



Understanding the Emotional and Practical Needs of Parents with Psychosis and those of their Children

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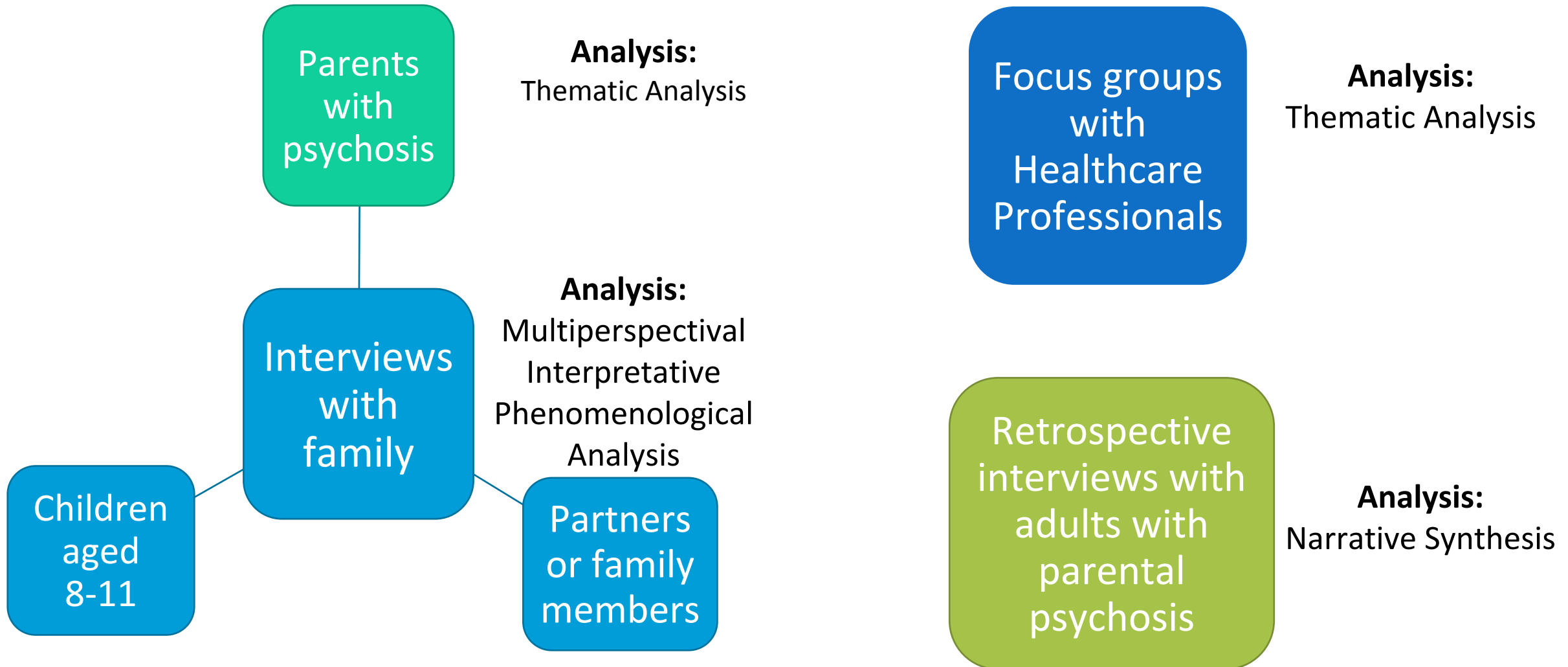
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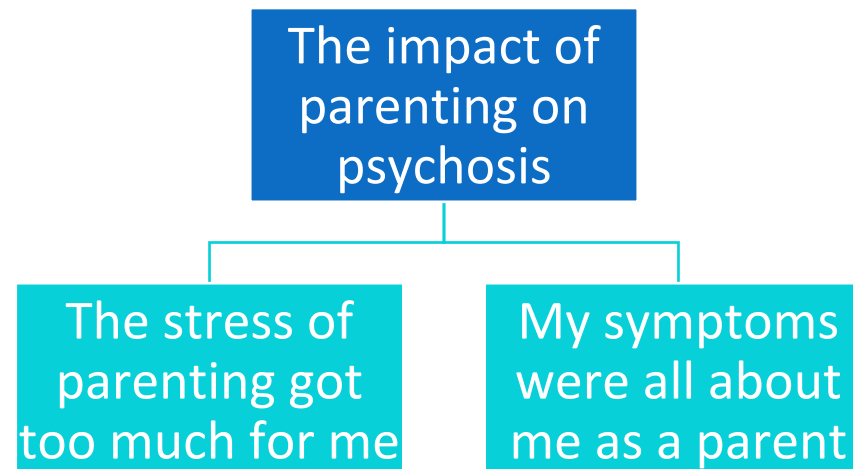
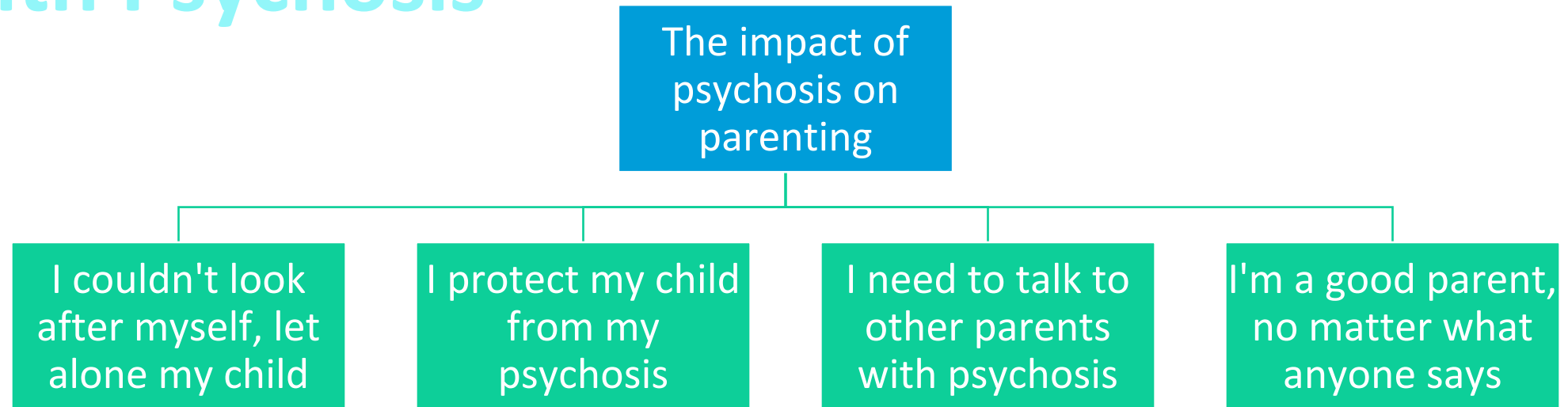
How does psychosis affect parenting from the perspectives of parents with psychosis, their families, and healthcare professionals?

