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Do carers of adolescents at first episode psychosis have distinctive psychological needs?:

A pilot exploration.

Authors

Alice McKenna^{1,2}, MSc
Dr Cassie M Hazell³, PhD
Rowan Souray¹, BSc
Wenyi Cai¹, BSc
Lai Chu Man¹, BSc
Lucy Brown¹, MSc
Caroline Floyd¹ MSc
Natasha Lyons¹, MSc
Kaya Widuch¹, MSc
Dr. Gareth James¹, DClinPsy
Dr. Debra Keay⁴, BA MBBS
Jonathan Souray¹, BSc
Dr. Roya Afsharzadegan¹, DClinPsy
Dr David Raune¹, DClinPsy; PhD

1. Harrow and Hillingdon Early Intervention in Psychosis Service, Central and North West London NHS Foundation Trust, London, UK
2. Community Transformation Project, East London NHS Foundation Trust, London, UK
3. University of Westminster- Department of Social Sciences
4. CAHMS Ash Tree, Central and North West London NHS Foundation Trust, London, UK

Corresponding Author:

Alice McKenna Vivienne Cohen House, Homerton High Street, Homerton, London, E9 6AS;alice.mckenna@nhs.net

Abstract

Background

Carers of patients experiencing first episode psychosis (FEP) are at an increased risk of mental and physical health problems themselves. However, little is known about how the psychological needs of carers may differ between those caring for an adolescent versus an adult who has FEP.

Aims

This pilot study aimed to explore any differences in the psychological needs of carers caring for adolescents versus adults with FEP.

Methods

We surveyed 254 carers of 198 FEP patients, (34 carers of adolescents of 24 FEP adolescent patients). Carers completed self-report measures of anxiety, depression, burnout, subjective burden, coping, and key illness beliefs. The sample was divided according to whether the patient was under (adolescent) or over (adult) age 18, and analysed using mixed model logistic regressions.

Results

Compared to the carers of adult patients, carers of adolescents were more than twice as likely (12% v 30%) to experience overall burnout syndrome (all three domains), and to develop it much quicker (19.4 v 10.1 months). However, there was no difference between carers in terms of anxiety, depression, beliefs and subjective burden. For carers of adolescents, burnout was independently predicted by: a negative belief about the consequences of psychosis for the adolescent patient and an incoherent understanding of the patient's mental health; and behavioural disengagement avoidance coping.

Conclusions

If our findings can be replicated in a larger sample, then Rapid-Onset-Burnout-Syndrome (ROBS) is a particular problem in carers of adolescents at FEP, suggesting a need for routine screening and possible prophylactic intervention. Carers of adolescents use of behavioural

escape coping maybe also require early intervention. Theoretically, consideration could be given to the development of an adolescent sub-branch to the cognitive model of caregiving.

Keywords: First episode Psychosis, Caregiver, Adolescence, Burnout, Avoidant Coping

1 Introduction:

The prevalence of psychotic disorders across all ages in the UK is 0.7% (National Institute for Health and Care Excellence, [NICE], 2013, p.35). For those under the age of 18, the prevalence of psychosis is somewhat less (~0.4%) (NICE, 2013, p.35; Stevens, Prince, Prager et al., 2014), but it is thought child and adolescent onset schizophrenia tends to be more severe, with a poorer prognosis and outcome (Remschmidt, 2001). Like adult-onset, adolescent-onset psychosis is typically characterised by hallucinations and delusions. However, adolescents with psychosis often present with more negative symptoms, (Remschmidt, 2001; Stevens et al., 2014) greater confusion and increased agitation, (Stevens et al., 2014).

It is increasingly common for family and friends to act as informal carers providing support for individuals with psychosis (Onwumere et al., 2018). Although often rewarding, (McCann, Lubman, Clark, 2009) caring for someone with psychosis can be demanding (Kuipers, Onwumere, Bebbington, 2010) and increases the risk of the carer themselves experiencing economic, emotional, and psychological difficulties (Kuipers, Onwumere, Bebbington, 2010; McCann et al., 2009) including anxiety, depression, guilt and self-blame, (Jansen et al., 2014) burnout (Onwumere et al., 2015) and subjective burden (Charles et al., 2020). There is some evidence to suggest that carers of patients with First Episode Psychosis (FEP), compared to carers of other mental health problems, may be particularly vulnerable to experiencing higher levels of distress (Onwumere, et al., 2018; Sadath et al., 2015). In line with the cognitive model of caregiving in psychosis, distress amongst carers is primarily associated with illness beliefs and adopted coping strategies, rather than the psychosis itself (Kuipers, et al., 2010). Carers' inability to cope can impede the recovery and increase risk of relapse for their care recipient with FEP (Jansen, et al., 2014; Kuipers, et al., 2010).

