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PATIENT-INITIATED VIOLENCE TOWARDS CAREGIVERS IN EARLY PSYCHOSIS

Caregiver correlates of patient-initiated violence in early psychosis

1. Introduction

Mental health care services in western nations are designed to support individuals with severe mental illnesses to cope with their difficulties whilst residing at home whenever possible. This current approach reflects the influential twentieth century ideology of community care (Means et al., 2008), as well as a growing economic dependence on informal caregivers to meet healthcare needs (van den Berg et al., 2004). Early Intervention in psychosis (EI) services, for example, in the United Kingdom (UK) and elsewhere, have been established to provide evidence-based interventions for people with initial psychotic experiences on an outpatient basis. EI services aim to provide a rapid response to clinical signs of deterioration to minimise risk of further disability, including hospital admission (Marshall and Rathbone, 2011). An important, yet often neglected, area of work in this process of deinstitutionalisation has been the development and delivery of interventions for informal caregivers of people with psychosis (Onwumere and Kuipers, 2017). Evidence suggests that informal caregivers (also referred to as unpaid caregivers or family caregivers) may become the principal source of social support for many people with psychosis (Palumbo et al., 2015), and may be expected to manage heightened levels of risk at home without dedicated support or expert training (Chan, 2008; Hanzawa et al., 2013).

Many caregivers report positive experiences in their role, including stronger family connections and greater empathy for others (Kulhara, 2012). However, the potential negative impacts of caregiving in psychosis can also be wide-ranging and variously effect caregivers' health and wellbeing, finances and relationships with others (Onwumere et al., 2016; Jansen et al., 2015). Psychosis caregivers have consistently been found to report poor mental wellbeing, for example, including by comparison to non-caregivers and caregivers in other

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conditions (Jansen et al., 2015; Gupta et al., 2015). A focus in caregiving research has therefore been in identifying predictors of negative responses in psychosis caregivers that might lead to decline in their own health status and the quality of the caregiving relationship (Barrowclough et al., 2014; Jansen et al., 2017; Raune et al., 2004). This area of research is particularly relevant since the benefits of supportive caregiving relationships for those with psychosis are well-evidenced. Caregivers have been found to be instrumental in encouraging engagement with mental health services on behalf of their family members (Del Vecchio et al., 2015; Fridgen et al., 2013), and their ongoing involvement has been associated with better outcomes from treatment, including improved life expectancy in patients (Doyle et al., 2014; Garety et al., 2008; Lee et al., 2013; Ramírez García et al., 2006; Revier et al., 2015).

Patient-initiated violence or aggression has been reported as a common reason for breakdown in the caregiving relationship in other disorders (Buhr et al., 2006; Yaffe et al., 2002). There is also evidence to suggest heightened levels of aggression are associated with psychotic illness, although the relationship between psychotic experiences and violence remains debated and complex (Bo, Abu-Akel, Kongerslev, Haahr, & Simonsen, 2011). Risk of violence in psychosis caregiving relationships therefore presents a research target that has potential implications for prioritizing those caregivers in need of support. Previous studies in longer-term psychosis caregivers have shown that violence is not uncommon (Chan, 2008; Hanzawa et al., 2013; Loughland et al., 2009; Onwumere et al., 2014). Between 31.0% (Chan, 2008) and 77.4% of caregivers (Loughland et al., 2009) have reported at least one incident of physical assault or aggression in the caregiving relationship respectively (Chan, 2008; Loughland et al., 2009; Onwumere et al., 2014). Additionally, caregivers who have experienced incidents of violence have been found to report more negative appraisals of caregiving, poorer mental wellbeing and greater criticism and hostility in caregiving

interactions (Chan, 2008; Loughland et al., 2009; Onwumere et al., 2014; Vaddadi et al., 2002).

