

## Understanding the emotional and practical needs of parents with psychosis and those of their children.

**Children and Young People's PhD Scholarship 2018: Department of Psychiatry, University of Oxford,**

**Supervisor:** Dr Louise Johns, with Professor Jane Barlow as co-supervisor

### **Summary:**

Healthcare policy prioritises early help for vulnerable children, to improve current and future wellbeing. Children of parents with psychosis are particularly vulnerable, with increased risk of developing social and psychiatric problems. Parental mental health can impact on parents' capacity to offer the consistent, responsive care required for healthy child development. Parents may not recognise these difficulties, or fear that their children will be removed from them, and hence do not seek help and their familial needs are poorly understood. This DPhil project will conduct a series of studies to investigate the specific needs of young children (aged 3-11) who have a primary caregiver with psychosis. It will collect information about the clinical and social circumstances of these families, and will interview parents with psychosis and their children (young and grown up) about their difficulties and support needs. The project will record parent-child interactions in a structured play situation, to understand the quality of these relationships. The study will also test associations between parenting stress, psychosis expression, and parenting behaviours in daily-life, via brief self-reports at intervals over a week. This research is an important first step in the development of psychological intervention approaches for these families, to increase positive parenting and quality of parent-child relationships, to improve health outcomes for this vulnerable group of children.

**Research Student:** Jessica Radley

Hi, I'm Jess and I'm due to start my DPhil in Psychiatry at the University of Oxford in October 2018.

My original background is in Linguistics, but after taking a module in psychology in my third year I decided to complete a psychology conversion MSc at the University of Edinburgh. For my dissertation, I performed a meta-analysis on the prevalence of depression in schizophrenia spectrum disorders. This year, I have been working as a research assistant at North East London NHS Foundation Trust on an NIHR-funded project trialling a computer-based intervention for children with social communication impairment.

I am excited to be pursuing a PhD related to both psychosis and children. My research project will be investigating the needs of parents with psychosis and the needs of their children. I look forward to being supervised by Dr Louise Johns and Professor Jane Barlow and to the chance to develop my research knowledge and skills. I am also very thankful to Mental Health Research UK for funding this opportunity.



**Start Date:** September 2018

## Scientific Goal:

The scientific goal is to identify the specific needs of parents with psychosis, the needs of their children, and the inter-relationship between them. This knowledge will inform the development and delivery of tailored interventions for these families.

