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Understanding the experience of ‘burnout’ in first-episode psychosis carers

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Abstract

Background: The first onset of psychosis can exert a significant negative impact on the functioning and positive wellbeing of family carers. Carer reports of ‘burnout’ have recently been recorded in early psychosis carers, though the literature is scarce detailing our understanding of how burnout relates to the primary experience of caregiving. The current study investigated reports of burnout and its relationship with beliefs about caregiving and wellbeing in a large group of early psychosis carers who were routinely assessed within an early intervention team.

Methods and Materials: Using a cross-sectional design, 169 early psychosis carers completed the Maslach Burnout Inventory alongside measures of caregiving experiences, affect and wellbeing.

Results: The mean illness length for patients with psychosis was 18 months. Their mean age was 24.4 years and most was male (65%). The majority of carer participants were parental caregivers and living with their relative with psychosis. Across the three key burnout dimensions, 58% of the sample reported high levels of emotional exhaustion; 31% endorsed high levels of depersonalization; and 43% reported low levels personal accomplishment. The most severe level of burnout, reflecting elevated rates across all three dimensions, was observed in 16% of the sample. Carer burnout was positively associated with negative caregiving experiences (i.e. burden), poor affect, and reduced levels of positive wellbeing and perception of being in good health.

Conclusions: Reports by early psychosis carers of exhaustion, feeling inadequate and expressing negativity towards the relative they care for is not uncommon and are ~~will be~~ closely associated with their overall negative appraisals of caregiving. The results underscore the importance of

developing targeted interventions during the early phase, which are designed to reduce the development and entrenchment of burnout responses in carers, but to also mitigate its negative sequelae.

Key words: Burnout, Psychosis, Carers, Families, First-episode psychosis, Burden

1.1 Background

The experience of psychosis is common and estimated to affect approximately 7% of the adult population before their 75th year [1] but with 50% of new cases presenting by 23 years old [2]. Psychotic disorders can be disabling and adversely affect an individual's social functioning [3] and access to and availability of relationships based on reciprocity [4-5]. Despite optimal pharmacological treatments, a large majority of individuals living with psychosis can experience persistent positive and/or negative symptoms following their first psychosis episode [6-8] which can render them dependent, in different ways, on informal care and support [9]. Many of those experiencing their first episode will be embedded with a family unit and receive informal care and support from close relatives [10]. These relatives, commonly referred to as carers, are mainly parents or close others such as siblings and partners [11-12]. The literature attests that support from informal caregiving relationships can lead to superior recovery outcomes for people with psychosis, including reductions in their rates of relapse and need for hospital care [13], improved mortality [14-15] and access to appropriate care, when needed [16].

In psychosis caregiving groups, reports of carer burden and emotional distress are high [17-19] particularly during the early years when the illness and its related issues are new [11, 20]. An estimated 30-40% of carers will meet criteria for depression and other stress related conditions such as anxiety [11, 21-22], and reports of trauma are also documented [9, 23]. Further, sleep disturbance, social isolation and a reduced quality of life are elevated in psychosis carers compared to non-caregiving peers [24-25] and carers from other illness groups [26]. Carer burden is positively linked to higher levels of expressed emotion (a measure of family environment that captures carers' expression of criticism and intrusiveness towards the relative they care for), which itself is predictive of greater patient relapse and hospitalization [27-28].

1.2 Burnout

There is a growing evidence base on reports of ‘burnout’ in healthcare staff [29-33]. Though variability exists in how it is defined and operationalized [34], earlier descriptions refer to it as a syndrome and chronic negative state of mind that develops gradually, following prolonged exposure to stress within the workplace [35-36]. Burnout is typically evidenced by key areas of *emotional exhaustion* (e.g. feeling drained, fatigue); *depersonalization* (e.g. withdrawal, negative attitudes towards care recipient and carer role, cynicism), and *decreased motivation and role effectiveness* (e.g. low sense of individual competence and achievement) [36].

Burnout amongst staff groups has been linked to a poorer quality of patient care [37] as measured by a higher frequency of medical errors [38]; use of less adaptive coping efforts, including substance misuse [39-40], and role disengagement and retention difficulties [41]. It is also more prevalent in those who might be more isolated (e.g. single/unmarried) [36, 42].

