

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

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FAM-WEST

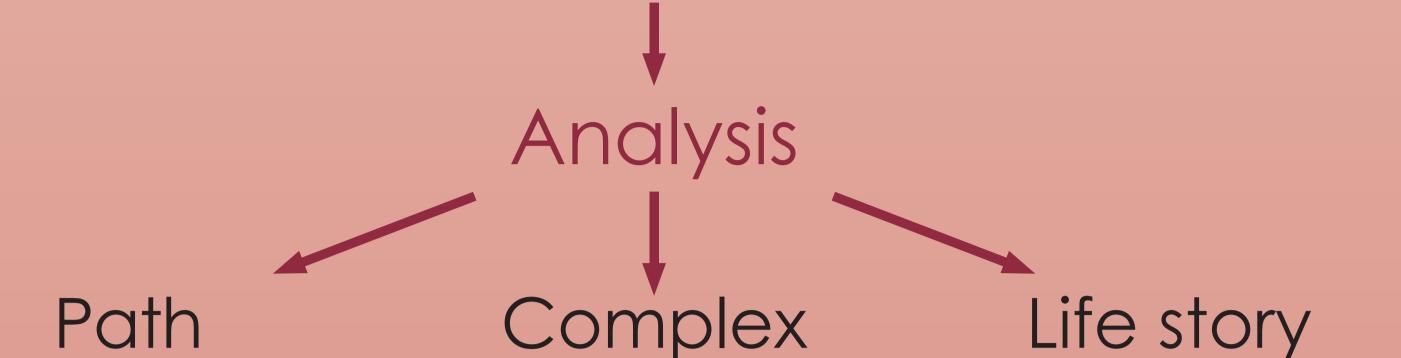
West Syndrom: building knowledge and singularity of the families experiences

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> 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)

