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Burnout in early course psychosis caregivers: the role of illness beliefs and coping styles

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ABSTRACT

Background: In occupational settings, burnout is a common response to chronic exposure stressors and has been frequently documented in formal caregivers (i.e. paid psychiatric staff). However, the literature is limited on reports of burnout amongst informal caregivers and particularly within early psychosis groups. The current study sought to investigate reports of burnout in carers of young adults treated within a specialist early psychosis service and links with key appraisals reported about the illness and coping.

Methods: Seventy-two carers completed the Maslach Burnout Inventory ¹ along with self-report measures of coping styles and illness beliefs.

Results: 78% of carers reported high burnout in at least one of the three key burnout markers (i.e. emotional exhaustion, depersonalisation or low personal accomplishment). Seven percent of carers met full criteria for high burnout across all the three domains. A carer's belief about the negative consequences of the illness for themselves was a significant predictor of emotional exhaustion and depersonalisation. Low personal accomplishment was linked to a carer's less optimistic beliefs about the illness timeline and fewer reports of adaptive coping.

Conclusions: The results provide preliminary support for the importance of asking carers in the early illness phase about their experiences of caregiving. Targeted assessment may serve as a helpful tool to identify and intervene with carers in need of additional support with stress management, use of adaptive coping strategies, and balanced recovery focused information about psychosis.

INTRODUCTION

Schizophrenia is globally recognised as a burdensome condition.² The first onset typically falls during late adolescence or early adulthood when individuals commonly negotiate key developmental milestones.^{3, 4} The duration of untreated psychosis, before an individual accesses optimal recommended treatments, can often be long with some studies reporting upper ranges of 46 months.⁵ The early psychosis phase can be characterised by elevated levels of trauma;^{6, 7} loss;⁸ aggression;⁹ self-harm including suicide,¹⁰ and relapse.¹¹

Many individuals with psychosis will live with or maintain regular contact with informal carers;¹² a picture that is particularly evident during the early illness phase.¹³ Patient outcomes can be improved with carer support. Carers play a key role in facilitating help seeking at the first episode, mobilising appropriate service responses^{5, 14} and facilitating service engagement.¹⁵

Caregiving experiences

The caregiving role can be stressful and impact negatively on wellbeing.¹⁶ Carers of people with psychosis experience elevated levels of stress^{17, 18} which can be enduring.¹⁹ The first episode can be particularly stressful relative to other illness phases.²⁰ Carers can experience clinical levels of depression²¹ which is also present at first episode.²²

Caregiving and burnout

In recent years there has been an increased focus on the experience of burnout in mental health staff. Burnout has been operationalised in several ways including reference to a persistent negative work related state of mind characterised by emotional exhaustion, dysfunctional attitudes and behaviours, and reduced effectiveness and motivation.²³

Positive associations exist between reports of staff burnout and indices of poorer wellbeing (e.g. poor sleep), reduced productivity, negative attitudes towards patients, and recruitment and retention difficulties.²⁴⁻²⁶ Recently, this research has been extended to informal carers. Carers can report burnout, and at levels similar to those reported by psychiatric nurses, particularly in areas of emotional exhaustion and depersonalisation.²⁷ Cuijpers and Stam²⁸ found that carers of patients with psychiatric problems, for whom most had psychosis, reported high levels of burnout in terms of emotional exhaustion. Carers of patients with longer illness histories reported greater emotional exhaustion. However, the relevance of burnout to early psychosis caregivers remains unclear.

Coping efforts characterised by carers engaging in less adaptive coping styles, such as avoidance, are linked to poorer carer outcomes in psychosis, including higher rates of distress^{29,30}. Burnout has also been positively linked to less adaptive coping strategies in paid mental health staff.^{1,31} Further, carers' appraisals of not feeling able to cope have been positively associated with emotional exhaustion.²⁸

The importance of carer appraisals in influencing carer outcomes is embedded in cognitive models of caregiving.³² Carer appraisals, including those expressed about the patient, illness and coping capabilities, play an important role in carer functioning and wellbeing, independently of patient symptomatology. Carers, for example, who appraise the illness more negatively in terms of the perceived timeline and the impact on themselves and the patient, are also more likely to report greater caregiver burden and stress.³³⁻³⁵

Current study

In the context of the cognitive model of caregiving in psychosis,³² the current study set out to document rates of burnout within an early psychosis carer sample and determine whether carer appraisals, specifically those reported about the illness and coping, relate to carer reports of burnout. In line with the literature, we predicted that reports of carer burnout would be positively linked to less adaptive coping styles, characterised by avoidance, and pessimistic beliefs about the illness in terms of the perceived consequences, timeline and amenability to control.