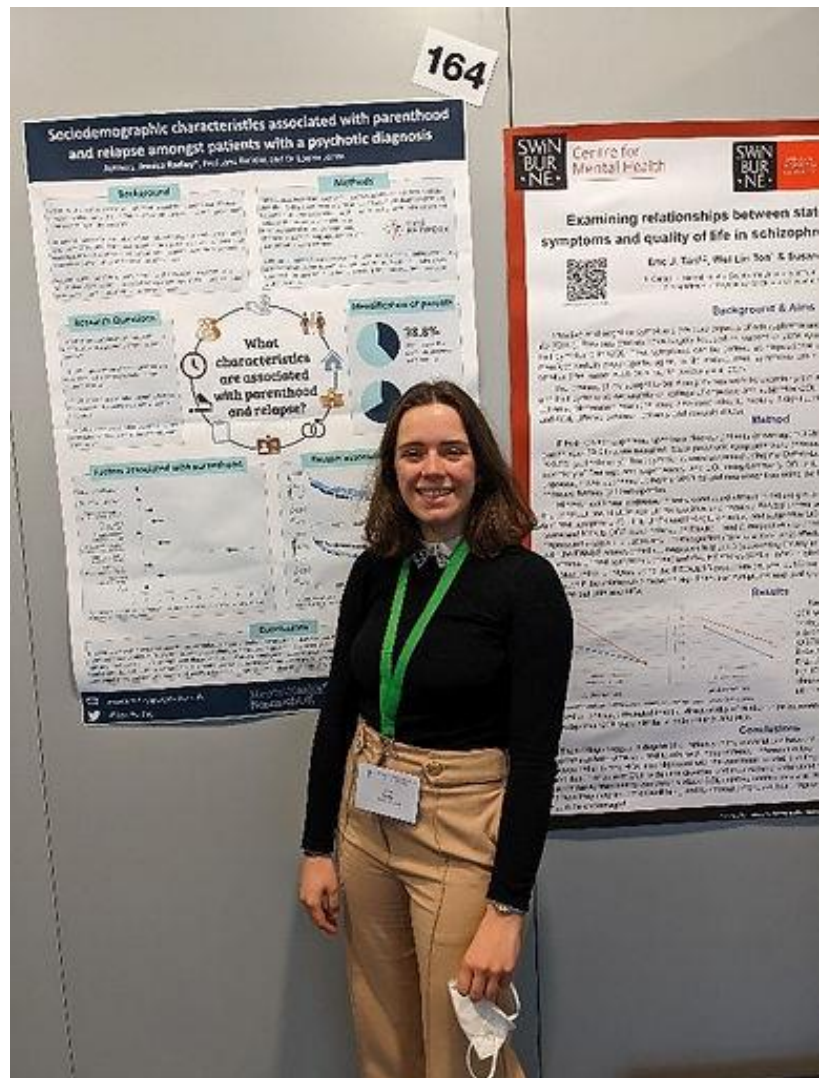
## Progress Report year 4, 2022

The first focus of my fourth year was to publish a scoping review of interventions for parents with psychosis. I submitted it for publication in Frontiers's special issue 'Parents with Mental and/or Substance Use Disorders and their Children, Volume II'

(<https://www.frontiersin.org/articles/10.3389/fpsy.2021.787166/full>).

The scoping review identified 34 interventions for parents with mental illness that might benefit parents with psychosis. Two interventions had been trialled with a group of parents with psychosis, however none had been tailored to meet the needs of this client group. This review forms the final data chapter of my thesis, and shows that there is still more work to be done to fully meet the needs of parents with psychosis and their families.

Recruitment finished in December 2021 for my study looking at the relationship between stress and psychosis. This study had used a methodology called 'experience sampling methodology', where participants were given mobile phones to track daily changes in psychosis, stress and mood. After analysing the results, we concluded that stress from parenting increased psychotic symptoms, and that the opposite relationship was also true. We also found that low mood was an important mediator of the relationship between parenting stress and psychosis. We had predicted that other characteristics, like social support, the parent's gender or levels of coping, would affect the relationship, however we did not find any evidence for this. This study was accepted as a registered report by the British Journal of Clinical Psychology (BJCP) in October 2020 before I began recruitment, where BJCP agreed to publish the study no matter what the results were and as long as I followed my methodology exactly. In June 2022, I submitted the manuscript back to the BJCP as a Stage 2 registered report and it is currently in peer review.



In November 2021, I started the analysis on my final two qualitative projects. Firstly, a study looking at families' experiences of parental psychosis where I interviewed parents with psychosis, their partners and their children. We found that psychosis greatly impacts all family members, and that families can be impacted more if they have less social support or less knowledge of mental health and services. I also found that the stigma surrounding psychosis led families to secrecy, and as a result children were not fully informed about their parent's mental health and sometimes assumed

the worst. I submitted this study for publication in June 2022. The second study was a narrative analysis with adult children who had grown up with a parent with psychosis. I asked participants to tell me the story of their lives, paying particular attention to the role of their parent's psychosis. We found that parental psychosis can have a different impact on children depending on factors like their age and the gender of their parent. Most participants had suffered from their own mental health problems, further demonstrating the importance for preventative interventions for these children.

This year also presented me with my first opportunity to attend conferences. I attended the Schizophrenia International Research Society (SIRS) conference in April 2022, where I presented a poster on a study using anonymised patient records which was published in *Social Psychiatry and Psychiatric Epidemiology* later that month

(<https://link.springer.com/article/10.1007/s00127-022-02279-x>). I will also be presenting at symposia at BABCP and EABCT later this year.

I have now finished writing my thesis and will submit it later this month. My viva is in September 2022. After this, I will begin training on the Doctorate in Clinical Psychology at Kings College London in October 2022. I am very grateful for Mental Health Research UK for all the opportunities they have given me during my PhD and I am looking forward to keeping up with MHRUK and other MHRUK scholars.

