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The caregiver experience of family members of people with persistent psychosis and negative symptoms: An exploratory mixed method analysis of metacognition, caregiver attributions, emotional over-involvement and distress.

Amy Homes, BSc (Hons), MSc. Forensic Psychology (Merit).

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical
Psychology

Institute of Health & Wellbeing College of Medical, Veterinary & Life Sciences University of
Glasgow

June 2019



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Chapter 1: Distress in caregivers of people experiencing multi-episodic persistent psychosis: a systematic review of models of caregiver distress.

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Systematic review

Distress in caregivers of people experiencing multi-episodic persistent psychosis: a systematic review of models of caregiver distress.

Abstract

Introduction

There have been several key concepts explored in relation to caregiver distress and burden (CDB), with studies regularly concluding best fit within a stress-appraisal-coping framework. However, most of these studies explore primarily patient functioning and symptomatology in caregivers of those with persistent psychosis, or use a First Episode Psychosis (FEP) population. Jansen et al. (2015) completed a systematic review of models of caregiver distress among a FEP population. It is important to better understand models of caregiver distress among those caring for a relative with persistent psychosis, to systematically explore variations in models of CDB and whether the psychological underpinnings change over the illness course. Findings can then be used to inform development of interventions to help reduce CDB and hopefully improve recovery for patients.

Methods

A systematic search of Medline, Embase, PsycINFO, Cochrane Central Register of Controlled Trials (CENTRAL), EBSCO and CINAHL was conducted. The studies were critically evaluated (using Crow and Shepherd's critical appraisal tool, 2011) and models underpinning CDB identified.

Results

Ten studies were identified. Underlying models fitted within a stress-appraisal-coping framework, with evidence of CDB associated with symptom severity and level of functioning; cognitive appraisals of the illness and attributions made by the caregiver; interactions between caregivers and their loved ones as well as caregiver coping strategies. In relation to caregiver cognitive appraisals of the illness and attributions they make, there was a direct positive association between negative cognitive appraisals and CDB. Generally, when critically appraised, the studies scored highly on preliminaries, clearly outlining primary objectives and using well-validated measures.

Conclusions

The review identified eight key psychological processes, resources or competences which account for variations in CDB in this population. There were similarities between CDB in caregivers of relatives with FEP and relatives of those with persistent psychosis. However, there were differences in relation to a feeling of having more influence or control over the illness in caregivers of those persistent psychosis as well as in patient and carer characteristics. High levels of CDB can lead to severing of contact with people exhibiting persistent psychosis. There is a need for more research to be conducted that uses a clearly defined definition of persistent psychosis, to help inform service delivery to better prevent relatives reducing or severing contact with the patient.

Introduction

Many relatives in a caregiving role for people diagnosed with schizophrenia experience a high level of psychological distress, reduced quality of life and financial costs (Jansen, Lysaker, Harder, Haahr, Lyse, Pedersen, Traulsen & Simonsen, 2014). However, most research efforts focus on the patient and there are fewer studies devoted to exploring carer distress.

There have been several key concepts used when exploring the literature on caregiver burden and distress (described as “CDB” for the remainder of this paper). Earlier studies used “objective” and “subjective” burden. Objective burden can be described as “verifiable and observable” burden, including effects on work, social/ leisure activities and finances (Platt, 1985). Subjective burden is described as the burden reported by the caregiver. There are multiple difficulties with this concept, including lack of inclusion of positive aspects of caregiving and lack of any psychological or social theory as a base (Bulger et al. 1993; Szmukler, 1996).

Later studies have agreed on a stress-appraisal-coping framework to understand how CDB develops (Jansen et al., 2015). In Lazarus & Folkman’s (1984) stress-appraisal-coping framework, they posit there are two types of coping responses which mediate a stress outcome. “Emotion focussed” attempts to reduce the negative emotional response associated with stress (for example, distraction, suppressing of emotions), and “problem focused” targets causes of the stress in practical ways that tackle the problem or situation causing the stress. In the context of caregivers, there is substantial evidence to support a relationship between the appraisals made by caregivers, the coping style they use (emotion focused or problem focused) and CDB (Onwumere et al., 2008; Onwumere et al., 2011). Negative appraisals are also associated with higher levels of social impairment and disability, a smaller social network as well as increased symptom severity and reduced functioning in the patient (Joyce et al; 2000; Smukler et al., 1996).

Within the stress-appraisal-coping framework, several other factors relating to CDB have been explored. There is a substantial body of literature focussing on a relational phenomenon of families' reported attitudes and behaviour towards the patient. Barrowclough and Parle (1997) defined high Expressed Emotion (EE) as a relationship between patient and caregivers characterised by criticism (CC) and/or emotional overinvolvement (EOI). The phenomena was first observed by Brown and colleagues (1972, 1962), when institutional care in the 1960s was replaced by a move to care in the community. They noticed relapse rates differed by level of EE in families. Higher levels of caregiver burden (CB) were related to higher levels of EE, and there is evidence EE acts as a psychosocial stressor that can precipitate relapse (Vaughan & Leff, 1976). Rascon et al. (2008) found patients' poor functioning and high symptom severity have generally been associated with increased EE, although studies have reported mixed findings (Brown and Birtwistle, 1998). More recent studies are less focussed on EE, in part because evidence shows it fluctuates, with carers often changing EE status within 12 months, usually from high to low (Patterson et al., 2005). The EOI subscale of EE is associated to CDB itself in both First Episode Psychosis (FEP) and persistent psychosis populations (Alvarez-Jimenez et al., 2010; Boye et al., 1998; Breitborde et al, 2009a). It has also been shown to involve increased carer participation, querying if it could be a mark of a caring family (Van Os et al., 2001).

In more recent literature, Metacognition has been proposed as an alternative conceptualisation to explore why some carers suffer less in the face of psychosis experienced by their loved ones. Metacognition can be broadly defined as "Thinking about thinking," including thinking about their own thoughts, those of others, as well as being able to place these in a real-life context (Lysaker, Buck & Hamm, 2011). There is emerging evidence that greater metacognition in caregivers could be an important protective/coping factor, as it is associated with more positive

experiences of caregiving and may reflect psychological capacities for dealing with interpersonal challenges and psychological pain (Jansen et al., 2014).

Jansen et al. (2015) recognised little was known about the psychological underpinnings of CDB in FEP. They argued improved understanding could inform needs-based support given to caregivers of FEP. They found 15 papers describing 13 studies, comprising 1056 caregivers. Nine different psychological variables were examined which were categorised into the following groups: coping (the associations between coping and distress), appraisal/attribution (including control, symptoms, loss) and interpersonal response (the association between EE and distress). They concluded, “there was considerable data to support the link between distress and psychological factors such as avoidant and emotional coping, appraisal and EOI” (Jansen et al., 2015, p56).

The Jansen et al. (2015) review focussed on caregivers of people with FEP for several reasons. Most service users live at home with their families at the early stages of illness and this sample of caregivers is thought to show higher levels of distress compared to those with a chronic course of the illness (due to the initial shock, subsequent grief, often poor understanding of the illness as well as navigating the challenges of the psychiatric system). However, there is a converse argument that it is also important to explore models of CDB among caregivers of people with more persistent psychosis (for example, those with higher numbers of hospitalisations or a longer period of duration of active symptoms post-diagnosis). It is important to look at this population and find out if the psychological factors underpinning CDB are similar to those in a FEP population and to ask whether the correlates of CDB change with the evolution of the psychosis illness pathway.

Aims and objectives

We will determine whether similar psychological processes or competences will be examined in the caregiver persistent psychosis literature in comparison to the Jansen et al. (2015) review.

We will review empirical studies of psychological factors associated with CDB in caregivers of people with persistent psychosis. Key findings in the studies will be summarised and the methodology evaluated.

The review will address the following questions:

- What is the methodological quality of these studies?
- Is CDB explained by any empirically demonstrated psychological processes or competences within caregivers of people with persistent psychosis?
- Do these processes or competences differ substantively to those found in the review of caregivers of those with FEP?
 - Do the psychological underpinnings of CDB change over time?

Methods

Search strategy

Systematic searches using Cochrane methodology were performed on the following databases: Medline, Embase, PsycINFO, Cochrane Central Register of Controlled Trials (CENTRAL), EBSCO and CINAHL. Databases were searched from November 2017 to March 2018. The computerised search used the following algorithm: (psychosis*/ or schizophrenia*/ or psychotic* episode) AND (Caregiver* OR carer* OR parent* OR famil* OR relative) OR partner* OR spouse*) AND (Distress* OR burden* OR wellbeing OR stress OR depression OR anxiety* OR mental health OR loss OR grief) AND (psychological theor* OR attribution* OR coping OR attachment OR metacognition OR “metacognitive belief” OR expressed emotion OR cogniti* OR simulation theory OR theory of mind OR mentalisation).

Criteria for including and excluding studies

Inclusion criteria were that studies 1) report data on CDB or well-being in caregivers of persons with persistent schizophrenia spectrum disorders; 2) included some analysis looking at CDB and psychological correlates, and 3) were published in peer-reviewed journals in English.

Papers were excluded if they were 1) studies with a primary aim of investigating predictors of EE or studies without a hypothesis on the psychological underpinnings of CDB; 2) studies with a focus on a solely FEP sample; 3) secondary publications (reviews, commentaries, editorials and letters); 4) theses, dissertations and conference papers and 5) qualitative reports.

No date restrictions were applied to the selection of studies. Amy Homes independently assessed the relevant articles for inclusion, based on inclusion criteria. Any studies where there was uncertainty about inclusion were reviewed by Hamish McLeod (Supervisor).

Study screening

The Prisma diagram (Figure 1) shows study screening in detail. Relevant studies in the Jansen et al. (2015) systematic review were hand searched.

Data Extraction and Quality Criteria

A data extraction template was designed which aimed to extract key information. All selected papers were evaluated in terms of methodological quality using Crow and Sheppard's (2011) critical appraisal tool. The Crowe Critical Appraisal Tool (CCAT) consisted of a rating form and the User Guide. This was chosen because it has been reported as a good instrument for reviewing the quality of both cross-sectional and observational studies.

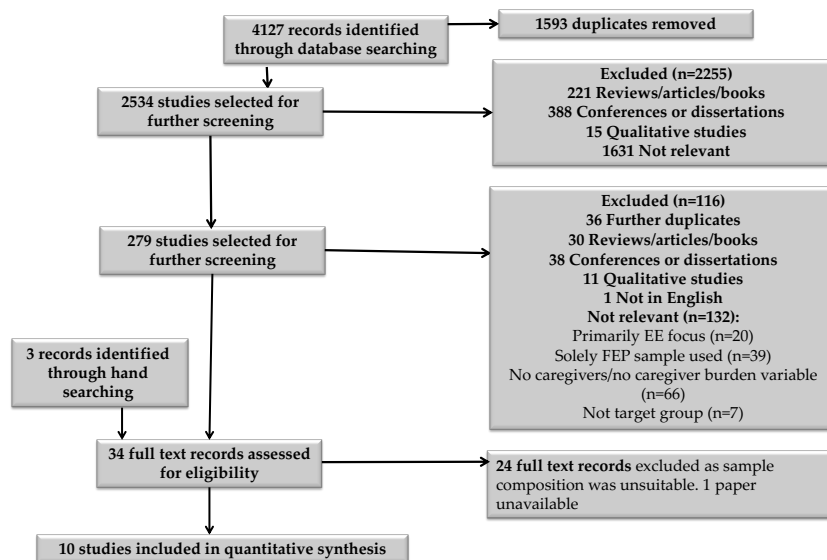
Each paper was scored on eight categories and 22 items. Each category received its own score on a 6-point scale. According to Crowe (2013), it is up to the appraiser to take into consideration

all aspects of each category and assign a score based on tick marks and judgement. Two reviewers, compiled information on the papers found through the database search (n=7). Any differences in opinion were reconciled by discussing their reasoning, reaching a consensus.

Results

The search and exclusion process is shown in Figure 1. The initial database search produced 4127 records, of which 1593 were identified as duplicates using RefWorks.

Figure 1: PRISMA diagram



Study characteristics

Half of the studies used consecutive sampling from pre-specified inpatient and outpatient clinics, although Lowyck, De Hert, Peeters, Wampers, Gilis & Peuskens (2004) supplemented this approach with relatives attending a self-help group for family members of psychiatric patients. Four of the studies used samples from existing prospective studies to identify patients (Hjarthag, et al. 2010¹; Barrowclough, Hatton & Quinn, 2001²; Onwumere, Kuipers, Bebbington, Dunn, Fowler & Garety, 2011; and Onwumere, Kuipers, Bebbington, Dunn,

¹ Clinical Long-term Investigation of Psychosis in Sweden, CLIPS.

² recruited from a subgroup of relatives recruited to a controlled trial of family intervention in schizophrenia.

Fowler, Freeman, Watson & Garety, 2008³). The latter, recruited the remaining caregivers (n=60) purposively from two specialist Early Psychosis Services.

The majority of studies found in the search were cross sectional. Koukia and Madianos (2005) present the only study to adopt an experimental design, exploring the effect of the participation of patients with a schizophrenia diagnosis in rehabilitation programmes on the atmosphere of their families and the emotional well-being of their caregivers. The control group was recruited by randomly selecting patients with the same diagnosis and sociodemographic characteristics who were not attending any rehabilitation programme.

Six of the studies specifically targeted patients with persistent symptoms. An additional four studies used mixed samples with patients of varying duration of illness. These were included in the review because they presented data on the subset of their sample who had persistent symptoms (using time since diagnosis or number of hospital admissions). Appendix 8 (p119) includes a table showing illness duration features for the specified studies.

People experiencing multi-episodic persistent psychosis

There were a total of (n=1,322) persons with persistent psychosis we could ascertain were included in 8 out of 10 of the studies. Of these persons, it is only possible to report other patient characteristics in 5 out of 10 of the studies (n=434). Patients had a mean age of 37.5 years, and were predominantly men (n=243) (Koukia and Madianos., 2005; Sagut & Duman, 2016; Hjarthag, 2010; Onwumere et al., 2008; Barrowclough et al., 2001).

In a further two studies, it was not possible to distinguish the proportion of FEP vs. persistent psychosis in the samples, as results were reported as a mixed sample (Lowyck et al., 2004;

³ used the PRP Trial (ISRCTN83557988), a British multicentre, Randomised Control Trial of Cognitive Behavioural Therapy and family intervention for psychosis.