What evidence-based interventions are currently available to support parents with psychosis?

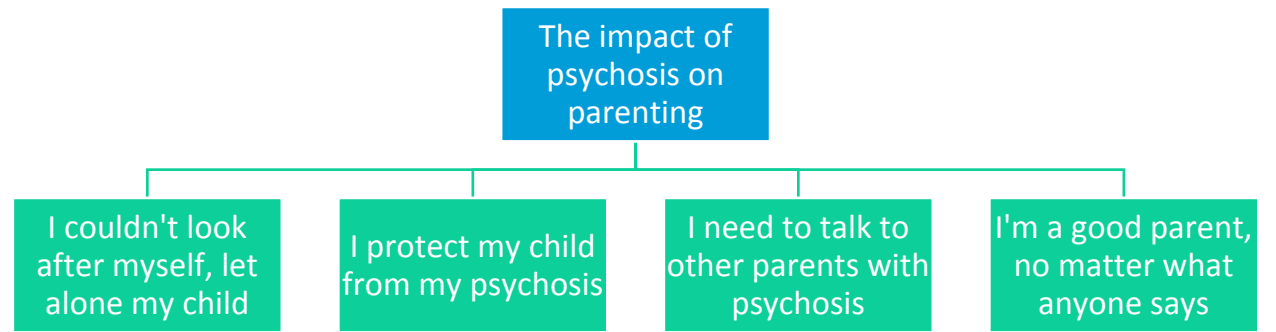
The Qualitative Work



Results from Thematic Analysis of Parents with Psychosis



The impact of psychosis on parenting



I couldn't look after myself, let alone my child

Key Quotes:

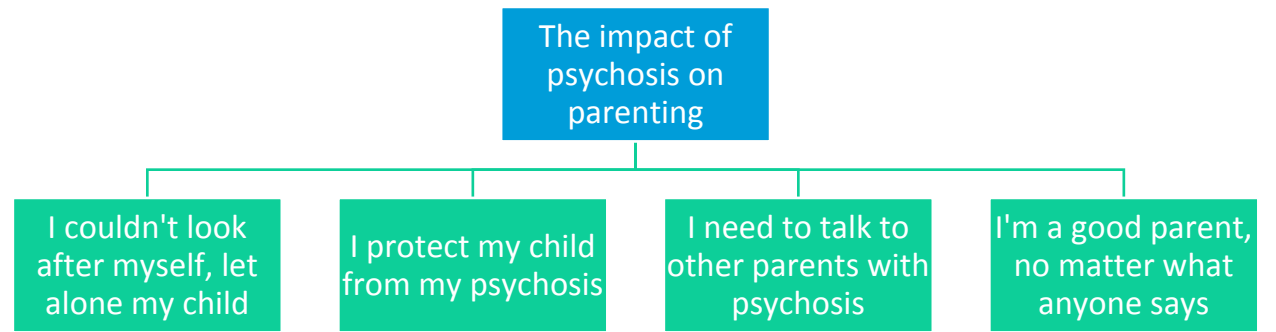
"Looking back I don't know how but I did, I always managed to feed them and bath them. But you know like their emotional needs I wasn't able to give them back then."

"I just wanted someone to take him away and look after him properly. Not... not in a horrible way but I just couldn't cope with him and I just needed somebody to look after him for me cos I couldn't even look after myself and that was the hard thing"

PPI commentary:

It didn't stop me parenting it just changed my parenting.

The impact of psychosis on parenting



I protect my child from my psychosis

Key Quotes:

"I'm trying to give them as normal life as possible and you know, I would rather keep it to myself and not worry them if I don't need to worry them."

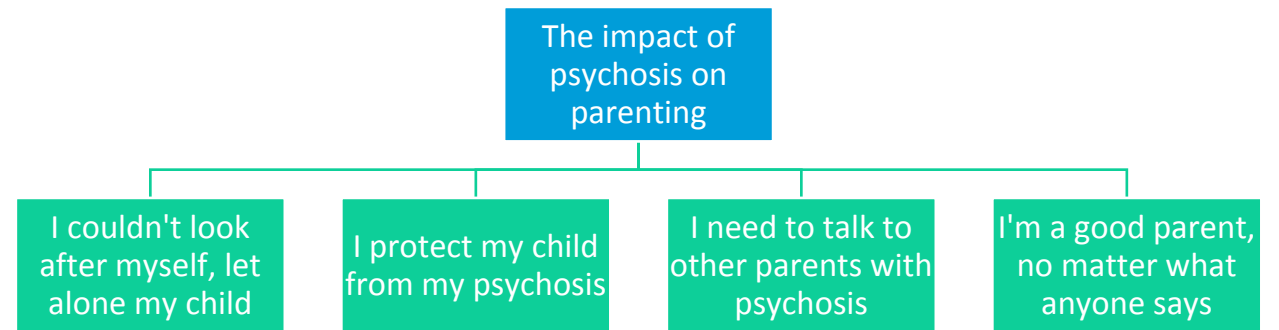
"It was a very hard point in their lives. And I don't want to hurt them anymore than they've already been hurt by it"

"I hope when he is teenager or something like that I would have sorted this problem, this is my hope. I'll say, 'look, your father had this and well, 15, 20 years' time but now I'm okay, I did this, this, this'."

PPI commentary:

I also don't tell them because I don't have the vocabulary to talk about mental health.

The impact of psychosis on parenting



I'm a good parent no matter what anyone says

Key Quotes:

"The sort of relentlessness of it [being a parent] and doing it with a mental illness is horrific. And trying to keep yourself well so that you can be a good parent."

