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

Sophie Arborio, Emmanuelle Simon, Stéphane Auvin, Anne de Saint Martin

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# FAM-WEST

## West Syndrom: building knowledge and singularity of the families experiences

**S. Arborio** (MCU HDR, Université de Lorraine, Crem) – sophie.arborio@univ-lorraine.fr

**E. Simon** (MCU, Université de Lorraine, Crem) – emmanuelle.simon@univ-lorraine.fr

**Pr. S. Auvin** (PU-PH, Hôpital universitaire Robert-Debré, Inserm) – stephane.auvin@rdb.aphp.fr

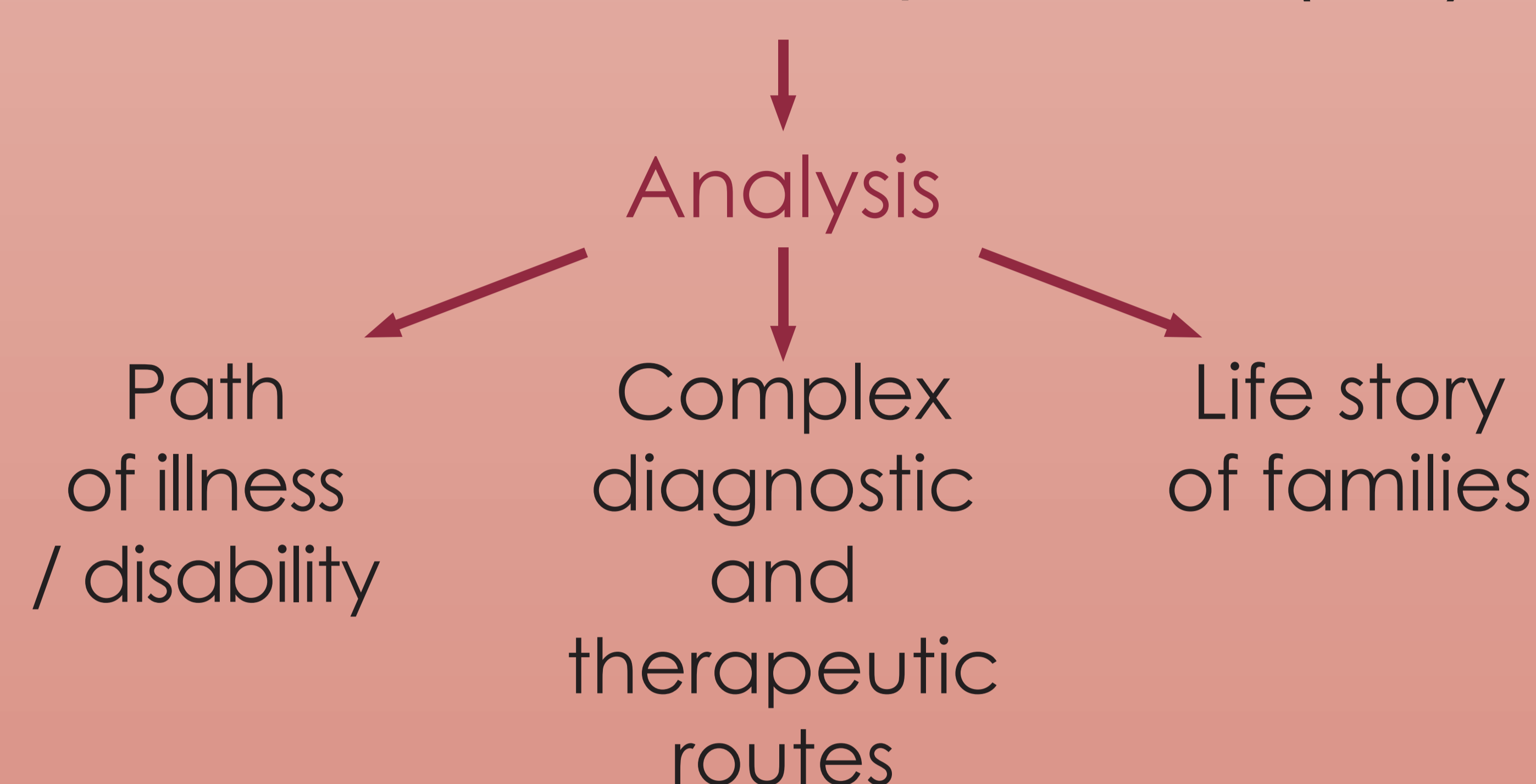
**Pr. A. De Saint Martin** (PH, Hôpital de Hautepierre) – anne.desaintmartin@chru-strasbourg.fr

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 ?