Radley, J., Barlow, J., & Johns, L. [submitted] *The needs and experiences of parents with psychosis: a qualitative interview study.*

Radley, J., Barlow, J., & Johns, L. [submitted] *A whole family perspective on parental psychosis: An interpretative phenomenological analysis study.*

Radley, J., Barlow, J., & Johns, L. [registered report – accepted at Stage 1, resubmitted at Stage 2] *Parenting and psychosis: An experience sampling methodology study investigating the inter-relationship between stress from parenting and positive psychotic symptoms. British Journal of Clinical Psychology.*

Radley, J., Barlow, J., & Johns, L. (2022) *Sociodemographic characteristics associated with parenthood amongst parents with a psychotic diagnosis: A cross-sectional study using patient clinical records. Social Psychiatry and Psychiatric Epidemiology, 1-10.*

Radley, J., Sivarajah, N., Moltrecht, B., Klampe M L., Hudson, F., Delahay, R., Barlow, J., & Johns L J. (2021) *A scoping review of interventions designed to support parents with mental illness that would be appropriate for parents with psychosis. Frontiers in Psychiatry, 2434.*

Radley, J., Barlow, J., & Johns, L. (2021). *Mental health professionals' experiences of working with parents with psychosis and their families: A qualitative study. BMC Health Services Research, 21(1), 1-11.*

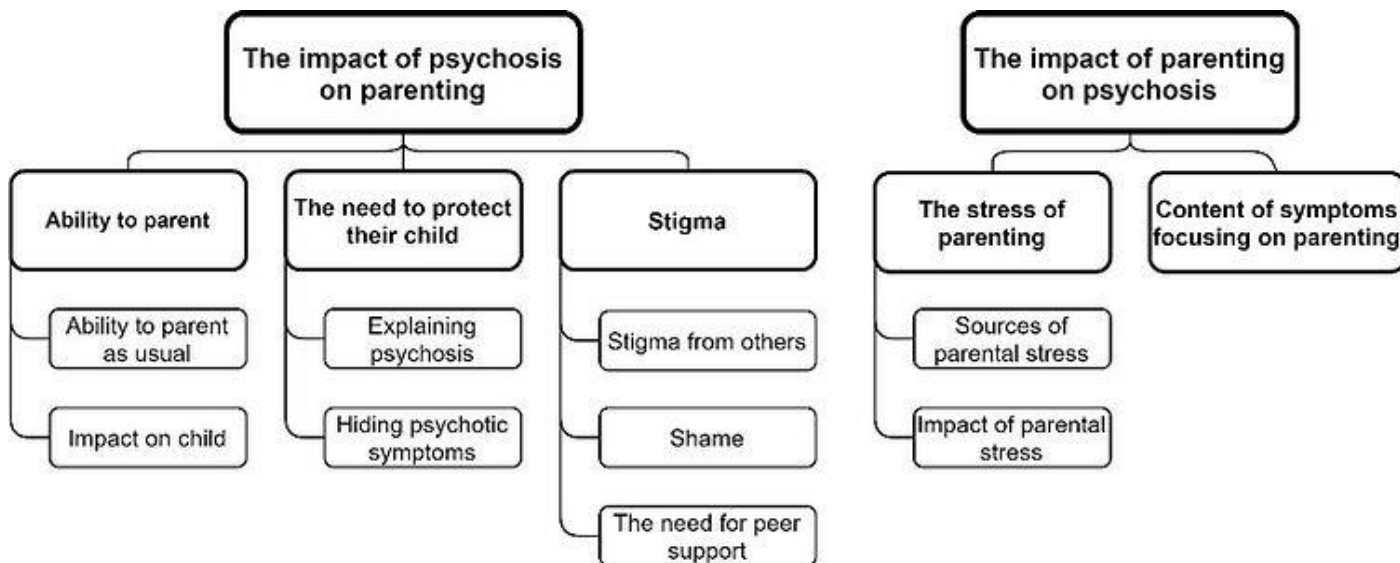
Radley, J., Grant, C., Barlow, J., & Johns, L. (2021) *Parenting interventions for people with schizophrenia or related serious mental illness [full review]. The Cochrane Database of Systematic Reviews, (10).*

Radley, J., Grant, C., Barlow, J., & Johns, L. (2020). *Parenting interventions for people with schizophrenia or related serious mental illness [protocol]. The Cochrane Database of Systematic Reviews, (2).*