- of illness / disability
- diagnostic and therapeutic

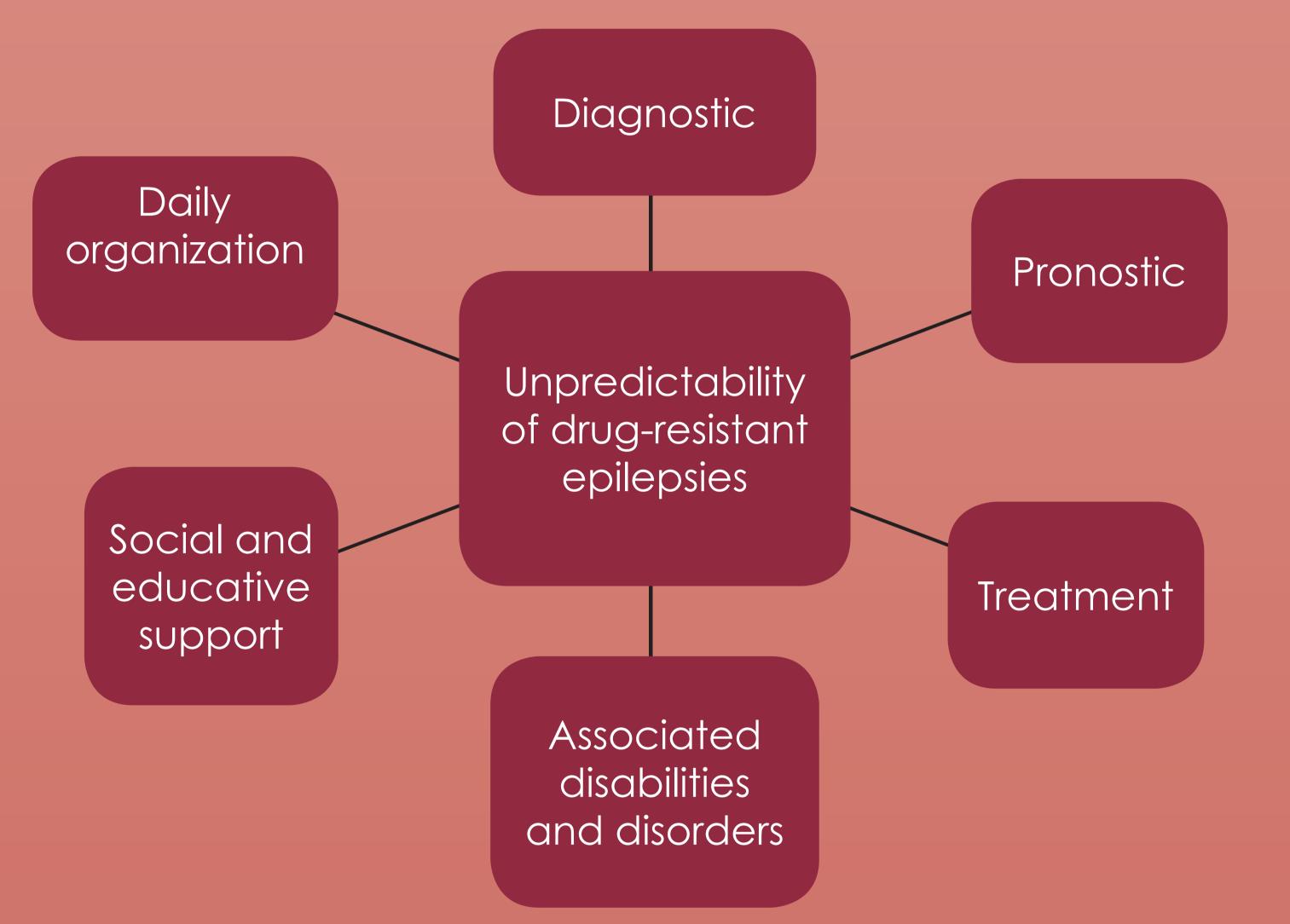
routes

of families

Preliminary Results

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

Knowing how to do with uncertainties?