Adeosun., 2013). As discussed earlier, these studies were included as they reported findings using duration of illness and/or number of hospitalisations as independent variables.

Caregivers of people with psychosis

A total of 2,020 carers were included across the 10 studies. Due to variation in the caregiver characteristics reported in each study, it was only possible to ascertain the gender split for six studies (n= 465, which included 151 men and 314 women) and the mean age of carer from five studies (n=418, 53.3 years).

Measurements of CDB

Table 1 shows a comprehensive list of the CDB measures used in the study. The majority of studies (n=6) used a measure of caregiver burden (CB). A total of 5 different measures of burden were adopted across the 7 studies.

Three studies used caregiver distress (CD) measures. Both the Onwumere et al. studies (2008 and 2011) and Barrowclough et al. (2001) used the General Health Questionnaire – 28 (GHQ-28). The latter used this alongside the Beck Depression Inventory (BDI). The GHQ-28 is a scaled version of the GHQ. It uses four subscales (somatic symptoms, anxiety and insomnia (stress), social dysfunction and severe depression) and the higher scores denote higher levels of distress.

Measures of psychological models and constructs

Several different measures were used in the studies to explore some of the psychological models underpinning CDB. These are shown in detail in Table 1. Key points to highlight include:

- The Positive and Negative Symptom Scale (PANSS) was the most regularly used measure, primarily as an index of illness severity (used by Gomez-de-Regil et al., 2014; Adeosun, 2013; Hjarthag et al., 2010 and Barrowclough et al. 2001).
- Five studies used measures to explore caregivers' cognitive appraisals, illness beliefs and/or adopted coping strategies (Lerner et al., 2018; Gomez-de-Regil et al., 2014: Onwumere et al., 2011; Onwumere et al., 2008 and Barrowclough et al., 2001).

Table 1: Summary table showing synthesis of studies

Study	Location	N Care-givers	Age of caregive rs (mean, S.D)	% Female	Design	Care-giver Distress measure	Psychological constructs	Measure of psychological constructs	Key findings
Gomez-de-Regil et al. (2014)	Mexico	65	48.7 (+/- 16.5)	74.00%	Cross-sectional	CBI, QoL	Attribution theory; Transactional model of stress/coping; Biological; maturation/habituation process; Expressed Emotion	PANSS, GAF, GHQ-28, IPQ SCV, FQ	Psychological distress accounted for more variance above patient variables in predicting EE, burden and QoL. Relatives burden can be predicted by perception of illness as chronic and belief the relative can influence recovery.
Hjarthag et al. (2010)	Sweden	99	58.99 (+/- 12.35)	34%	Prospective study - 12 years	BIRP, Distress index, Life quality	Severity of illness related to CB (partly perception based)	PANSS, CGI, GAF, RAVLT, LNS, WAIS-R, WCST	Symptoms were significantly lower for patients with relatives in the "no burden" group as compared to others. Better function and cognitive ability also significantly better. Patients less bothered by illness have caregivers in no burden group.
Lerner et al. (2018)	U.S.A	1,142	55.6 (+/- 13.0)	82%	Cross-sectional online survey	PSS	Attribution theory; Transactional model of stress/coping	Descriptive characteristics of patient, social supports, coping resources, cognitive appraisal of caregiving. FEIS	CB linked to several variables especially role demands. Risk of medication being discontinued and concern about medication also effected distress. Negative cognitive appraisals of caregiving increase distress.

Sagut & Duman (2016)	Turkey	79	44.69 (+/- 13.35) and 50.45 (+/- 10.46)	63% both samples	Descriptive	CBI	Severity and duration of illness related to CB	Descriptive characteristics - data form	Higher overall burden on time dependent; developmental; physical & social burden (vs. FEP). No sign. difference in emotional burden.
Lowyck et al. (2004)	Belgian	150	Not reported	69%	Cross-sectional descriptive	IFB	Severity and duration of illness related to CB	Symptomatic behaviours questionnaire	Extent of burden closely linked to symptomatology; positive correlation btw no. of times patient admitted and face to face contacts.
Adeosun (2013)	Nigeria	181	44.8 (+/- 8.3)	60%	Cross-sectional/observational	ZBI	Severity and duration of illness related to CB; Attribution theory; Transactional model of stress/coping	PANSS, MINI	Longer duration of illness is correlated with higher burden on financial/ physical strain, time/dependence and uncertainty subscales.
Koukia and Madianos (2005)	Greek	136	56.6 (+/- 9.8) and 53.3 (+/- 11.92)	33%/34 %	Experimental design	FAS, CES-D	Improvement of psychosocial knowledge reduces CD	GAS	Families of patients in rehabilitation experience lower level of family disruption and psychosocial problems also exhibit fewer depressive symptoms.

Onwumere et al. (2008)	UK	146	47.1 (+/- 9.73) and 53.2 (+/- 12.8)	88%/72 %	Cross-sectional	GHQ-28	Attribution theory; Cognitive model; Illness beliefs	IPQ SCV, ECI	Caregivers of patients with longer illness histories reported high levels of positive caregiving appraisals. Caregivers appraised more negatively when perceive an illness as having severe consequences (for carer and patient)
Onwumere et al. (2011)	UK	141	50.2 (+/- 11.8)	79.3%	Cross-sectional	GHQ-28	Coping strategies	COPE	Less adaptive coping strategies are present regardless of illness length and are uniformly linked to CD.
Barrowclough et al. (2001)	UK	47	Not reported	68.1%	Cross-sectional	GHQ-28, BDI	Cognitive model; Illness beliefs, Attributions, Expressed Emotion	IPQ-SCV, FQ, FMSS, SBAS, SFS, PANSS, GAS	Carer cognitive representations of illness have important implications for both carer and patient outcomes.

Note. N=number; S.D=Standard Deviation; Burden Inventory for Relatives to Persons with psychotic disturbances (BIRP), CB Inventory (CBI); Interview for family burden (IFB); Zarit Burden Interview (ZBI); Family Questionnaire (FQ); Five Minute Speech Sample (FMSS); Experience of Caregiving Inventory (ECI); CB Inventory (CBI), Quality of Life WHO BREF scale (QoL); Perceived Stress Family Atmosphere Scale (FAS); Multi-dimensional Coping Inventory (COPE); Centre for Epidemiological Studies Depression Scale (CES-D); Global Assessment Scale (GAS); Global Assessment of Functioning Scale (GAF); Mini International Neuropsychiatric Interview (MINI); Social Behaviour Assessment Schedule (SBAS); Social Functioning Scale (SFS); Family Experience Interview Schedule (FEIS); General Health Questionnaire (GHQ); Camberwell Assessment of Need (CAN); Illness Perception Questionnaire (IPQ SCV); Clinical Global Impression Scale (CGI); Rey Auditory Verbal Learning Test (RAVLT); Letter Number Sequencing (LNS); Weschler Adult Intelligence Schedule- Revised, Vocabulary subtest (WAIS-R); Wisconsin Card Sorting Test (WCST).

Methodological quality of the studies

In general, studies scored highly on the preliminaries (aims, design, quality of writing) as well as clearly outlining primary objectives and using well validated measures. Agreement was met between the reviewers in all cases. Scores are not individually reported as the writer advises to not use the total score as the sole criterion on which to assess papers as it is not necessarily an accurate way of interpreting the data. However, these are included in Appendix 9 (p120), with scores reported individually by CCAT category as well as a total of the 22 items.

Psychological processes or competences within caregivers of people with persistent psychosis

Across the 10 studies, several factors were examined and tested in terms of their association with psychological distress in caregivers. Similar to the approach used by Jansen et al. (2015) these have been organised into four higher level themes: 1) Patient and carer characteristics; 2) Attributions and Appraisals; 3) Interactions between caregiver and relatives and 4) Coping strategies. These are outlined in the remainder of this section.

- ***Patient and carer characteristics***

Five studies explored patient symptomatology and functioning. All reported increased symptom severity, frequency and impaired functioning was associated with increased carer/family burden (Sagut and Duman, 2016; Hjarthag et al, 2010; Lowyck et al., 2004; Adeosun, 2013; Gomez-de-Regil et al., 2014).

Interestingly, Lowyck et al. (2004) reported a positive correlation between the total amount of symptomatic behaviour and CB, however they found no significant difference by length of illness.

There were several carer characteristics reported as being associated with higher CB and/or distress. These included:

- Younger caregivers (Lerner et al., 2010)
- Primary caregivers, and/ or those with less people living with them and/ or less social support (Lerner et al., 2010; Adeosun, 2013);
- Caregivers living in urban areas (Lerner et al., 2010; Adeosun, 2013);
- Employed caregivers (Lerner et al., 2010; Adeosun, 2013):
- Those with their own health problems (Lerner et al., 2010, Adeosun, 2013) and,
- Caring for relatives with “chronic” psychosis (Sagut & Duman, 2016).

There are several factors which may better explain these findings. Firstly, people from socially deprived backgrounds are likely to live in urban areas and are more likely to have health problems and financial difficulties. The prevalence of psychosis in these environments is also likely to be higher, due to residents having high levels of trauma and stress (the latter in relation to factors such as financial difficulties, unemployment and health challenges). Secondly, they may also have less support available to them, due to financial or time restrictions.

Sagut and Duman (2016) found the average CB in caregivers of patients with chronic psychosis was significantly higher than that in caregivers of patients with FEP. Using the Caregiver Burden Inventory (CBI) they found a significantly higher level of burden for caregivers of those with “chronic psychosis” on nearly all burden subscales. No such difference was detected for emotional burden (the negative feelings of caregiver that are aroused by the patient), suggesting caregivers in both groups are likely to be having an intense emotional experience, despite the duration of caregiving.

- *Attributions and Appraisals*

Four studies explored associations between how CDB was related to cognitive appraisals of the illness and attributions, with all finding a direct positive association between negative cognitive appraisals and CDB. The negative cognitive appraisals positively associated with increased CDB included the caregivers' perception of:

- their relatives' illness as chronic and/or having a greater frequency of symptoms (Gomez-de-Regil et al., 2014; Barrowclough et al., 2001; Onwumere et al., 2008)
- the consequences of the illness for themselves (Gomez-de-Regil., 2014; Barrowclough et al., 2001; Onwumere et al., 2008)
- the consequences of the illness for the patient (Gomez-de-Regil., 2014; Barrowclough et al., 2001; Onwumere et al., 2008).
- the amount of influence or control the patient has over the illness themselves (Gomez-de-Regil., 2014; Barrowclough et al., 2001;
- the amount of influence or control the caregiver has over the illness themselves (Barrowclough et al., 2001).

Barrowclough et al. (2001) also found a strong illness identity (derived from a list of symptoms), was, "related to relatives perceiving themselves to have less control over the illness" (p377). This suggests if relatives' view the illness as more chronic or as the relative having a higher frequency of symptoms, the resultant increase in CDB could be because they feel a degree of hopelessness as they don't feel they can do anything to help.

Findings by Onwumere et al. (2008) also potentially support this viewpoint. When comparing positive attributions made by caregivers of those with FEP in comparison to those caring for longer-term ill patients, caregivers of longer-term ill patients were more

likely to make positive attributions of caregiver experiences than those carers in the shorter illness group ($t=2.2$, $p<0.05$). They also found caregivers of those with longer-term illness were more likely to perceive the caregiver themselves could have some control over the illness, in comparison to those caregivers with relatives in the shorter illness group ($t=2.3$, $p<0.05$). Caregivers of those in the shorter illness group, felt the patient had a higher level of control of their illness than caregivers in the longer illness group. The differences in these control/cure variables between carers of relatives with shorter and longer term illness, may explain the increased amount of positive appraisals made by caregivers of those with multi-episodic persistent psychosis.

In contrast, Gomez-de-Regil et al. (2014) found Mexican caregivers reported increased burden when they thought they could exert some control over or influence their relatives' illness. It is possible this could be a cultural difference, or potentially explained by the more socially deprived sample used in this study, as these caregivers may have less resources to enable them to help in the way they feel they need to influence change in their relative.

- ***Interactions between caregivers and relatives with multi-episodic persistent psychosis***

Three studies explored interactions between caregivers and relatives, and association with CDB (Gomez-de-Regil et al., 2014; Barrowclough et al., 2001; Koukia and Madianos). Gomez-de-Regil et al. (2014) and Barrowclough et al. (2001) used the Family Questionnaire (Widemann et al., 2002), a 20-item self-report instrument for measuring EE status of relatives of patients with schizophrenia. Gomez-de-Regil et al. (2014) explored whether the psychological distress and illness perception of a sample of relatives of patients with psychosis can predict their levels of expressed emotion, burden and quality of life above patients' clinical and functional status. They found relatives' psychological distress itself,

accounted for more variance in the prediction of EE, burden and QoL than patient characteristics. For example, carers could potentially misinterpret the severity of the problems, feel particularly overwhelmed or distressed by a patient's symptoms and start to worry about if they are going to get better and the duration of the illness. This leads to higher burden, higher expressed emotion and reduced QoL. The previous associations discussed with caregivers' perceptions of the illness as chronic and with the magnitude of the consequences for themselves and the patients support this interpretation.

Barrowclough et al. (2001) completed the Five Minute Speech Sample (FMSS) with 39 carers exploring models of illness in carers of schizophrenia. From this speech sample, carers were assessed to be high/low EE, and associations with IPQ subscales were subsequently explored. They found CC were associated with identifying a perceived greater frequency of symptoms (0.45, $p < 0.01$). They found this association remained when the objective severity of illness (PANSS score) was controlled for ($r = 0.45$). They also found the greater CC, the less sense the caregiver had of the illness being amenable to control or cure ($\rho = 0.42$, $p < 0.05$). A weak negative association between the patient's negative feelings towards the carer and the relative-control cure scale ($\rho = 0.27$, $p < 0.07$) indicates these interactions are possibly relational. Where carers saw more negative illness consequences for the patient, the more the patient both expressed negative feelings towards the relative and perceived negative feelings from them (expressed, $\rho = 0.31$, $p < 0.05$; perceived, $\rho = 0.31$, $p < 0.05$).