1.2. Informal carers and burnout

In recent years, there has been a growing interest in measuring burnout in family carers of people with longer-term mental health problems [29]. Though variability exists in how it is defined and operationalized [30], earlier descriptions refer to it as a syndrome and chronic negative state of mind that develops gradually, following prolonged exposure to stress within the workplace [31-32]. Burnout is typically evidenced by key areas of *emotional exhaustion* (e.g. feeling drained, fatigue); *depersonalization* (e.g. withdrawal, negative attitudes towards care recipient and carer role, cynicism), and *decreased motivation and role effectiveness* (e.g. low sense of individual competence and achievement) [32].

with results attesting high levels of burnout and at comparable levels to those recorded in paid frontline psychiatric staff. Angermeyer and colleagues [33] undertook a comparison of burnout in mental health carers and psychiatric staff and observed similar levels between both groups particularly in their reports of emotional exhaustion and depersonalisation. More recent and preliminary work from our group identified burnout in early psychosis carers with 78% reporting high burnout in at least one of the key domains of emotional exhaustion, depersonalization and low personal accomplishment [34].

Caregiving is complex and impacted by a range of factors [35-36]. The initial psychosis phase can represent a very confusing time for families; carers can find themselves exposed to challenging situations with their relative that may include unpredictable, unusual and disruptive behaviours, persistent and confusing symptoms alongside substance misuse, anti-social and risk behaviours [37-39]. In response, carers can experience a broad range of emotions comprising shock, frustration, bewilderment, grief, guilt, anger, worry, and stigma [40-44]. To date, much of the attention on caregiving experiences has been focused, predominately, on measurement of carer burden and expressed emotion; the impact of other aspects of the carer role and experience has been overlooked. Though we have preliminary findings illustrating links between burnout and pessimistic beliefs carers report about psychosis in terms of its timeline and impact [34], the literature remains scarce on the relationship between carer burnout and overall appraisals of caregiving experiences (e.g. burden) and wellbeing. Such data would facilitate a better understanding of the impact of care during the early illness phase and highlight potential areas to intervene to support better carer outcomes. To address these gaps, the current study sought to investigate relationships between carer burnout and carer appraisals about their day-to-day caregiving experiences and wellbeing. We predicted that greater burnout would be positively

related to negative appraisals about caregiving (i.e. burden) and poorer affect, and inversely related to positive caregiving appraisals and perceptions of positive wellbeing.

2. Methods

2.1 Participants

Participants were identified carers of young people accessing a specialist early intervention in psychosis service in a London National Health Trust. The service accepts cases of first episode psychosis with duration of untreated psychosis, of less than 12 months and aged 14-34 years in a defined catchment area. Service users with an identifiable carer were eligible for inclusion in the study. For the purposes of the service and of the study, carers were those who assumed an unpaid caregiving role for the identified patient (e.g. a parent, romantic partner, sibling, adult child of the patient) and maintained weekly contact. In some households there could be two identified carers, which reflected the instances where there were two parents who were equally involved in the caregiving role. All carers to the service are routinely identified by the admitting staff members or graduate (assistant) psychologists. The carers are routinely approached by the graduate psychologist to complete assessments.

2.2. Design

A cross-sectional design was employed and data were collected by graduate level psychologists. All graduate psychologists, as part of their role, were trained in the engagement of carers and administration of the reported measures. Training was delivered by a doctoral level psychologist and involved a period of apprenticeship where the graduate psychologist was required to demonstrate competency and understanding of the key issues areas of measurement before undertaking independent assessment. The current findings are based on routine service data

collected on carer needs and where carer participants also provided consent for data to be published. Collection of routine service data and resultant publications met with criteria laid out within research development and governance standards of the NHS Trust.

2.3 Measures

Social-demographic data, inclusive of carer age, gender, employment, type of caregiving relationship and amount of weekly contact participants had with their relative, were recorded.

2.3.1 Maslach Burnout Inventory-Human Services Survey (MBI [45])

The 22-item self-report MBI is the gold standard and most recognised measure of burnout. Burnout is assessed across key domains of emotional exhaustion, depersonalization and low personal accomplishment. Respondents are required to read through statements reflecting feelings and attitudes towards their caregiving role (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'. The MBI yields individual subscale scores. Burnout is indicated by higher mean scores for emotional exhaustion (>21) and depersonalization (>8), and lower mean scores for personal accomplishment (<28). The measure has been used with informal carer samples [29,34].