Thus far, the literature has largely looked at the experience of carers of FEP patients as a single cohort. This type of design is quite blunt and may miss important subgroups who might

have distinctive psychological needs. The evidence suggests that the age of onset for psychosis can affect its clinical presentation (Remschmidt, 2001), so it is possible that this may in turn effect the caregiving experience. The sole study specifically of carers psychological appraisal in this area, which involved carers of chronic psychosis, found that patient's age is associated with relative's appraisals of caregiving, with carers of younger adult patients perceiving the caregiving experience as more negative, therein increasing psychological distress for carers themselves (Harvey et al., 2001). However, to our knowledge, no study has ever specifically compared the psychological needs of carers of *adolescents* with carers of adults at FEP, or indeed at any stage of psychosis. Therefore, here, we provide an analysis of this to better understand the psychological needs of carers of adolescents with FEP.

2 Method:

2.1 Design:

The present study used a cross-sectional design comparing the psychological needs of carers of adolescent (age under 18) versus adult FEP patients. The study was based in an Early Intervention Service (EIS) for Psychosis within the Central and North West London Trust (CNWL) NHS Foundation Trust. The service was open to patients aged 14-34 with a duration of untreated psychosis of less than 12 months.

2.2 Participants:

Carers were any family, partner or friend who provided unpaid care to the patient at least once a week. Multidisciplinary team members asked carers if they wanted the team's routine Carers Assessment and 257 carers completed the assessment. Data were collected between July 2011 and January 2017. The final sample of carers who gave written informed consent on standard NHS Trust forms to publish totalled 254: with 220 caring for an adult patient and 34 caring for an adolescent patient. Of the 254 carers, 56 patients were cared for by more than one carer (e.g. two parents of the same patient).

2.3 Measures:

Carers were asked to provide demographic information and complete several routine self-report measures assessing their psychological needs. All of the measures were part of the routine clinical assessment conducted with all carers of patients within the service.

2.3.1 Illness Perception Questionnaire for Schizophrenia: Relatives' Version (IPQS-RV)

(Lobban, Barrowclough, Jones, 2005):

The IPQS-RV assesses the beliefs carers hold regarding the care recipient's psychosis. Carers were asked to indicate how much they agreed or disagreed with statements on a 5-point scale, ranging from strongly disagree to strongly agree. The questionnaire consists of 63 items divided into 11 subscales: perceived timeline: acute/chronic; perceived timeline: cyclical (how variable the symptoms are); Consequences for patients; Consequences for caregiver; Personal control: patient helplessness; Personal control: relative helplessness; Personal Control: patient blame; Personal control: relative blame; Treatment control; Illness coherence (how much a participant believes they know about the illness); and Emotional representations. We did not include the latter subscale in our present paper because it measures emotions not a key illness belief (we used the Hospital Anxiety and Depression Scale for emotional disorder measurement). A higher subscale score indicates greater perceived negative illness consequences, longer illness timeline and greater optimism about illness control. The IPQS-RV has good internal consistency and has been used in FEP carer populations (Hazell et al., 2020; Lobban, et al., 2005)

2.3.2 COPE Inventory (COPE) (Carver, Scheier, Weintraub, 1989):

The COPE consists of 30 items aimed at assessing 15 methods of coping.

Each subscale represents a distinct strategy used by carers to cope with difficult situations. The coping strategies can be further grouped into 3 superordinate themes: (1) problem-focused coping (strategies used to actively resolve or alter the stress), (2) emotional-focused coping (resorting to alleviating emotional distress but without changing the stressor directly) and (3)

avoidant coping (coping through avoiding the problem through e.g. denial or alcohol). Carers are asked to rate each item on a 4-point scale ranging from 1 (I have never done this) to 4 (I have done this a lot). Scores within a scale are calculated by adding the items together and mean scores are calculated for each subscale. A higher score indicates a higher frequency of utilising that coping strategy. The COPE has good internal consistency, (Baumstarck, Alessandrini, Hamidou et al., 2017) and has been used in FEP carer populations (Raune et al., 2004).

2.3.3 *Experience of Caregiving Inventory (ECI)* (Szmuckler et al., 1996):

The ECI measures caregiving subjective burden over 66 items divided into 10 subscales: eight of which represent negative experiences (difficult behaviours, negative symptoms, stigma, problems with services, effects on family, the need to provide backup, dependency, loss) and two of which represent positive experiences (rewarding personal experiences and good aspects of the relationship) with the patient. A paper currently in preparation focuses exclusively on a comprehensive analysis of positive carer outcomes and therefore the positive ECI scales are not reported here (Souray et al., in preparation). Respondents are required to rate how often they have thought about a particular issue in the past month on a 5-point scale ranging from ‘never’ to ‘nearly always’. Higher scores in a subscale indicate increased burden. The ECI has been used within FEP carer populations, has a strong face validity and good to excellent internal consistency (Charles et al., 2020).

