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# First episode psychosis: A comparison of caregiving appraisals in parents caring for the same child

Juliana Onwumere[1,2] | Sophie Wilson[3] | Jo Billings[4] | Lucy Brown[3] | Caroline Floyd[3] | Kaja Widuch[3] | Natasha Lyons[3] | Lai Chu Man[3] | Gareth James[3] | Roya Afsharzadegan[3] | Sanna Khan[3] | Mellisha Padayatchi[3] | Jonathan Souray[3] | David Raune[3]

[1]Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

[2]The National Psychosis Unit & PiCuP Services, South London and Maudsley NHS Foundation Trust, Bethlem Royal Hospital, Beckenham, UK

[3]Harrow & Hillingdon Early Intervention in Psychosis Service, The Pembroke Centre, Central and North West London NHS Foundation Trust, London, UK

[4]Department of Clinical, Educational and Health Psychology, University College, London, UK

**Correspondence**
Juliana Onwumere, Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK.
Email: juliana.1.onwumere@kcl.ac.uk

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## Abstract

**Background:** The first onset of psychosis can be a traumatic event for diagnosed individuals but can also impact negatively on their families. Little is known about how parents of the same child make sense of the illness. In mothers and fathers caring for the same child with early psychosis, the current study assessed their similarities and differences in key areas of their caregiving role.

**Methods:** Using a cross-sectional design, parental pairs caring for the same child treated within an early intervention in psychosis service, completed self-report measures on their caregiving experiences, illness beliefs, coping styles and affect.

**Results:** Data from 44 mothers and fathers were analysed. Analyses confirmed that parents reported similar levels of emotional dysfunction and conceptualized the illness in broadly similar ways with regard to what they understood the illness to be, their emotional reactions to the illness, perceived illness consequences and beliefs about treatment. Significant differences were identified in their beliefs about the timeline of the illness and reported approaches to coping.

**Conclusions:** With exception of beliefs about illness timeline and an expressed preference for use of emotion-based coping, parent caregivers of the same child in early psychosis services are likely to report similar illness beliefs and caregiving reactions. Efforts to ensure staff awareness of the potential areas of divergence in parental caregiving appraisals and exploring the implications of the divergence for the caregiving relationship and patient outcomes are indicated.

KEYWORDS
carers, families, first-episode psychosis, parents

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Juliana Onwumere and Sophie Wilson are equal first authors.

## 1 | BACKGROUND

The first episode of psychosis (FEP) can occur at various stages in one's life but will have its peak onset during the late adolescence and the early adulthood phase. It is characterized by a broad range of key symptoms that can include delusional beliefs and hallucinatory experiences, alongside impairments in cognition, affect and social functioning (American Psychiatric Association, 2013). Levels of trauma, (Wang et al., 2013); self-harm, including suicide (Robinson et al., 2010), relapse (Robinson et al., 1999), stigma (Zäske et al., 2018) and aggression, are often prevalent during the initial episode (Winsper et al., 2013).

Though isolated, many individuals diagnosed with a psychotic disorder will remain in close contact with informal carers (Palumbo, Volpe, Matanov, Priebe, & Giacco, 2015), which is particularly observable during the early illness phases when many are likely to be living with or will return to live within the family home (Addington, Coldham, Jones, Ko, & Addington, 2003). Informal carers are a diverse group; however, most are parental caregivers particularly during the early years post first onset (Cotton et al., 2013). The important role played by carers to secure improved outcomes for relatives with psychosis is widely recognized within the literature. There is evidence to attest the positive impact carers can have on facilitating help seeking and ensuring that relatives receive relevant and timely input from services, and significantly reducing their rates of relapse, hospitalization (Norman et al., 2005), and premature death (Revier et al., 2015).

### 1.1 | The caregiving experience

Carers can report having positive experiences that include an improved relationship with the person they care for and identifying new personal strengths (Kulhara et al 2012). The caregiving role, however, can be stressful. Carers report experiencing high levels of psychological distress for which approximately 40% can fall within clinical ranges (Hamaie et al., 2016; Sadath et al 2017). Reports of loss, stigma, confusion and fear can be commonplace in caregivers and are already evident at the first episode (McCann, Lubman, & Clark, 2011; Onwumere et al., 2018; Patterson, Birchwood, & Cochrane, 2005).

Cognitive models of caregiving responses in psychosis (eg, Kuipers, Onwumere, & Bebbington, 2010) highlight the importance of carer appraisals about the illness, caregiving experiences and coping styles to their own wellbeing, interface with services and patient outcomes. Carers' reports of negative caregiving experiences (burden) are positively associated with pessimistic beliefs about the illness, particularly as they relate to the timeline of the illness, its impact on different life domains and responsiveness to treatment and control (Onwumere et al., 2008; Patel, Chawla, Krynicki, Rankin, & Upthegrove, 2014). Further, carer coping efforts that are characterized by avoidance (eg, trying to not think about issues, just wishing things would go away) are positively linked to poorer functioning in carers, including greater emotional distress and reports of burden (Kuipers et al., 2006; Onwumere et al., 2011; Raune, Kuipers, & Bebbington, 2004), and caregiving relationships characterized by greater levels of critical and negative interactions (Birchwood & Cochrane, 1990).

