



Proposing a project on parental stress and wellbeing using the RECAP Preterm cohorts

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My name is Valerie Benhammou and I am going to present you the different steps we are currently following to develop a project on parental stress and wellbeing using the RECAP cohorts.



Introduction

<p>Sabrina Laroche Neonatologist involved in developmental follow-up Part of the Epibel cohort</p> 	<p>Valerie Benhammou Research Engineer Coordination of the Epipage 2 cohort</p>
<p>Epibel</p> <ul style="list-style-type: none"> • Population-based cohort of infants born at <27 weeks' gestation in 1999 and followed up at 3 and 11-15 years • Data collection on mortality and morbidity at discharge from the hospital and on child's outcomes. 	<p>Epipage 2</p> <ul style="list-style-type: none"> • Population-based prospective study of very PT (22-34 GW) infants enrolled at birth in 2011 and followed up until adolescence • 3 follow-up waves (1, 2 and 5 years) • Next follow-up at 10 years will start in December 2021 • Child's global health, physical, motor and cognitive development • Parental quality of life

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I will begin with a short introduction of my co-worker on that project and of myself. Sabrina Laroche is a neonatologist at the University Hospital of Antwerp, in Belgium and she is part of the Epibel cohort. Epibel is a population-based study that enrolled infants under 27 weeks of gestation in 1999, in Belgium, with 3 follow-up waves, up to 15 years of age. They collected data on mortality, morbidity at hospital discharge and child's outcomes. I am a research engineer at the Inserm Institute, in France, and I am the study coordinator of the Epipage 2 study. Epipage is a population-based cohort that enrolled very preterm infants at birth, in 2011, who will be followed up until adolescence. So far 3 follow-up waves have been performed, and the next one, at 10 years, is planned at the end of 2021. We collect data on child's global health, physical, motor and cognitive development and parental quality of Life.

Parental stress and wellbeing project

- Public health issue with various consequences on parent's health, child's development and family functioning
- Among the highest ranking priorities in the Delphi process

Steps to develop a protocol on key questions on parental stress and wellbeing

- To describe how RECAP preterm cohorts address parental stress
- To identify in the literature knowledge gaps and key questions that still need to be addressed
- To evaluate whether these gaps could be addressed using the available tools in our cohorts



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We decided to work on a project on parental wellbeing and stress, because parental stress is a public health issue with various consequences on parent's health, child's development and family functioning. It was also among the highest ranking priorities in the Delphi process performed at the beginning of the RECAP project.

To develop a protocol on that topic, we decided to follow 3 steps:

The first one was to get an overview of what has already been done on that topic in the RECAP cohorts,

The second one was to identify in the literature knowledge gaps and key questions that could be relevant to address,

The third one is to evaluate whether those gaps could be addressed using the available tools in our cohorts

Step 1: Parental wellbeing in the RECAP cohorts - Published data

Cohort	Publications	Child's age at assessment	Participants
PIPARI	Korja et al. (2008) Korja et al. (2009) Huhtala et al. (2011) Huhtala et al. (2012) Huhtala et al. (2014)	6 months, 2 years CA, 4 years CA	~ 200 mothers of PT born between 2001 and 2006 Full term control
ACTION	Cacciani et al. (2013)	2 years CA	~ 200 mothers of PT born between 2003 and 2005
EIPPAGE 1	Garel et al. (2004) Garel et al. (2007)	2 months after discharge and 1 year CA	21 mothers of PT born between 1998 and 1999
EIPPAGE 2	Cambonie et al. (2017)	6 months	160 mothers of PT born in 2011
BLS	Wolke et al. (2017)	27 Years	446 parents of VP and VLBW born January 1985 and March 1986 Full term control

- Out of the 23 RECAP cohorts
- 5 cohorts only with published data on this topic
 - **Mainly short term evaluations**
 - **Relatively small samples**



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In a first step, we gathered the published data on this topic in the RECAP cohorts. As you see here, out of the 23 cohorts involved in the RECAP project, only 5 cohorts published data on parental stress, mainly short-term evaluations and on relatively small samples.

Step 2 : Scoping review of recent studies



- Search on PubMed®, Web of Science™, Scopus on title and abstract
- (QoL OR “quality of life” OR “life quality” OR depression OR Anxiety OR “psychological stress” OR “psychological distress” OR “mental health” OR wellbeing OR “well being”) AND (mother* OR father* OR parent* OR family OR maternal OR paternal) AND (premature OR preterm OR neonatal).
- Additional search on resilience: ‘Coping, resilience’ added to the algorithm
- **Inclusion criteria:**
 - Original observational studies, on PT
 - English language
 - Published between 2017 and 2020 → latest findings on the topic
 - Performed in high income countries → same settings as RECAP cohorts
- **Data collected :**
Type of study/ research question addressed/ tools used to evaluate parental WB, child’s age at assessment / main results/ further research needed
- **2 reviewers / paper**

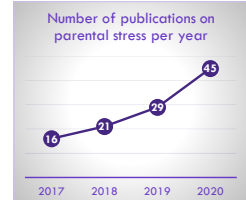


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In a second step, to identify research gaps, we performed a scoping review. The search was made on 3 data bases, using the algorithm presented on this slide. We included original, observational studies on preterm children, English written, published between 2017 and 2020 to get the latest findings on that topic, performed in high income countries to be in the same settings as the European cohorts. For each study, we collected a set of data, presented here on this slide. Each paper was reviewed by 2 independent reviewers.