2.3.4 *Maslach Burnout Inventory- Human Services Survey (MBI-HSS)* (Maslach, Jackson, Leiter, 1997):

The MBI-HSS contains 22 items measuring 3 key domains of burnout: emotional exhaustion, depersonalisation and reduced personal accomplishment. A higher mean score for emotional exhaustion (>21) and depersonalisation (>8), and a lower mean score for personal accomplishment (<28) indicates high burnout, collectively referred to as full burnout syndrome. Respondents are required to rate the frequency of each statement on a 7-point scale from ‘never’

to 'everyday'. The MBI has been used previously with informal carer samples (Onwumere et al., 2015), and good internal consistency (Maslach et al., 1997).

2.3.5 Hospital Anxiety and Depression Scale (HADS) (Zigmon, Snaith, 1994):

The HADS is designed to screen clinically significant levels of anxiety and depression. It consists of 14 items, which are divided into 2 subscales, measuring depression and anxiety respectively. Each item is rated on a 4-point scale ranging from 'As much as I ever did' to 'Hardly at all'. A score of >11 in each subscale indicates clinical levels of depression or anxiety. A higher score indicates great anxiety or depression symptoms. The HADS has been used previously with carer samples, and has good psychometric properties (Zigmon et al., 1994).

2.3.6 Patient data:

Clinical and demographic data collected on the patients related to each of the carers from their case notes and collated into summary statistics.

2.4 Procedure:

Data were collected by graduate level psychology assistants under the supervision of a Clinical Psychologist. The assessments were all part of the routine clinical assessments conducted with all carers linked to the service. Where there were two carers caring for the same patient, they completed the assessments independently. Participants received an information document asking for permission to publish their data as well as outlining what the data would be used for. Carers were asked to provide written consent to publish their routine clinical data using the standard NHS Trust consent form. Three of the 257 carers declined to provide consent – their data is therefore not included in the present analysis. We do not know the reason(s) for the refusal of these three carers.

2.5 Data-analysis plan:

The data was analysed using SPSS (version 24). Descriptive statistics were calculated for all demographic variables and outcome measures. To identify any differences between the carers of adolescents versus adults in terms of their demographics, we used Chi² tests or Fisher's exact test. We assessed whether all continuous data was normally distributed. Where data was found to be non-normal, non-parametric alternatives were utilised. For the main analysis, we used a univariate mixed model logistic regression to investigate whether carers' psychological needs could differentially predict carers of adult patients versus adolescent patients. The mixed model was used to statistically control for data clustering, i.e. where some of the patients had more than one carer. The following variables were entered into the regression as predictors: 10 illness beliefs (Lobban et al., 2005), 15 strategies and 3 styles of coping (Carver et al., 1989), full burnout syndrome (yes/no) and its 3 components (Maslach et al., 1997), 8 negative aspects of burden (Szmuckler et al., 1996), depression and anxiety disorder case (yes/no) (Zigmon et al., 1994). Significant predictors were then placed into a mixed model multivariate logistic regression and backwards eliminated until the model contained independently significant predictors. The multivariate logistic regression was used to isolate independent predictors and a backwards elimination was used to allow for joint predictive ability of independent variables.

2.6 Post-Hoc data analysis plan:

A post-hoc mixed model univariate logistic regression was performed on the adolescent data to investigate whether carers beliefs and coping strategies could predict high levels of full burnout syndrome (i.e. high emotional exhaustion and depersonalization with low personal accomplishment) in the carers of adolescents. The 10 beliefs and 15 coping strategies were entered into the regression as predictors, with high burnout and the dependent variable. Significant predictors were then placed into a mixed model multivariate logistic regression and backwards eliminated until the model contained all significant predictors. The same procedure was then conducted on the data for the adult carers' high burnout.

3 Results:

3.1 Demographics:

3.1.1 Carers

Of the 254 carers who participated in the study, the majority were female, non-White, spoke English as their first language, were in a relationship, employed, and were born outside the UK. Most carers had extensive face-to-face contact (>35 hours) with the care recipient (62%) (Table 1).

The carers of adolescents ($n=34$) versus adults ($n=219$) significantly differed in terms of age, length of caring, and relationship to patient. That is, carers of adolescents were significantly younger (adolescent carers $r=25.4-63.0$, $M=46.66$ vs adult carers $r=18.1-74.3$, $M=49.81$), had reportedly cared for the care recipient for a significantly shorter period of time, and identified as the parent or step-parent of the patient, whereas a significant proportion of the carers of adults identified otherwise.

3.1.2 Patients

Of the 198 patients on the team's caseload at the time of the carers assessments, 174 were adults ($r=18.1-36.4$, $M=24.7$) and 24, adolescents ($r=14.0-17.9$, $M=16.56$). The majority were male, White or Asian, had a diagnosis within the schizophrenia spectrum and few were inpatients at the time of carer's assessment.

Demographics of adolescents versus adults significantly differed in terms of age, age at illness onset and length of psychosis. That is, adolescents were significantly younger than the adults, were younger at the onset of the illness and had lived with psychosis for a less amount of time. However, duration of *untreated* psychosis was nevertheless similar (Table 2).