Across a broad range of physical and mental health conditions that include attention deficit hyperactivity disorder, diabetes and asthma, there remains an ongoing interest in exploring parental experiences and beliefs about having a child living with chronic health condition (Zaraket et al. 2011; Lowry, Schatz, & Fabiano, 2018; Iverson, Graue, Haugstvedt, & Raheim, 2018). However, the study of two parents of the same child and measurement of variables of interest in one parent, independently of the other and comparison of findings, represents a rare design feature in most caregiving studies including those within psychosis. Most studies focusing on caregiving experiences in psychosis have tended to report on parental caregiving (Tuck, du Mont, Evans, & Shupe, 1997; Young, Digel Vandyk, Daniel Jacob, McPherson, & Murata, 2019) but where the focus has been specifically on mothers (Kaya Kilic & Saruc, 2015) or participant samples comprised mainly mothers (Knudson & Coyle, 2002; Mcauliffe, O'Connor, & Meagher, 2014; Young, Digel Vandyk, et al., 2019). Where perspectives of other carers have been explored, they have tended to be studied in isolation (eg, Bowman et al. 2017) without comparison to other carers. Understanding and comparing the experiences of two parents caring for their child with psychosis is scarce within the literature and there is only a small handful of studies reporting the experiences of fathers (Weins & Daniluk, 2009). Conclusions from a recent systematic review of parental caregivers of children with a diagnosis of schizophrenia called for more exploration of the different experiences of mothers and fathers in their roles. (Young, Murata, McPherson, Jacob, & Vandyk, 2019). Such an approach, however, would help to facilitates a more in-depth and nuanced understanding of family caregiving experiences and possible individual differences. In the Kuipers et al. (2010) model, it is conceivable that parental caregivers for the same patient with psychosis could also report different appraisals related to their individual experience of caregiving, how they understand and make sense of their child's illness, and their own (ie, parent) psychological health and functioning. These appraisals could impact their patterns of engagement with their relative and service providers. However, such arguments have yet to be empirically investigated in FEP psychosis. In addition, understanding the experience and needs of males and father caregivers has tended to be overlooked in the literature with its almost exclusive focus on female caregivers (Cotton et al., 2013), particularly mothers (Cotton et al., 2013; King, Ricard, Rochon, Steiger, & Nelis, 2003). Drawing the literature's attention to fathers and assessing the differential needs that might exist in parental dyads, could highlight opportunities to offer more evidence driven and targeted carer focused interventions. There are some indicators from the literature highlighting differences in parental caregiver experiences with mothers expressing more concern about difficult behaviours and negative symptoms, compared to fathers (Addington et al., 2003). Determining whether differences are present during the early illness phase could help clinical services to be more responsive and support future intervention planning.

Earlier work from Chesla's (1991) hermeneutic phenomenological approach with 21 parents exploring caring styles for children living with a diagnosis of schizophrenia highlights some parental differences across the genders. This qualitative data suggested that fathers had tended to adopt a less hands on and "distanced care" approach that relied more on the mother to provide direct care and feedback on issues. This approach, however, rendered them more emotionally vulnerable. In a recent systematic review of 31 studies exploring illness models in parents of young and adult children with severe mental health conditions, including psychosis, results confirmed that it was difficult for parents to make sense of the problems facing their child and often held themselves responsible for the illness. Reports of self-blame were particularly an issue for mothers relative to fathers. These reports tended reflect a range of underlying beliefs that included those related to having been a bad parent and not having been attentive to their child's illness and responding appropriately (Hasson-Ohayon, Goldzweig, Lavi-Rotenberg, Roe, & Pijnenborg, 2019).

In an early psychosis population, the current study aims to explore whether two parents, caring for the same child, in primary caregiving roles, appraise the illness and their caregiving experiences in similar ways. Informed by the literature, we hypothesised that mothers, when compared to fathers, will report greater levels of distress, negative caregiving experiences and use of emotional (less adaptive) coping strategies. No specific a priori hypotheses were offered about illness beliefs.

## 2 | METHODS

A cross-sectional design was employed.

### 2.1 | Sample

Participants were the self-identified parental carers of a young person accessing care from a specialist early intervention in psychosis in a London National Health Service (NHS) Trust. The service intervenes with all known cases (aged 14-34 years) of first-episode psychosis in a defined catchment area and with duration of untreated psychosis of less than 12 months. Patients are only accepted into the service if they meet criteria for first-episode psychosis. All informal carers in the service are routinely identified by team personnel. Carer assessments took place as soon as possible after the service user was taken on by the service and both parental carers were contacted and assessed. Depending on availability, carer participants would be assessed on the same day or a few days apart, to suit individual timetables. Data collection for service users and carers, and manuscript preparation, were undertaken in accordance with criteria laid out by the participating NHS Trust research development and clinical governance protocol. Data for clinical purposes and service monitoring is routinely collected, and informed written consent to publish anonymised data is also routinely sought, in line with Trust ethics procedures and protocols. Data were collected by graduate level psychologists who had received training from a doctoral level of psychologist in carer engagement and administration of measures.

### 2.2 | Measures

Socio-demographic characteristics such as carer age, gender, employment and accommodation status were collected.