2.3.2 The Experience of Caregiving Inventory (ECI [46])

The ECI is a 66 item, self-report questionnaire measuring the negative and positive appraisals of caregiving experiences. Respondents are required to endorse how often they have thought about a particular issue in the last month prior to completing the questionnaire on a five-point scale

(range: 0- never to 4-nearly always). The measure comprises ten subscales. Eight scales assess negative experiences (i.e. difficult behaviours, stigma, problems with services, effects on family, dependency, need to back up family, negative symptoms) and 2 scales measure positive experiences (i.e good aspects of the relationship; rewarding personal experiences). The ECI yields two summary scores reflecting the sum total of the negative and positive scales, respectively. Negative total scores range from 0-208 and for positive scores it ranges from 0-56. Higher scores denote higher levels of negative/positive caregiving experiences. The scale has good reliability and validity and has been used extensively with carer populations [46-48].

2.3.3 Hospital Anxiety and Depression Scale (HADS [49])

A 14 item self-report measure that screens levels of clinically significant anxiety and depression. Items are rated on a 4-point scale to reflect a participant's level of endorsement of each item. The subscale scores range from 0-21 with a score of ≥ 11 on one or both subscales being indicative of clinical levels of distress. The HADS has good psychometric data [49] and has a long history of use with different caregiver groups [e.g. 47, 50].

2.3.4 Psychological General Wellbeing Index (PGWBI [51])

A 22 item self-report measure that takes approximately ten minutes to complete, and designed to assess an individual's representation of their general wellbeing. It assesses six dimensions of wellbeing comprising anxiety, depressed mood, positive well-being, self-control, general health and vitality. Respondents rate items using a 6 point Likert scale ranging from zero (to reflect the most negative experience) to 5 (to reflect the most positive experience). The measure yields a

global score for general wellbeing, which reflects a sum of the subscales, and individual subscale scores. The current study was based on prorated data from four subscales (i.e., positive wellbeing, self-control, general health and vitality). Higher scores are indicative of more positive wellbeing. The PGWBI has been used with several groups and is available in different languages.

2.4 Data analysis

All data were analysed using SPSS Version 22 [52]. Data were initially subject to descriptive statistics. Bivariate analyses (Pearson) were undertaken to explore the hypothesised associations between burnout and key variables of interest. In addition, Pearson partial correlations were also completed to assess the relationship between burnout and caregiving experiences whilst controlling for affect. The alpha level was set at $<.01$.

3. Results

The sample comprised 169 carer participants. Participants mean age was 50.2 years (SD = 11.0, Range = 54.1-72.3). They were mostly female (67.7%, n=119), the parents of the service user (n=148, 85%), including two parent carers from the same patient household (29.7%; n= 44), and 49.5% (n=87) were self-identified as coming from a Black or minority ethnic background. Most participants were living with the relative they cared for (n=149, 86%). Almost 40% of participants had caregiving responsibilities for more than one person. The patient group was predominately male (65%, n=114), unemployed (53%, n= 93) with a mean age of 23.4 years (SD= 4.8). The mean length of psychosis was 18 months (SD=13.27, range = 0.5 -64 months).

Insert Table 1 about here

3.1 Burnout and caregiving experiences

The subscale MBI mean scores for burnout and other clinical variables are reported in Table 1. High burnout was observed in 58% (n=98) of participants for emotional exhaustion; 31% (n=52) for depersonalisation and 43% (n=72) for low personal accomplishment. Sixteen percent (n=27) of the sample was classified as high burnout across all three scales.

Carer ECI burden was positively correlated with reports of burnout in terms of emotional exhaustion ($p = .529$, $P = .000$, $N = 162$) and depersonalisation ($p = .388$, $P = .000$, $N = 162$). Partial correlations confirmed that after controlling for depression, burden continued to be positively associated with emotional exhaustion (*Partial r* = .443, $P = .000$) and depersonalisation (*Partial r* = .325, $P = .000$). There was no significant relationship between burden and personal accomplishment ($P = .112$).