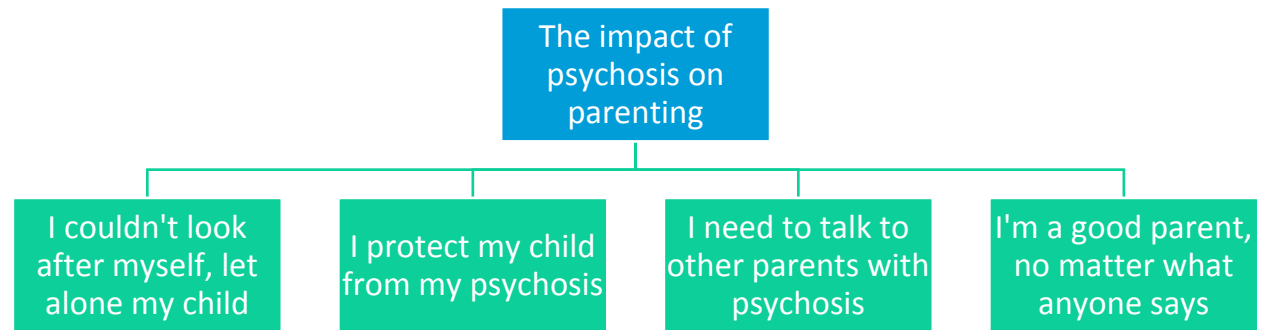
*"I try my best with my children. So for me I needed help not criticism. Um and so it [being involved with social services] was really hard... really hard yeah. Cos I kept thinking I've seen so many mums grab their kids and wallop them or call them a f***** little whatever and I'm horrific you know and I'm just thinking I don't do any of those things and I make sure he has like proper dinners and proper of everything"*

"Even if I'm a minute late I get the kids to school on time, they get fed properly. I've just got no worries about it. I know that it'll happen. Even if I've got no money I'll find the money"

PPI commentary:

It's not just others, you judge yourself as well.
This is the recovery period not the acute psychotic period

The impact of psychosis on parenting



I need to talk to other parents with psychosis

Key Quotes:

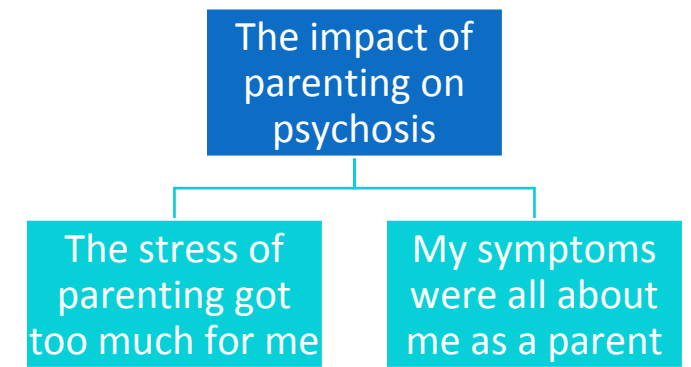
"I think because you can't really talk about psychosis with anyone else because no-one really understands that if you talked in a group setting with other parents where they understood what psychosis was and you could share different um experiences and then maybe share things that have worked and then also it's then sociable as well and you may gain sort of friends out of it."

PPI commentary:

This is the most important theme for me

The impact of parenting on psychosis

The stress of parenting got too much for me



Key Quotes:

“You do lose a part of yourself and you have to be very selfless. You can’t really be selfish anymore. She comes first. Everything that you need kind of gets put a bit on the backburner until everything that she needs is done. Even things like going to the toilet. Until she’s got what she’s needs I have to wait until I have a shower or go to the loo or brush my teeth or anything really”

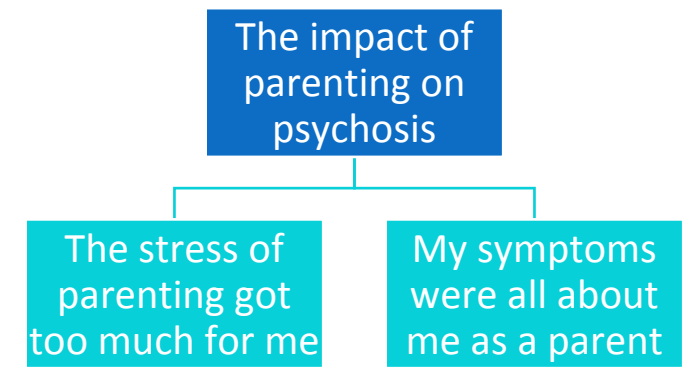
“Um and because I’m full-time mum, what’s happened is... because I’ve not got a good balance in my life all of me is to do with my children. So anything that goes wrong with them it’s personal well it’s like ‘oh well it’s me. I’m doing a rubbish job”