*Illness Perception Questionnaire for Schizophrenia: Relatives' Version* (IPQS-RV; Lobban, Barrowclough, & Jones, 2005). The 10 item IPQS-RV is designed to assess carers' appraisals about their relatives' illness across different domains such as beliefs about the illness timeline, illness consequences (for self and relative) and degree of control over the illness. Questionnaire items are rated on a Likert scale that ranges from 1 (*strongly disagree*) to 5 (*strongly agree*). The measure has been widely used and has good psychometrics (Lobban et al., 2005).

*Cope Inventory* (COPE; Carver, Scheier, & Weintraub, 1989) The COPE is a 30-item self-report measure assessing 15 different coping strategies. Respondents read through brief statements and are required to rate on a four-point Likert scale the degree to which the statement best applies. Each of the 15 scales has two items, and the total score for each scale is computed by adding the items together. Mean scores are calculated for each subscale. This measure has good psychometrics and widely used with psychosis carer samples (Onwumere et al., 2011; Raune et al., 2004). The avoidant scale has eight items comprising the Denial, Behavioural Disengagement, Mental Disengagement, Alcohol-drug disengagement subscales. Emotion focused scale has 12 items comprising: seeking support for emotional reasons, positive reinterpretation and growth, acceptance, turning to religion, humour and venting subscales. The problem focused scale has 10 items and included: planning, suppression of competing activities, restraint, seeking support for instrumental reasons, active coping scales.

*Experience of Caregiving Inventory* (ECI; Szmukler et al., 1996). The ECI is a 66-item, 10 subscales self-report measure that assesses carers' negative (8 subscales) and positive (2 subscales) appraisals of mental health caregiving experiences. Participants are asked to read through brief statements and indicate, on a five-point Likert scale ranging from "never" to "nearly always", the amount they had thought about the issue in the last month. The ECI has two summary scores that reflect the sum of the negative and positive subscales; higher summary scores denote greater levels of negative and positive caregiving experiences. The ECI has been extensively used in mental health caregiving research (Gleeson et al., 2010; Thompson, de la Cruz, Mataix-Cols, & Onwumere, 2016).

*Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1983). The HADS is a 14-item self-report measure assessing levels of clinical distress. Participants read through statements and rate the degree to which statements best apply over the last week on a four-point scale. Subscale scores range from 0 to 21 and scores >8 indicate clinical levels of distress. The subscales can be measured independently or in combination to provide a measure of psychological distress. This measure has been widely used within carer populations and is psychometrically sound (Tomlinson, Onwumere, & Kuipers, 2014).

For the patient sample, socio-demographic and clinical data such as gender, ethnicity, age and length of illness, were extracted from case note review.

### 2.3 | Data analyses

Analyses were performed using SPSS version 22 (SPSS for windows, 2013) and Stata version 8 (StataCorp, 2003). All analyses were related-measures tests, in that each mother and father caring for the same child were directly compared to each other for all outcomes. Bootstrapping was employed to manage skewed distributions using 1000 samples (DiCiccio & Efron, 1996). Univariable tests examined differences between parental pairs on key outcomes (ie, paired *t* tests; the McNemar's test and the Mantel-Haenszel test; Mantel, 1963). Multivariable analyses were performed using linear and logistic multilevel models to control for potential confounders, (carer age, carer employment status), and to see if any differences that were found in the univariable analyses remained.

## 3 | RESULTS

The sample comprised 44 matched parental pairs who were drawn from a large (N = 257) broader group of carers (eg, non-matched parental carers) (see Table 1). There were three carers who refused permission to publish and were therefore excluded from the reported data. The mean ± SD age of the parents was 54.2 ± 7.6 years (range 41-74). Mothers were on average, around 5 years younger than fathers (51.7 ± 6.6 and 56.7 ± 7.9, respectively). Most participants were from a White British (N = 34, 37%) or Asian (N = 26, 30%) ethnic background, with less than half of mothers (34%, n = 15) and fathers (43%, n = 19) born in the United Kingdom. Most parental participants were living in the same household with their child with psychosis (91%, n = 40).

The patient group were mostly male (n = 33, 75%), with a mean ± SD age of 22.4 ± 5.1 years (Range 13-33). Approximately one half of the patient sample were not in work or education (n = 23, 52%). The mean length of psychosis was 18.3 months (SD = 14.6 months). Most patients were from White British (N = 16, 36%) or Asian (N = 18, 41%) ethnic groups (see Table 2).

*Illness beliefs*: After controlling for carer demography (eg, age, employment), participants who were mothers, when compared to fathers, were more likely to endorse illness beliefs that recognized psychosis as having a cyclical course (95% confidence interval [CI]: −0.74 to −0.06, *P* = .021). They were also perceived themselves as having less control over their child's illness (95% CI: 0.02 to 0.81, *P* = .041). However, this finding failed to remain significant after controlling for carer demography.