## **Progress Report Year 3, 2021**

I began my third year with a focus on getting one of my projects accepted as a 'registered report'. In this format, a journal provides peer-review for your study's plan, and before you have collected the data and obtained results. Then it agrees to publish your study as long as you have kept to this plan, and no matter how 'exciting' your results are. My project is looking at the relationship between stress and psychosis in parents who have experienced psychosis. It uses 'experience sampling methodology', whereby participants track their stress and psychosis symptoms many times throughout the study on a mobile phone during their day-to-day lives. The aim of the project is to establish whether stress from parenting comes before a rise in psychotic symptoms, and whether any other life factors (e.g. social support or the parent's gender) has an impact on this relationship. In November 2020, the *British Journal of Clinical Psychology* accepted my registered report and I began recruitment. I have currently recruited 22 parents with psychosis, with another 10 to recruit by December 2021.

For my qualitative work, I finished two papers by the end of 2020. One contained interviews with parents with psychosis, and the other contained focus groups with mental health professionals. Both of these papers used thematic analysis, where I looked at patterns of meaning in participants' transcripts and developed themes as a result. You can see the themes I developed for the parents paper in the image.



For the parents paper, the main finding I described is that all parents agreed that their experience of psychosis had an impact on them and their families, however some parents also stated that the stress they'd experienced from parenting had triggered their psychosis or even made symptoms worse. This paper is currently under peer review. For the mental health professionals paper, the main finding is that some professionals felt they do not have enough time or training to work with their service user as a parent, and that changes need to be made in order for mental health services to be more family focused. This paper was published in BMC Health Services Research in April 2021.

In early 2021, I returned to my work using CRIS (Clinical Records Interactive System), which contains anonymised patient records. Using these records, I found that over a third of patients with psychosis are a parent. And that with a diagnosis of psychosis, one is more likely to be a parent if they are female and of an older age. They are also more likely if they have a more 'settled' lifestyle, that is, renting or owning their home and having ever been married. Patients with a diagnosis of schizophrenia were the least likely to have children out of all the other types of psychosis diagnosis (e.g. brief psychotic disorder, schizoaffective disorder). This is likely because those who have a diagnosis of schizophrenia experience the highest level of symptoms which may results in less opportunity to meet a partner and have children. I submitted this paper in July 2021 and it is currently in peer review.

The final chapter of my PhD will be a review of current parenting interventions that would be appropriate for parents with psychosis. I started searching for relevant studies in January 2021. After reading through these and comparing my decisions to a colleague's, 32 papers were chosen to be included in the review. This paper will report on 1) who these parenting interventions are designed for, 2) what are the components of these interventions and 3) have any evaluations been carried out and what has been found. I am currently writing up this paper for publication and am hoping to publish it in late September.

Radley, J., Barlow, J., & Johns, L. [submitted] Sociodemographic characteristics associated with parenthood amongst parents with a diagnosis of psychosis: A cross-sectional study using patient clinical records

Radley, J., Barlow, J., & Johns, L. [In Principle Acceptance (registered report) after Stage 1 peer review] Parenting and psychosis: An Experience Sampling Methodology Study Investigating the Inter-Relationship Between Stress from Parenting and Positive Psychotic Symptoms. *British Journal of Clinical Psychology*.

Radley, J., Barlow, J., & Johns, L. [submitted] *The Experiences of Parents with Psychosis: A Qualitative Interview Study of Content and Expressed Emotion*.

Radley, J., Grant, C., Barlow, J., & Johns, L. [in peer review]. Parenting interventions for people with schizophrenia or related serious mental illness [full review]. *The Cochrane Database of Systematic Reviews*

Radley, J., Grant, C., Barlow, J., & Johns, L. (2020). Parenting interventions for people with schizophrenia or related serious mental illness [protocol]. *The Cochrane Database of Systematic Reviews*, 2020(2).

## Progress Report Year 2, 2020

I began my second year by attending the Oxford-Berlin Open Science course for early career researchers in September 2019. Open Science is something I was passionate about even before beginning my PhD so I was very excited to attend this course. Presentations and workshops were held on the topics of preregistration of research ideas, the importance of reproducing others' experiments, biases that are frequently found in psychology, and how to publish your work 'Open Access' so as many people as possible can read it without having to pay.