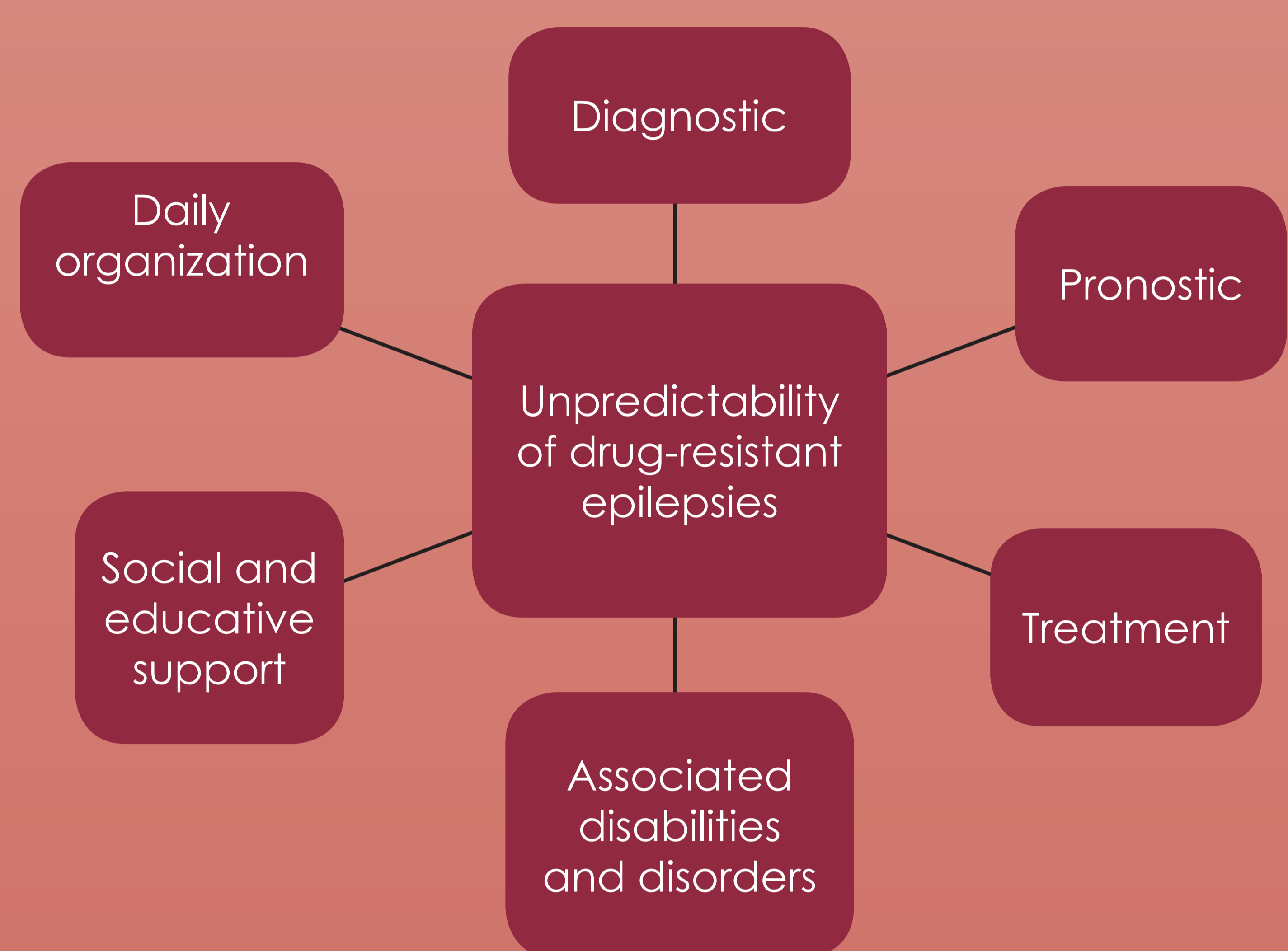


Diagram 1: The different levels of unpredictability

#### Experiencing the knowledge