ECI positive appraisals of caregiving were positively associated with personal accomplishment ($p = .515$, $P = .000$, $N = 162$) and shared a small negative correlation with depersonalisation ($p = -.163$, $P = .038$, $N = 162$).

3.2 Burnout, affect and wellbeing

Carer anxiety was positively linked with burnout in terms of emotional exhaustion ($p = .561$, $N = 161$) depersonalisation ($p = .348$, $N = 161$) and negatively correlated with low personal accomplishment ($p = -.288$, $N = 161$), all at $P = .000$. A similar pattern of significant results at $P = .000$ were observed in the positive relationship between carer reports of depression and

emotional exhaustion ($p = .444$, $N=160$), depersonalisation ($p = .291$, $N=160$), and negative relationship with low personal accomplishment ($p = -.276$, $N=160$).

Carer wellbeing was inversely correlated with burnout in terms of emotional exhaustion ($p = -.621$, $P=.000$, $N=167$), depersonalization ($p = -.464$, $P=.000$, $N=167$), and positively correlated with personal accomplishment ($p = .384$, $P=.000$, $N=167$).

3.3. Regression analyses

Multiple regression analyses were performed to investigate how much variance in burnout dimensions could be explained by independent variables of burden, anxiety, depression, whilst controlling for carer gender. Gender was transformed into a dummy coded variable with males as the reference group coded 0 and females as 1.

For emotional exhaustion, $F(4, 148) = 23.9$, $p = .000$, $\text{adj } R^2 = 37\%$, two significant predictors were negative caregiving experiences (burden) ($b = .137$, $SE = .030$, $SE[b] = .341$, $t = 4.60$, $p = .000$, $95\% \text{ CI} = .078 \text{ to } .196$) and carer anxiety ($b = 1.09$, $SE = .314$, $SE[b] = .322$, $t = 3.48$, $p = .001$, $95\% \text{ CI} = .474 \text{ to } 1.71$) and

For depersonalisation, $F(4, 148) = 8.95$, $p = .000$, $\text{adj } R^2 = 17\%$, burden proved to be the only significant predictor ($b = .042$, $SE = .012$, $SE[b] = .305$, $t = 3.60$, $p = .000$, $95\% \text{ CI} = .019 \text{ to } .065$).

For low personal accomplishment, $F(4, 149) = 3.32$, $p = .014$, $\text{adj } -R^2 = 0.05$. No significant predictors were identified.

4. Discussion

This study sought to investigate reports of burnout in a large routine sample of early psychosis carers and explore its pattern of associations with caregiving experiences, including burden, and levels of carer affect and wellbeing. In line with original predictions, the results confirmed high levels of carer burnout across the individual domains of emotional exhaustion, depersonalisation, and low personal accomplishment. Sixteen percent of the sample obtained the highest level of burnout across all three burnout indicators. The findings validate previous work documenting burnout in early course [34] and longer-term psychosis informal caregivers [29]. Our current findings suggest that carer burnout is particularly evident in reports of emotional exhaustion, where almost sixty percent of participants scored above threshold levels. ~~and also surpassed levels reported in a recent systematic review of medical doctors in the United Kingdom [29]. Levels of depersonalisation (31%) and low personal accomplishment (43%) were also comparable to the elevated rates of burnout in a sample of doctors [29].~~

We know that reports of fatigue have been recorded in caregiving populations and are particularly understandable during the early phases, when the illness, its impact and what constitutes the best responses from carers are likely to appear somewhat less clear. Carers, during the early phase, will find themselves having to respond to several novel and unexpected situations with their relative, including issues related to treatment and service provision. Responding to the new situations and dealing with the evolving nature of psychosis is likely to impact on carers' subjective reports of exhaustion. This would also be consistent with research highlighting the increased likelihood of burnout in the early phases of one's professional career when individuals appear more vulnerable to the impact of work based stressors [53-54].