The experiences of individuals caregiving in the earlier stages psychosis of patient-initiated violence have been subject to limited investigation (Onwumere et al., 2018). This is despite at least one recent review suggesting that violent behavior in patients may even be greater at this time than during the later stages of illness (Látalová, 2014). An understanding of the potential frequency and impact of violent incidents in caregiving interactions in the early stages of psychosis might inform decisions about whether and when to offer interventions for caregivers, and of what these should comprise (Lobban et al., 2013; Onwumere et al., 2014; Yesufu-Udechuku et al., 2015). Reported risk of violence might represent a means by which to identify caregivers in need of more intensive statutory psychological support within putative triaging systems for caregiver interventions (Onwumere and Kuipers, 2017).

The current study therefore aimed to assess caregiver reports of patient-initiated violence in early psychosis and to explore associated outcomes for caregivers. We focused on the relationships between reported violence, negative appraisals of caregiving (burden) and overall perceived mental wellbeing (Jansen et al., 2015). We also examined the relationship between violent incidents and the constructs of Expressed Emotion (EE), as the most widely validated outcome measurement of the quality of social interaction between caregivers and care recipients (Van Humbeeck et al., 2002). The relationships examined therefore followed a cognitive model of caregiving in psychosis, which has proposed one way in which to formulate individual responses to caregiving within a stress-appraisal-coping framework, and based on an integration of the literature elaborating the concept of EE (Kuipers et al., 2010; Lazarus and Folkman, 1984). Evidence suggests that the way in which people appraise or

evaluate their relative's behaviours and the caregiving experience, alongside social supports and coping styles, are influential in determining overall levels of caregiver distress and resultant EE (Joyce et al., 2003; Kuipers et al., 2010). The constructs of high EE – criticism and emotional over-involvement in caregiving relationships - have in turn been shown to be strong predictors of symptom relapse in psychosis (Amaresha and Venkatasubramanian, 2012; Bebbington and Kuipers, 1994; Butzlaff and Hooley, 1998) and represent treatment targets in Family Interventions in psychosis (Onwumere et al., 2011).

We hypothesised that caregiver reports of patient-initiated violence in early psychosis would be associated with more negative appraisals of caregiving, higher levels of distress and high EE ratings in the caregiving relationship.

2. Methods

2.1 Procedure

Ethical approval for the study was granted by the Berkshire Research Ethics Committee, United Kingdom, REF: 10/H0505/79. Participants were recruited across ten National Health Service EI clinical teams in the city of London. EI services are multidisciplinary community mental health teams that provide rapid assessment and support for people experiencing a first presentation of psychosis or at high risk of developing psychosis (National Institute for Health and Care Excellence, NICE, 2016). EI support typically continues for three years and services aim to provide a range of interventions for people with psychosis, and support for their caregivers, consistent with the national evidence-based guidelines for treatment (NICE, 2014). Potential study participants were identified by care coordinators based on the study inclusion criteria. Participants had to be identified by both patients and themselves as fulfilling a main caregiving role. To be included in the study they had to have maintained regular contact, of at least 10 hours per week, with a minimum

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of one face-to-face interaction per week, over a period of at least three months. Interviews and questionnaires were completed in a face-to-face interview conducted at home or in a clinical setting of their choosing, as part of a wider study examining ethnic differences in caregiving processes in psychosis (Smith et al., 2018). In addition to the measures below, a standard form was used to collect information on caregiver and patient socio-demographics and clinical characteristics. Caregivers reported patient characteristics including age, gender, number of admissions and estimated illness time in weeks (calculated from first presentation at emergency services in which a diagnosis was given or registration date with EI teams).

2.2 Measures

Camberwell Family Interview, CFI, (Vaughn and Leff, 1976)

The CFI is a standardized semi-structured interview that is designed to assess caregiver attitudes and reported behaviour towards a patient. Probes in the interview schedule encourage free-flowing speech about the quality of the caregiving relationship, including details about illness onset, development and patient symptomatology. Despite ratings being based on the responses of caregivers, EE is recognised as a measure of social interaction in which patients and caregivers are ‘*involved in a system of mutual influence.*’ (Hooley and Gotlib, 2000, p.136). Quantitative ratings are made from audio-taped interviews on 5 index scales of EE: critical comments (frequency count), hostility (0 – 3), emotional-overinvolvement, EOI, (0-5), warmth (0-5) and positive comments (frequency count). Threshold scores on critical comments (≥ 6) or EOI (≥ 3) can be used to classify ‘high EE’ interactions. In the current study, the scales for criticism and EOI were examined as continuous and dichotomous variables. Analyses were also made across low and high EE groupings of caregivers. Inter-rater reliability for the EE constructs was calculated on a 5% sub-sample of randomly selected recorded interviews. High intra-class correlations were obtained for the main EE indices as continuous variables: EOI: $r_s = .88$; Critical Comments: $r = 0.96$; Warmth: $r_s = .89$ and for Hostility and overall EE class