“And bedtime is actually the thing that I find the hardest cos she’s quite tricky at bedtime. And there’s sometimes where I’ve been stood outside her room just crying thinking “I just wish there was somebody here who could go through it with me and me not have to do it on my own”

PPI commentary:

All agreed, but some saw a more direct relationship than others

The impact of parenting on psychosis



My symptoms were all about me as a parent

Key Quotes:

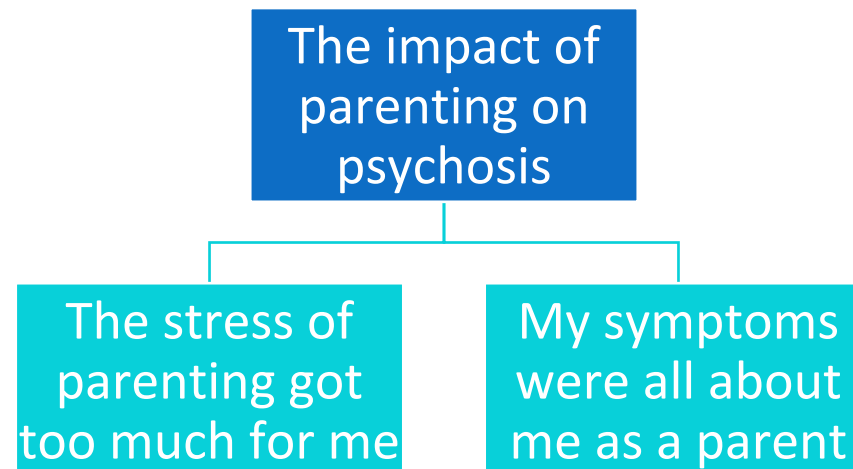
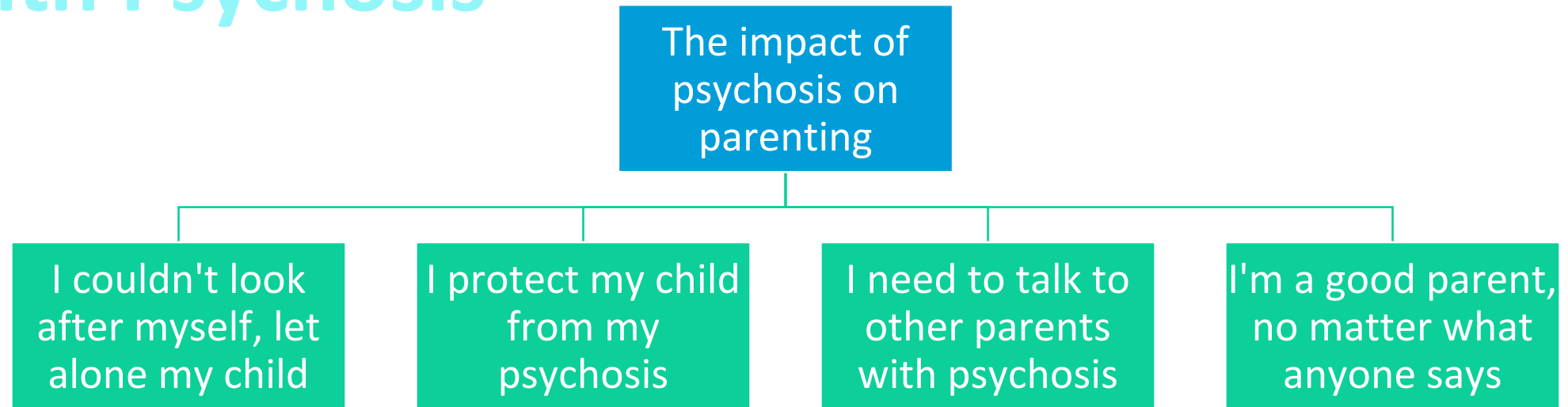
“It was testing me to see what I would notice. Would I notice the lights? And then I heard my little boy come through singing and I was like ‘ah [child’s name]. It’s [child’s name]’. And it was just... but I was tested. And it was about... just about being a good parent really”

“She kept crying. I was then convinced that my milk had turned to water and that she wasn’t getting any food and so that’s when I started to believe that I’d killed her so then I called 999 in the morning saying ‘my daughter’s dying... my daughter’s dying you need to come’”