Positive and negative appraisals of caregiving were linked to different aspects of burnout which provides further evidence of the independence of these appraisals and their relevance for caregiving outcomes [55-57]. In partial support of our hypothesis, negative caregiving experiences (burden) was positively linked with carer burnout in terms of emotional exhaustion and depersonalisation and these relationships were independent of carer reports of depression. Further, in the multivariate analyses burden proved a significant contributor to burnout in the form of emotional exhaustion and depersonalisation. It is possible that exposure to the difficult and challenging aspects of the caregiving role such as negative symptoms, stigma, and loss, offers the right environment for carers to feel emotionally fatigued and lacking in positive affect towards their relative. This association is likely to be complicated by any patient behaviour such as substance misuse and aggression that can adversely affect the illness process. Though patient behaviours were not recorded as part of the current study, we know from the literature that these types of difficulties reflect a very common issue in early psychosis populations [37, 58].

The results indicated that where carers were appraising their caregiving experiences in a more positive manner such that they were able to identify uplifting experiences and good aspects of their caregiving relationship, then they were more likely to feel that they were doing a good job and had achieved something worthwhile. There is increasing interest in prosocial processes in caregiving [59] including positive caregiving appraisals [60]; however, there has been limited success with identifying their key correlates. Identifying relationships between positive caregiving experiences and reduced rates of burnout in terms of personal accomplishment, extends our understanding about the potential value and utility of exploring positive caregiving processes. The protective role that a carer's ability to identify positive aspects of the patient's

character and their relationship may confer on helping a carer to feel good about and satisfied with their caregiving role is worthy of further exploration. Given that most carers were co-resident with their relative with psychosis, developing a more informed understanding of this association would seem timely.

4.1 Implications

In line with treatment recommendations and best practice guidance for carers of people with psychosis [61], the pattern of our preliminary findings suggest that carers may benefit, at first onset, from being screened for burnout responses and offered supportive interventions to address the negative impact (e.g. exhaustion, coping difficulties) on their functioning. Given the wider literature, all carers are likely to benefit from balanced information about the potential challenges they may encounter in their wellbeing as part of their caregiving role. This may help to counter negative self-beliefs about their ability to cope and that their reactions are so unusual and specific to themselves only. Burnout will be a marker for carer difficulties and thus, a likely marker for poorer outcomes. Naming and normalising the potentially difficult ~~emotional~~ aspects linked to caring for a relative experiencing their first episode of psychosis may help to raise carers' awareness about difficulties they may experience and the importance of seeking help and at an earlier stage. This may also help to minimise the potential for carers to make negative self-appraisals about their competences as a carer and draw unfavourable comparisons with others over how they assume they would have coped and a dealt with situations they encounter. This is particularly relevant for psychosis carers, for whom evidence suggests are 10 times more socially isolated than non-caregiving peers [25]. Given the emotional dysfunction linked with high burnout, the application of existing evidence based interventions, such as cognitive behavioural

therapies would be indicated. Since burnout emerges following a prolonged exposure to a stressful situation, it is important that carers are actively encouraged and supported, from the very earliest point, to have planned time away from their role. The time away could take many forms including time engaged in non-caring related activities that address needs for psychological, physical and social wellbeing, offer opportunities for mastery and pleasure, and enhance esteem. These are the key domains adversely affected by carers' experience of burnout. Staff can play an important role in routinely communicating with carers about the importance of scheduling regular 'time off' from their role. Clinical experience highlights that carers can often be reluctant to engage in activities that focus on promoting their needs and wellbeing, which can include the idea of taking some time off. Therefore, supporting carers to also identify the relevance to patient outcomes of focusing on their own wellbeing needs remains key. In psychiatric staff (e.g. psychological therapists), recent evidence suggests lower burnout and less patient disengagement are recorded when staff groups have greater access to supervision [62]. In a similar vein, carers may also benefit from regular opportunities to reflect and make sense of their experiences and role and to problem solve specific issues with a professional or trained peer. The available evidence suggests that opportunities to be with other carers and share experiences can positively impact on carer wellbeing and outcomes [63-64]. Further, pilot data indicating the benefits of undertaking brief individual and group needs led interventions with carers of people with longer-term psychosis have also been encouraging [65-66]. The results underscore the importance of working closely with and supporting early psychosis carers to learn about and engage with effective and adaptive problem solving strategies. We already know that carers can report less use of adaptive coping skills during the early illness phases, which are positively associated with distress and indicators of poorer functioning. [67, 68]. In recent

years, however, there is growing evidence in support of interventions to facilitate carers' self-directed [69] or clinician supported use of effective problem solving approaches. [70]

It seems important, however, to also acknowledge the participants who did not report burnout across any of its key dimensions. To date, we know very little about what constitutes a 'normal' process of adjustment in families following the first onset of psychosis in a relative. Exploring the factors that help to minimise a carer's vulnerability to burnout would support a more targeted approach to offering interventions.