METHOD

Design

This was a cross-sectional design. Participants were the identified carers of patients under the care of an Early Intervention in Psychosis Service in the Central and North West London NHS Foundation Trust. The service accepts cases of first episode psychosis, aged 14-34 years, with duration of untreated psychosis of less than 12 months. All patients with an identifiable carer were eligible for study inclusion. The results are based on routine service data collected on carer needs, following their relative's entry to the service, and where carers provided consent for data to be published. The collection of routine service data and publication met criteria laid out within research and development standards of the NHS Trust.

Measures

Carers

Socio-demographic data were collected on carers including age and employment status.

*Maslach Burnout Inventory-Human Services Survey (MBI)*¹

The MBI is a 22-item, measure of burnout across three domains: emotional exhaustion (i.e. feeling drained and overextended in work), depersonalisation (i.e. negative attitudes and responses to care recipient), and personal accomplishment (feeling incompetent, inadequate and ineffective in role). The measure requires respondents to read through statements about personal feelings and attitudes towards their caregiving (e.g. I feel like I am at end of my rope) and rate the frequency on a 7-point scale ranging from 'never' to 'everyday'. Individual subscale scores are calculated. Higher mean scores for emotional exhaustion (>21) and depersonalisation (>8), and lower mean scores for personal accomplishment (<28) are indicative of higher burnout. The measure has been previously used with informal carer samples.²⁸

*COPE Inventory (COPE)*³⁶

The COPE is a 30-item multidimensional coping instrument designed to assess fifteen conceptually distinct methods of adaptive (e.g. active coping) and less adaptive coping (e.g. denial). Respondents rate how much they complete each of the coping behaviours using a 4 point Likert scale ranging from 1 (*I have never done this*) to 4 (*I have done this a lot*). Each of the 15 scales has 2 items; scale total scores are computed by adding the items together. Mean scores are calculated for each subscale.

*Illness Perception Questionnaire for Schizophrenia: Relatives Version (IPQS-RV)*³⁴

The IPQS-RV assesses a carer's beliefs about their relative's illness across different domains including the perceived timeline, illness consequences (for self and relative), and degree of control over the illness (from self, relative, treatment). Items are rated on a Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Higher subscale scores indicate greater perceived negative illness consequences, longer illness timeline and greater optimism about illness control.

*Hospital Anxiety and Depression Scale*³⁷

The Hospital Anxiety and Depression Scale is a 14 item self-report measure designed to assess levels of clinical distress. Items are rated on a four point scale that reflects the participants' level of agreement with each item. Scores on each subscale can range from 0-21 and scores above eight indicate clinical levels of distress. The measure has been widely used with caregiver groups and has good psychometric data.³⁸

Patients

Clinical and demographic data were collected from case notes including age, gender, ethnicity, diagnosis and length of illness, which was calculated from the emergence of first psychosis symptoms.

Procedure

Data were collected by graduate level psychology assistants.

Data analysis

Data were analysed using SPSS Version 19.³⁹ Bivariate analyses were undertaken to determine the strength of the relationship between burnout and key variables. Based on the results of the bivariate analyses, multiple regression were undertaken to develop a prediction model for each burnout domain. No severe violations of the assumptions of multiple regression (normality, linearity, low multicollinearity) were found. Effect sizes were interpreted following Cohen⁴⁰ recommendations. Statistical testing was conducted with an alpha level of $<.05$.

RESULTS

Participants:

Seventy-two carers provided consent to complete routine measures. Data were collected from July 2011 to April 2012. One carer completed the assessment but did not consent to permission to publish.

The average length of caring was 21.1 months (SD = 11.4, Range 1-47 months). The mean age of carer participants was 52.1 (SD = 10.4, Range, 18-71). Most carers were female (67%) and from Black and minority ethnic groups (47%) or white (43%). Over half the carer sample was recorded as being employed (54%). Carers were mainly the parents of patients (85%) and most were living with the patient at the time of the assessment (83%). The mean hours of face-to-face contact per week between carers and patients was 50.1 hours (SD = 35.1 Range 0-143). Twenty-two percent of carers were also providing care for another person. The total mean scores on the Hospital Anxiety and Depression Scale was 14.1 (SD=7.37, Range 0-36); one third of carers (30.9%) scored within the clinical range for depression or anxiety.

Patients

The patient sample comprised 60 patients who were mainly outpatients (92%) with a mean age of 23.4 years ($SD = 4.46$, Range 14.0 -34.4). The average length of psychosis was 21.5 months ($SD = 11.7$, Range, 2-47) and more than half had a case note diagnosis of schizophrenia. Most patients were male (72%) and few were in paid employment (20%). Over half the sample was classified as Black and minority ethnic background (52%) or white (45%).