Experiencing the knowledge

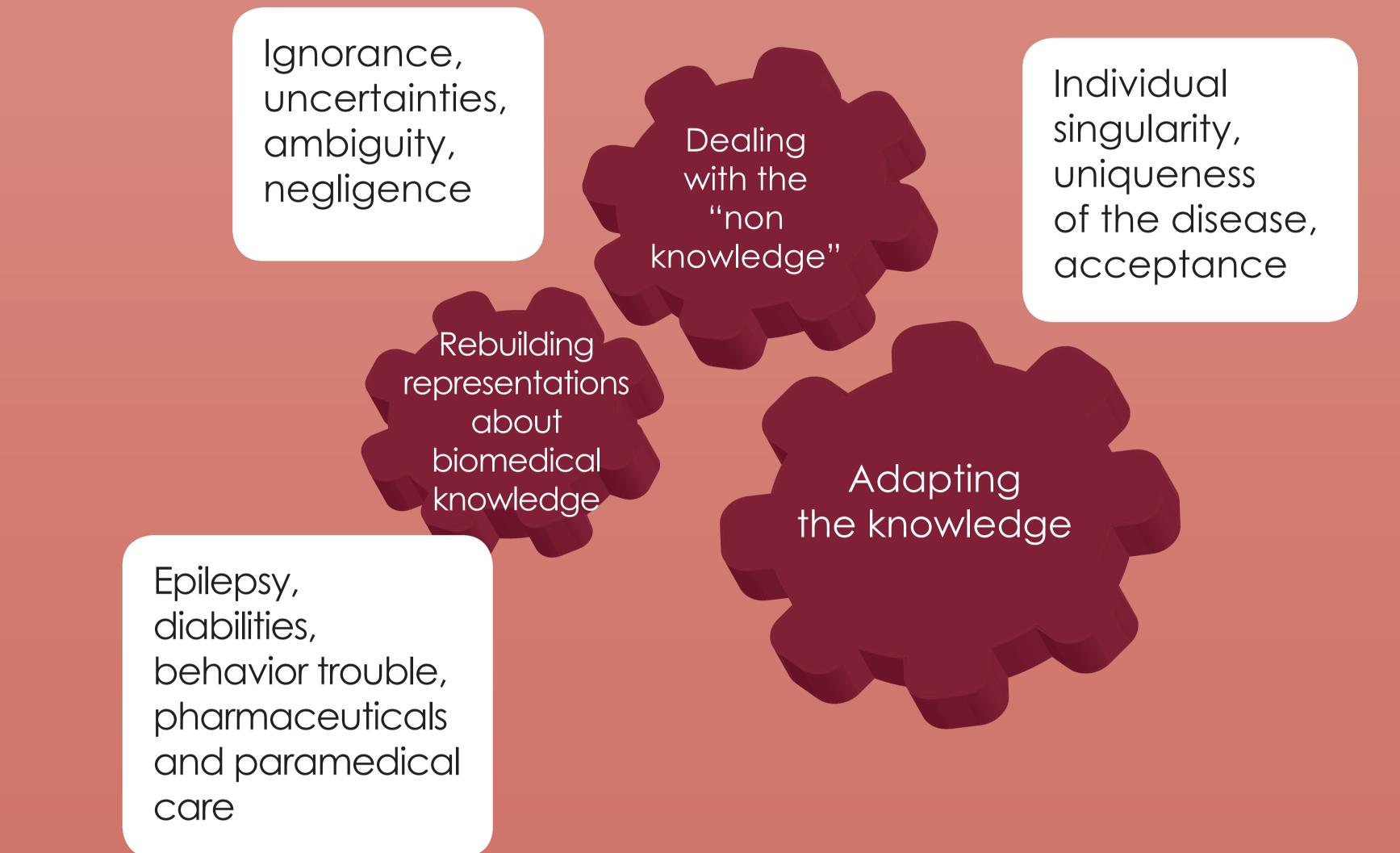
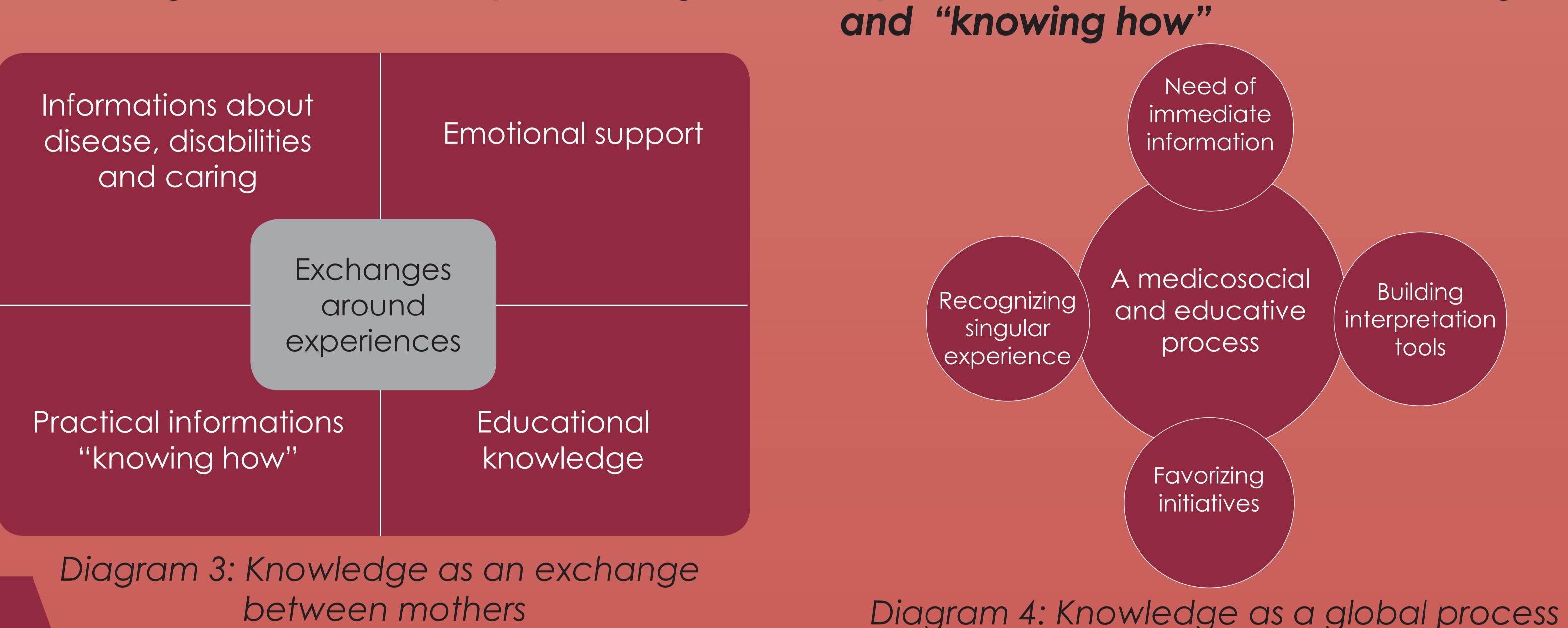


Diagram 1: The different levels of unpredictability

Knowledge as a necessary exchange

Diagram 2: Knowledges as a building process

A process as the interface of knowing



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.

maladie

rares

Emphazing on a global approach rather than a medical one

Privileging experience as a possible answer to uncertainties

de parents d'enfants extraordinaires

Viewing educational program as a structured and social exchange

Offering time to rebuild parental identity

Les Hôpitaux

Universitaires

de STRASBOURG

Hôpital universitair

Robert-Debré

ASSISTANCE DE PARIS

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Association française

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