Literature review – Main results

- Growing interest in this topic over the last 4 years
- Many different topics addressed




ANTENATAL STRESS	POSTNATAL STRESS
<ul style="list-style-type: none"> • Characterization (Prevalence, phenotype, risk factors) • Effect on birth outcome • Effect on child’s development • Effect on mother-child interactions • Biological mechanisms 	<ul style="list-style-type: none"> • Characterization (Prevalence, phenotype, risk factors, comparison between mothers and fathers) • Effect on family functioning, mother-child’s relationship • Effect on child’s outcome • Trajectories of postnatal parental stress and predictors • Effect of child’s health on parental stress • Resilience in Parents • Biological mechanisms

The first interesting result was the increase in the number of published papers, showing a growing interest for this topic over the past 4 years. We also found out that the issues addressed on parental stress are very broad as you can see on this table, with questions on antenatal and postnatal stress, that can be studied either as an exposure (in green on the slide) or as an outcome (in red).


Literature review - research gaps 

- Large, diverse samples to compare prevalence and predictors of parental stress
- Evaluations of trajectories of parental stress over time
- Long-term impact of parental stress on the child's development
- Parental Stress in fathers and comparison of mothers and fathers
- Studies on resilience
- Interventions to reduce parental stress in the NICU or after discharge
- Biological mechanisms explaining the relationship between parental stress and adverse child's outcomes

➤ **What do we have in the RECAP Preterm cohorts to address these questions ?**


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Here is a summary of the research gaps we identified from the review, that could be addressed in large cohorts from different countries with a long-term follow-up. The last step is now to select some of these themes according to the available tools in the RECAP cohorts.

Step 3 : Available data within the RECAP cohorts 

Search based on:

- Data dictionaries and metadata published on the platform
- RECAP Preterm Cohorts Questionnaires
- Published articles from the cohorts

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We therefore made a search on data dictionaries and metadata published on the RECAP platform, on the RECAP cohorts questionnaires and on the published articles.

Cohorts with longitudinal evaluations (standardized tools)


Cohort	Start year	Child's age at assessment	Tool/ Scale
ACTION	2003	2 years CA (Action 1)	GHQ-12: General health questionnaire
		9 years (Action 2)	GHQ-30
		9 years (Action 3)	Parental Stress Index (PSI)
AYLS/ BEST/BLS	1985	Birth	Parent-Infant Relationship Index (PIRI) Family Adversity Index (FAI) Psychosocial Stress Index (PSI)
		5 months/ 20 months	Family Adversity Index (FAI) Psychosocial Stress Index (PSI)
		56 months	Psychosocial Stress Index (PSI) Family Adversity Index (FAI)
		8 years (BEST/BLS)	Parent-child interactions Etch-a-Sketch (AMCIES) (Parent-child interactions)
EPIICE	2011	2 years CA	Mental Health Inventory (MHI-5)
		5 years	Mental Health Inventory (MHI-5)
PIPARI	2001	6 months	Edinburgh postnatal depression scale (EPDS) Parent-Child Early Relational Assessment (PCERA)
		12 months	Edinburgh postnatal depression scale (EPDS) Parent-Child Early Relational Assessment (PCERA)
		2 years / 4 years	Beck depression inventory (BDI) Parental stressing index (PSI) Sense of Coherence Scale (SOC)
EPIPAGE 2	2011	Birth	Center for Epidemiologic Studies- Depression (CESD) State-Trait Anxiety Inventory (STAI)
		1 / 2 years CA	Modified SF12 - Mother self-rated health
		5 years	Modified SF12 - Mother self-rated health

We found 5 cohorts using standardized tools to evaluate parental stress. You can see here the kind of tools used by each cohort and child's ages at parental stress assessment.

Cohorts with longitudinal evaluations (unstandardized tools)


Cohort	Start year	Child's age at assessment	Tool/ Scale
EPIcure 1	1995	2,5 years CA	Overall, how stressful have the last 12 months been for you ? Overall, how satisfying have the last 12 months been for you ? General Health over the last 3 months - 28 item scale Things that have happened to you over the last 3 months - 17 item scale
		6 years	Overall, how stressful have the last 12 months been for you ? Overall, how satisfying have the last 12 months been for you ? 11 item scale about feelings in the last month Scale to describe family
		19 years	Mental health
DNBC	1996	6 months	Feel in low spirits or sad? Been more touchy and quick-tempered than you used to be? Feel that any little task demands a huge effort? Feel tense or exhausted? Feel that the demands made were too high? On average, how have you felt mentally since the birth? Now, I would like to know if you ever had any problems during your schooldays because you were particularly troubled or restless? Did the child's birth father have any problems during his schooldays because he was particularly troubled or restless? Did you - as a child or and adult - need support due to
		18 months	Have you- after the child has turned 6 months old- felt burdened by any of the following things: economy, housing,work,relationship with partner, relationship with family and friends, disease in child, own disease, disease in partner, disease in family or close friends, other things) How have you been feeling on average mentally from the time when the child has turned 6 month and until now

2 other cohorts have also data on parental stress but they use isolated questions that are presented on the slide.



Next steps

- 7 of the RECAP Preterm cohorts have some information on parental stress, but use many different instruments
- Develop a protocol to investigate
 - ✓ prevalence and predictors of parental stress on larger and more diversified samples,
 - ✓ Longitudinal patterns of parental stress,
 - ✓ Long term impact of postnatal parental stress on the child's development

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To sum up this information, we identified 7 cohorts with some information on parental stress, but they with many different instruments to evaluate it..

Using the information collected through this whole process, we are currently writing a protocol to investigate :

Prevalence and predictors of parental stress on larger and more diversified samples,

Longitudinal patterns of parental stress,

Long term impact of postnatal parental stress on the child's development



Thank you

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Thank you