**TABLE 1** Demographic characteristics of related mothers and fathers

| | Mothers (N = 44) | | Fathers (N = 44) | |
|---|---|---|---|---|
| **Characteristic** | **N** | **%** | **N** | **%** |
| Age (M ± SD years) | 51.7 ± 6.6 | | 56.7 ± 7.9 | |
| Ethnicity | | | | |
| White | 17 | 39 | 17 | 39 |
| Asian | 13 | 30 | 13 | 30 |
| Black | 5 | 11 | 6 | 14 |
| Other | 9 | 21 | 8 | 18 |
| First language is English | | | | |
| Yes | 23 | 52 | 28 | 64 |
| Born in the UK | | | | |
| Yes | 15 | 34 | 19 | 43 |
| Marital status | | | | |
| Married | 42 | 96 | 40 | 91 |
| Lives with partner | 2 | 5 | 4 | 9 |
| Employment status | | | | |
| Paid full-time | 13 | 30 | 24 | 55 |
| Paid part-time | 11 | 25 | 5 | 11 |
| Retired | 5 | 11 | 7 | 16 |
| Homemaker | 10 | 23 | 0 | 0 |
| Other | 5 | 11 | 8 | 18 |
| Primary carer | | | | |
| Yes | 41 | 93 | 27 | 61 |
| Length of time cared for the child since the onset (M ± SD months) | 19.3 ± 15.1 | | 19.9 ± 15.1 | |
| Carer lives with the patient | | | | |
| Yes | 40 | 91 | 40 | 91 |
| Face-to-face contact per week (M ± SD hours) | 55.0 ± 35.9 | | 47.0 ± 32.4 | |
| Face-to-face 35 hours threshold | | | | |
| <35 hours | 15 | 34 | 15 | 34 |
| >35 hours | 26 | 59 | 28 | 64 |
| Carer cares for more than one person | | | | |
| Yes | 22 | 50 | 20 | 46 |
| The other person they care for has psychosis | | | | |
| Yes | 3 | 7 | 5 | 11 |

*Note:* Missing data: shown as N, % per mothers and fathers—most missing data were found on number of face to face contact hours per week: 4 values (mothers: 3, 7%, fathers: 1, 2%); face to face threshold contact: 4 values (mothers: 3, 7%, fathers: 1, 2%). For all the other demographic variables, the quantity of missing data was low (<3 values, <7% each for mothers and fathers).

*Caregiving experiences*: Overall, parental participants were reporting high levels of negative caregiving experiences (burden). Parental pairs, however, did not significantly differ in their reported negative and positive caregiving appraisals (see Table 3).

*Coping styles*: After controlling for carer demographics, mother participants were more likely to report using emotion-focused coping strategies compared to fathers (95% CI: −5.54 to −0.31, *P* = .028). No

**TABLE 2** Demographic and clinical characteristics of patients in the early course of psychosis

| | Patients (N = 44) | |
|---|---|---|
| **Characteristic** | **N** | **%** |
| Gender | | |
| Male | 33 | 75 |
| Age | 22.4 ± 5.1 | |
| Ethnicity | | |
| White | 16 | 36 |
| Asian | 18 | 41 |
| Black | 5 | 11 |
| Other | 5 | 11 |
| First language is English | | |
| Yes | 38 | 86 |
| Marital status | | |
| Single | 43 | 98 |
| Long term partner | 1 | 2 |
| Employment status | | |
| Employment (full time, part time, voluntary) | 6 | 14 |
| Not in work or education | 23 | 52 |
| Student | 13 | 30 |
| Diagnosis | | |
| Schizophrenia spectrum | 33 | 75 |
| Affective psychosis | 8 | 18 |
| Other | 2 | 5 |
| Duration of untreated psychosis (Mean ± SD months) | 5.4 ± 9.2 | |
| Psychosis onset age | 20.9 ± 4.9 | |
| Length of psychosis (Mean ± SD months) | 18.3 ± 14.6 | |
| Currently inpatient | | |
| No | 37 | 84 |

*Note:* Missing data: shown as N, %. Most missing data was found on Duration of untreated psychosis (16 values, 36%). For all the other demographic variables, the quantity of missing data was low (<5%).

further statistically significant differences in coping styles were observed between parental groups (see Table 3).

*Distress*: The analysis revealed that 44% of mothers (n = 17) and 28% (n = 11) of fathers met the cut off criteria for clinical severity of anxiety. Eight mothers (20%) and six fathers (15%) met the cut off for clinical severity of depression. No significant differences were identified in the parental groups in their mean levels of anxiety and depression and case-ness status (see Table 4).

## 4 | DISCUSSION

In parents caring for the same child accessing care from an early intervention in psychosis service, the current study sought to compare their appraisals on key areas known to impact the caregiving relationship and outcomes (eg, illness beliefs, coping styles). To the best of our knowledge, the current paper represents the first empirical investigation of these key issues in this population.

Contrary to predictions, the overall pattern of findings suggests that mothers and fathers in primary caregiving roles for the same child with early psychosis will broadly report more similarities in how they conceptualize and make sense of their child's illness, their day-to-day caregiving experiences and levels of psychological distress. This concurs with recent work from Chan et al. (2015), who examined carer knowledge about psychosis, including risk potential and medications, and observed similar beliefs between carers from different gender groups.