Levels of burnout and links with demographic and clinical factors

The burnout subscale mean scores were: emotional exhaustion (24.1, $SD = 14.9$, Range 0-54); depersonalisation (5.8, $SD=5.5$, Range 0-21) and personal accomplishment (32, $SD=9.7$, Range 7-48). 78% ($n = 54$) reported high burnout in at least one dimension and seven percent of carers ($n = 5$) were classified as high burnout across all scales.

Patient gender was associated with carers' reported level of both emotional exhaustion and depersonalisation. Carers who looked after a female patient had lower mean scores on emotional exhaustion ($M = 18.4$, $SD = 15.5$, $n = 17$) and depersonalisation ($M = 3.29$, $SD = 2.85$, $n = 17$) in comparison to those caring for a male patient (emotional exhaustion: $M = 28$, $SD = 14.4$, $n = 41$; depersonalisation: $M = 7.1$, $SD = 6.1$, $n = 41$). A Mann-Whitney U Test confirmed both mean differences to be statistically significant ($p = .04$ and $p = .03$ respectively), and the corresponding effect sizes for these mean differences were moderate to strong (Cohen's $d = .65$ and $d = .81$ respectively). No further carer or patient demographic factors were significantly related to burnout scales ($P > .05$).

Burnout and coping styles

Small negative correlations were observed between depersonalisation and: planning (-.26, $P = 0.03$); emotional support (-.27, $P = 0.03$), and positive reinterpretation and growth (-.28, $P = 0.02$). Depersonalisation was positively correlated with denial (.26, $P = 0.03$).

Personal accomplishment was positively correlated with active coping (.31, $P < .01$), positive reinterpretation and growth (.34, $p < 0.01$), and turning-to-religion (.42, $P < 0.01$)

No relationships were observed between emotional exhaustion and carer coping ($P > .05$).

Burnout and illness beliefs

There were positive correlations between emotional exhaustion and carer negative perceptions of illness consequences for themselves (.60, $P < .01$) and the patient (.44, $p < .01$). There was also a positive association between depersonalisation and illness consequences for the carer (.44, $P < .01$). Carer perceptions of a chronic illness timeline and personal accomplishment were negatively related (-.38, $P < .01$).

Multivariate analyses

Emotional exhaustion

Multiple regression analyses were completed to assess how much variance in emotional exhaustion could be explained by independent variables of illness beliefs (i.e. consequences for patient and carer) and patient gender. Patient gender was transformed into a dummy coded variable with males as the reference group coded 0. The three independent variables explained a significant amount of the variance in emotional exhaustion, $F(3,53) = 13.4$, $p < .001$, $\text{adj-R}^2 = 40\%$. Perceived consequences for the patient was an insignificant predictor

and removed from the model, F -change (1, 53) = .98, p = .33. The results of the final model are presented in Table 1 revealing that perceived consequences for the carer was a strong predictor of emotional exhaustion ($beta$ = .58) whereas patient gender reached just borderline significance suggesting that carers for female patients felt generally less emotionally exhausted by a modest amount ($beta$ = -.20) when controlled for by their perceived illness consequences. (Table 1).

Depersonalisation

The independent variables selected to predict the variance in depersonalisation scores were: patient gender, coping (i.e. planning, emotional support, positive interpretation & growth, denial), and illness consequences for carer. The model explained 23% (Adj R^2) of the variance, $F(6,50) = 3.78$, $p < .003$, but several predictors in the model were insignificant ($p > .10$) and therefore removed one at a time using a backward selection algorithm. After excluding 3 predictors (i.e. emotional support, positive interpretation & growth, denial) the final model explained 26% (Adj R^2) of the variance, $F(3, 53) = 7.53$, $p < .001$. Perceived consequences for carer and planning were both predictors of depersonalisation. (Table 2).

Personal accomplishment

The predictors entered were coping (i.e. active coping, turning to religion, positive reinterpretation and growth) and illness timeline. The four predictors explained 29% (Adj R^2) of variance in personal accomplishment scores, $F(4, 64) = 7.79$, $p < .001$; coping via religion was not a significant predictor and removed from the model, F -change (1, 64) = 2.35, p = .13. Table 3 displays the results for the final model with three predictors. Belief about illness timeline was the strongest predictor ($beta$ = -.36). The remaining two coping predictors had a moderate influence on personal accomplishment in the expected direction. (Table 3)

Insert Tables 1-3 here

DISCUSSION

This study investigated reports of burnout in caregivers of patients accessing an early intervention psychosis service, and examined its relationship to carer appraisals about the illness and coping. To our knowledge, this represents the first study of its kind to investigate burnout in recent onset carers and its links to carer appraisals.