PPI commentary:

This resonated highly with some and not at all with others

Results from Thematic Analysis of Parents with Psychosis

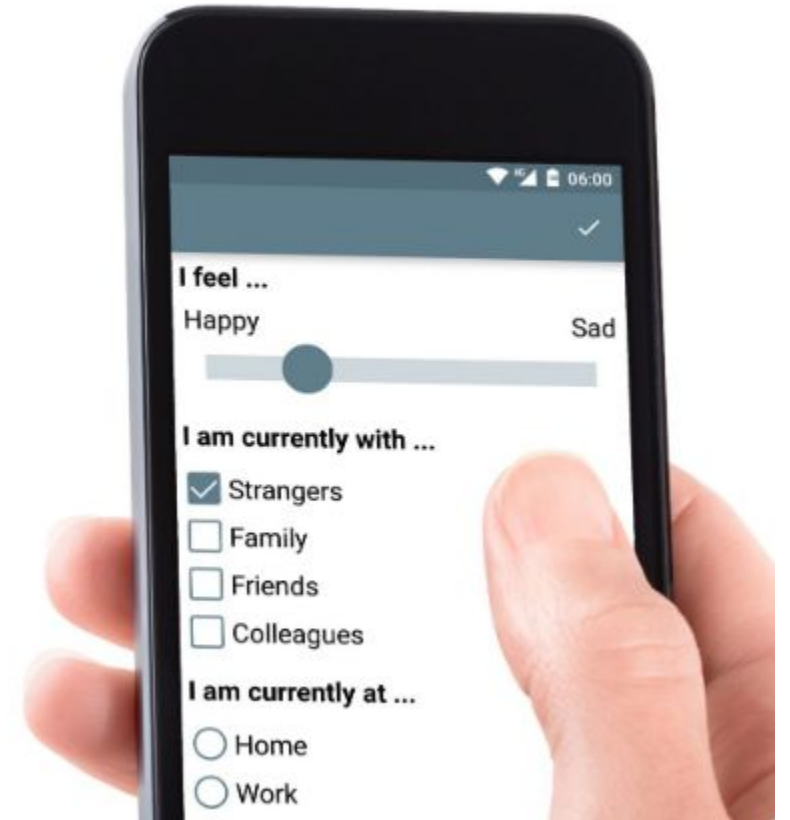


How Qualitative Research leads on to ESM study

- Investigating subtheme **‘The stress of parenting got too much for me’**
 - What is the relationship between stress from parenting and symptoms
- Elements found in the qualitative research which might affected this relationship
 - Having a partner
 - Child behaviour
 - Parenting self-belief (also raised by PPI group)
 - Gender of parent

Experience Sampling Methodology – why?

- In psychology, we often ask people to complete booklets of measures
- Typical situation:
 - In a clinic
 - One ‘snapshot’ of life
 - Asks to reflect on previous two weeks