There were, however, two areas of divergence between the mother and father carer participants. In line with predictions, our findings suggest that mothers were more likely to report using emotion focused coping; an approach comprising strategies such as venting of emotions and turning to religion. Such approaches can often be considered less adaptive and linked to poorer outcomes, particularly in situations that demand a more problem focused and active approach. Evidence from previous work highlights a positive association between carer reports of emotion focused coping and a greater tendency to engage in self-blame and perceive a greater level of negative illness consequences (Rexhaj, Python, Morin, Bonsack, & Favrod, 2013). We also know that emotion focused coping is usually linked to poorer levels of emotional functioning (Matheson & Anisman, 2003) and females, when compared to male peers, are more inclined to report use of emotion focused coping (Craciun, 2013; Kelly, Tyrka, Price, & Carpenter, 2008; Matud, 2004; Ptacek, Smith, & Dodge, 1994). They are also more likely to obtain poorer outcomes compared to male peers employing the same coping skills (Mazure & Maciejewski, 2003). Though mothers and fathers in our current sample did not differ in their overall levels of reported psychological distress and majority of illness beliefs, it is possible that mothers have a greater preference in using emotion focused strategies such as sharing how they feel and using religious coping to deal with the inherent distress linked to their illness beliefs. Moreover, females might find it easier to engage with and/or endorse using emotion focused strategies. The results might also speak to prevailing views that emotion focused coping, per se, should not automatically be dismissed as being less effective or unhelpful since the context and situational demands remain key influencing factors.

The current results also compliment the work of Gerson et al. (2011) in psychosis and other conditions (Hastings et al. 2005). Gerson noted non-significant differences between early psychosis male and female carers, with males reporting greater levels of some aspects of emotion focused (ie, positive reinterpretation and growth, venting) and avoidant coping (ie, substance use). In contrast to their male peers, female carers were more likely to report greater emotion focused coping in the form of religious coping. Previous work has failed to identify links between gender and avoidant coping across carers of early psychosis and longer-term patients, although comparisons were not specifically drawn between matched male and female parental carers and those from within the same family (Onwumere

**TABLE 3** Univariable and multivariable analyses of the primary outcomes: Illness perception questionnaire, experience of caregiving inventory and cope inventory

| Questionnaire | Summary statistics | | Unadjusted analyses[b] | | | Adjusted analyses[c] | | |
|---|---|---|---|---|---|---|---|---|
| | M ± SD in mothers (N = 44) | M ± SD in fathers (N = 44) | Mean difference | 95% CI | P value | Mean difference | 95% CI | P value |
| Illness Perceptions Questionnaire (IPQ)[d] | | | | | | | | |
| Timeline acute/chronic[g] | 3.02 ± 0.73 | 3.03 ± 0.84 | 0.02 | −0.30 to 0.26 | .893 | −0.10 | −0.32 to 0.30 | .949 |
| Timeline cyclical | 3.70 ± 0.75 | 3.47 ± 0.78 | −0.23 | −0.04 to 0.51 | .098 | −0.40 | −0.74 to −0.06 | .021* |
| Negative consequences for patient[a] | 3.55 ± 0.69 | 3.67 ± 0.73 | 0.12 | −0.40 to 0.16 | .400 | 0.11 | −00.13 to 0.36 | .364 |
| Negative consequences for relative[h] | 3.23 ± 0.74 | 3.23 ± 0.71 | 0.00 | −0.32 to 0.31 | .979 | 0.18 | −0.12 to 0.48 | .245 |
| Personal control (patient helplessness)[a,i] | 3.78 ± 0.74 | 3.65 ± 0.74 | −0.13 | −00.17 to 0.43 | .387 | −0.17 | −0.41 to 0.77 | .181 |
| Personal control (relative helplessness)[a,j] | 3.54 ± 0.84 | 3.13 ± 0.75 | 0.41 | 0.02 to 0.81 | .041* | 0.00 | −0.31 to 0.31 | .998 |
| Patient blame[k] | 3.07 ± 0.83 | 3.03 ± 0.74 | −0.04 | −0.34 to 0.41 | .849 | 0.12 | −0.20 to 0.44 | .466 |
| Relative blame | 2.56 ± 0.82 | 2.68 ± 0.71 | 0.12 | −0.46 to 0.22 | .474 | 0.29 | −0.06 to 0.63 | .106 |
| Treatment control[l] | 3.68 ± 0.61 | 3.89 ± 0.60 | 0.21 | −0.46 to 0.03 | .090 | 0.02 | −0.23 to 0.28 | .850 |
| Emotional representations[m] | 3.26 ± 0.81 | 3.25 ± 0.81 | 0.01 | −0.26 to 0.26 | .988 | −0.10 | −0.37 to 0.18 | .493 |
| Illness coherence[a] | 2.62 ± 0.81 | 2.48 ± 0.78 | −0.14 | 0.14 to 0.42 | .293 | 0.03 | −0.29 to 0.35 | .851 |
| Experience of Caregiving Inventory (ECI)[e] | | | | | | | | |
| Total negative burden score[n] | 93.31 ± 32.63 | 97.36 ± 7.90 | 4.06 | −19.30 to 11.19 | .593 | 9.28 | −6.39 to 25.00 | .246 |
| Difficult behaviour[o] | 13.48 ± 8.43 | 13.43 ± 8.63 | −0.05 | −3.22 to 3.32 | .977 | −0.73 | −3.22 to 3.07 | .963 |
| Negative symptoms[p] | 11.14 ± 7.12 | 12.86 ± 6.69 | 1.71 | −4.62 to 1.19 | .241 | 1.81 | −0.83 to 4.46 | .180 |
| Stigma[q] | 7.26 ± 4.28 | 7.53 ± 5.40 | 0.28 | −2.48 to 1.92 | .799 | 0.49 | −1.81 to 2.79 | .676 |
| Effect on family[r] | 10.23 ± 6.16 | 10.33 ± 7.54 | 0.10 | −2.93 to 2.73 | .942 | 1.24 | −1.87 to 4.35 | .435 |
| Need to back-up[s] | 11.02 ± 4.48 | 12.00 ± 5.43 | 0.98 | −2.86 to 0.91 | .302 | 1.13 | −0.76 to 3.01 | .241 |
| Dependency[t] | 12.31 ± 4.03 | 11.95 ± 4.74 | −0.36 | −1.48 to 2.19 | .696 | 0.68 | −0.79 to 2.15 | .364 |
| Loss[u] | 11.40 ± 5.59 | 11.70 ± 5.32 | 0.30 | −2.59 to 1.98 | .791 | −0.53 | −2.62 to 2.51 | .967 |
| Problems with services[a,v] | 14.36 ± 6.82 | 15.18 ± 7.07 | 0.82 | −3.87 to 2.26 | .585 | 0.99 | −2.15 to 4.12 | .537 |
| Total positive burden score[w] | 31.80 ± 10.90 | 32.24 ± 11.83 | 0.44 | −4.88 to 4.00 | .842 | −0.49 | −5.01 to 4.02 | .831 |
| Positive personal experiences[x] | 16.69 ± 6.86 | 17.54 ± 7.48 | 0.86 | −3.79 to 2.08 | .559 | −0.04 | −3.24 to 3.16 | .982 |
| Good aspects of the relationship[a,y] | 15.07 ± 5.65 | 14.71 ± 5.71 | 0.36 | −1.59 to 2.43 | .724 | −0.40 | −2.49 to 1.70 | .710 |
| Cope Inventory (COPE)[f] | | | | | | | | |
| Avoidant-focused coping[z] | 13.73 ± 3.32 | 13.82 ± 4.10 | 0.10 | −1.71 to 1.51 | .903 | 0.62 | −1.19 to 2.44 | .500 |
| Behavioural disengagement[a, a1] | 3.34 ± 1.41 | 3.27 ± 1.55 | −0.07 | −0.54 to 0.71 | .821 | 0.18 | −0.51 to 0.87 | .613 |
| Denial [a, b1] | 2.56 ± 1.28 | 2.61 ± 1.28 | 0.05 | −0.61 to 0.49 | .845 | 0.50 | −0.78 to 1.08 | .090 |
| Alcohol-drug disengagement [a, c1] | 2.80 ± 1.62 | 3.29 ± 1.83 | 0.49 | −1.20 to 0.20 | .171 | 0.17 | −0.58 to 0.91 | .662 |
| Mental disengagement [a, d1] | 5.02 ± 1.81 | 4.66 ± 1.71 | −0.37 | −0.34 to 1.15 | .317 | −0.34 | −1.20 to 0.52 | .442 |