Burnout, as measured by dimensions of emotional exhaustion, depersonalisation, and low personal accomplishment was, as predicted, reported by carers of recent onset patients. Whilst a small proportion of the sample (7%) were defined as having high overall burnout – in terms of scoring high emotional exhaustion and depersonalisation, and low personal accomplishment – 78% reported high burnout in at least one key dimension. The finding that carers can report features of burnout even during the early phases of the psychosis illness attest to the reported challenges of the caregiving role, and concurs with the evidence drawn from early career psychiatric staff where evidence of burnout was already present.⁴¹ We already know of the elevated levels of distress and depression that can be found in early psychosis caregivers.²⁰ We also know that the period before formal services are involved can be protracted for many first episode patients. Thus, carers may have been undertaking a caregiving role for some time and therefore increased the risk for it to impact on their wellbeing. It is worth noting that 22% of the sample failed to report any burnout; further investigations of what factors protect against less adaptive functioning in carers during the early illness phases are indicated.

In terms of explaining the variance in emotional exhaustion, patient gender and carers' negative perceptions of illness related consequences for themselves were identified as important predictors, but a carer's negative appraisal of the impact of the illness for themselves was more relevant accounting on its own for 33% of the variance. The results are consistent with previous literature that has identified links between carers' perceived negative consequences of the illness and carers' negative appraisals of their caregiving experiences.³³ Carer outcomes, such as burden and expressed emotion, relate more to carers' cognitive appraisals than the event itself.^{32, 42}

Carer beliefs about illness consequences for themselves also proved to be a key predictor for depersonalisation; slightly stronger in its effect size than the other key predictors (i.e. planning coping styles). Carers reporting more negative attitudes towards their relative (i.e. depersonalisation) are also seemingly more negatively affected by the impact of the illness on different aspects of their lives (e.g. financial concerns). A carer's negative appraisal of the consequences of the illness for themselves may make it difficult to simultaneously report positive beliefs about the patient, who might be a constant reminder of the perceived negative impact of the illness on the carer's life.

Nearly one third of the variance in personal accomplishment scores was explained by optimistic beliefs about the timeline of the illness (i.e. believing it to be an acute rather than chronic condition) and active and positive reappraisal coping efforts. It would seem important that for early phase carers to report a sense of accomplishment in their role, optimism about how long the illness will last alongside active coping styles and skills in positive reappraisal are important.

Limitations

The study had some limitations. The cross-sectional design limits conclusions about causal processes and directionality of the findings. Whilst it seems plausible to argue that the predictors we investigated are psychological antecedents of experiences of burnout, it is possible that burnout experiences amplify or provoke pessimistic illness beliefs and less adaptive coping. A prospective design, involving multiple time point analysis, would be a helpful consideration for future research to disentangle the causal processes. Further studies are required to understand the current levels of high burnout found in the sample relative to other carer populations. Two previous studies have measured burnout in caregivers, but overall rates of high burnout were not reported and precluded comparisons.^{27, 28}

Clinical implications

Over three quarters of the sample reported high burnout in at least one of the three burnout dimensions. Burnout is likely to render a carer at greater risk of poor role functioning. Routine assessment of caregivers for reports of burnout during the early phase could be helpful for triaging needs and offering targeted interventions.

The current pattern of results highlighted an important role in carer burnout for illness specific appraisals, particularly those related to perceived negative consequences of the illness for the carer and the long term nature of the condition, and coping styles. Interventions designed to help early psychosis carers to develop a more balanced appraisal of the illness and strategies to promote problem focused coping and therapeutic optimism could be of benefit. This approach would be consistent with recent treatment guidance,⁴³ educational and supportive initiatives for first episode carers,⁴⁴ and a developing evidence base on carer outcomes in psychosis.⁴⁵

CONCLUSIONS

Carer involvement can be important for optimising patient outcomes in psychosis. However, the role, for many, can be highly stressful. Improving our understanding of the type and range of reactions caregivers can report in their role, even during the early illness phase, should remain a key component in our attempt to provide tailored, needs led interventions to carers.

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TABLE 1: Multiple regression predicting emotional exhaustion

Model	Predictors	β (beta)	t	p
Adj.-R ² = .40	Consequences for relative (carer)	.58	5.53	.01
	Patients gender (female)	-.20	-1.89	.06

TABLE 2: Multiple regression predicting depersonalisation

Model	Predictors	β (beta)	t	p
Adj.-R ² = .26	Consequences for relative (carer)	.33	2.83	.007
	Planning	-.28	-2.39	.02
	Patients gender (female)	-.21	-1.77	.08

TABLE 3: Multiple regression predicting personal accomplishment

Model	Predictors	β (beta)	t	p
Adj.-R ² = .27	Timeline: acute/chronic	-.36	-3.48	.001
	Positive re-interpretation and growth	.25	2.34	.02
	Active coping	.27	2.55	.01