4.2 Limitations

The study had some limitations. Firstly, it employed a cross-sectional design that precluded conclusions being drawn about direction of findings. Repeated exposure to negative caregiving experiences may well give rise to burnout. It is possible, however, that carers who exhibit greater burnout are probably also more likely to approach and appraise their role and experiences more negatively. The lack of a control group is a second limitation. Though reports of carer burnout are discussed and comparison to previous literature measuring burnout in psychiatric staff, medical practitioners and mental health carer samples offered, the study lacked the inclusion of a healthy control group or carers of adult patients with similar challenging disorders. This information would help to clarify evidence on whether clinical efforts should be focused on psychosis specific carer interventions versus more transdiagnostic approaches to support carers. Thirdly, data were derived entirely from self-report measures of burnout, caregiving experiences, affect and wellbeing, with the latter measure using prorated scores based in 4 of the 6 subscales. Though these measures are well known with good psychometrics, the absence of independent or observer rated data is acknowledged. A more informed and detailed understanding of carer

reports of burnout and caregiving impact might have been achieved with the inclusion of additional measures of carer experience and functioning such as personality traits, which can impact on carer outcomes.[71, 72] Likewise, a consideration of a carer's highest education level and their degree of pattern of engagement with carer support therapeutic activities would have been helpful. It should also be noted that the absence of data on medical and psychiatric comorbidity, which are not uncommon in caregiving population represents a clear limitation in the study methodology and the conclusions derived from our findings. Fourthly, the sample, whilst typical of caregiving relationships observed in early psychosis and repeat episode groups [11, 67] were predominately female and the parents of the service user; therefore the generalisability of findings to other carer groups cannot be assumed. It is possible that the experience of burnout in other carer groups who were under represented in the sample (eg. partners) may follow a different pattern. The failure to explore links to patient outcomes remains a limitation.

The current findings would have been strengthened with the inclusion of additional patient related information, which would help to characterise the sample and contextualise the results further. For example, carers of patients whose pathway into services came via the criminal justice system and/or were subject to legal powers of detention (e.g. Mental Health Act 2007) [73] may report varying levels of burnout. Though carer functioning is an important area of study and target for interventions, and is also recognised as being independent of patient characteristics and owing more to carer appraisals [68], future research and conclusions would be strengthened by inclusion of more comprehensive clinical datasets. Moreover, given the established links between burnout in formal carers and poor patient outcomes [74], and in the context of cognitive models of caregiving responses in psychosis [75], future studies may wish to explore the

pathway (if any), through which carer burnout impacts patient functioning and outcomes. The absence of information on participants who declined the offer to complete assessments further limits the generalisability of the findings. It is possible that carers who participated were those who were most affected by their role and caregiving experiences. Likewise, it could also be argued that those most affected by their role were those that declined to participate and our current figures represent an underestimate of the full extent of difficulties with burnout responses at first episode.

4.3 Conclusions

The current findings offer important areas for consideration in terms of how we best understand and approach carer wellbeing in early psychosis. We have known for several decades that the bulk of the care and treatment in psychosis will take place in community settings and often facilitated and augmented by family carers. These are carers who are at the ‘frontline’ of our services, and exhibiting different elements of burnout, which are themselves closely linked to other areas of their caregiving experiences and environment. As a group, carers will be vulnerable to burnout given their high levels of social isolation [25] and the stressors associated with caring for a relative with psychosis [42]. Thus, further work is needed to develop more effective methods of identifying, at the earliest possible stage, carers who are (or are likely to become) negatively impacted by their role and can benefit from evidence based interventions [61]. The likelihood of early course carers relinquishing their role due to burnout and the implications this presents for service providers should not be overlooked. Developing a more comprehensive understanding of the impact of caregiving in early psychosis is important for helping to support improved carer and service user outcomes [76].

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