Table 1 Carer sample characteristics

Sample characteristic	Adult				Adolescent				Test statistic	P Value
	<i>n</i>	<i>M</i>	<i>SD</i>	(%)	<i>n</i>	<i>M</i>	<i>SD</i>	(%)		
Age (years)	219	49.81	11.38	NA	34	46.66	7.11	NA	U=2732.500	0.01* ^a
Gender										
Female	149	NA	NA	(67.7)	22	NA	NA	(64.7)	NA	0.73 ^b
Religion									NA	0.50 ^c
No religion	15	NA	NA	(7.2)	4	NA	NA	(13.3)	NA	0.27 ^b
Christianity	97	NA	NA	(46.4)	12	NA	NA	(40.0)	NA	0.51 ^b
Islam	44	NA	NA	(21.1)	7	NA	NA	(23.3)	NA	0.78 ^b
Hinduism	31	NA	NA	(14.8)	2	NA	NA	(6.7)	NA	0.39 ^c
Other religions (Sikh & other religions)	22	NA	NA	(10.5)	5	NA	NA	(16.7)	NA	0.32 ^b
Ethnicity									NA	0.46 ^c
White (British, Irish, Other)	69	NA	NA	(31.7)	15	NA	NA	(44.1)	NA	0.15 ^b
Indian	55	NA	NA	(25.2)	4	NA	NA	(11.8)	NA	0.13 ^c
Black (Black Caribbean, Black African)	43	NA	NA	(19.7)	7	NA	NA	(20.6)	NA	0.91 ^b
Other ethnicities (Middle Eastern, Mixed Race, Oriental, Mediterranean, Other)	51	NA	NA	(23.4)	8	NA	NA	(23.5)	NA	0.99 ^b
First language is English	129	NA	NA	(59.2)	21	NA	NA	(63.6)	NA	0.63 ^b
Age came to UK (years)	133	24.37	12.28	NA	16	23.44	11.14	NA	U=1056.500	0.96 ^a
Marital status									NA	0.73 ^c
Has partner (Married, Living with long term partner)	158	NA	NA	-72.1	26	NA	NA	(76.5)	NA	0.68 ^c
Employment status										0.69 ^b
In paid employment	133	NA	NA	-61	23	NA	NA	(67.6)	NA	0.46 ^b

Relationship to patient										
Is a parent or step-parent to the patient	175	NA	NA	(79.5)	34	NA	NA	-100	NA	0.001** c
Is primary carer	193	NA	NA	(88.5)	27	NA	NA	(79.4)	NA	0.14 b
Provided continuous care since psychosis onset	207	NA	NA	(94.5)	32	NA	NA	(94.1)	NA	1.00 c
Lives with patient	187	NA	NA	-85	32	NA	NA	(94.1)	NA	0.19 b
Length of time providing care since psychosis onset (months)	213	19.42	15.64	NA	31	10.13	7.87	NA	U=2130.000	0.001** a
Hours of FTFC* contact with patient per week	213	48.33	32.91	NA	32	51.53	33.61	NA	U=3213.500	0.60 a
High FTFC* contact (>35 hours/week)	132	NA	NA	-62	19	NA	NA	(59.4)	NA	0.78 b
Caring for >1 patient	88	NA	NA	-40	18	NA	NA	(52.9)	NA	0.15 b
Caring for >1 person with psychosis	13	NA	NA	(6.0)	3	NA	NA	(8.8)	NA	0.46 c

a:Mann-Whitney U test; b:Chi²; c:Fishers Exact Test *Face To Face Contact

Table 2 Patient sample characteristics

Sample characteristic	Adult				Adolescent				Test statistic	P Value
	<i>n</i>	<i>M</i>	<i>SD</i>	(%)	<i>n</i>	<i>M</i>	<i>SD</i>	(%)		
Age (years)	174	24.7	4.51	NA	24	16- 56	1.15	NA	U=0.000	0.001** a
Gender (female)	64	NA	NA	(36.78)	12	NA	NA	-50	NA	0.21 b
Religion									NA	0.20 c
No religion	20	NA	NA	(14.60)	3	NA	NA	-25	NA	0.69 c
Christianity	54	NA	NA	(39.42)	2	NA	NA	(16.67)	NA	0.21 c
Islam	30	NA	NA	(21.90)	5	NA	NA	(41.67)	NA	0.12 b
Hinduism	21	NA	NA	(15.33)	0	NA	NA	0	NA	0.22 c
Other religions (Sikh, Other)	12	NA	NA	(8.76)		NA	NA	(16.67)	NA	0.10 b
Ethnicity									NA	0.92 c
White (British, Irish, Other)	55	NA	NA	(31.61)	13	NA	NA	(54.17)	NA	0.07 b
Black (Caribbean, African, Arab and Other)	33	NA	NA	(18.97)	4	NA	NA	(16.67)	NA	1.00 c
Asian (Indian, Pakistani, Bangladeshi and Other)	55	NA	NA	(31.61)	5	NA	NA	(20.83)	NA	0.28 b
Mixed (White & Black Caribbean, White & Black African, White & Asian and Other)	10	NA	NA	(5.75)	0	NA	NA	0	NA	0.61 c
Other (Chinese, Arab, Afghan, Somali, Other and I do not wish to state)	21	NA	NA	(12.07)	2	NA	NA	(8.33)	NA	1.00 c
First language is English	140	NA	NA	(81.87)	21	NA	NA	(91.30)	NA	0.38 b
Marital status									NA	0.23 c
Has a partner (Married, Lives with partner, Long term partner, Civil partnership)	25	NA	NA	(14.37)	1	NA	NA	(4.17)	NA	0.32 c
In paid employment	30	NA	NA	(17.65)	2	NA	NA	(8.33)	NA	0.38 c
Age at illness onset	164	22.61	4.62	NA	23	15.48	1.45	NA	U=125.000	0.001** a