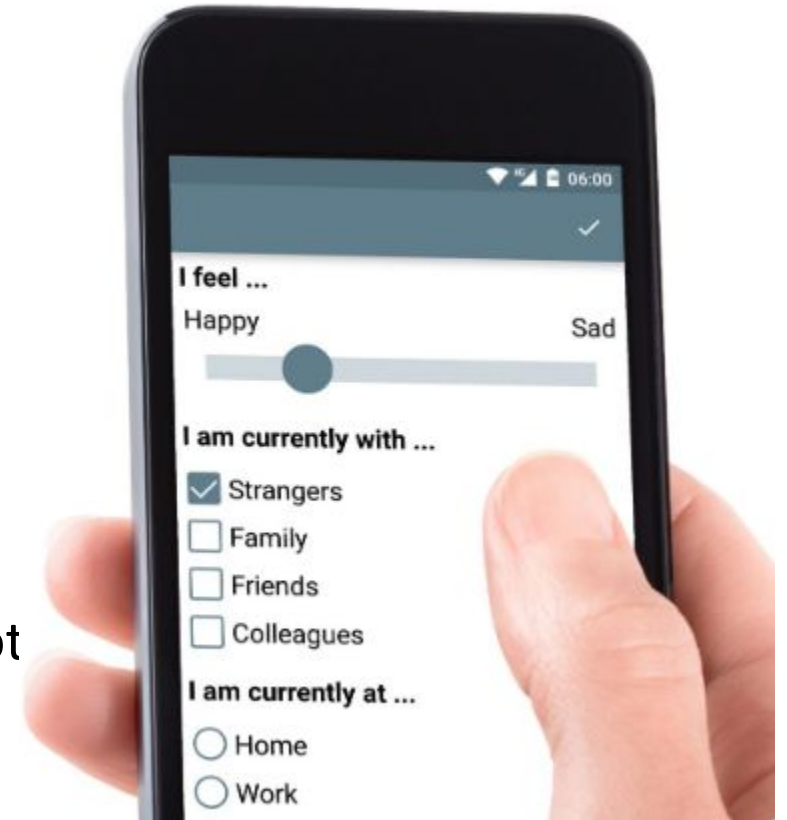
An example

Is this an accurate way of measuring mood?

PATIENT HEALTH QUESTIONNAIRE - 9				
<i>Comments:</i>				
Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
				0 + _____ + _____ + _____ = Total Score: _____
<p>If you checked off <u>any</u> problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?</p> <p> Not difficult at all <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Very difficult <input type="checkbox"/> Extremely difficult <input type="checkbox"/> </p>				
<small>Developed by Drs. Robert L. Spitzer, Janet B. W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. Copyright © Pfizer Inc. All rights reserved. Reproduced with permission. EP12005.PHC09P</small>				
Patient's name:				Date:

Experience Sampling Methodology – why?

- Experience Sampling Methodology
 - Participants are given a device to take home
 - Asks participants the same question multiple times
 - Ask participants to report on how they're feeling 'right now'
- Why is this better?
 - Measured in day-to-day life rather than in a clinic - a 'real' experience)
 - Mood changes frequently during a day - one snapshot may not capture the whole picture
 - Are we even that good at remembering how we felt over the last two weeks? - Our current mood may affect our memory of our previous mood



ESM Design

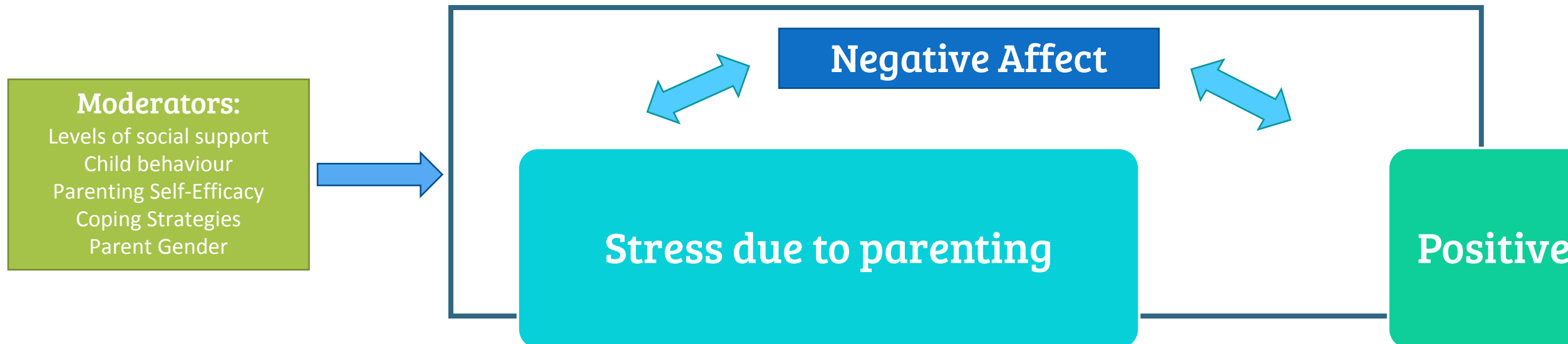
Primary Hypothesis:

1) **Stress due to parenting** will affect **positive psychotic symptoms**. This effect will be *mediated* by **negative affect**

Secondary Hypotheses:

2) **Positive psychotic symptoms** will affect **stress due to parenting**. This effect will be *mediated* by **negative affect**

3) These **five variables** will moderate some of the pathways between **stress due to parenting**, **positive psychotic symptoms** and **negative affect**



Next stages

- Ethical approval
- Publish in a registered report journal
- More PPI/piloting?



Thank you to

Mental Health Research UK

My supervisors:

Dr Louise Johns

Professor Jane Barlow