I completed my qualitative interviews in November and in total had conducted twelve interviews with parents with psychosis, four with the partners of these parents, and four interviews with their children. I also conducted three focus groups with nineteen healthcare professionals who work with these parents and four retrospective interviews with adult children who had been raised by a parent with psychosis. I plan to do a number of analyses with these interview data. The first two analyses that I have completed are thematic analyses of data from the interviews with parents with psychosis and with the focus groups of healthcare professionals. My supervisors and I have reviewed discussed the results in detail, and I am currently writing a paper to submit for publication this year.

In February 2020, I published the protocol for my systematic review with Cochrane Schizophrenia. This systematic review aims to determine what parenting interventions currently exist for parents with psychosis, and what their effectiveness is. My co-author, Claire, and I have since been through the papers considered in the review and plan to publish the full report later this year.

When I started working at home in March due to covid-19, I took the opportunity to start more data cleaning with CRIS, the Clinical Record Interactive System. I will soon be in a position to produce the final results on how many patients with psychosis in Oxford Health NHS Foundation Trust (OHFT) have children, and the demographic and clinical characteristics of this group. Covid-19 has slightly delayed when I will start recruiting for my ESM study, due to the requirement to amend the protocol. The study has passed ethical review and my supervisor and I have made amendments so that participants are able to complete most elements of the study virtually. I plan to start recruitment for this at the end of the summer.

As well as my academic work, I was trained in Behavioural Family Therapy (BFT) with the Early Intervention in Psychosis Team at OHFT. Alongside another family worker, I now deliver weekly one-hour BFT sessions.



**Publications:** Radley, J., Grant, C., Barlow, J., & Johns, L. (2020). Parenting interventions for people with schizophrenia or related serious mental illness. *Cochrane Database of Systematic Reviews*, (2).

## **Progress report Year 1, 2019**

I wanted to start my PhD from the ground up by interviewing the people who are at the heart of my research topic, namely parents with psychosis, their partners, and their children. In March 2019, I gained approval from the University of Oxford ethics committee to conduct these interviews and as of August 2019, I have interviewed seven participants about their experience of being a parent who has experienced psychosis. I am in discussion with some of these parents about also interviewing their partners (or close family members) and children, which will hopefully add an interesting layer to my research findings.

I chose to conduct this project using Grounded Theory, which has meant that I've been able to steer the project through what has appeared in the analysis. So far, I have found it easier to recruit women and also those from Early Intervention services, which has meant that I have mostly heard about the experiences of mothers who have had only one episode of psychosis. Therefore, I am now trying to recruit from different teams where the service users will have had multiple episodes of psychosis and may have a diagnosis of schizophrenia. From these discussions, I hope to understand what it is like for those parents who are more familiar with managing their psychosis, and whether there are differences between these service users.

Alongside this, I have been working with some big data using CRIS, the Clinical Record Interactive System, which allows researchers to access anonymised patient data. I am searching for anybody with a diagnosis of psychosis and then seeing how many of those people have children. There has been more missing data than expected so it has taken some time to search through clinical notes in the hope of obtaining details of potential children. Once I have built up a database of patients and their dependants, I will start to look for factors that predict having children, such as being female or being over a certain age.

Outside of my research, I have also had the opportunity to attend a number of training courses. At the beginning of my course, I attended a course by The Association for Child and Adolescent Mental Health on 'Parental Mental Illness' in order to hear about the effect of parental psychosis from a child's perspective. This gave valuable insight into the realities of these experiences. I have also attended week-long courses in both interview skills and statistics, delivered at my university. In March, I had the opportunity to attend a workshop on Experience Sampling Methodology (ESM), which I hope to use later in my research. When ESM is used in a study, participants are asked to rate their thoughts and feelings at a specific moment, rather than having to reflect overtime. Using this method can help researchers better understand small changes overtime and reflect on patterns.

For the next stage of my PhD, I intend to use ESM in a novel way by integrating the technology into smartphones to investigate the relationship between the stress of parenting and experiencing psychotic symptoms. Each participant would be asked to use a smartphone to record their symptoms and stress levels over a two week period, with automated messages reminding them to complete the assessments. I have received a £750 grant from the NIHR to do some PPI (Public and Patient Involvement) work to inform my ESM study, which will hopefully involve some small group discussions in November this year.