Duration of untreated psychosis (months)	155	3.73	7.91	NA	21	2.10	3.49	NA	U=1325.000	0.16 ^a
Length of psychosis (onset - carer's assessment) (months)	164	19.74	15.71	NA	23	12.7	10.60	NA	U=1370.000	0.03* ^a
Diagnostic category										
Schizophrenia spectrum	125	NA	NA	(73.10)	15	NA	NA	(62.5)	NA	0.28 ^b
Affective disorders	27	NA	NA	(15.79)	7	NA	NA	(29.2)	NA	0.11 ^b
Other	19	NA	NA	(11.11)	2	NA	NA	(8.3)	NA	1.00 ^c
Inpatient at time of carer's assessment	15	NA	NA	(8.82)	5	NA	NA	(20.8)	NA	0.07 ^b

a : Mann-Whitney U test; b : χ^2 ; c : Fishers Exact Test.

3.2 Prevalence of the psychological needs of carers of adolescents

Around a third of carers of adolescents met the threshold for clinical anxiety, while 15% met the threshold for depression, and 24% of carers scored high in their use of drugs and/or alcohol to cope. Strikingly, 29% of carers of adolescents experienced high levels of burnout in all three burnout domains i.e. full burnout syndrome: high emotional exhaustion; high depersonalization and low personal accomplishment, after only 10 months of caring.

3.3 Regression analysis:

Of the 46 variables psychological needs entered into univariate regressions, three were found to be significant (Table 3): Avoidant coping as a style, behavioural disengagement coping (a specific physical escape strategy within used in avoidant coping) and full burnout syndrome, were associated with caring for an adolescent with FEP.

Two of the three significant variables - behavioural disengagement and full burnout syndrome - were placed into a multivariate logistic regression model. Behavioural disengagement was placed into the model over avoidant coping due to its specificity and clinical relevance. When entered into the model together, high burnout was reduced to non-significance while behavioural disengagement remained a significant predictor of discriminating whether the carer is a caring for adult or child. The final model is not shown, as the variable is independent of other variables.

Table 3. Univariate Multi-Level Logistic Regression on self-report measures for carers of adolescents and carers of adults. (Experience of Caregiving Inventory; Hospital Anxiety and Depression Subscale; Illness Perception Questionnaire for Schizophrenia- Relatives Version; Maslach Burnout Inventory; COPE Inventory)