**TABLE 3** (Continued)

| Questionnaire | Summary statistics |  | Unadjusted analyses[b] |  |  | Adjusted analyses[c] |  |  |
|---|---|---|---|---|---|---|---|---|
|  | M ± SD in mothers (N = 44) | M ± SD in fathers (N = 44) | Mean difference | 95% CI | *P* value | Mean difference | 95% CI | *P* value |
| Emotion-focused coping [a, e1] | 32.07 ± 4.54 | 28.23 ± 6.59 | −3.83 | 1.33 to 6.27 | .012* | −2.93 | −5.54 to −0.31 | .028* |
| Acceptance [a, f1] | 5.77 ± 1.69 | 5.18 ± 1.43 | −0.59 | −0.13 to 1.31 | .127 | −0.51 | −1.29 to 00.27 | .202 |
| Humour [a, g1] | 2.76 ± 1.28 | 2.56 ± 1.30 | −0.20 | −0.27 to 0.73 | .466 | 0.12 | −0.62 to 00.37 | .627 |
| Positive re-interpretation and growth [a, h1] | 5.64 ± 1.60 | 5.51 ± 1.89 | −0.13 | −0.51 to 0.74 | .703 | −0.71 | −0.91 to 0.76 | .866 |
| Seeking support for emotional reasons [a, i1] | 6.10 ± 1.98 | 5.49 ± 1.94 | −0.62 | −0.08 to 1.36 | .103 | −0.24 | −1.25 to 0.77 | .643 |
| Turning to religion [a, j1] | 5.54 ± 2.34 | 4.54 ± 2.57 | −1.00 | −0.17 to 2.17 | .094 | −0.65 | −1.55 to 0.25 | .159 |
| Focus on and venting emotions [a, k1] | 5.51 ± 1.90 | 4.78 ± 1.90 | −0.73 | 0.02 to 1.41 | .047* | −1.02 | −1.91 to −0.14 | .024* |
| Problem-focused coping [a, l1] | 27.73 ± 5.00 | 28.50 ± 6.93 | 0.77 | −3.90 to 2.46 | .646 | 1.49 | −1.32 to 4.31 | .298 |
| Active coping [a, m1] | 6.13 ± 1.47 | 5.85 ± 1.69 | −0.28 | −0.28 to 0.87 | .358 | 0.32 | −4.33 to 1.07 | .408 |
| Planning [a, n1] | 5.46 ± 1.76 | 5.58 ± 1.96 | 0.13 | −00.95 to 0.77 | .769 | 0.60 | −0.32 to 1.53 | .199 |
| Suppression of competing activities [a, o1] | 5.85 ± 1.60 | 5.51 ± 1.71 | −0.33 | −.41 to 1.08 | .418 | −0.60 | −0.83 to 0.71 | .880 |
| Restraint coping [a] | 5.03 ± 1.51 | 5.10 ± 1.85 | 0.07 | −0.85 to 0.69 | .853 | 0.09 | −0.71 to 0.91 | .835 |
| Seeking support for instrumental reasons [a, p1] | 5.21 ± 1.67 | 5.46 ± 1.85 | 0.25 | −1.00 to 0.51 | .518 | 0.78 | −0.08 to 1.65 | .075 |