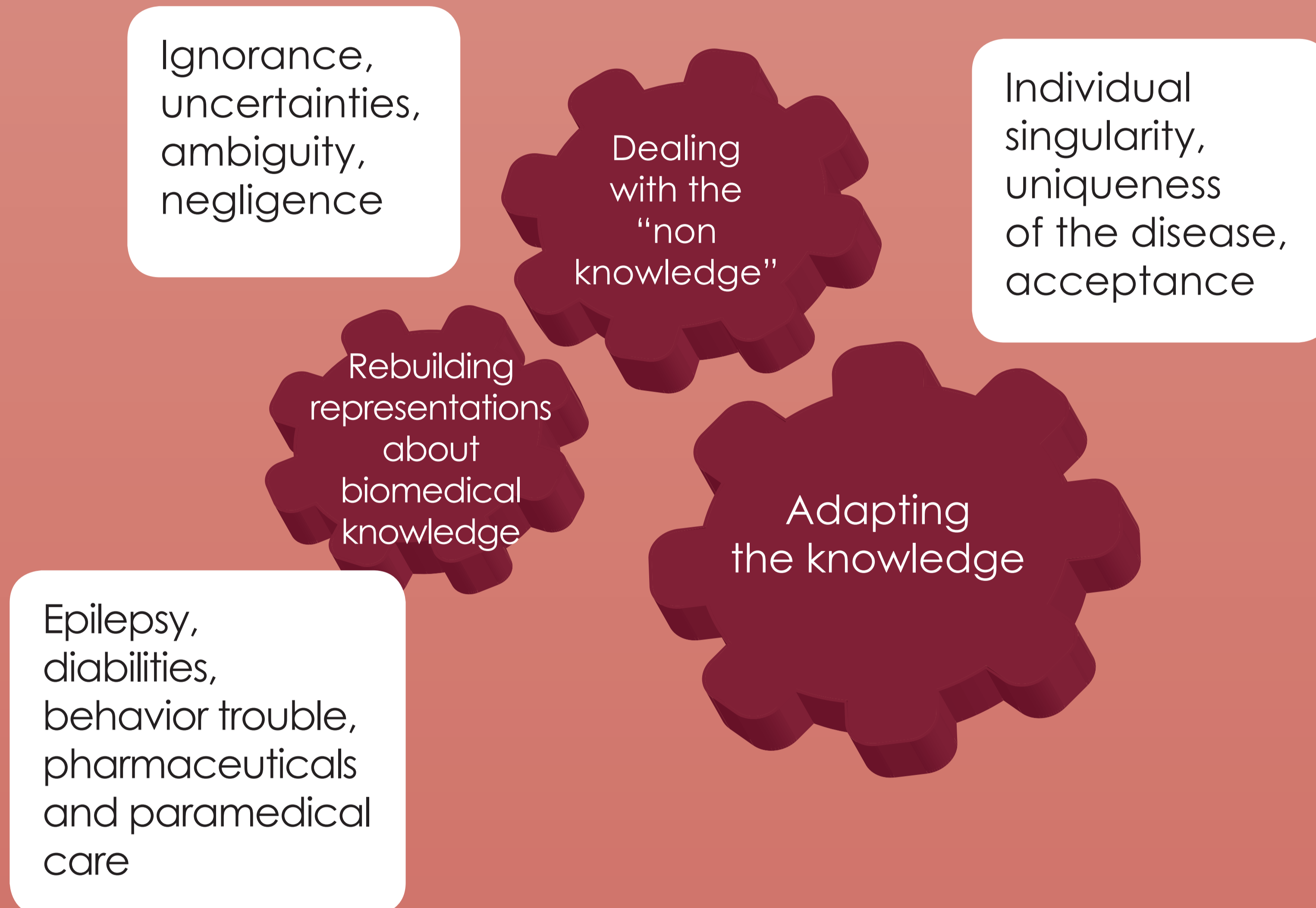


Diagram 2: Knowledges as a building process

#### Knowledge as a necessary exchange