Koukia and Madianos (2005) explored the effects of the participation of patients with a schizophrenia diagnosis in rehabilitation programmes, on the atmosphere of their families and the emotional well-being of caregivers. The family atmosphere of the patients who were participating in a rehabilitation programme was found to be more positive, showing a higher degree of patient's acceptance, autonomy and compliance as well as fewer psychosocial

problems. They also found caregivers of those participating in rehabilitation programmes exhibited less depressive symptomatology.

- *Coping strategies*

Onwumere et al. (2011) compared carer coping strategies across different illness durations. They hypothesised that avoidant coping strategies would be associated with increased distress and would be more apparent in carers of FEP patients, in comparison to caregivers' of relatives with longer, more established psychosis. They found distress was positively linked with avoidance coping ($r=0.505$, $p<0.01$), but not with duration of illness. They concluded, "less adaptive coping strategies are present, regardless of illness length, and are uniformly linked to carer distress" (p424).

Although not exploring coping strategies directly, Lowyck et al. (2004) found a positive correlation between the number of times the patient was admitted and the contact with family and friends of the respondent that was severed or lost ($p<0.01$). It is possible this could be related to the use of avoidant coping strategies by these caregivers, related to the findings by Onwumere et al. (2011).

Discussion

Psychological factors in CDB

This review has identified eight key psychological processes which may account for variations in CDB in this population. We divided these into themes to enable further analysis and synthesis – Patient and Carer characteristics; Appraisals and Attributions; Interactions between Caregivers and their Loved ones and Caregiver Coping Strategies.

Positive associations between symptom severity, frequency and impaired functioning and CDB were found in all studies that explored these relationships (n=5). The higher the number of symptoms and the poorer the functioning of the individual with multi-episode persistent psychosis, the more distress and burden was reported by caregivers.

The illness appraisals and attributions of caregivers were also key factors in predicting CDB. Caregivers' burden was found to be associated with five key appraisals or attributions, including their (1) perception of the illness as chronic; (2) the consequences of the illness for themselves; (3) the consequences of the illness for the patient; (4) the influence or control the patient has over the illness, and/or (5) the influence of control the caregiver themselves can have over the illness (Gomez-de-Regil., 2014; Barrowclough et al, 2001; Onwumere et al., 2008).

The importance of caregiver attitudes towards family members and resultant interactions has been well-documented in the EE literature. There is evidence that CC made by caregivers are likely to be increased if they identify the illness as more chronic and feel neither they nor the patient have control of influence over the illness (Barrowclough, 2001). This is likely borne out of frustration and uncertainty as to how or if the patient will recover, potentially struggling with the consequences for themselves and/or their loved one. There

is evidence this response is noticed and responded to, with the patient also expressing negative feelings towards the relative, possibly as a result of perceiving negative feelings from the caregiver. This interaction is being further explored in the metacognitive literature, and there is emerging evidence of a relationship between metacognitive ability and the development and maintenance of negative symptoms, albeit in a FEP population (McLeod, Gumley, MacBeth, Schwannauer and Lysaker, 2014).

The coping strategies used by caregivers are also important in mediating CDB, with the use of avoidant coping strategies increasing the level of CBD. Caregivers who are younger, live on their own, have financial difficulties and have less social support, are also more likely to experience higher levels of CDB (Lerner et al., 2010, Adeosun, 2013).

How do these processes or competences differ to those caregivers of people in FEP?

Jansen et al. (2015), found nine psychological factors were examined in the included studies which could be categorised into non-mutually exclusive groups including coping, appraisal/attribution and interpersonal response. The current review found approximately eight psychological factors, which were divided into similar groups, with the addition of the Patient and Carer characteristics group.

There were the most similarities reported between the coping strategies and appraisal/attribution sections in the reviews. Both reviews found avoidant coping was associated with CDB. There were also similar findings on caregivers' appraisal of the impact, consequence of the illness and perceived control of the illness and carer's burden/ distress. However, one study reported caregivers of those with longer-term illness were more likely to perceive the caregiver themselves could have some control over the illness, in comparison to those

caregivers with relatives in the shorter illness group, which may increase positive appraisals made by caregivers.

The studies differed in other reported findings. Jansen et al. (2015) reported a study by Addington et al. (2003) which found, “specific characteristics seem to play a minor role in families’ appraisal of their situation (p288).” In the current review, there was evidence of associations between symptom severity and level of functioning, as well as specific caregiver characteristics and CDB in caregivers of people with persistent psychosis. However, it is possible there is a research bias, with these characteristics being explored more regularly among caregivers of patients with persistent psychosis. Jansen et al. (2015) reports less research in this area with FEP, due to the fact small sample sizes have, “rarely enabled these kinds of analyses” in a FEP population (p62).

Despite evidence that points to the fact there is habituation on behalf of the caregiver to the acceptance of the psychosis in the patient (Foldemo et al., 2005), findings from this review support the view this should not imply CDB is less in caregivers of those with persistent psychosis (Sagut & Duman, 2016). It is more likely there are frequent fluctuations in CBD for these carers. At key points such as relapse, change of medication and re-hospitalisation, there are times where CDB is once again elevated (Lerner et al., 2018; Lowyck et al., 2014). This is supported by Barrowclough et al. (2001) who found increased levels of distress in caregivers if they felt there was not a cure for the illness, or that it could not be controlled. These perceptions are likely to be exacerbated at the triggers in the caregiver/patient journey highlighted above. As described in Gomez-de-Regil (2014), it is also likely this may leave carers in, “a constant state of alarm”(p176). Of particular pertinence is the findings by Lowyck et al. (2014) that show the higher the number of hospitalisations, the more likely caregivers are to dis-engage from the patient. One can only hypothesise that this is primarily

due to levels of distress and burden. For each re-hospitalisation, concerns in relation to finances, the future and impact on both patient and carer will re-emerge, resulting in increased distress and burden.

Strengths and limitations of the review

There are several strengths and limitations of the current review. Firstly, research appears to be conducted with a different focus among caregivers of patients in FEP and late psychosis. The latter is more characterised by research looking at symptom severity and level of functioning than with FEP. This is problematic as the results from these studies may show associations between CDB and patient presentation, however we cannot confirm if this is different between a FEP population and a persistent population. Equally, research conducted with carers of patients in a FEP population seems to be more multi-faceted. Studies in relation to Metacognition and Theory of Mind, have been completed within this population but not in caregivers of those with persistent psychosis. More studies need to be conducted to see if a metacognitive approach may be useful to caregivers of, and patients with persistent psychosis.

It is likely some of the findings on underlying psychological factors within studies may be influenced by the country where the research has taken place. The studies were conducted in different countries, with varying levels of social deprivation, access to social support and differences in availability of healthcare. For example, Gomez-de-Regil et al. (2014) conducted their study in Mexico, restricting recruitment to the inhabitants of the city of Merida. This city has a high level of social deprivation and a high proportion of patients/relatives have a low educational level. This is likely to result in higher levels of financial difficulties and social restrictions for carers when looking after an ill relative which would increase caregiver burden. This is in turn likely to impact on the attributions made by carers,

the way they interact with their ill relative and the coping strategies they adopt. Adeosun (2013) also highlights low resource levels in Nigeria and difficulties accessing healthcare, which would also result in higher levels of caregiver burden where comprehensive health insurance schemes are lacking and mental health is reported as “only being procured by out of pocket payment” (Adeosun, 2013, p6). Relatives and patients who live in countries where there is more access to work, more social support and better access to healthcare are likely to have some degree of socioeconomic advantage which may mitigate some of the negative impacts of caregiving.

There are also cultural differences to take into account. For example, Gomez-de-Regil et al. (2014) highlight studies have shown Mexican inhabitants are generally less critical of their relatives than Caucasians and exhibit lower EE levels. Weiner’s attribution-emotion model of stigmatisation (1996) implies that pity and anger are two central emotions that have different implications for behavioural tendencies with ill patients. So, if culturally caregivers are less critical towards their relatives, this is potentially because they may feel pity, which motivates prosocial behaviour and reduces social rejection (Dijker & Koomen, 2003).

Of equal importance is the fluctuating nature of illness presentations. It is likely when illness course fluctuates in a relative, this will lead to resultant fluctuations in caregiver distress, but also the psychological constructs underlying it. For example, if again we consider Weiner’s attribution-emotion model (1996), it is likely this fluctuation will have an impact on attributions made by carers about the illness, and resultant emotions which may impact on interactions with the relative.

Clinical implications and future research

There are implications for community mental health teams and inpatient services offering services to patients with persistent psychosis. By understanding the caregivers' illness beliefs and appraisals, the different support systems and challenges they face, it may be possible to estimate those caregivers and patients who are more likely to experience high level of distress and have more interpersonal difficulties with their relative. More research needs to be conducted to explore suitable tools for gathering this information in a clinical setting, as well as to assess if this is feasible in a clinical setting.

It is important the viewpoint taken by professionals is one that recognises interpersonal challenges are commonplace in the caregiver/ relative relationship within this population, and they are offered interventions which will help limit CDB, as well as its effect on the patient. It is likely that providing psycho-education to these caregivers, normalising their responses, and helping to improve their understanding of the patient and the way they are responding, would improve quality of life for both parties, however more research needs to be conducted in this area. At the very least, there needs to be recognition that with increased amounts of hospitalisation, there is an increased risk of caregivers disengaging, potentially as a coping strategy due to a resurgence of levels of distress .

Conclusion

This review has identified eight key psychological processes or competences which account for variations in CDB in this population. There were similarities in models and processes underpinning CDB between a FEP and a persistent psychosis population. However, there were also several key differences which may impact on service delivery. More research

needs to be conducted that has a clearly defined definition of persistent psychosis, to better explore these differences.

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Chapter 2: The caregiver experience of family members of people with persistent psychosis and negative symptoms: An exploratory mixed method analysis of metacognition, caregiver attributions, emotional over-involvement and distress.

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Plain English Summary: Understanding how caregivers think about people experiencing psychosis with negative symptoms

Background

The experience of psychosis can involve ‘positive’ and ‘negative’ symptoms. Positive symptoms are unusual experiences that are not usually present. Negative symptoms are those that reflect a loss of functioning, for example a loss of ability to take part in activities or to socialise. Patients with negative symptoms generally have a more difficult recovery and are more likely to show a reduced response to conventional treatment.

But, we do not know much about the origin of these negative symptoms. One possibility is that difficulties in thinking about your own thoughts and thoughts of others (Metacognitive Ability), arise as a way of coping with interpersonal pressures. For example, patients may develop difficulties with thinking about the thoughts of others (low Metacognitive Ability) as a way of avoiding unpleasant interactions with a caregiver, resulting in negative symptoms.

A recent study (Jansen et al., 2014) examined the impact of metacognitive ability in family members of people recently diagnosed with a schizophrenia spectrum disorder. The study showed that carer’s who were good at thinking about their own thoughts and those of others, were more able to understand how and why the people they cared for were behaving the way they do. This study explores whether this pattern is also seen for caregivers of those with persistent psychosis.

Methods

A mixed method study was adopted. Interviews were conducted with caregivers of people with persistent psychosis, about their caregiving experience. Themes in these interviews were explored, alongside scores on Metacognitive Ability. Patients were also asked to identify the level of negative symptoms they experienced. Nine patient/carer dyads were recruited, with patients having a diagnosis of a schizophrenia spectrum disorder, and multi-episodic persistent psychosis dominated by negative symptoms.

Results

Four main themes emerged in analysis of caregiver narratives on their experience of caregiving, including “Caregiver causal attributions about the patients illness,” “Experiences of Services and Support”, “Responses by the caregiver towards the patient” and “Current and past coping strategies.” Themes were different according to how good carer’s were at thinking about their own thoughts and those of others. Caregivers who were better at this, were more able to understand how and why the people they cared for were behaving the way they do, which seemed to help them in how they viewed the illness as well as how they accessed support and the type of coping strategies they used. There was a significant negative correlation between the number of negative symptoms the patient reported, and how good a carer was at thinking about their own thoughts and those of others. This could be an indicator that negative symptoms could be in part developed as a way of helping patients’ cope with interpersonal pressures.

Conclusions

Further exploration, in larger studies should be conducted into the relationship between how good caregivers are at thinking about their own thoughts and those of others, and the development of negative symptoms in a persistent psychosis population. This would help develop future treatment to improve metacognitive ability in caregivers and hopefully reduce caregiver distress and improve patient recovery.

Abstract

Background: Many relatives caring for someone experiencing psychosis, display high levels of psychological distress. This can result in poorer mental health for both the carer and patient. Negative symptoms have been shown to especially hamper recovery, although little is known about their development and maintenance. Jansen et al. (2014) found greater metacognitive ability in the caregiver can improve coping and reduce distress in caregivers of those with FEP. This study explores the relationship between caregiver experience and metacognitive ability in those with multi-episodic persistent psychosis, exploring if caregivers with greater metacognitive ability have reduced levels of distress and whether there are indicators that negative symptoms are developed and maintained in a relational context.

Methods: A mixed method approach was adopted recruiting patient/carer dyads from inpatient and outpatient settings. This approach was adapted from previous studies examining metacognition, early psychosis and caregiver experiences. Patients negative symptoms were assessed using a self-report measure. Their caregiver was recruited if the patient reported a high enough threshold of negative symptoms. The caregiver was interviewed and asked about their experience of being a caregiver. Transcripts were thematically analysed and coded for metacognitive ability, to deductively explore the influence of metacognitive ability on caregiver appraisals, emotional over-involvement and distress.

Results: Four main themes emerged from caregiver narratives: “Caregiver causal attributions about the patients illness,” “Experiences of Services and Support”, “Responses by the caregiver towards the patient” and “Current and past coping strategies.” On deductive exploration of metacognitive ability on these themes, there were distinct differences by level

of metacognitive ability in the caregivers. Caregivers with higher metacognitive ability showed: a relatively better understanding of the illness and made less apparent negative appraisals; had a relative further along the illness trajectory; evidenced more proactive coping strategies (in comparison to using emotion focussed coping) and had increased levels of external support, than those with lower metacognitive ability. A significant negative correlation was also found between patient score on self-reported negative symptoms and metacognitive ability of caregiver, although no causation can be implied due to design of the study.

Conclusions: Greater metacognitive ability is likely to positively influence the stress-appraisal-coping framework. Higher levels of metacognition appear to increase the capacity to understand the complex reasons patients behave the way they do, thereby reducing negative appraisals of symptomatology and simplistic and hostile/critical attributions. Further exploration, should be conducted into the relationship between metacognitive ability and negative symptoms in a persistent psychosis population, preferably using pre-existing sampling frameworks from larger studies. Findings can be used to develop services to help reduce distress in caregivers and potentially improve relapse rates in patients.