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examined as dichotomous variables: $\phi = 1.00$. All authors involved in rating the CFIs had been trained to criterion standards by the schedule developers (Vaughn and Leff, 1976).

Ratings of violent behaviours

A specific question within the CFI asked caregivers directly whether or not the individual “*had ever hurt or hit anyone*” or “*been destructive or damaging to property*”. Following Onwumere et al., 2014, violence was defined as any physically aggressive act toward another person or property. Ratings of caregivers’ reports of patient-initiated violence were made from transcripts of CFI audiotapes and were made blind to EE ratings and to other caregiver outcomes. All responses were coded by two raters, Cohen’s K was calculated to assess inter-rater agreement over and above the level of chance. There was good agreement between the two coders ($K = .761$, 95% CI, .696 - .826 $p < .0001$).

[INSERT TABLE 1 HERE]

Experience of Caregiving Inventory, ECI, (Szmukler et al., 1996)

The ECI measures subjective appraisals of the caregiving role, care-recipient behaviours and symptoms (Szmukler et al., 1996). The instrument was developed and validated within populations with severe mental illness (Harvey et al., 2008), and is a strong predictor of caregiver wellbeing in psychosis (Jansen et al., 2015). The questionnaire consists of eight negative subscales (difficult behaviours, negative symptoms, stigma, problems with services, effects on the family, the need to provide back-up, dependency, loss) and two positive subscales (rewarding personal experiences, good elements of the relationship). Items reflect the ‘time spent thinking’ on particular issues in the past month. The ranges for overall summed subscales are ECI-negative = 0-208 and ECI-positive = 0-56.

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RAND 36-item Health Survey 1.0, (SF36), (Ware and Sherbourne, 1992)

The SF-36 is an internationally validated self-report measure of generic physical and mental health outcomes (Stewart and Ware, 1992; Ware and Sherbourne, 1992). The Mental Component Summary score, comprising four out of eight available health domains, was used in the current study as a measure of overall perceived mental wellbeing. The SF-36 has demonstrated strong reliability, validity and sensitivity in discriminating changes across general population and patient groups, including caregivers (Gutiérrez-Maldonado et al., 2005, McHorney et al., 1994; McHorney et al., 1993). Norm-based scoring (population mean = 50, s.d = 10) was employed following the computational rules for combining items outlined in the components manual (Ware et al., 2000).

2.3 Statistical analyses

Descriptive statistics were calculated to summarise socio-demographics, clinical characteristics and to assess the frequency of incidents of patient-initiated violence. Comparisons in mean or median scores on outcome variables were made across groups of caregivers e.g. with and without experiences of patient-initiated violence. The distribution of all variables was examined graphically. Transformation procedures were attempted for skewed variables (Tabachnick and Fidell, 2012). Mean or median differences were assessed for statistical significance at an alpha level of .05 and 95% confidence intervals, using t tests and Mann Whitney U tests. Chi-squared statistics were calculated for categorical variables. As an indication of effect size in group differences Cramer's ϕ_c was calculated for chi-squared comparisons in categorical outcome variables. Cohen's d was calculated for differences in continuous variables (Cohen, 1988). All analyses were conducted in SPSS 22 (IBM Corp. Released 2013. IBM SPSS Statistics for Mac, Version 22.0. Armonk, NY: IBM Corp).

2.4 Participants

A total of 80 caregivers consented to participate in the study and completed the measures. Overall, approximately 1 in 4 families who were approached about the study decided to take part. The majority were mothers (86%, 68/80), looking after adult sons (69%, 54/80). Additional sociodemographic details for the sample are given in Table 1. There were two cases of missing data relating to violence from the CFI, where unexpected demands on the caregivers' time meant that the interview had to be terminated before completion.