*$P < .05$.

[a] Bootstrap results are based on 1000 bootstrap samples.

[b] Paired *t* tests.

[c] Linear multi-level model adjusting for age, employment status and primary carer.

[d] Subscale scores range from 0 to 5—higher subscale scores showing greater illness beliefs.

[e] Subscale scores range from 0 to 32 for difficult behaviour, problem with services and positive personal experiences; scores range from 0 to 28 for effects on family and loss; scores range from 0 to 24 for negative symptoms, need to back up and good aspects of relationship; scores range for 0 to 20 for stigma and dependency—greater scores on the negative subscales indicate more negative experiences& greater scores on positive subscales indicate more positive experiences.

[f] Subscale scores range from 0 to 8; problem-focused &avoidant-focused scores both range from 0 to 40; emotion-focused scores range from 0 to 42—higher scores indicate they do this a lot.

Missing data: [k, r] 5 pairs (mothers: 2, 4.5%, fathers: 3, 6.8%);[l1] 8 pairs (mothers: 3, 6.8%, fathers: 5, 11.4%); [h] 10 pairs (mothers: 6, 13.6%, fathers: 5, 11.4%); [n,v, z, k1,] 4 pairs (mothers and fathers: 2, 4.5% each); [q, b1, i1] 3 pairs (mothers: 1, 2.3%, dads: 2, 4.5%); [m] 3 pairs (mothers: 2, 4.5%, dads: 1, 2.3%); [y]2 pairs (mothers and fathers: 2, 4.5% each); [l, n1, e1, h1]2 pairs (mothers and fathers, 1, 2.3% each); [o] 2 pairs (fathers: 2, 4.5%); [i, u, p] 2 pairs (mothers: 2, 4.5%); [j, t, w, x, a1, d1, c1, g1, j1, m1, o1] 1 pair (fathers: 1, 2.3%); [g, s, f1, p1]1 pair (mothers: 1, 2.3%).

**TABLE 4** Univariable and multivariable analyses of the primary outcome: Hospital Anxiety and Depression Scale

| | Summary statistics | | Unadjusted analyses[b] | | | Adjusted analyses[c] | | |
|---|---|---|---|---|---|---|---|---|
| Questionnaire | M ± SD in mothers (N = 44) | M ± SD in fathers (N = 44) | Mean difference | 95% CI | *P* value | Mean difference | 95% CI | *P* value |
| Hospital Anxiety and Depression Scale (HADS)[g] | | | | | | | | |
| Anxiety total[i] | 8.97 ± 4.72 | 7.74 ± 5.26 | −1.23 | −.64 to 3.10 | .191 | −0.90 | −3.22 to 1.42 | .448 |
| Depression total[d, j] | 6.63 ± 4.47 | 5.63 ± 4.69 | −1.00 | −1.20 to 2.93 | .384 | −0.98 | −3.09 to 1.13 | .364 |

| | Summary statistics | | | | Unadjusted analyses[d] | | | Adjusted analyses[e] | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Mothers | | Fathers | | | | | | | |
| Questionnaire | N | % | N | % | OR[f] | 95% CI | *P* value | OR | 95% CI | *P* value |
| Hospital Anxiety and Depression Scale | | | | | | | | | | |
| Clinical case of anxiety[k] | 17 | 44 | 11 | 28 | 0.40 | 0.09 to 1.39 | .180 | 0.38 | 0.10 to 1.46 | .160 |
| Clinical case of depression[l] | 8 | 20 | 6 | 15 | 0.71 | 0.18 to 2.61 | .774 | 0.59 | 0.11 to 3.06 | .524 |

*Note*: Pair cases were removed if a value is missing for one of the parents.

[a] Bootstrap results are based on 1000 bootstrap samples.

[b] Paired *t*-test.

[c] Linear multi-level model adjusting for carer age, employment status and primary carer.

[d] McNemar test.

[e] Logistic Multi-level model adjusting for carer demography.

[f] Mantel–Haenszel test.

[g] Possible scores range from 0 to 21 on each subscale, scores above 11 indicate clinical levels of distress.