Introduction

Studies have shown that caring for a relative with a psychotic disorder can result in greater levels of distress than usually experienced by the general population (Lerner et al., 2017). These elevated levels of psychological distress, can result in poorer mental and physical health of carer(s) (Jansen et al., 2014). There is also research showing this distress can impact the family environment and subsequently hamper recovery. This is increasingly pertinent, as many patients are cared for in the community, at least in part, by relatives.

The ‘Expressed Emotion’ (EE) body of research has set a precedent, which highlights the importance of the family environment on the clinical presentation of the patient and recovery rates. EE is a composite measure of critical comments (CC), hostility (H) and/or emotionally over-involved (EOI) behaviour. Vaughan and Leff (1976) found people diagnosed with schizophrenia, living with families who exhibited high levels of EE, had higher rates of relapse in comparison to those patients living with families with low EE. It is now accepted that EOI is a natural attempt to influence the behaviour of the patient, often with the best intention of helping (van Os, Marcelis, Germeys, Graven & Delespaul, 2001).

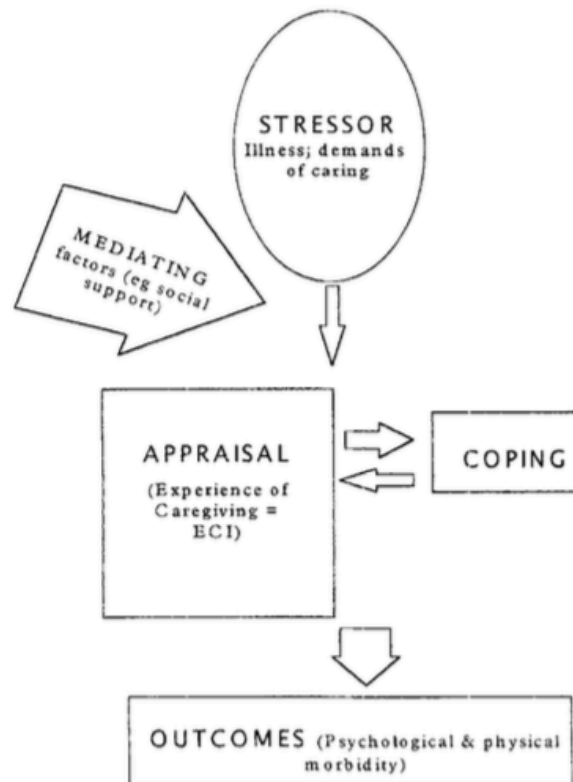
The impact of negative symptoms on caregiver distress and patient recovery

Negative symptoms often include affective flattening, alogia, anhedonia, asociality and avolition (Kring, Gur, Blanchard, Horan & Reise, 2013). Patients with a predominantly negative symptom presentation generally have a poorer prognosis than those with predominantly positive symptoms (Rabinowitz, Levine, Garibaldi, Bugarski-Kirola, Berardo & Kapur, 2012). Several studies have shown that caregiver burden can be higher if patients’ have a predominantly negative symptom presentation, (Roick, Heider, Toumi, Angermeyer, 2006). Further examination is needed into how negative symptoms develop, are maintained and how they contribute to carer distress.

A stress-appraisal-coping framework

Generally, it is accepted that a stress-appraisal-coping framework is most useful for understanding caregiver distress (Lerner et al., 2017).

Figure 1: A stress coping model of caregiving, reproduced from Szmukler et al. (1996).



Szmukler et al. (1996) include stressors such as the patients' illness and the demands of caregiving in their model (Figure 1). Outcomes are a result of the interaction between the actual stressors, caregiver appraisals of the patients illness and their caregiving role, and the carer's coping strategies (which are cognitive or behavioural, aimed at controlling the demands of the stressor). They also recognise the carer's personality, quality of family relationships and degree of social support are "mediating factors" on the outcome.

Metacognition as a mediating factor in a stress-appraisal-coping framework

The way people think about their own and others mental states (metacognition) is relevant to the understanding of EE and impaired functioning. The term is related to theory of mind (Brune, 2005), mentalisation (Fonagy & Bateman, 2011) and reflective function (RF) (Braehler & Schwannauer, 2011). All these traditions have a similar theoretical base and are understanding of one's own mind as well as the minds of others. Metacognition is used as an umbrella concept to refer to a number of sub-functions including understanding of the self and others; putting this understanding in the context of seeing the world as existing with others and using it to find solutions if necessary when faced with interpersonal challenges or conflicting emotions. Metacognition could also be viewed as an additional “mediating factor” within the stress-appraisal-coping framework, as it has been found to underlie many difficulties adapting to psychological challenges for people (Dimaggio, Semarari, Carcione, Nicolo & Procacci, 2007).

Braehler & Schwanneur (2011) explored RF in recovery from adolescent-onset psychosis. They found ability to mentalize was important in recovery. If an adolescent had impaired RF, they were less able to process what was happening to them, resulting in difficulties in adjusting and individuating. If RF is related to ability for the adolescent to process what is happening to them, it is important to explore whether this is also a factor in helping caregivers process what has happened to their loved ones.

Metacognition in caregivers and development and maintenance of negative symptoms

Jansen et al. (2014) completed the first study examining metacognitive capacities in caregivers of people with FEP. Findings showed greater metacognitive ability was associated with better coping, as it likely helped broaden the perspective of caregivers, therefore positively influencing the stress-appraisal-coping framework.

Replicating the above findings with caregivers of patients with persistent psychosis is important considering the emerging evidence of a relationship between metacognitive ability and the development and maintenance of negative symptoms (Lysaker et al., 2005; Hamm, Renard, Fogley, Leonhardt, Dimaggio, Buck, and Lysaker (2012); Nicolo et al., 2012; McLeod, Gumley, MacBeth, Schwannauer and Lysaker, 2014). It is possible that metacognition in patients may reflect or emulate the ability of primary carers'; implying metacognition is, at least partially, learnt in a relational context. For example, patients may develop lower metacognitive abilities and an increased negative symptom presentation (such as avolition) in part as a way of avoiding unpleasant interactions with a caregiver. This pattern may be shaped over a long time scale and could begin prior to the development of initial symptoms and onset, with poor premorbid interpersonal and academic adjustment and subsequent risk of psychosis (Cannon-Spoor, Potkin & Wyatt, 1982).

Recent studies support this hypothesis, with metacognition predicting higher levels of negative symptoms across several time points, even after controlling for baseline negative symptoms, neurocognition, defeatist beliefs and capacity for affect recognition (Lysaker, Kukla, Dubreucq, Gumley, McLeod, Vohs, Buck, Minor, Luther, Leonhardt, Belanger, Popolo and Dimaggio, 2015). Hamm et al., (2012) also reported metacognition as relatively stable over two points of time.

McLeod, Gumley & Schwannauer (2014) summarised studies that examined the relationship between MAS or MAS-A Metacognition Scores and Negative Symptom Ratings and concluded that impoverished metacognitive functioning may indeed have a specific impact on negative symptom formation and maintenance. For example, if a person has difficulty thinking about their own thoughts, desires, goals and sources of enjoyment, it will likely lead

to negative symptoms such as loss of drive and diminished engagement in goal orientated behaviour. Poor ability to think about the mind of others in a complex or nuanced way may lead to simplistic and critical attributions about negative symptoms by carers, for example, judging the patient as lazy or deliberately socially avoidant. McLeod et al. concluded there is, “clearly scope for translating the findings of research on cognitive processes such as metacognition into scientifically informed and effective treatment protocols” (p131).

As metacognitive ability in caregiver’s of patients with persistent psychosis has not yet been explored, the study originally aimed to replicate the Jansen et al. (2014) study with a persistent psychosis population. However, patient/carer dyads can be difficult to recruit among this population, primarily as patients who have been ill for a period of time are often no longer in contact with their caregiver. There are multiple other difficulties in securing participants, including the fact people with a negative symptom presentation often lack motivation so may not want to take part in a study. It was therefore difficult to achieve the necessary sample size so the study is more exploratory in nature, looking at key themes in caregiver experience and metacognitive ability. Additionally, it will include an exploration of the metacognitive ability of a caregiver and the development and maintenance of negative symptoms in the patient, as it is possible metacognition in patients may partially reflect or emulate the ability of primary carers’.

Rationale for this study

A qualitative approach will therefore be used to generate hypotheses about the caregiver experience throughout the course of the illness, and to deductively explore the influence of metacognitive capacity on caregiver appraisals, emotional over-involvement and distress.

The qualitative data will then be triangulated with other measures including a self-report measure of negative symptoms completed by the patient. This approach has been informed by Braehler & Schwanneur (2011). As in Jansen et al., (2014), associations between metacognitive capacity, caregiver attributions, emotional over involvement and levels of caregiver distress will also be explored.

Aims and hypotheses:

The study explored:

- key themes in caregivers' experience of interacting with family members with persistent psychosis and negative symptoms;
- whether caregiver metacognitive ability influences themes in the caregiver narrative;
- if metacognitive capacity of the caregiver relates to negative symptom presentation in the patient/family member and,
- any links between themes, metacognitive ability, caregiver attributions, EOI and levels of caregiver distress.

We sought to explore if caregivers' with a higher metacognitive ability will be capable of forming a narrative which is more complex in their representation of themselves and others. They will therefore make more positive appraisals towards the role, demonstrate less hostile and critical comments towards their relative, show better acceptance of the patients illness and be using a variety of proactive coping strategies to respond to and/or prevent psychological problems. The converse is predicted for caregivers with a lower metacognitive ability.

The capacity to test the second hypothesis, will depend on the number of patient/carer dyads interviewed, however there may be some indication of a negative association between

caregivers metacognition and patients' negative symptoms. Patients who have high self-reported negative symptoms may have caregivers with lower metacognitive capacity, showing negative symptoms may be developed (at least in part) in a relational context.

Methods

Design

The study used a mixed method approach. Semi-structured interviews were conducted and transcripts subsequently analysed using thematic analysis. Transcripts were also coded for metacognitive ability, and triangulated with the results from the thematic analysis. Quantitative data was analysed alongside the qualitative data.

Ethical Approval

Before the study commenced, ethical approval was granted by the West of Scotland Research Ethics Service (17/WS/0208) – Appendix 3, p108. Approval was also sought from NHS Greater Glasgow and Clyde Research and Development Department and NHS Lothian Research and Development Department. The multi-site co-ordinating centre for Scotland were also notified.

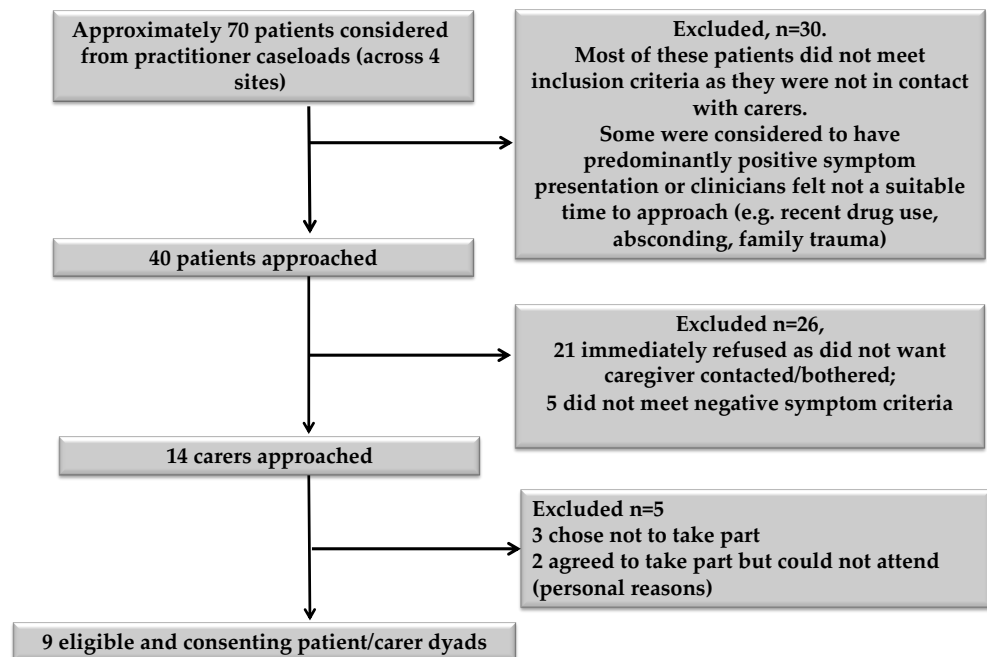
Participants

In total, there were approximately⁴ 70 patients across 4 services, that were screened by clinicians to take part in the study. To be included, patients had to have a primary diagnosis of ICD-10 criteria for Schizophrenia Spectrum Disorders; a predominantly negative symptom presentation, and at least weekly contact with their caregiver (either face to face or by telephone). Individuals with FEP and those with predominantly a positive symptom

⁴ It is not possible to give an exact number as some clinicians gave an approximation.

presentation were excluded. Figure 2 details a recruitment flow chart, showing the flow of participants through the study.

Figure 2: Flow chart showing stages of recruitment and exclusions



Procedure

A combination of inpatient and outpatient settings in NHS Greater Glasgow and Clyde and NHS Lothian were used to recruit patients and caregivers for the current study. Clinicians identified eligible patients, made the initial approach giving them an information sheet about the study and gathering informed consent (using the forms in Appendices 4, p108, and 7, p115). Patients who consented to being approached were asked to complete the SNS. This was returned to the researcher via the lead clinician. Eligible patients were then asked to choose relative(s) or significant others to participate in the research. Once this permission was granted, they were asked to provide contact details and the preferred mode of contact for their caregiver(s). Subsequently, potential carer participants were invited by the researcher to take part in the study, usually in writing or by telephone. If in writing, the letter

contained an introductory letter, information sheet (Appendix 5, p109) and consent form (Appendix 6, p115). An appointment was then scheduled to complete a full interview with the caregiver.