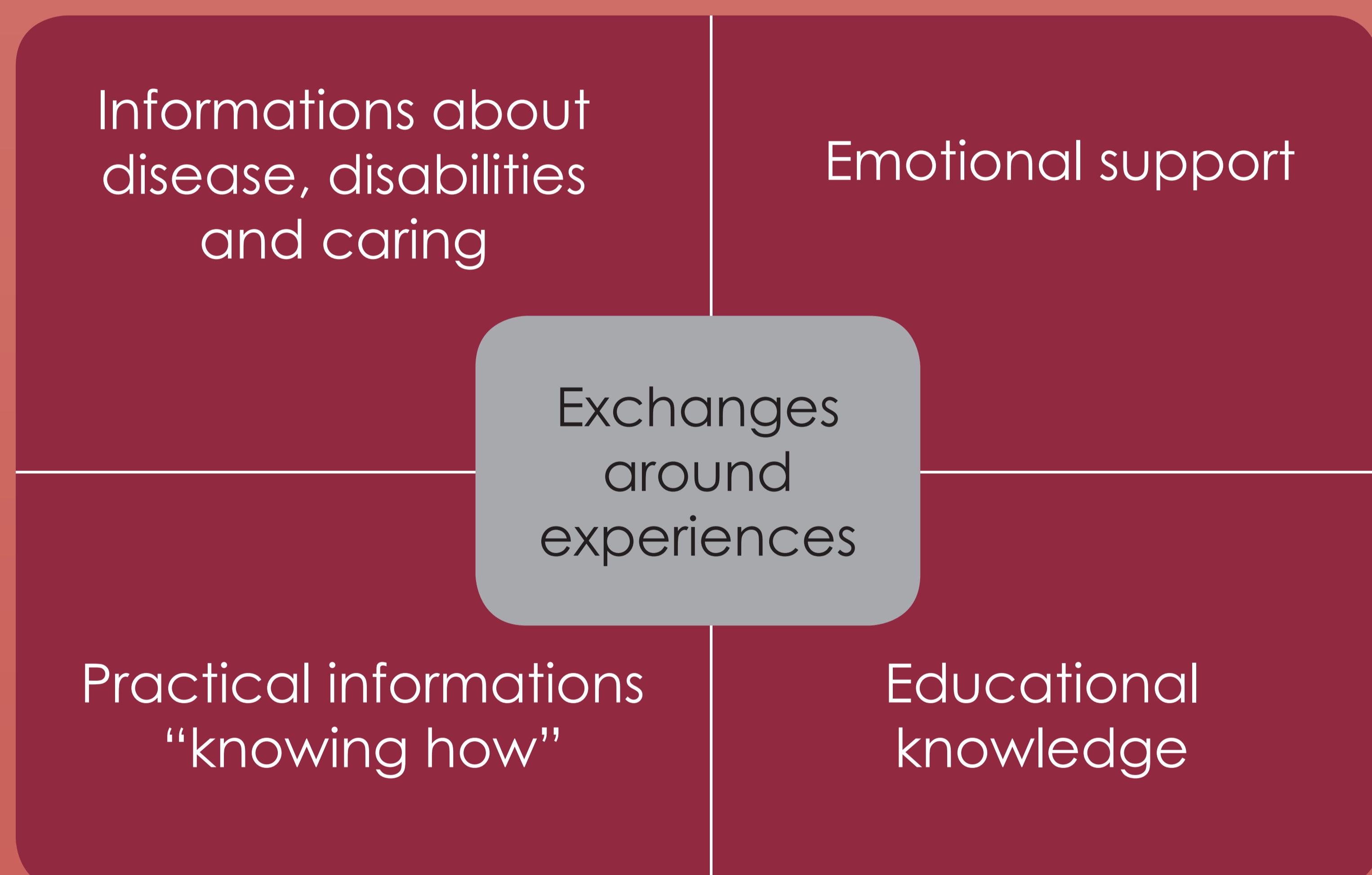


Diagram 3: Knowledge as an exchange between mothers

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