[INSERT TABLE 1]

3. Results

Caregiver reports of patient-initiated violence

In total, a third of the sample (33.3%, 26/78) reported at least one incident of physical violence from patients towards themselves (14.1%), another family member (3.8%, e.g. a sibling) or a person outside of the family (15.4%, e.g. a friend, nurse or police officer). A further 5.1% reported destruction of property only. Table 2 provides verbatim examples of reported incidents of violence per category. The majority of caregivers (61.5%) said that their relative had neither hit nor hurt anyone nor anything, to their knowledge.

[INSERT TABLE 2]

Patient correlates of physical violence

Rates of violence were significantly higher amongst male patients ($\chi^2 (1, 78) = 3.854, p = .05$), who were younger (any history of violence, $M = 22.8$ years, $SD = 3.39$, versus no history of violence, $M = 25.7$ years, $SD = 5.03$; $t (76) = 3.033, p = .001$; mean difference = 2.895, 95% CI = 0.994 – 4.797). Additionally, trends towards significance were observed in

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relationships between rates of violence and more frequent admissions ($p=.15$), as well as a longer estimated illness duration ($p=.06$).

Caregiver correlates of physical violence

This was a predominantly low EE sample (73%, 58/80). However, caregiving relationships were significantly more likely to be characterised by high EE interactions where there had been a previous incident of patient violence ($\chi^2(1, 78) = 9.695, p < .005, \phi_c = .35$). In 91% of cases in which caregivers reported previous physical violence towards themselves, a rating of high EE was estimated from CFI transcripts (10/11). This compared with 17% high EE ratings in households in which no previous violent incidents were recorded (7/41). The relationship between patient-initiated violence was significant for EE categorisations made on the basis of criticism alone, but not EOI or EOI and criticism. Additionally, physical violence was associated with greater hostility in caregiver reports ($t(76) = 2.341, p < .05$, mean difference = 0.48, 95% CI to 0.064 - 0.902, $d = .644$).

Patient-initiated violence was unrelated to caregiver age, gender, ethnicity or face-to-face contact hours. Caregivers who reported at least one incident of patient-initiated violence were significantly more likely to report negative experiences of caregiving on the ECI ($M = 88.97$ vs $70.20, t(76) = 2.194, p < .05$; mean difference = 18.76, 95% CI = 1.57 - 35.94, $d = .547$) and poorer overall mental wellbeing on the SF-36 ($Mdn = 34.70$ vs $42.67, U = 449, p < .05, d = .664$).

Finally, in an exploratory analysis, caregivers were split into those who reported no incidents of violence, those who reported violence towards an individual outside of the home or to property, and those with direct experiences of violence towards themselves or a family member. A relationship was observed between proximity to violence and more negative appraisals of caregiving on the ECI (Figure 1). This same pattern of results was observed for

proximity to violence and poorer mental wellbeing.

[INSERT FIGURE 1 HERE]

4. Discussion

In psychotic disorders, caregivers play a key role in facilitating patient outcomes. We set out to report on early psychosis caregiver accounts of patient-initiated violence and correlates with key caregiver experiences known to influence health outcomes. The rate of violence reported by this caregiver sample was consistent with, although at the lower end of, estimates observed in previous patient samples (Large and Nielssen, 2011) and in studies of longer-term caregivers in psychosis (Kageyama et al., 2016; Onwumere et al., 2014). Caution must be reserved in making comparisons across studies when inconsistent definitions and variation in the methods for measurement make it difficult to establish exact prevalence of domestic violence in caregiving relationships (Serper, 2011). Nonetheless, the results do indicate that exposure to patient-initiated violence may occur from the early stages of caregiving in psychosis and that is not an uncommon experience for caregivers.