When a caregiver (and patient) agreed to take part, an appointment was scheduled to complete a full interview. Informed consent from the caregiver was taken before the interview commenced, if it had not been taken previously. Participants were interviewed with the IPII (Appendix 10, p121). The interviewer followed guidance for administering the IPII from the MAS Coding Manual (Lysakker et al., 2011). All questions remained the same as in the guide. The average length of the IPII was 45 minutes. Participants were subsequently asked to complete the ECI, the FQ and the GHQ-28 (as in Jansen et al., 2014). The average total length of interview was an hour and 15 minutes.

Measures

The Self-evaluation of Negative Symptoms (SNS) – This self-report measure was developed from the verbatim accounts of negative symptoms described by patients. Responses are on a 3-point scale: “Strongly agree”, “Somewhat agree” or “Somewhat disagree” for 20 items exploring experiences during the previous week. Cronbach’s coefficient ($\alpha = 0.867$) suggests good internal consistency. The SNS significantly correlated with the Scale of Assessment of Negative Symptoms ($r = 0.628$) supporting good convergent validity. A cut off point of 12 on the SNS was deemed appropriate to determine eligibility of negative symptom predominance, as reported by the authors.

Indiana Psychiatric Illness Interview (IPII): The IPII was originally designed to assess illness narratives in patients with Schizophrenia (Lysaker, Clements, Plascak-Hallberg, Knipscheer & Wright, 2002). In line with previous studies examining metacognitive ability in non-

clinical populations, the instrument was modified so instead of asking about their psychiatric illness, participants were asked about an important life challenge – being a caregiver. The interview typically lasted 60 mins and was audiotaped and transcribed. There were no direct questions of specific symptoms and the interviewer only asked for clarification when unsure (Jansen et al, 2014).

Metacognitive Assessment Scale – Abbreviated (MAS-A): The MAS was originally designed to assess metacognitive abilities and was designed to be used on psychotherapy transcripts. The MAS-A is a modified version adapted to use on IPII transcripts (Lysaker, Carcione, Dimaggio, Johannesen, Nicolo, Procacci & Semerari, , 2005). This abbreviated version contains four scales: “Understanding one’s own mind”, “Understanding of others’ minds”, “Decentration” and “Mastery”. Decentration refers to the ability of seeing the world as existing with others and Mastery refers to the ability to use the first two scales to find solutions when faced with conflicting emotions or interpersonal challenges. Higher ratings on each scale reflect metacognitive ability, with a maximum score of 28.

Experience of Care Inventory (ECI) – This inventory is designed to measure subjective experience of caregiving for a patient with “serious mental illness” (Jansen et al., 2014). The 66 item self-report questionnaire consists of 10 subscales, including 8 areas of negative caregiving and two positive. It measures how often caregivers have thought about each of these issues over the last month. Items are scored on a 5 point Likert scale, with a maximum score of 208 for the negative subscale and 56 for the positive subscale.

Family Questionnaire (FQ) – The FQ is used to assess caregivers’ level of EE (Wiedemann, Rayki, Feinstein & Hahlweg, 2002). The 20-item self-report questionnaire focuses on how families deal with everyday challenges, especially negativity and EOI. The measure consists

of two subscales: Critical Comments (CC) and EOI. Critical comments are unambiguous statements of disapproval or resentment, rejecting remarks or statements. EOI refers to self-sacrifice, over protection or over identification with the patient. Recently, the subscale of EOI is increasingly being viewed as a more reliable measure in predicting caregiver distress than the overall EE measure (Alvarez-Jimnez, Gleeson, Cotton, Wade, Crisp, Yap, McGorry, 2010). Items are scored from 1 to 4, with a maximum of 40 in each subscale. Caregivers scoring 23 or greater on CC or if they score greater than 27 on the EOI subscale, are classed as High EE.

General Health Questionnaire (GHQ-28) – was used as a general wellbeing and distress measure (Goldberg & Williams, 1988). The 28-item self-report involves rating how often particular symptoms occur on a likert scale ranging from 0 to 3. The total score varies between 0 and 90.

Data Analysis

The two stage approach used by Braehler & Schwannauer (2011) was adopted for the qualitative analysis. An additional analysis stage, based on Jansen et al. (2014) was added to include findings from the quantitative data.

Stage 1 – Thematic analysis of IPII narratives

The IPII was audiotaped and later transcribed. Throughout interviewing, the first author kept a fieldwork diary and this was used to help identify key themes. Initially, all interviews were subject to line-by-line open coding, with the most frequent and/or significant themes being condensed into higher level themes to develop a code frame. Unlike Braehler & Schwannauer (2011), a thematic approach was adopted instead of grounded theory. This was informed by Braun and Clarke (2006). The analysis code-frame was inputted into NVIVO

(a qualitative analysis package), which was used to help draw out verbatim from transcripts into the code frame. The code frame was developed iteratively, as each transcript was analysed. The final code frame is shown in Appendix 9, p120.

Stage 2 – Coding Metacognitive Capacity from IPII narratives

After thematic analysis was completed, the transcripts were rated using the MAS-A by the first author. A sample from one of these transcripts, alongside subsequent MAS-A coding, is included in Appendix 10, p121. A sample of transcripts rated using the MAS-A were checked by the MAS-A developer (n=4). Major themes in the thematic analysis were then analysed by MAS-A coding totals. Common links between specific themes/sub themes and caregivers metacognitive ability were noted across participants.

Stage 3 – Carer and patient characteristics were reported descriptively. SPSS (IBM Inc., Chicago, USA) was used to analyse the quantitative data and to calculate the mean and standard deviations where appropriate. Analysing the data from the ECI, FQ and GHQ-28 was completed after the thematic coding and subsequent MAS-A coding, to prevent bias.

Results

The following section details findings from the 3-stage analytical approach. Table 1 summarises the participants' demographics. Only two patient/carer dyads were recruited and interviewed from the same family.

Table 1: Patient/carer characteristics by patient/carer dyad									
	1	2	3	4	5	6	7	8	9
Patient/ carer dyad	Charlotte/ Amanda	Tony/Gill	Will/Tim	Will/ Natasha	Steve/ Theresa	George/ Hannah	Bruno/ Helen	Chris/ Jessica	Ryan/Daniel
Patient:									
Sex	Female	Male	Male	Male	Male	Male	Male	Male	Male
Currently inpatient/outpatient	Inpatient	Outpatient	Outpatient	Outpatient	Outpatient	Outpatient	Outpatient	Outpatient	Inpatient
Caregiver:									
Relationship	Sister	Mother	Father	Mother	Mother	Mother	Mother	Mother	Father
Sex	Female	Female	Male	Female	Female	Female	Female	Female	Male
Living with patient	No	No	No	No	No	Yes	No ⁵	No	No

⁵ Did not live with patient but bi-daily visits between houses and cooks all their food

Themes in the narratives of caregivers' experiences over time

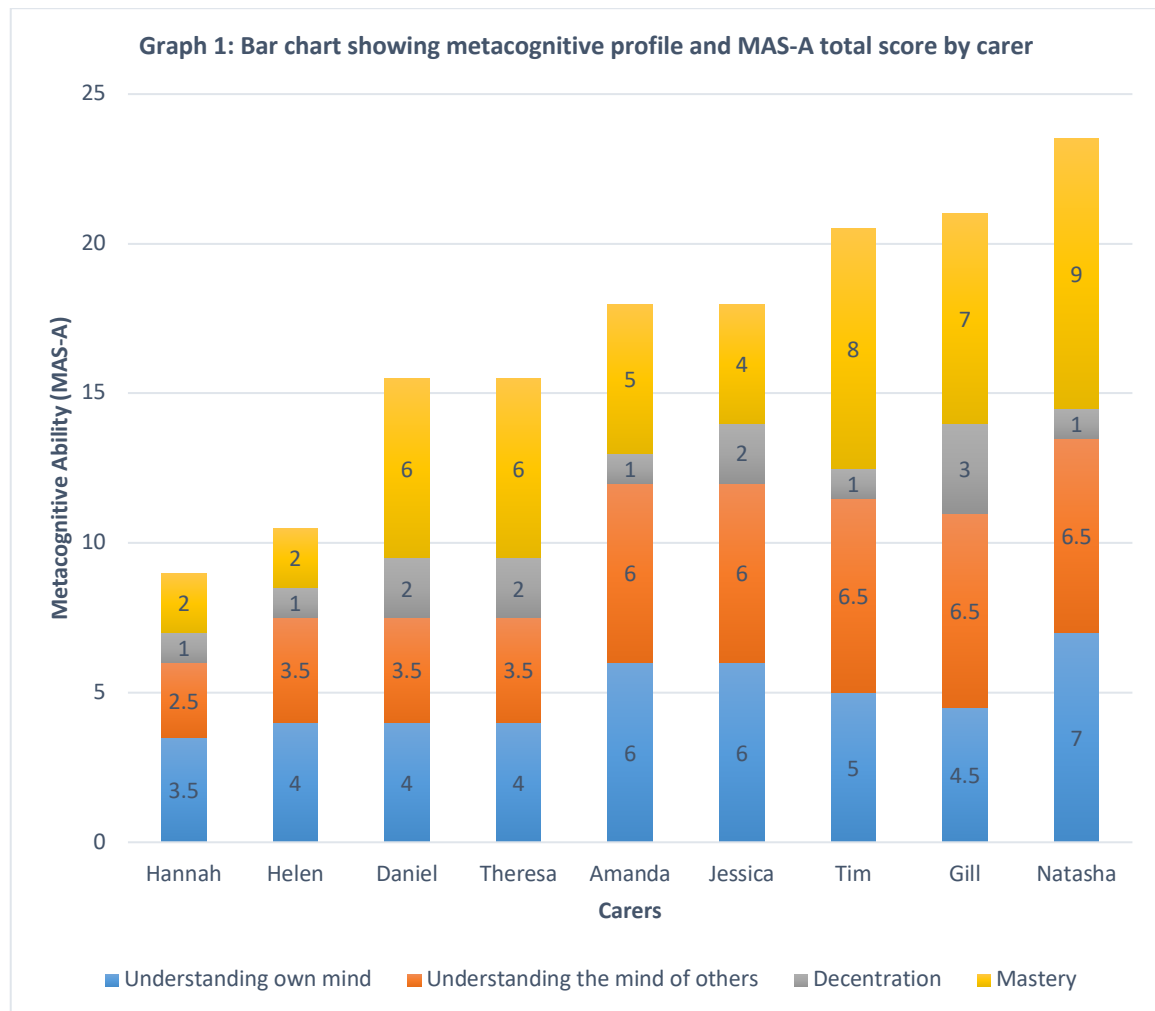
Four main themes emerged: “Caregiver causal attributions about the patients illness,” “Experiences of Services and Support”, “Responses by the caregiver towards the patient” and “Current and past coping strategies.” These themes, alongside subthemes are included in Table 2. A more detailed description, with verbatim, is included in Appendix 11, p123.

Table 2: Themes and subthemes identified from thematic analysis

	Themes	Subthemes
1	Cognitive Appraisals made by the caregiver about the causation and presentation of the patients' illness.	Causation of the illness Symptoms of the illness
2	Experiences of Services and Support by caregivers	Hospitalisations Accessing support staff Concerns for future
3	Responses by the caregiver towards the patient	Emotional over involvement, self-sacrificing behaviour, general criticism. Resentment vs. acceptance
4	Current and past coping strategies	Avoidant coping Accessing support

Caregiver MAS-A profiles

The MAS- A total and subscale scores for each caregiver are shown in Graph 1 (below).




Three carers (Gill, Tim and Natasha) showed greater levels of metacognition, four (Daniel, Jessica, Amanda, Theresa) scored medium levels and two showed poorer ability (Hannah and Helen). Thresholds were informed by findings from Jansen et al. (2014). Carers were categorised as “High” if they scored 20 or more on the MAS-A, “Medium” if they scored 15 or more on the MAS-A and “Low” if they scored less than 15. There were noticeable differences on all scales, with caregivers with a lower metacognitive capacity scoring lower on all subscales than those with greater metacognitive capacity.

Metacognitive capacity in narratives of caregiver's experiences

Themes are summarised in Tables 2 a-d. As in Braehler and Schwanneur (2011), themes are shown in the left hand column and subsequent differences between the themes by level of caregiver metacognitive capacity are summarised in the right hand side of the tables.

Caregiver causal attributions about the patients' illness

Table 2a.		Level of Metacognitive capacity	
	Low	Medium	High
			
Theme 1:	Caregiver causal attributions about the patients illness		
Causation of the illness	Simplistic Attributing sole cause	More complex More nuanced and evidence based attributions	
Symptoms of the illness	Lack of understanding of negative symptoms	Better understanding of negative symptoms More concern articulated for impact symptoms have on patients rather than themselves	
	Relates the impact of the symptoms to their own feelings		

Caregivers with a greater metacognitive capacity were able to recognise the aetiology of the illness as not being simplistic, attributing it to a biopsychosocial model, as evidenced by Daniel (Ryan's father).

Daniel: "We have been told that the schizophrenia was always there. But his grandmother passed away about [X] years ago now, and we believe that was a contributing factor. He really went off the rails after she died. And he's always at loggerheads with his mother as well."


Caregivers with a greater metacognitive capacity also tended to show a better understanding of negative symptoms, accepting they are a difficult part of the illness, which they found upsetting but did not commonly assign blame to the individual exhibiting them.

In contrast, caregivers with a lower metacognitive capacity tended to make more simplistic appraisals of the causation of the illness, which resulted in less understanding of negative symptoms. In her interview, Hannah (George's mother), spoke about the years of drug addiction which had preceded her son's psychosis. She felt the psychosis was due to, "*The heroin rotting his brain.*" This simplistic appraisal, alongside a lack of understanding of negative symptoms, understandably appears to have contributed to increased frustration on her behalf as she does not attribute George's behaviour to necessarily be part of his illness.

Hannah: "*I thought he is lazy when I look at him sometimes.*"

Experiences of Services and Support by caregivers

The key themes of experiences of services and support are highlighted in the table below by level of caregiver metacognitive capacity.

