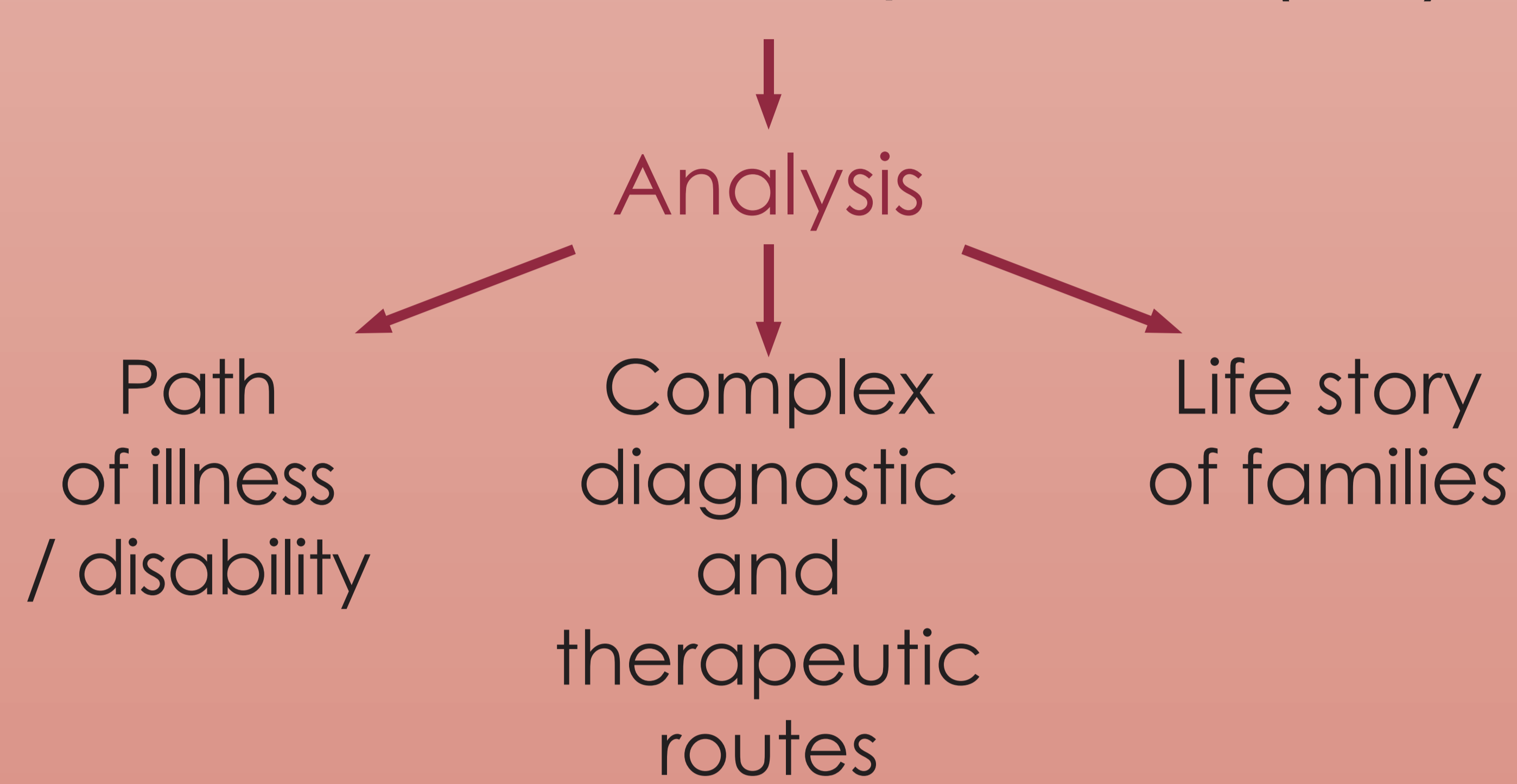
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Associations

Les Enfants de West, ASTB, Injeno

Purpose

How knowledge and “know-how” are constructed by families in the case of West’s syndrome (WS)?