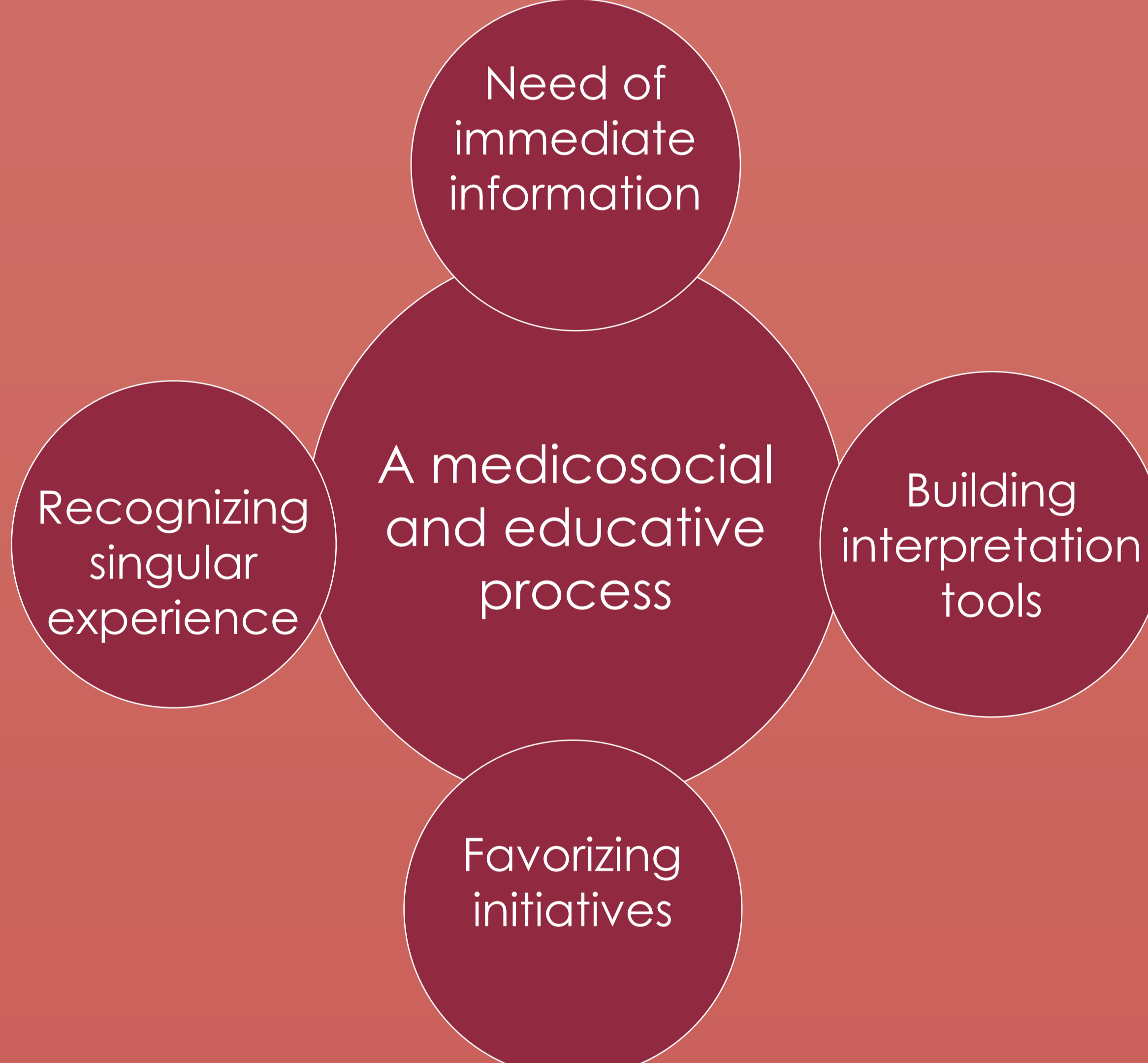


Diagram 4: Knowledge as a global process

### 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