Table 2b.	Level of Metacognitive capacity		
	Low	Medium	High
			
Theme 2: Experiences of Services and Support			
Hospitalisations	Simple narrative provided		More complex narrative
	No reflection of experience of patient hospitalisations		Reflective of how they coped
	No mention of trauma memories or trauma to themselves in general		Mastery to help improve the system
			Reflects and recognises the impact relative's hospitalisations has had on them
Experiences of support staff	No mention of support staff		Reflective on how having additional support has improved the situation
Concerns for future	Concerned about who will look after patient after they die		Concerned about lack of social support (other than support staff) and how this will affect the patient after they die
	Concern about how feeling like this effects their life, unfair to have this worry		How this issue will affect the patients quality of life

As all carers had relatives with enduring symptoms, they had been involved with services for a long time. Caregivers with a greater metacognitive capacity reflected on

this more frequently, commenting on their experiences with GPs, Psychiatrists as well as hospitalisations.

Amanda: “...to be quite honest, the help she got back then was pathetic. It was like, in hospital stomach out, pumped, see a psychologist/psychiatrist once a week for two or three months, take medicine.”

They also usually reflected on how services have improved as the years have gone by, including MDT working and routine enquiry of whether someone is a carer.

Natasha: “I would say in the rehab ward was the best... Because he was getting much more attention. He was getting some psychology input. And it just seemed a better environment all together...when he was in the acute ward, when they thought he was well enough they would throw him home. There was nothing.”

All caregivers with a high metacognitive capacity, were able to reflect on the effect the hospitalisations had on them, in relation to being traumatised by the experience. They spontaneously recognised they were on “*high alert*” as they never knew when they may get a phone call saying their relative had relapsed and needed to be re-hospitalised.

Natasha: “It was unbelievable. It’s the unpredictability of things coming out of the blue. That’s the most unsettling thing for me. It’s always at the back of your mind. When you’re expecting a phone call from him and that phone call doesn’t come, you think... immediately you think... whenever I hear a police siren, you know.”

Several of these carers had, as a result, tried to contribute to improving services for carers in some way or another, which will be discussed in the latter section on coping strategies.

In contrast, caregivers with lower metacognitive capacity exhibited minimal reflection on historical services and their experiences of them. They focussed more on recent experiences, most likely as these caregivers' relatives were less likely to be as far along in their recovery. They were also more likely to be living with or more heavily involved in day to day care of their relative. They understandably focussed on recent difficulties with services, voicing criticism and/or frustration with care teams and services in general.

Helen: "Just the other day...I phoned up and said to them he's threatened to kill himself and I can't get anyone at the end of the phone. I said what's happening with being put through to the crisis team? She's like... Oh you should have got put through. I said I know I should of but I didn't. I was phoning all day."


All caregivers expressed concern about what was going to happen to their relative in the future, especially when they were not able to be involved in their care anymore. Caregivers with a lower metacognitive capacity seemed to report greater levels of concern about this, usually because they were also the least likely to have support from services in place, so they were handling more aspects of care than those carers with greater metacognitive capacity.

Hannah: “It has been a long time now, it was only supposed to be for a short time and I told the council that, I could only do it in the short period.....not in the long period....and it has went on and on and now he is homeless what chance have I got.”

Hannah, who is currently living with George, is understandably concerned about the future and she is focused on how the situation is affecting her.

Responses by the caregiver towards the patient

The key themes of carer interpersonal communication with patients are highlighted in the table below by level of metacognitive capacity.

Table 2c.	Level of Metacognitive capacity	
		
	Low	Medium High
Theme 3: Responses by the caregiver towards the patient		
Emotional over involvement, self-sacrificing behaviour, general criticism	More evidence of being emotionally over involved or showing self-sacrificing behaviour, general criticism or negative comments.	Less evidence of being currently emotionally over-involved, more able to have some distance, usually as external support involved. Reflection on times earlier in recovery process on interpersonal response
Resentment vs. acceptance	Feel the patient's illness has negatively affected their life and can appear resentful.	Can recognise the time and resource constraints needed to care for the patient but have reached a point of acceptance

Caregivers with a greater metacognitive capacity reflected on their interpersonal responses with their relatives. They reported fewer recent interpersonal interactions involving general criticism or critical comments. This could be in part due to greater metacognitive capacity but also because relatives of these caregivers are further along the recovery journey and they have more resources available so are arguably under less stress than those still carrying greater carer burden.

A few caregivers with greater metacognitive capacity were able to reflect on times earlier in their relative's illness trajectory, when they know they were more hostile and critical towards their relative.

Gill: "...there was a time when it just took over my life, I don't like to think back to the times when...I would think oh my god, I would wake up in the morning.....and I knew if he had been in the house I would be so angry with someone lying in the bed, the mess and this that and the other....there were huge times when I was not happy to go away on holiday or for a day as I did not know what would happen."

Some caregivers with a middling metacognitive capacity, were able to recognise they had been very emotionally invested in their child's illness for a long time and could question how useful this has been to either them or the patient.

Theresa: "I very easily get sucked into being a carer. And I've been a single parent all those years. I was just ready to go. I can sort it. And I can't sort it. But I can hang in there and go in every day and you know, see his washing is done. And I do worry that's not helping him and not helping me, and I've remained far too involved... helping to infantilise him."

There is a struggle with knowing how to change this interpersonal interaction, potentially due to a lower mastery score in their MAS score. However, these carers are also the ones who do not have the resources they feel they need to ensure their child is being (what they would consider) to be "adequately" looked after. This would therefore explain why it is difficult for them to take a step back.

Theresa: “That is such a cause of worry for me. Who will look out for him. How will he live? Who is going to be there to hassle the support organisation or whatever it is. It’s horrible. You mustn’t think about that.”

Another carer with a middling metacognitive capacity, was able to reflect on how she was more emotionally over involved earlier in the illness trajectory and on how this affected their behaviour.

Jessica: “Now I’m probably a lot better than I was when it first happened. When it first happened I was a guilt-ridden maniac who just wanted to fix everything and make everything better. Now I know actually I can just be there. That’s what I do.”

Jessica recognised a change in her mindset, realising after several years from the onset of illness, she could not make Chris’ illness go away. She appears to have become more accepting of this, but realised she can still be there to support him. However, at the same time, there is evidence she is still using quite an avoidant coping strategy (discussed further in section below).

Caregivers with a lower metacognitive capacity more frequently described being hostile and critical towards their relative. They also were less likely to reflect on how useful this was for either party. In the example below, George gives Hannah some food he has made whilst at the rehabilitation services and subsequently she has thrown it in the rubbish bin when it is given to her.

Hannah: "I said not everybody makes things [food] ...from scratch but they showed him a couple of times how to cook, it was to make mince.....well they said take it home to your mothers, but eh it went in the bucket."

There is no reflection on how this may have been considered critical behaviour or how this may have impacted George.

These caregivers also appeared to have less understanding about negative symptoms, and as a result made more negative appraisals towards patient behaviours. There was a consistent theme of resentment among these lower metacognitive capacity carers.

Hannah: "I can't talk to George the way they can [professionals]. I'm too angry, I can't do it. I can't shut my mouth. I can't start feeling sorry for him. I give him back like... what you've done to your life is affecting my life. It needs to stop. I can't handle it. "


Some of the examples of exchanges provided in narratives involved verbal hostility and critical comments, as well as high levels of reported anger.

Helen: "He's a tall boy. We're shouting. But I thought I'm not backing down here. I'm staying here. Try it, I said try hitting me and swear to god I'm jailing you. he just said I'm finished with you and out the door... The other week. He started the emotional blackmailing, saying I'll just kill myself. And aye right, so you will."

In the example above, Helen is angry with Bruno and she expresses this with hostility and critical comments. There is no reflection in the narrative in relation to her response.

Caregiver coping strategies

The key themes in relation to caregiver coping strategies are highlighted in the table below by level of metacognitive capacity.

Table 2d.	Level of Metacognitive capacity	
		
	Low	High
Theme 4: Caregiver coping strategies		
Avoidant coping	More evidence of avoidant coping and a lack of recognition about the implications of using this strategy	More accepting and able to implement a variety of coping strategies
Support network	Less support generally accessed from friends and services	More likely to have established a support network and recognise the importance of this in helping them cope

Carers with greater metacognitive capacity seemed to adopt proactive coping strategies based on acceptance, although the difficult journey they have had to acceptance is apparent in the narratives.

Tim: *“So you get used to them, you cope, and try and look for ways that will help. One way or another.”*

They used various methods to reach this point of acceptance. Gill found it useful to compare Tony’s mental illness to someone with a physical illness,

Gill: "It could have been something else, as I used to say to Tony, he would say "Why me?", and I would say it could have been something else, you know 1 in 100, he could have been a diabetic child and we would have learnt to deal with that."

A common theme among caregivers with a greater metacognitive capacity was 'loss' or 'grief' at the life they wanted their relative to have, recognising and being able to articulate this loss and the sadness associated with it.

Natasha: "I just feel so sad about it all really. He's not going to get married... we just try and make life as good as we can for him really."

These carers have also recognised, either themselves or through help from services, that they need adequate support from external agencies. These carers recognise the importance of this help for their relatives' quality of life and recovery, but also for their own well-being.

Gill: "I was beyond making any decisions and he certainly wasn't going to come to my house which sounds mean, but I now fully understand that was the best answer."

It is unclear whether the acceptance of the longer term effect of the illness preceded this help, or whether she sought help once she realised it was beneficial for the recovery of

her relative and their quality of life. It could also have simply coincided with getting appropriate support from a psychosis service.

Coping strategies used by carers with greater metacognitive capacity tended to include strategies such as recognising they needed to feel they were helping the relative in recovery, or helping to try to improve services for future carers and their relatives and/or using humour.

Tim: "... so it's quite interesting talking to people who don't know about the problem and look terribly serious when you try and explain Will's problems and whatnot. And actually you say we find some of this quite funny, you have to."

These carers also reflected on the difficulties they had talking to friends about their relatives illness initially. However, all carers with greater metacognitive capacity appeared to now have supportive networks of friends who they felt listened to what they had to say in a non-judgemental way.

Carers with middling metacognitive capacity, seemed to have longer periods of struggling to make this adjustment from using an avoidant strategy to one of acceptance, or were still in the process of doing so. However, they were able to recognise and reflect on this due to their greater metacognitive capacity.

Theresa: "I just can't believe how awful it was. Mostly now it's just, after 30 years I finally think I'm fairly accepting of how it is. As the memory fades of what it was like before, how he was, the

potential loss and everything. Now it's just a part of life I suppose. But if I allow myself, if I don't keep busy enough, I have to think it's just... so ghastly. That level of mental illness is just totally devastating...I always think some of it I tried not to hear."

Carers with a lower metacognitive capacity were more likely to use avoidant, or emotionally focussed coping strategies. They did not seem to recognise they were being avoidant. There was also no reflection, or understanding, on the methods they use to cope with their relative's illness.

A theme among carers with a lower metacognitive capacity, was the recognition that at some point they would have to access more resources for their relative and take a step back, as they were finding it difficult to cope. Carers with lower metacognitive capacity also seemed to have more difficulty accessing supports, primarily from friends and family, denying there is a problem or not feeling they can talk to them.

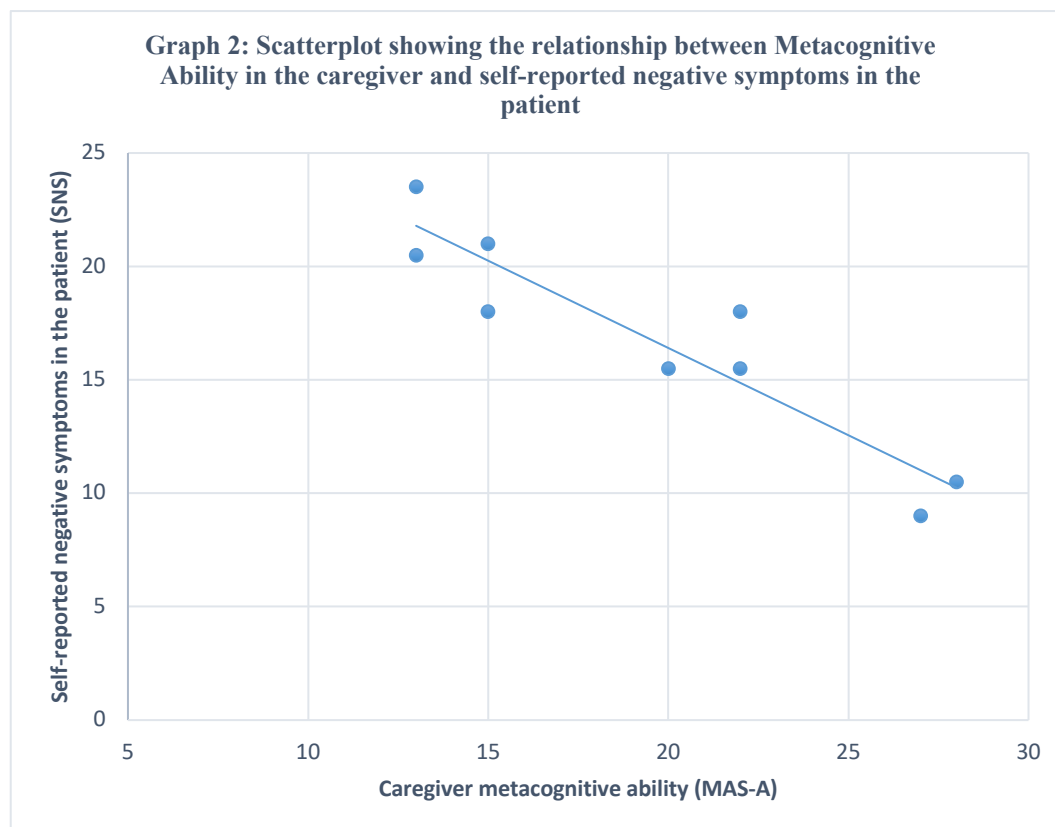
Exploratory quantitative data analysis

Descriptive statistics are provided for all measures in the table below. The mean MAS score for participants was 16.83, a 'Medium' level MAS Score. There were low levels of significant distress in five out of nine caregivers (having a GHQ-case score of <5), in comparison to 50% ($n=20/40$) in Jansen et al. (2014). Four out of nine caregivers could be characterised as critical (scoring ≥ 23 on FQ, CC subscale), and four could be characterized as emotionally overinvolved (scoring ≥ 27 on FQ, EOI subscale). These groups were not mutually inclusive. There was a higher proportion of caregivers categorised as critical and/or EOI than in the Jansen et al. (2014) study.