Methods

A multidisciplinary research

- **30 families** with children ages from 11 months to 15 years
- **60 semi-structured interviews** with the mothers
- **Participating observations** at the hospitals and at the families homes (18 months)
- **Exchanges analysis** through the discussion forum (Facebook Enfants de West)

Preliminary Results

Emphasize the importance of experience in building mothers’ knowledge of care.

Knowing how to do with uncertainties ?

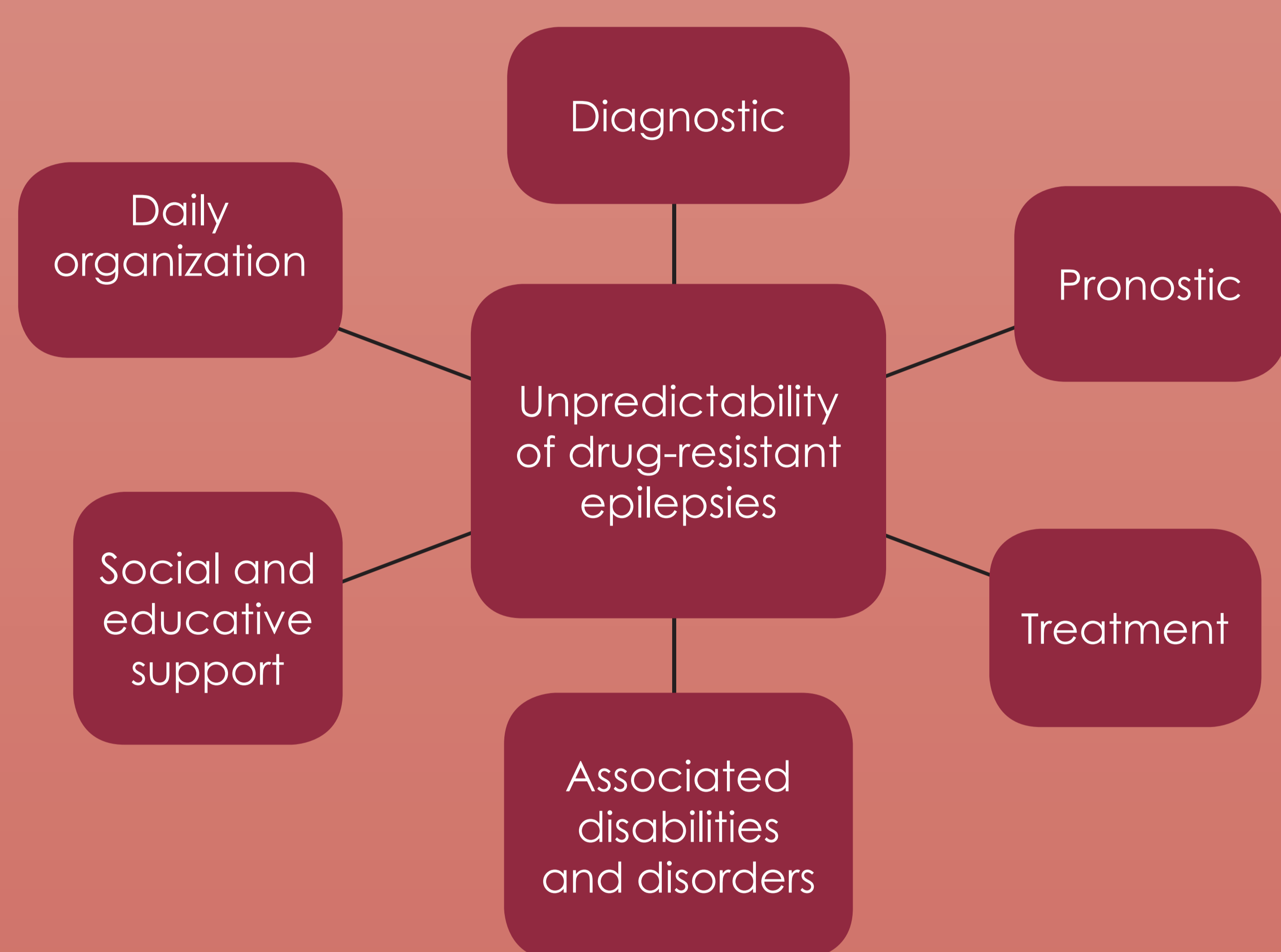


Diagram 1: The different levels of unpredictability

Experiencing the knowledge

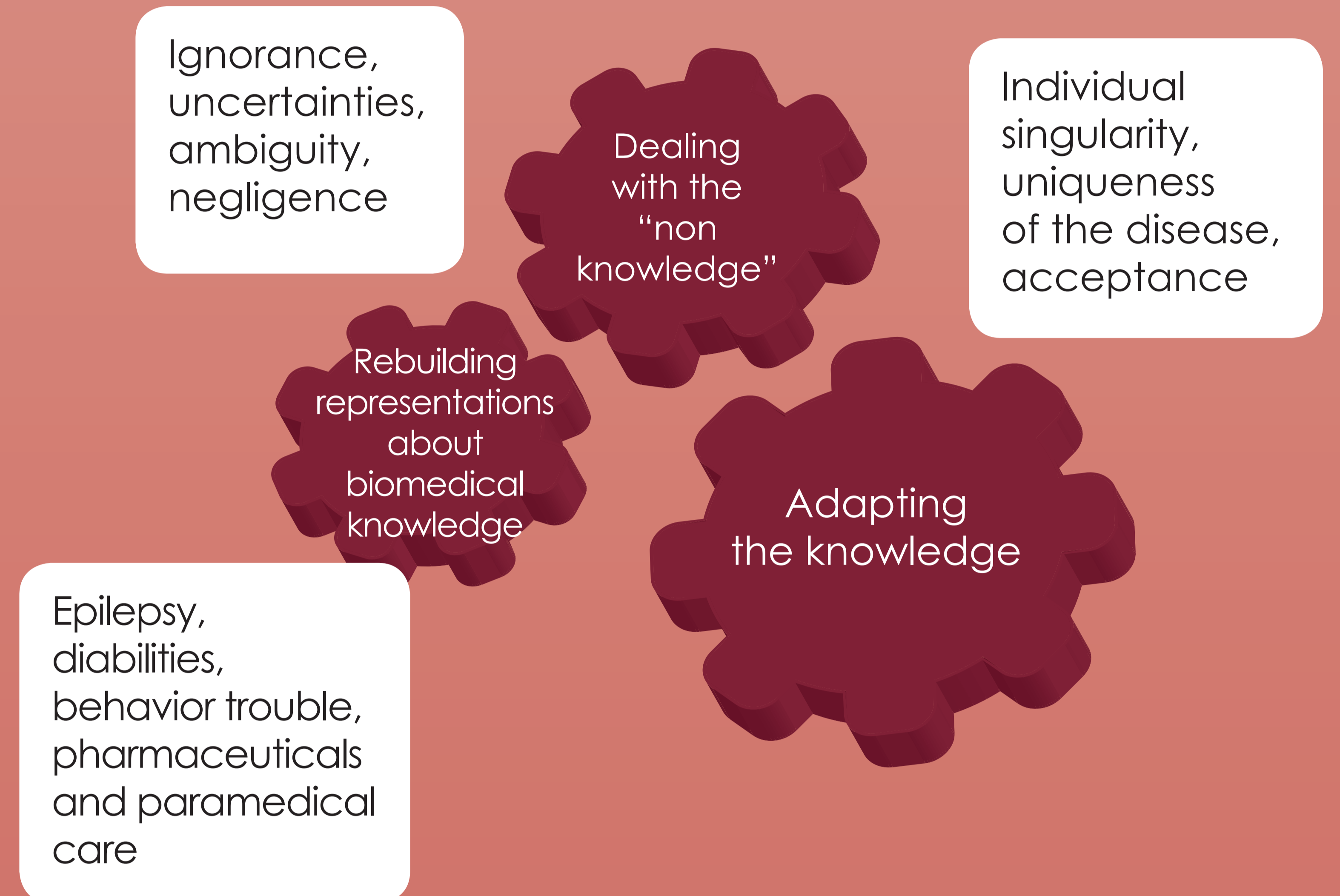


Diagram 2: Knowledges as a building process

Knowledge as a necessary exchange

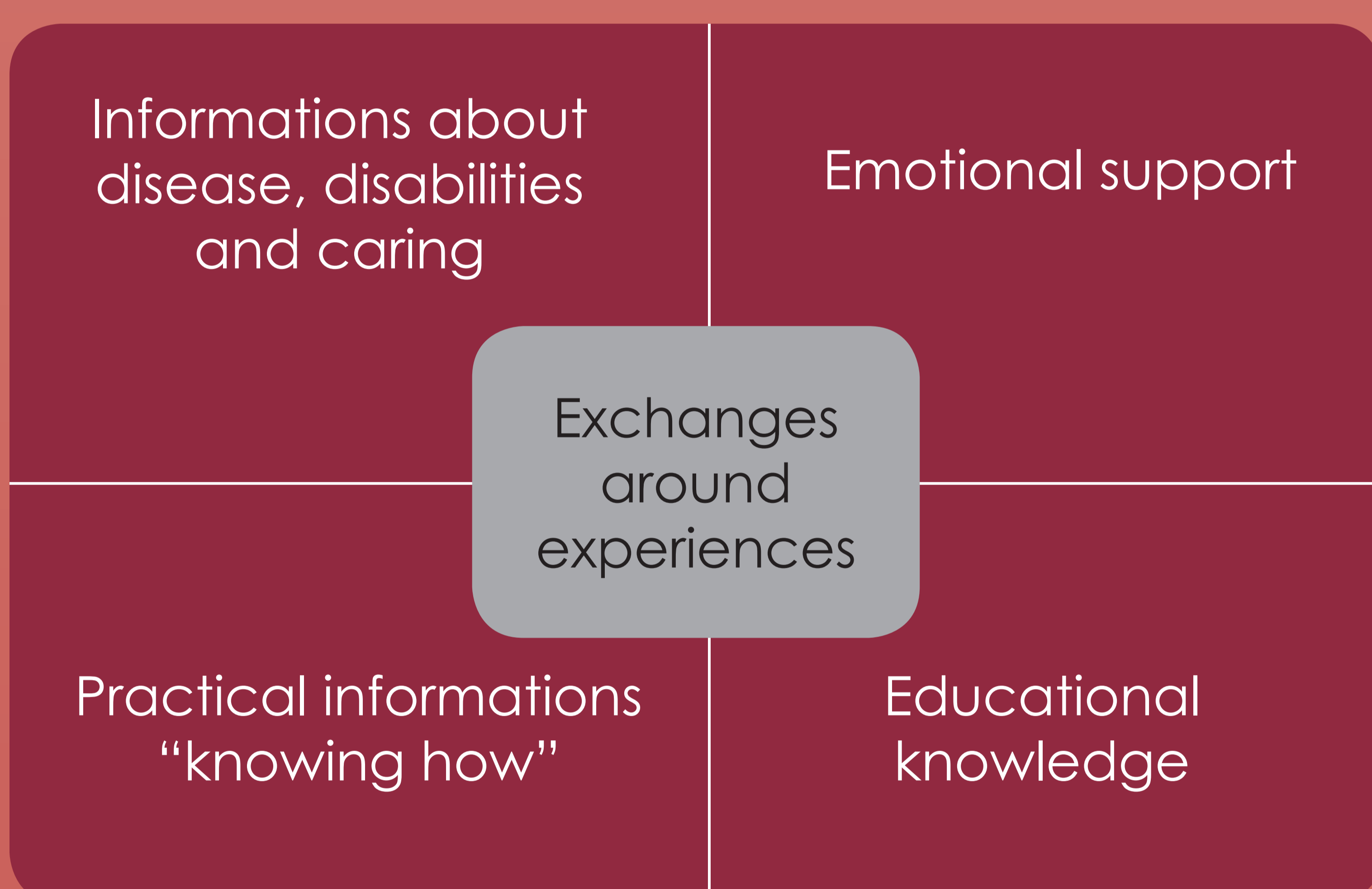


Diagram 3: Knowledge as an exchange between mothers

A process as the interface of knowing and “knowing how”



Diagram 4: Knowledge as a global process

Conclusion

How to build patient educational programs?

Emphazing through a diachronic process **the families experiences (“knowing how”)** instead of only the medical “knowing that” **help to adapt educational programs** to families daily care.

Emphazing on a global approach rather than a medical one

Privileging experience as a possible answer to uncertainties

Viewing educational program as a structured and social exchange

Offering time to rebuild parental identity