Missing data: [i, k]: 5 pairs (mothers: 4, 9%, fathers: 2, 5%). [j, l] 4 pairs (mothers: 3, 7%, fathers: 2, 5%).

et al., 2011). Hastings and colleagues (2005), in their exploration of coping strategies in mothers and fathers of autistic children, revealed that coping strategies were largely similar between parents in the same family. However, mothers, when compared to fathers, were more likely to report greater levels of active avoidance and problem focussed coping strategies.

The results also highlighted that mothers conceptualized the illness timeline significantly differently from father peers such that they were more likely to perceive the illness as having a more cyclical (ie, a remitting relapsing) course. It is possible that during the early psychosis stage, mothers are more likely to recognize or be aware of the cyclical nature of the condition and therefore, the vulnerability of their relative to episodes of acute ill health. This would represent an informed view, in line with the general understanding of psychosis and how it typically manifests for many of those affected (NICE, 2014). Consequently, the observed difference might reflect a different level of knowledge between the parental carers. It is also possible, that the noted difference between mothers and fathers coping strategies could be linked to mothers' beliefs that the illness would last a long time. We know that appraisals of a long illness timeline are linked with more parental distress (Fortune et al. 2005; Onwumere et al., 2008; Kuipers et al 2007). However, the contribution of other factors such as trait coping styles cannot be ruled out.

## 4.1 | Clinical implications

This study provides empirical evidence that in early psychosis groups, parental caregivers are likely to report largely similar cognitive appraisals when caring for the same child and be equally as affected in terms of caregiving experiences and distress. Thus, if one parent presents to an early psychosis service with psychological wellbeing needs, the co-parental caregiver is very likely to be exhibiting similar needs too. In line with treatment guidance (NICE, 2014), the results underscore the importance of offering evidence based psycho-educational and support interventions to both parents who assume informal caregiving roles for relatives experiencing early psychosis. The importance of routinely identifying all those in the family system with caregiving roles and directly offering (or signposting to) relevant support is also indicated. Recognizing, however, that in a parental pair, informal carers can have divergent views and experiences in some areas (eg, coping styles) which, in itself, might serve as a proxy measure for information and support needs. Consequently, supporting carers, particularly mothers, to identify and utilize coping strategies that are adaptive for different types of situations are indicated, and have proven efficacy in FEP populations (McCann et al., 2012).

## 4.2 | Limitations

Though the study is novel and offers preliminary insights about parental appraisals in early psychosis, it had notable limitations. The small sample size and analyses approach of not controlling for multiple comparisons are key limitations. The failure to identify a greater range of differences between mothers and fathers might have reflected issues pertaining to the modest sample size and insufficient power to aid detection of differences. Further, the authors acknowledge the potential risk for type 1 errors. Despite including a wide range of target appraisal areas (illness beliefs, caregiving experiences, distress and coping styles) it is possible a broader inclusion of other key factors known to impact outcomes and caregiving experiences (eg, metacognition, personality, Jansen et al., 2014) may reveal a different pattern of relationships between parental caregivers. The cross-sectional design precludes any conclusions being drawn about causal and contributory processes, and directionality of the findings. It is unclear, for example, what factors impact on the observed divergence in parental appraisals about coping and illness beliefs regarding the timeline. It is important to note that the capacity for parents' appraisals to alter over time. A prospective design, therefore, involving multiple-time point analysis would be indicated to capture these changes and examine whether any patterns do emerge. Further, the failure to explore links between different parental caregiving appraisals and implications for illness course, patient outcomes and quality of the caregiving relationship was a limitation. In families of young people living with a long-term physical health condition (ie, atopic eczema), similar illness beliefs reported by matched parental pairs were associated with improved general wellbeing in patients though not less strain (Salewski, 2003). Prospective designs, incorporating carer and patient outcomes, should help to address these issues. Although the participant sample is diverse and reflective of the local communities affected by early psychosis in this one London region, the current study is based on data sourced entirely from one service in one geographical area and thus, a sample bias might exist. The London area from which the sample was extracted has high levels of economic and social deprivation, which might impact patient presentation and carer needs. Moreover, we do not have data on the number of carers who declined the service routine assessments. Our current sample offers a representation of family carers in a routine London early psychosis service that are willing to be assessed. However, we also recognize the sample limitations. It is possible that carers who declined assessments might have been more emotionally affected by their circumstances and perhaps less likely to report similar views with their parental peer. Equally, participating parental carers might have enjoyed more harmonious relationships, and shared duties, and were, therefore, more likely to engage with assessments and report shared caregiving appraisals. We remain unaware of how many of the non-matched carers had other family situations such as being single parents with sole caregiving responsibility or cases where there are several carers in a parental type role such as grandparents and siblings too. Further, The resulting limitations on the extent to which the findings generalize and reflect the broader early psychosis parental caregiving groups are therefore acknowledged. Future research should consider the purposive recruiting and sampling of parent carers who may be single dwelling, co-parenting and/or married.

### 4.3 | Conclusion

The experience of psychosis in young offspring can be a difficult, confusing and an emotional exhausting experience for any parental caregiver. In two parent households, both parents are likely to make sense of the illness and be impacted in similar ways but with exceptions to their approaches to coping and specific beliefs about illness timeline. Replication of findings in larger different samples are required and determining the implications for outcomes are the next steps.

## ORCID

*Juliana Onwumere* https://orcid.org/0000-0001-7119-7451

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