Table 3: A table showing descriptive statistics of quantitative measures

	Patient measures	Caregiver measures				
		<i>ECI negative</i>	<i>ECI positive</i>	<i>EOI</i>	<i>GHQ-30</i>	<i>MAS-A</i>
	<i>SNS</i> (n=9)	(n=8)	(n=8)	(n=7)	(n=7)	(n=9)
Mean	18.88	96.25	30.5	28.29	4.43	16.83
Range	13-28	65-123	12-41	25-33	0-14	9-23.5
Standard deviation	6.08	22.32	11.08	3.25	4.86	4.78
Benchmark from Jansen et al. (2014)	n/a	74.73	25.90	n/a	n/a	

It is important to highlight only 9 patient/carer dyads were included in this study due to the recruitment challenges faced. However, there was a significant negative bivariate correlation between the patients score on the SNS and their MAS score ($r = -0.915$, $p > 0.01$). Graph 2 shows this negative correlation, with relatives of caregivers with a greater metacognitive capacity reporting less negative symptoms than those with lower metacognitive capacity.



There was also a significant positive correlation between a positive score on the ECI and the negative score on the ECI ($r = 0.793$, $p > 0.01$). Relatives who reported a higher negative score on the ECI were also likely to report a higher positive score. However, as this scale was only completed by 5 carers, it should be interpreted with caution. Further descriptive statistics and correlations are included in Appendix 12, p125.

Discussion

Evidence from the thematic analysis by metacognitive capacity, supports our original primary hypothesis. Metacognitive capability of the caregiver appears to influence caregiver experience, attributions and appraisals made by the caregiver, illness beliefs, coping strategies adopted as well as shaping their interaction with their relative. These findings add further support to those reported by Jansen et al. (2014). Albeit in a FEP sample, they found greater metacognitive ability in carers does not necessarily reduce

distress but may help broaden the perspective of caregivers, therefore positively influencing the stress-appraisal-coping framework. Higher levels of metacognition are likely to increase the capacity to understand the complex reasons patients behave the way they do, thereby reducing negative appraisals of symptomatology and simplistic and hostile/critical attributions. For example, instead of thinking the person they are caring for is lazy, and deliberately not helping them/ causing the carer elevated levels of stress, they would recognise the negative symptoms as symptoms of an illness. However, It is important to highlight that alternative interpretations of the data should also be taken into account. Although higher levels of metacognition are likely to increase the capacity to understand complex reasons patients behave the way they do, so do other variables including level of education and other related socioeconomic advantages (e.g. time, additional social support, etc). These must also be considered as potential alternative interpretations for greater capacity of understanding and subsequent reduction of negative appraisals of symptomatology and simplistic attributions.

Metacognition and the development and maintenance of negative symptoms

Our study also aimed to add to the evidence base by providing exploratory data on metacognition in the caregiver and negative symptoms. There was a negative correlation between caregiver metacognitive capacity and patient self-reported negative symptom presentation, albeit with a small sample size of patient/carers. Patients who have high self-reported negative symptoms may have caregivers with lower metacognitive capacity, showing negative symptoms may be developed (at least in part) in a relational context.

There are two plausible interpretations of these findings. As hypothesised, it could be that caregivers with lower metacognitive ability contribute to the development of negative symptoms in the patient. Relatives with psychosis may develop lower metacognitive abilities and an increased negative symptom presentation as a way of avoiding unpleasant interactions with a caregiver. This could be in response to a caregiver exhibiting high levels of emotional over involvement, or criticism, and negative symptoms could be developed as a way of protecting themselves from this interaction with the caregiver.

An alternative explanation, is that carers of people with severe negative symptoms could protect themselves against negative affect by closing themselves down to their own and their relatives' mental states. This phenomenon is highlighted by McGlashan (1987) in relation to difficulties people with psychosis have in processing their experience, which can result in 'sealing over.' It is plausible that carers may respond in a similar way to minimise the impact the relationship with the carer has on themselves. Braehler & Schwanneur (2011) highlight this is more likely to happen in people with an insecure attachment and more adverse childhood experiences.

As stated previously, carers with a lower metacognitive ability tended to have relatives who could be perceived as being less far along in their recovery journey (higher negative symptoms and less recently hospitalised). However, they were also less likely to be engaged with services than patients with caregivers with a higher metacognitive capability. It is plausible that due to their lower metacognitive capacity they are less able to access appropriate services, also hampering recovery outcomes. This view is further supported by a recent study by Jansen, Lysaker, Traulsen, Luther, Haar, Lyse, Pedersen and Simonsen (2017) who explored whether higher levels of mastery (a

subscale of metacognition) would predict better outcomes for patients. When exploring treatment history, they found greater levels of mastery were related to decreased DUP., with these findings persisting even when symptom severity was controlled for. This means that caregivers with higher mastery levels help the caregiver get their relative to enter treatment sooner rather than waiting for even greater crises.

Clinical implications

This study highlights the importance of involving caregivers in the treatment of relatives. This is important for the wellbeing of the carers, as well as potentially improving recovery outcomes for patients. Services and therapies for people with predominantly negative symptoms might be improved by taking into account patients and carers ability to mentalise, and how maintenance of ability in each could be relational.

It is also likely caregivers would also benefit in compiling a narrative about their experiences. This sense of being on high alert may indicate they are having a trauma reaction due to their experiences as a caregiver. Staff in acute services and psychiatric rehabilitation services need to be aware of the likelihood of this happening to caregivers of people with psychosis, and potentially screen for these reactions. Barton and Jackson (2008) found emotional disclosure can help carers who are experiencing trauma symptoms following a relative's first episode of psychosis, albeit in a relatively small pilot study. It is likely an approach similar to this would also benefit carers of those with persistent psychosis and should be explored further. Applying a grief model to psychosis might not only help the person with psychosis empathise with their own emotional reactions, it may also help their carers. This clinical support is especially important in caregivers of those with persistent psychosis, as they tend to be an ageing population, so may have additional health issues of their own.

Limitations

This study has several limitations. The key limitation is the design of the study as it does not allow any conclusion to be made in relation to causation. Firstly, a small sample size was obtained, due to the difficulties with recruiting this population, meaning there is an increased possibility of a Type-I error. Secondly, there is no control for other potentially confounding variables. Although findings could indicate a relational component to the development of negative symptoms, there are numerous other factors which could affect this, including level of education of carers and levels of social deprivation. It cannot be ignored that carers with a greater metacognitive capacity, also appeared to be those living in less socially deprived areas, with better education. How much of that is due to their metacognitive ability? Or their social situation and accessing of appropriate services? These are questions this study could not answer due to limitations in study design.

Conclusion and future research

Greater metacognitive ability is likely to positively influence the caregiver experience and the stress-appraisal-coping framework. Higher levels of metacognition appear to increase the capacity to understand the complex reasons patients behave the way they do, thereby reducing negative appraisals of symptomatology and simplistic and hostile/critical attributions. The current study has also provided some interesting exploratory findings to add to the emerging evidence base for metacognitive ability in caregivers and the development and maintenance of negative symptoms.

These findings warrant further exploration but with a larger sample of patient/carer dyads. These should be obtained by using pre-existing sampling frameworks from

larger studies, as shown in several studies included in the systematic review (Hjarthag et al, 2010; Onwumere et al., 2011). Recruiting from inpatient and outpatient wards on an individual level is not going to provide the necessary sample size for appropriate analysis, including controlling for other relevant variables.

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Edited By: Katherine Berry and Sandra Bucci

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Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies and [Registered Reports](#). The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of

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Institute of Health
& Wellbeing

DOCTORATE IN CLINICAL PSYCHOLOGY

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Matriculation Number:

Name of Assessment: MRP Proposal

Title of Project: Metacognition in caregivers of patients with psychosis and negative symptoms: Caregiver experience, emotional overinvolvement and distress

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Metacognition in caregivers of patients with psychosis and negative symptoms:

Caregiver experience, emotional overinvolvement and distress

Background. There is preliminary evidence that greater metacognitive ability can affect positive experiences of caregiving in carers of people with psychosis (Jansen et al., 2014) but more exploratory research is needed.

Aim. The current study aims to replicate and extend previous findings by further examining how caregiver metacognitive ability impacts on caregiving experience, emotional overinvolvement and distress. It will also explore associations between caregiver metacognitive ability and negative symptoms in service users.

Methods. Thirty-five patients/carer dyads will be recruited from late 2017 - 2018. All patients with negative symptom presentations on clinicians caseload (in forensic and non-forensic clinic settings) and will be approached to take part in the study. Once consent has been obtained to complete and pass the research instrument to the research team, the patient will complete the self-report instrument (Self-evaluation of Negative Symptoms, SNS). Once the questionnaire is analysed, if the patient is eligible a local clinician (e.g. nurse, ward psychologist) will then approach a caregiver(s) during visiting time. Potential carer participants will be invited via a letter from the researcher, given an information sheet and asked to complete a permission slip for their details to be passed onto the research team. Those who agree to their details being passed on will be contacted via telephone and will be invited to participate in a structured interview. The Indiana Psychiatric Illness Inventory (IPII) will be used in the interview to gather information about an important life change (becoming a carer of someone experiencing psychosis), which will be coded using the Metacognitive Assessment Scale - Abbreviated (MAS-A). We will also measure perceived attribution and control over negative symptoms using the Experience of Care Inventory (ECI); the Family Questionnaire (FQ) and the General Health Questionnaire-30 (GHQ-30).

Applications. The findings will add to the evidence base and help to decide whether treatment to improve metacognitive ability in caregivers should be further developed.

Introduction

Many relatives in a caregiving role for people with schizophrenia experience a high level of psychological distress, reduced quality of life and financial constraints (Jansen, Lysaker, Harder, Haahr, Lyse, Pedersen, Traulsen & Simonsen, 2014).

There is a substantial body of literature focussing on Expressed Emotion, a composite measure of relatives' reported attitudes and behaviour towards the patient. Barrowclough and Parle (1997) defined high EE as a relationship between patient and caregivers characterised by criticism and/or emotional overinvolvement (EOI). High levels of caregiver burden has been related to higher levels of EE, which acts as a psychosocial stressor that can precipitate relapse and possibly initial episodes of psychosis.

Despite this important role in illness exacerbation, EE is far from understood (Jansen et al., 2013). There are several theories that postulate EE is an attempt to influence the behaviour of the patient, often with the best intention of helping (van Os, Marcelis, Germeys, Graven & Delespaul, 2001). Others view EE according to the relatives' appraisal of circumstances. For example, low EE carers make significantly more positive attributions about positive events and fewer about negative events than high EE carers (Grice, Kuipers, Bebbington, Dunn, Fowler, Freeman, Garety, 2009). They also found high EE carers were more likely to have difficulty making sense of others' actions and mental states and use fundamental attribution error, attributing the cause of bad events to internal, stable and enduring aspects of the persons' mind.

Metacognitive ability

The way that people think about their own and others mental states (metacognition) can inform understanding of EE and impaired functioning. The term relates various traditions such as theory of mind and mentalisation. These refer to very similar processes about the understanding of one's own mind as well as the minds of others. Metacognition is used as an umbrella concept to refer to a number of subfunctions including understanding of the self and others; putting this understanding in the context of seeing the world as existing with others and using it to find solutions when faced with interpersonal challenges or conflicting emotions. There is accumulating evidence that metacognition is a key factor in the development and maintenance of negative symptoms (Lysaker et al., 2007; Hamm et al., 2012).

The Impact of Metacognition on Negative Symptoms

The concept of positive and negative symptom presentation can be traced to the early 19th Century, where the distinction is made between symptoms that are abnormal because of their presence (e.g. hallucinations, tremor) and those which reflect reduced or lost normal functioning (Carpenter, Heinrichs, Wagman, 1988). In more recent studies, negative symptoms are often summarised as the 'five A's'; including affective flattening, alogia, anhedonia, associativity and avolition (Kring, Gur, Blanchard, Horan & Reise, 2013). Patients with a negative symptom presentation generally have a poorer prognosis than those with predominantly positive symptoms. Negative symptoms are also thought to have a greater impact on daily functioning than positive symptoms (Rabinowitz, Levine, Garibaldi, Bugarski-Kirola, Berardo & Kapur, 2012). Despite research showing that severe negative symptoms are found in as many as 28-36% of patients with a diagnosis of schizophrenia, historically less attention in research and clinical practice has been paid to negative symptoms (Blanchard, Horan & Collins, 2005; Dolfus 2015). This is likely because negative symptoms are considered

more treatment resistant (Kirschner, Aleman & Kaiser, 2016). However, given the strong effects of negative symptoms on caregiver burden plus their effects on functioning, there is a need for more research aimed at elucidating the factors that affect negative symptom expression and impacts.

Several studies have explored the impact of metacognitive ability and negative symptom presentation, finding patients with primary negative symptoms were more likely to perform poorly on tasks important for social interaction (Corcoran, Cahill & Frith, 1997). McLeod, Gumley & Schwannauer (2014) summarised studies that examined the relationship between MAS or MAS-A Metacognition Scores and Negative Symptom Ratings and concluded that impoverished metacognitive functioning may have a specific impact on negative symptom formation and maintenance. For example, if a person has difficulty thinking about their own thoughts, desires, goals and sources of enjoyment, it will likely lead to negative symptoms such as loss of drive and diminished engagement in goal orientated behaviour. Poor ability to think about the mind of others in a complex or nuanced way may lead to simplistic and critical attributions about negative symptoms by carers, for example, judging the patient as lazy or deliberately socially avoidant. McLeod et al. concluded there is, “clearly scope for translating the findings of research on cognitive processes such as metacognition into scientifically informed and effective treatment protocols”.

Metacognitive capabilities of caregivers

Contemporary metacognition research has not ascertained how metacognitive abilities may impact the relationship between caregivers and service-users. A recent study by Jansen et al.⁶ (2013) examined metacognitive capacities in family members of people with first episode psychosis. Findings showed greater metacognitive ability does not necessarily reduce distress but may help broaden the perspective of caregivers. Higher levels of metacognition increase the capacity to understand the complex reasons patients behave the way they do, thereby reducing simplistic and hostile/critical attributions.