	Predictor	Adult carers				Adolescent carers				Odds ratio	(95% CI)	P value
		<i>n</i>	<i>M</i>	<i>SD</i>	(%)	<i>n</i>	<i>M</i>	<i>SD</i>	(%)			
ECI	Difficult behaviours	216	17.62	7.39	NA	33	17.55	6.98	NA	0.97	(0.92- 1.02)	0.24
	Negative symptoms	216	15.31	5.16	NA	34	15.29	5.46	NA	0.93	(0.93 - 1.05)	0.79
	Stigma	219	12.53	8.43	NA	33	14.79	8.91	NA	0.98	(0.90 - 1.06)	0.56
	Problems with services	216	12.09	7.26	NA	34	12.38	7.11	NA	0.98	(0.92 - 1.04)	0.42
	Effect on family	217	7.12	4.92	NA	34	7.74	5.81	NA	0.96	(0.90 - 1.02)	0.20
	Need to back-up	214	12.40	6.92	NA	33	13.91	7.93	NA	1.06	(0.98 - 1.16)	0.15
	Dependency	213	9.42	6.05	NA	34	11.50	8.14	NA	0.94	(0.85 - 1.04)	0.26
	Loss	215	12.01	5.39	NA	33	10.18	5.26	NA	0.97	(0.90 - 1.04)	0.36
HADS	Anxiety score	214	8.26	4.82	NA	31	9.10	4.57	NA	0.97	(0.88 - 1.06)	0.50
	Depression score	213	6.40	4.64	NA	32	6.56	4.46	NA	0.99	(0.90 - 1.09)	0.77
	Anxiety case	63	NA	NA	(29.40)	12	NA	NA	(38.70)	0.70	(0.28 - 1.75)	0.44
	Depression case	40	NA	NA	(18.8)	5	NA	NA	(15.6)	1.10	(0.34 - 3.54)	0.87
IPQS-RV	Timeline: acute/chronic	216	17.51	4.66	NA	34	18.74	5.71	NA	0.95	(0.86 - 1.04)	0.22
	Timeline: cyclical	219	4.61	2.85	NA	34	14.06	3.63	NA	1.04	(0.91 - 1.20)	0.56
	Consequences for patient	214	39.34	7.30	NA	33	38.55	7.70	NA	1.01	(0.95 - 1.07)	0.73
	Consequences for caregiver	199	27.43	6.33	NA	29	28.76	6.96	NA	0.97	(0.91 - 1.05)	0.48
	Personal control: patient helplessness	218	5.34	2.59	NA	33	15.21	2.19	NA	1.02	(0.85 - 1.21)	0.85
	Personal control: Relative helplessness	219	14.85	2.70	NA	34	14.32	2.89	NA	1.07	(0.92 - 1.25)	0.39
	Personal control: patient blame	209	8.82	2.57	NA	31	8.06	2.57	NA	1.13	(0.95 - 1.35)	0.18
	Personal control: relative blame	218	7.91	2.32	NA	34	6.97	2.05	NA	1.2	(0.98 - 1.47)	0.08

	Treatment control	215	18.94	2.92	NA	34	18.85	3.36	NA	1.01	(0.88 - 1.17)	0.85
	Illness coherence	217	12.20	3.66	NA	33	12.70	4.49	NA	0.96	(0.86 - 1.08)	0.54
MBI	Emotional Exhaustion	217	22.35	15.38	NA	34	24.82	17.12	NA	0.99	(0.96 - 1.02)	0.47
	Depersonalisation	214	5.32	5.23	NA	34	5.82	5.27	NA	0.99	(0.91 - 1.07)	0.75
	Personal Accomplishment, n, Mean (SD)	214	31.96	10.05	NA	33	30.12	10.82	NA	1.02	(0.97 - 1.06)	0.50
	High burnout score on emotional exhaustion (high score >21)	113	NA	NA	(52.1)	20	NA	NA	(58.8)	0.74	(0.30 - 1.79)	0.50
	High burnout score on depersonalisation (high score > 8)	63	NA	NA	(29.4)	14	NA	NA	(41.2)	0.63	(0.26 - 1.56)	0.32
	High burnout score on personal accomplishment (high score >28)	82	NA	NA	(38.3)	14	NA	NA	(42.4)	0.85	(0.36 - 2.03)	0.72
	High burnout in 3 domains (burnout syndrome)	26	NA	NA	(12.3)	10	NA	NA	(30.3)	0.36	(0.13 - 1.00)	0.05*
COPE	Active coping	219	5.97	1.52	NA	34	5.82	1.57	NA	1.05	(0.80 - 1.39)	0.73
	Planning	219	5.56	1.82	NA	34	5.56	1.46	NA	1.00	(0.78 - 1.28)	0.99
	Suppression of competing activities	217	5.71	1.60	NA	34	5.94	1.28	NA	0.90	(0.67 - 1.21)	0.47
	Restraint coping	218	4.98	1.83	NA	34	5.12	1.61	NA	0.96	(0.76 - 1.22)	0.74
	Seeking social support for instrumental reasons	220	5.14	1.72	NA	33	5.55	1.68	NA	0.88	(0.68 - 1.13)	0.31
	Seeking social support for emotional reasons	219	5.54	2.03	NA	34	5.91	2.05	NA	0.92	(0.74 - 1.14)	0.44
	Positive reinterpretation and growth	219	5.40	1.84	NA	34	5.65	1.72	NA	0.92	(0.72 - 1.18)	0.50
	Acceptance	220	5.63	1.80	NA	33	5.91	1.67	NA	0.91	(0.71 - 1.16)	0.44
	Turning to religion	219	5.51	2.37	NA	34	5.21	2.67	NA	1.05	(0.88 - 1.25)	0.61
	Focus on and venting emotions	219	5.16	1.81	NA	34	5.47	1.96	NA	0.90	(0.71 - 1.15)	0.41
	Denial	217	2.62	1.20	NA	33	2.82	1.42	NA	0.89	(0.65 - 1.23)	0.49
	Behavioural disengagement	218	3.30	1.46	NA	34	4.21	1.77	NA	0.72	(0.55 - 0.94)	0.02*