Additionally, we observed links between reports of violent interactions in caregiving relationships and high EE (rated on the basis of criticism and hostility), as well as more negative appraisals of caregiving and poorer mental wellbeing in caregivers. In other words, caregivers reporting greater burden (i.e. greater negative caregiving experiences) and poorer psychological wellbeing were also more likely offer reports about patient-initiated violence. These observations are relevant as heightened distress may reduce caregiver ability to provide support and possibly even necessitate their own requirement for healthcare. Caregiver criticism is also strongly associated with symptom relapse in patients and caregiver interventions typically attempt to moderate levels of criticism in caregiving interactions

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through psychoeducation about symptoms and adaptive coping skills to manage difficult behaviours (Alvarez-Jimenez et al., 2012).

The direction and nature of causal influence in these relationships is unclear; however, and represents an area for future research. The observation that caregivers who were directly involved in, or were proximal, to patient-initiated violent incidents reported more negative appraisals of caregiving suggests that these experiences are linked. Yet there may be multiple pathways to violent interactions and associated distress between patients and caregivers, which evidence suggests may or may not be influenced by psychotic experiences (Winsper et al., 2013). Further research is required to examine the specific contextual factors or the moment-to-moment interactions that gave rise to violent incidents, potentially via experience sampling methods (Sullivan et al., 2011), whilst also assessing the role of other known patient risk factors for aggression e.g. substance misuse (Spidel et al., 2010). Future studies would benefit from collecting data from patient groups to provide a more comprehensive narrative of the nature and pattern of incidents of violence within the caregiving relationship. Additional sources of information might also be collected in parallel to caregiver reports (e.g. general physician data, police reports, emergency department visits or staff reports). Further details that can help to determine the existence of different sub-groups of early psychosis patients who repeatedly engage in violence within caregiving relationships would represent an important development in the literature and might advance existing conceptual models of risk factors for violence in caregiving relationships (e.g. Solomon et al., 2005).

Within the context of a cognitive model of caregiving (Kuipers et al., 2010), further research into caregivers' beliefs about the causes of patient-initiated violence could reveal the extent to which psychotic experiences versus other factors are considered to be influential in determining acts of violence. Future studies might also examine caregiver appraisals of

violent incidents and coping strategies as potential targets for interventions for violence (Onwumere et al., 2018). Previous research, for example, has suggested that antisocial behaviors including physical violence may be more likely to attract controllability appraisals by caregivers (Barrowclough and Hooley, 2003; Brewin, 1994). Evidence has also shown that caregivers who appraise certain behaviours as within a patient's control (and therefore assume they are blameworthy) are more likely to express high levels of criticism towards patients (Barrowclough and Hooley, 2003; Vasconcelos e Sa et al., 2013).

Clinical Implications

The results suggest the need for early identification of caregivers who might be experiencing domestic violence from their relatives. In the UK, it is a mandatory requirement that caregivers are offered an assessment of needs under the Care Act 2014 (c. 23, Department of Health, 2014). A standard assessment of needs pro-forma will typically include a general question concerning a caregiver's perceived safety at home. However, a more direct yet sensitive line of questioning may be required to identify those with specific needs. Caregivers may under-report violent incidents for different reasons including a concern for the patient and perceived need to avoid their relative 'getting into trouble' or requiring a higher intensity of care (Onwumere et al., 2018).

Previous research has highlighted that therapeutic options targeting violence for individuals and families are limited (Wehring and Carpenter, 2011), although not entirely absent (Haddock et al., 2009). There now exists a range of interventions for caregivers in psychosis, of varied content and administration (Lobban et al., 2013; Yesufu-Udechuku et al., 2015), and family based interventions have proven efficacy in early psychosis (Claxton et al., 2017; Ruggeri et al., 2017). Informed by research insights into the causes of violent incidents in caregiving relationships, several components of these interventions might be envisaged to

be adapted to target patient-initiated violence and associated caregiver distress. For example, psychoeducational components that aim to increase patient and caregiver mutual understanding of the potential impact of psychotic symptoms, or interventions that aim to increase positive coping strategies in caregivers towards aggressive behaviours (Madathumkovilakath., 2018). In line with guidance on violence and aggression (NICE 2015) supporting family caregivers to identify early indicators of patient violence including interpersonal triggers would also be indicated as a helpful intervention for consideration.