Mental disengagement	218	4.83	1.81	NA	34	5	1.61	NA	0.95	(0.74 - 1.22)	0.69
Alcohol-drug disengagement	218	2.77	1.49	NA	34	3.35	1.84	NA	0.81	(0.63 - 1.04)	0.10
Humour	218	2.80	1.53	NA	34	3.29	1.80	NA	0.84	(0.66 - 1.09)	0.19
Problem-focused coping	214	27.38	5.56	NA	33	28.00	4.62	NA	0.98	(0.90 - 1.06)	0.58
Emotion-focused coping	218	30.07	6.15	NA	33	31.67	5.66	NA	0.96	(0.89 - 1.03)	0.24
Avoidant coping	215	13.55	3.55	NA	33	15.45	4.30	NA	0.88	(0.79 - 0.99)	0.04*

* $p=0.05$; SD = standard deviation; n = number of cases in analysis

3.4 Post-hoc analysis:

3.4.1 Full burnout syndrome in carers of adolescents

Four of the 25 predictors entered in the post-hoc univariate logistic regression were significantly and positively associated with higher levels of burnout when caring for an adolescent with FEP. That is, carer's beliefs in the negative consequences for themselves (OR 1.27, CI [1.035, 1.56], $p=0.02$); the patients (OR 1.23, CI [1.03, 1.48], $p=0.03$); incoherent understanding of mental health problems (OR 1.49, CI [1.10, 2.01], $p=0.01$); and coping by behaviourally disengaging (OR 1.74, CI [1.02, 2.97], $p=0.04$) predicted high burnout.

The four significant predictors were placed into a multivariate model and a backwards elimination was performed. The final model (Table 4) consisted of two predictors: carer's beliefs in negative consequences for the patient and their incoherence in understanding mental health problems. Carers who believe in greater negative consequences for their care recipient and carers who had amore incoherent understanding of mental health problems had greater risk of experiencing burnout syndrome.

Table 4. Final Model for High burnout in all three dimensions in carers of adolescents; Post Hoc Multivariate Mixed Model Logistic Regression

Measure	Predictor	Odds Ratio	(95 % CI)	P-value
Illness belief (IPQS-RV)	Belief in greater negative consequences for patient	1.24	(1 - 1.53)	0.05*
	Coherence of understanding Mental Health problems	1.39	(1.02 - 1.89)	0.04*

* $p<0.05$

3.4.2 Full burnout syndrome in carers of Adults:

Two of the 25 predictors, consequences for the patient (OR 1.10, CI [1.03, 1.17], $p=0.01$) and consequences for the carer, entered in the post-hoc univariate logistic regression were significantly and positively associated with higher levels of burnout when caring for an adult with FEP. The final model indicated a significant positive association between high burnout

and carer's beliefs in negative consequences for themselves (OR 1.20, CI [1.10, 1.30], $p < 0.001$). Carers of adults who believed in greater negative consequences for themselves were at greater risk of experiencing burnout syndrome.

4 Discussion

Our study is the first to investigate, at any stage of psychosis, how the psychological needs of carers of adolescents might differ from those of carers of adults. We recruited one of the largest and most ethnically diverse samples of FEP carers. Our study's statistical strengths combine: multilevel analysis to statistically control for the use of assessing multiple carers per patient; multivariate modelling to isolate independent predictors; and backwards elimination to allow for joint independent predictive ability of variables. Carers of adolescents reported greater prevalence of what we have named Rapid-Onset-Burnout-Syndrome (ROBS) and more frequent use of behavioural disengagement coping compared to the carers of adults. We also identified that while carers perception of negative consequences of the illness for *themselves* predicted full burnout syndrome amongst carers of adults, for carers of adolescents' burnout was associated with perceived negative consequences for the *patient*, as well as an incoherent understanding of the illness. The rates of clinical anxiety, depression and drug or alcohol use is also a cause for concern in the carers of adolescents.

A higher proportion of the sample caring for adolescents were identified as experiencing full burnout syndrome, compared to the sample caring for adults with FEP. It is known that burnout syndrome develops following prolonged exposure to stress in the workplace (Onwumere, Zhou & Kuipers, 2018), and so, we would expect those having cared for the patient the longest to experience higher amounts of burnout. Strikingly however, carers of adolescents experienced two and a half times the prevalence of burnout yet in only about half the time of carers of adults, which provided us with the rationale to explore what predicted

the high burnout in the carers of adolescents and adults exclusively. Not only did post hoc analysis confirm the findings of Onwumere et al, (2015); that carer's beliefs about the negative consequences for themselves predicted higher burnout in the carers of adult's; it extended this by finding that it was the carer's beliefs about the negative consequences for the patient that predicted full burnout syndrome when caring for an adolescent. Perhaps carers might view the adolescent as more vulnerable than an adult with FEP. We also hypothesise that the level of independence and autonomy that is taken away from the carer when caring for an adolescent experiencing a FEP is less than when caring for an adult, leading to carers of adults focusing on the consequences for themselves more than the consequences for the patient. Furthermore, it was a carer's incoherent understanding of mental health illnesses that also predicted full burnout syndrome for carers of adolescents. Previous research reported the frustration carers often feel when trying to make sense of psychosis, calling it 'incomprehensible' (Wainwright et al., 2014).

Carers of adolescents were associated with adopting behavioural disengagement more frequently as form of avoidant coping compared to the carers of adults, thus suggesting that their primary appraisals of the associated stressors surpassed their coping resources (Raune et al., 2004). The increased risk of a diminished illness trajectory, poor treatment response and risk of relapse in families who display these high levels of escape-coping (Bebbington, Kuipers, 1994) is of particular concern and highlights just how challenging it is to care for an adolescent experiencing a first episode of psychosis. Challenging family relations have previously been associated with avoidant coping (Onwumere et al., 2011; Raune et al., 2004), So it is possible that the blurred lines between care of the psychiatrically ill and disciplining an adolescent contributes to exacerbating challenging family relations and increases the risk of adopting avoidant coping styles, such as behavioural disengagement.

As our carer sample was mainly female, ethnically diverse and the majority of carers were not born in the United Kingdom, it is worth considering the role ethnicity, migration and gender has on caregiving. Literature indicates that carer beliefs, emotions, behaviours and attitudes are all mediated by culture, with cultural values seen as fluid and dynamic across generations rather than remaining solely connected to the previous culture (Jenkins & Karno, 1992). For example, levels of carer expressed emotion are thought to differ in immigrants inter-generationally (Lopez et al., 2009). Onwumere et al. (2008) found that black carers believed patients had more control over their illness compared to Caucasian carers. Our carer sample was primarily female and it is known that high expressed emotion by emotional over-involvement is found mainly with female carers (e.g. Bentsen et al., 1996), illustrating an important role for gender in carer experiences. In line with the cognitive model of caregiving (Kuipers et al., 2010), each culturally diverse belief may contribute to different experiences and coping in the caregiving role, potentially influencing differences found here between carers of adolescents versus adults.

4.1 Limitations:

Our data set was large and required an extended period of time to collect (July 2011- January 2017). We acknowledge that there could have been changes in carers experiences across the years, but we would have required a larger sample of adolescent patients to obtain the necessary statistical power to test for differences across time in relation to the key aim of examining differences between carers of adolescent patients versus carers of adult patients. A related limitation is that our adolescent sample size was unequal compared to the adult sample. Third, it is possible that there are some distinctive features of adolescent caregiving that we did not explore, for example, specific illness beliefs related to childhood. Finally, we do not know how many carers came through the service but did not have an assessment.

4.2 Clinical, theoretical and research implications:

4.2.1 Clinical implications

If our results can be replicated using a larger sample, our findings suggest a need to prioritise the screening of FEP carers of adolescents for ROBS. The quicker emergence of burnout amongst adolescent carers suggests the need for support to be provided in a timely manner. Carers who actually flee from their adolescent would need support to utilise less avoidant coping strategies as behaviourally avoiding the child might have an impact on the young person's self-esteem and provide less containing social support, which is known to and reduce loneliness and anxiety (Sündermann et al., 2013). There might also be a need for interventions targeting anxiety, depression and the use of drugs and alcohol as a form of coping.

4.2.2 Theoretical implications

Theoretically, our results could inform a potential extension to the existing cognitive model of caregiving (Kuipers et al., 2010). Previous studies have proposed the model to include a FEP extension (Charles et al., 2020). Our results would support this notion and would extend this further to include an Adolescent sub-branch to the model.

4.2.3 Research implications:

Future research should seek to replicate these findings using a larger adolescent carer sample. Our results displayed two non-significant trends: the carers of adults blamed themselves more frequently for the care recipients' illness ($p=0.075$); and the carers of adolescents resorted to drugs and alcohol more frequently to cope ($p=0.098$). It is possible that these interesting pathological trends would become sharper with a larger sample size. If future research were to establish an aetiological role for beliefs about consequences for the patient and an incoherent understanding of the illness, then these might be intervened with to reduce or even prophylactically prevent burnout. Following this, intervention studies investigating the efficacy of enhancing carers understanding of the patients' illness and de-catastrophizing the carers perceived consequences for patient would be fundamental in developing our understanding of

carers psychological needs when caring for adolescents with FEP. Furthermore, we hypothesise a link between behavioural disengagement and the development of burnout, particularly regarding the domain of depersonalisation, which is often characterised by withdrawal from care. Future research could aim to explore this further.

4.3 Conclusion:

These findings indicate just how challenging it can be when caring for an adolescent experiencing a first episode of psychosis. If our findings can be replicated using a larger sample, our findings suggest a need for routine screening for carer ROBS at initial clinic assessment, and the provision of timely interventions aimed at addressing avoidant coping strategies and negative illness beliefs.

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6 Declaration of conflicting interest:

All author(s) have declared that they have no competing or potential conflicts of interest.

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