Strengths and limitations

The study benefitted from the use of measurement instruments that were developed and validated in psychosis populations to obtain responses from a convenient and diversified group of caregivers. The extended schedule of the CFI is considered a gold-standard measure of EE and the interviewer remains neutral to allow the caregiver time to talk freely about his/her difficulties, problems and relationship (Van Humbeeck et al., 2002). However, several limitations should also be noted that impact the generalisability and conclusions drawn from the findings. First, we had no means by which to cross-check the caregiver reports, although this remains an issue for behaviours that are anti-social and occur within family environments. Second, despite high inter-rater reliability in the reports of violence, there still remained some ambiguity in certain verbatim responses if follow-up probes were not sufficient. Discrepancies were resolved through discussion. Third, the focus of our study was on patient acts of physical aggression. This focus may have inadvertently underplayed the relevance and importance of other forms of aggression in family relationships such as verbal and psychological aggression, which we know can also impact psychosis caregiving relationships (Chan 2008; Kageymama et al., 2016). Fourth, we were unable to collect data on refusal to participate and therefore cannot comment on the representativeness of the sample. However, the patient (e.g. predominantly male) and caregiver (e.g. mostly female)

demography were consistent with similar EI samples (e.g. Onwumere et al., 2018). Fifth, the cross-sectional design of the study additionally limited our ability to make causal inferences. Sixth, the absence of a comparison group of non-psychosis caregiver reports limits the scope of the final conclusions drawn.

Conclusion

Caregiving relationships in psychosis can be complex and challenging. Patient-initiated violence towards caregivers will invariably complicate such relationships and most likely adversely affect their viability and sustainability. The results of the current study have highlighted that patient violence towards caregivers might be anticipated from the earliest episodes of illness. Violence may place a particular strain on the caregiving relationship and have potential negative implications for caregiver wellbeing, of which service providers should be aware. Consequently, further efforts are required to identify caregivers exposed to domestic violence in the caregiving relationship and to evaluate the impact of interventions to minimize risk and improve outcomes. Future research that focuses on elucidating the contributing factors and pathways to specific incidents of violence in caregiving relationships might inform more targeted interventions.

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PATIENT-INITIATED VIOLENCE TOWARDS CAREGIVERS IN EARLY PSYCHOSIS

Tables

Table 1: Sociodemographic characteristics of early psychosis caregivers and patients

	Proportion in %, (n)
Total number of carers	(80)
Gender: Female	86,(69)
Age (mean years)	51.9 ± 8.8
Relationship to patient: Parent	90, (72)
Living with SU	79, (63)
Face-to-face contact (hours)	mean = 17.6 ± 13.1
Ethnicity:	
White British	44, (35)
Black British	16, (13)
Black Caribbean	20, (16)
Black African	14, (11)
Other	6, (5)
Employment status:	
FT paid	26, (21)
PT paid	21, (17)
Self-employed	14, (11)
Unemployed/sick leave/incapacity benefit	25, (20)
Retired/volunteering/studying	14, (11)
Marital status:	
Single	34 ,(27)
Married/civil or long term partner	60, (48)
Divorced/separated/widowed	6, (5)
Patients: Gender: Male	69, (55)
Age (years)	mean = 24.6 ± 4.7
Illness time (weeks since first admission)	mean = 92.5, ± 84.8, min = 9, max = 313*
No. of inpatient admissions	mean = 1.0, min =0, max=4

*exclusion of one outlier

Table 2: Caregiver reports of patient-initiated violence from the CFI

<i>Violence towards caregiver</i>	“she lashed out at me....she pushed my stomach where my stitches are” “extreme violence, he thumped me one”
<i>Violence towards other family</i>	“once he did sort of attack her (sister)” “he took a weapon and he wanted to strike his brother”
<i>Violence towards non-family</i>	“he’s hit people but not family (hospital worker)” “he attacked one of his ex-girlfriend’s friends”
<i>Violence towards property</i>	“he broke my phone in half, which had my mother’s voice on the answer machine” “he threw the TV out of the window”