The present study will aim to replicate the Jansen et al study in people with more chronic and enduring symptoms. We will also extend the Jansen et al. (2013) study by examining the relational context of metacognitive ability and negative symptom presentation. By examining the metacognitive ability of caregiver(s) alongside negative symptom presentation of patients it will be possible to explore the relationship between caregiver(s) and patient's metacognitive ability. It is plausible that metacognition in patients may reflect or emulate the ability of primary carers'; implying metacognition is, at least partially, learnt in a relational context. This will add to the evidence base on the development of metacognitive ability and negative symptom presentation. For example, patients may develop lower metacognitive abilities and negative symptom presentations (such as avolition) as a way of avoiding unpleasant interactions with a caregiver. This pattern may be shaped over a long time scale and could begin prior to the development of initial symptoms and onset. This further evidence can then be used to inform development of family interventions for people with a negative symptom

⁶ To the authors' knowledge, this study is the only one of this kind to use MAS-A to assess metacognition in caregivers of persons with first-episode psychosis.

presentation and subsequently improve the outcomes for these patients, who have a poorer clinical outcome and arrested recovery (Milev, Ho, Arndt & Andreasen, 2005).

Aims and hypotheses:

The study will explore:

- the strength of associations between the metacognitive ability of the caregiver; caregiver attributions; emotional over involvement and levels of distress.
- if metacognitive ability in caregivers of people with psychosis is associated with type and severity of negative symptom presentation displayed by the patient.

The following hypotheses are made, based on the Jansen et al., (2013) paper:

- The current study will replicate the findings, in the Jansen et al. (2013) study and caregivers who have greater levels of metacognition will report having more positive experiences of caregiving.
- Caregivers who report greater levels of distress and overinvolvement will report having more negative experiences of caregiving.

Plan of investigation

Design and participants

We will use a cross sectional design derived from previous research (Jansen et al., 2013).

Target recruitment is 35 patient/caregiver dyads⁷ (slightly fewer than the sample used in the Jansen et al., 2013). To ensure the current study is sufficiently powered, we used the Pearson correlation coefficients from Jansen et al. (2013) and calculated the average of the EOI, Distress and MAS-A effect sizes. We used the total average of these effect sizes to generate a

⁷ One dyad includes one caregiver and one patient.

composite effect size. Using G*Power 3.1 (see table below) a sample size of at least 32 will be need to detect a medium effect size ($r=0.43$) at 80% power (2 tailed).

Table 1. Pearson correlations from the Jansen et al. (2013), average effect size calculations and G*Power sample size calculation for current study. Positive and negative caregiver experience, EOI, wellbeing and capacity for metacognition.

	Positive experiences	Negative experiences	Average effect size	G*Power sample size calculation n (based on an averaged effect size = .43)
EOI	0.191	0.665*	0.428	
Distress (GHQ-30)	0.024	0.621*	0.3225	
Capacity for metacognition (MAS-A)	0.518*	0.030	0.533	
Total average effect size			0.43	32

EOI = emotional overinvolvement; GHQ-30 = General Health Questionnaire 30 item version; MAS-A = Metacognitive Assessment Scale Abbreviated. * $p < 0.01$.

Inclusion/exclusion criteria

All patients will be:

- men/women over 18 years;

- have a primary diagnosis of ICD-10 criteria for Schizophrenia Spectrum Disorders;
- Had more than one episode of psychosis;
- and have a predominantly negative symptom presentation.

The following patients will be excluded from the study:

- Individuals with first episode psychosis will be excluded from the study (due to the already heterogeneous nature of patients' with first episode psychosis);
- those with predominantly a positive symptom presentation and;
- patients' caregivers who do not speak English.

In previous studies of caregivers of patients with psychosis, there has been little clarity about the operational definition of a "caregiver." For the purpose of this study we have adapted the definition provided in Scazufca & Kuipers (1996) paper (p580). The definition is adapted to, "a relative living or in close contact with the patient (at least once a week) either currently, or in the 3 months prior, to the admission."

All caregivers will also be:

- men and women over 18 years of age;
- carers of people who have met the above criteria;

Caregivers who do not speak English will be excluded from the study.

Recruitment

A combination of forensic and non-forensic settings will be used to recruit caregivers for the current study. Clinical Psychologists at several sites in NHS Greater Glasgow and Clyde and NHS Lothian will approach all patients on their caseload exhibiting negative symptoms. This will help to reduce selection bias. Clinicians will make the initial approach, fully explaining the study and give an information sheet about the study for patients to keep. They will also gain

consent by asking the patient to sign a consent form. Patients who consent to take part will be asked to complete the SNS (Self-evaluation of Negative Symptoms scale). A cut off point of 12 on the SNS is currently deemed to detect people with a significant problem with negative symptoms. Clinicians will calculate the score on the SNS and tell the patient if they are eligible to take part and if so, explain the next steps. If a patient scores below 12 on the SNS, the clinician will explain to the patient that their symptom pattern is not in the range required for inclusion in this study. Those who are below the SNS cut-off will be thanked for their participation and told that they do not need to do anything further for the research. The research team will also ask staff to confirm the relative predominance of negative symptoms and absence/minimal impact of positive symptoms as a further confirmation check. Subsequently, the SNS questionnaire and the signed consent form will be given to the researcher via the lead clinician.

Patients will also be asked if the clinician (or a member of their healthcare team) can approach one or two caregivers to participate in the research. If they agree, the clinician will approach the caregiver(s) during visiting time to take part in the study. The clinician will fully explain the study and give them an envelope from the research team containing study documents. This will contain an introductory letter, information sheet and a permission slip, which they will sign to consent to their details being passed onto the research team. The decision by the carer(s) will be noted in the patient's records to ensure an audit trail is available. They will be given at least half an hour to read the information, or offered some help in reading it (if necessary). If they require longer to decide whether or not they want to take part, the caregivers can choose whether they would like to give their details for a researcher to contact them by telephone at a later agreed date or whether they would like to tell the healthcare staff of their decision at one of their next visits by returning the slip. The caregivers will have until December 2018 to return the slip and take part. Those who give permission to being

approached by the research team, will be telephoned and an appointment scheduled to complete a full interview, where written consent to take part in the interview will be collected. At interview they will also be asked to complete three questionnaires on their experiences of caregiving.

Measures

The Self-evaluation of Negative Symptoms (SNS) – This self-report measure was developed from the verbatim accounts of negative symptoms described by patients. Responses are on a 3-point scale: “Strongly agree”, “Somewhat agree” or “Somewhat disagree” for 20 items exploring experiences during the previous week. Cronbach’s coefficient ($\alpha = 0.867$) suggests good internal consistency. The SNS significantly correlated with the Scale of Assessment of Negative Symptoms ($r = 0.628$) supporting good convergent validity.

Indiana Psychiatric Illness Interview (IPII) – Adapted form: The IPII was originally designed to assess illness narratives in patients with Schizophrenia (Lysaker, Clements, Plascak-Hallberg, Knipscheer & Wright, 2002). In line with previous studies examining metacognitive ability in non-clinical populations, we will modify the instrument in collaboration with its first author (Paul Lysaker)(Rabin, Hasson-Ohayon, Avidan, Rozencwaig, Shalev & Kravetz, 2014; Jansen et al., 2013). In line with these studies, the IPII will be modified so instead of asking about their psychiatric illness, participants will be asked about an important life challenge – being a caregiver. The interview typically lasts 30-60 mins and is audiotaped and transcribed. In Jansen et al. (2013) the IPII was divided into five sections. First rapport is established by asking the caregiver to tell the story of their family in as much detail as possible start with the birth of the child (if the carer is a parent) or the first meeting with the person with a diagnosis of schizophrenia (if the person is a significant other). Second, they are asked whether they feel the person they are caring for has a mental illness. Thirdly, they are asked to consider whether

this has had any influence on their lives and fourthly, how being a caregiver controls their lives and how they cope with it. Finally they will be asked how they think the patient's need for care will develop in the future. There are no direct questions of specific symptoms and the interviewer only asks for clarification when confused. This approach will be replicated in the current study. The sole purpose of the IPII is to provide the information needed to apply the Metacognitive Assessment Scale – Abbreviated (MAS-A), to ascertain their metacognitive ability.

Metacognitive Assessment Scale – Abbreviated (MAS-A): The MAS was originally designed to assess metacognitive abilities and was designed to be used on psychotherapy transcripts. The MAS-A is a modified version adapted to use on IPII transcripts (Lysaker et al, 2011). We will be applying the MAS-A to IPII transcripts (discussed above) to ascertain metacognitive ability. This abbreviated version contains four scales: “Understanding one’s own mind”, “Understanding of others’ minds”, “Decentration” and “Mastery”. Decentration refers to the ability of seeing the world as existing with others and Mastery refers to the ability to use the first two scales to find solutions when faced with conflicting emotions or interpersonal challenges. Higher ratings on each scale reflect metacognitive ability, with a maximum score of 28.

Experience of Care Inventory (ECI) – This inventory is designed to measure subjective experience of caregiving for a patient with “serious mental illness” (Jansen et al., 2013). The 66 item self-report questionnaire consists of 10 subscales, including 8 areas of negative caregiving and two positive. It measures how often caregivers have thought about each of these issues over the last month. Items are scored on a 5 point Likert scale, with a maximum score of 208 for the negative subscale and 56 for the positive subscale.

Family Questionnaire (FQ) – The FQ is used to assess caregivers' level of EE (Wiedemann, Rayki, Feinstein & Hahlweg, 2002). The 20 item self-report questionnaire focuses on how families deal with everyday challenges, especially negativity and emotional over involvement. The measure consists of two subscales: Critical Comments (CC) and EOI. Critical comments are unambiguous statements of disapproval or resentment, rejecting remarks or statements. EOI refers to self-sacrifice, over protection or over identification with the patient. Items are scored from 1 to 4, with a maximum of 40 in each subscale. Caregivers scoring 23 or greater on CC are classed as High EE; or if they score greater than 27 on the EOI subscale.

General Health Questionnaire (GHQ-30) – This general measure of wellbeing and distress will be measured using the GHQ-30 (Goldberg & Williams, 1988). The 30-item self report involves rating how often particular symptoms occur on a likert scale ranging from 0 to 3. The total score varies between 0 and 90.

Procedure

Consent will first be obtained to take part in the study by asking caregiver's to sign a consent form. They will then be interviewed with the IPII, followed by completing three questionnaires: the ECI, the FQ and the GHQ-30 (as in Jansen et al., 2013).

The expected average length of interview will be 1 hour. The IPII will be audiotaped and later transcribed. The ratings of the transcripts will solely be used to establish the metacognitive ability of the caregiver (using the MAS-A). This coding will be completed before analysing the data from the ECI, FQ and GHQ-30 to prevent bias. Ratings using the MAS-A will be randomly checked by the MAS-A developer.

Health and Safety Issues

Interviews will be conducted on multiple sites, as interview locations will be dependent on the site where the participant was recruited. If recruited from a hospital, a clinical room will be reserved for the researcher to undertake the interview at that location. If recruited in a forensic setting a clinical room will be available for the researcher to undertake the interview at the place where they were recruited. There will be an alarm system in place in the interview room. The researcher will be informed about the security alarm protocol on arrival. Further details are offered in the Health and Safety form in the appendices. There are no participant safety issues other than ethical considerations, covered in the Ethics section.

Data Analysis

The following table details the aims and objectives alongside the analytical approach, which will be used to answer the questions.

<i>Aims and objectives</i>	<i>Analysis</i>
The study will explore the strength of associations between the metacognitive ability of the caregiver; caregiver attributions; emotional over involvement and levels of distress.	Associations between metacognitive ability, caregiving experience, distress and attributions will be explored with parametric correlations (or non-parametric equivalents) using the same approach as Jansen et al. (2013). If more than one caregiver is recruited from a family, these data will be pooled (i.e. each respondent can be treated independently).

<p>The study will explore if metacognitive ability in caregivers of people with psychosis is associated with type and severity of negative symptom presentation displayed by the patient.</p>	<p>Correlations between metacognitive ability of caregivers (score on the MAS-A total) and SNS data will be calculated to explore whether metacognitive ability of the caregiver is associated with negative symptom presentation in the patient.</p> <p>These exploratory analyses do not imply any causal association or direction of effect. Where more than one family carer is a respondent, the dyad pairs will be analysed separately. It is unlikely there will be many dyad pairs so reporting will only describe any patterns in the data.</p>
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Inter-rater reliability will be assessed for a sample of transcripts (n=3). Cronbach's alpha will be reported for each measure as an estimate of reliability of a psychometric test and to explore the expected correlation of two tests measuring the same construct.

Dissemination

The author will prepare the results of the research as a thesis in partial fulfilment of the Doctorate in Clinical Psychology at the University of Glasgow. A copy of the thesis will be stored in the University library. There is also the intent to publish the findings in a scientific journal, as advised by the academic supervisor, and present at a conference if feasible. All patient and caregiver participants will be approached to see if they would like key findings in a plain English summary written by the research team. If they express interest, these will be sent to them using their preferred method (postal or email).

Ethics

Local governance and research approval processes will be followed for all sites. Submissions will also be made to NHS REC's because of the vulnerable nature of the sample. R&D approval will also need to be sought.

Participant information sheets detailing the study for patients and caregivers will be in an accessible format and in correspondence with the NHS GG&C Accessible Information Policy. Information given to participants will make it clear they can withdraw from the study at any point and this will not effect their treatment or rights in anyway. No information potentially identifying participants will be identified in the write up.

Data will be stored in accordance with the Data Protection Act, local and national guidance and legislation. The transcripts of the interviews will be anonymised and password protected. These will be kept for a minimum of 10 years following completion of the study. The questionnaire data will be stored in a locked filing cabinet and also retained for 10 years. All electronic data files will also be anonymised and password protected. The unique identifiers will be stored in a separate encrypted folder. The Data Protection Act will be adhered to and the efficacy of obtaining caregiver information from patients will be scrutinised.

Financial Issues

In line with guidance from the handbook the programme has limited resources to support trainee research so costs should be kept to a minimum for all projects. Further details on cost are provide in the Research Equipment form. I can confirm that the costs for this project will total approximately £79.20. I plan to use the twenty GHQ-30 questionnaires currently in the department and am waiting on permission to use the remaining 15 for free.

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Appendix 3 – Ethics approval letter

WoSRES

West of Scotland Research Ethics Service

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Version 2 – GP letter for carers updated at students request

Dear Dr McLeod

Study title: Metacognition in caregivers of people with psychosis
exhibiting negative symptoms: Caregiver experience,
emotional over involvement and distress
REC reference: 17/WS/0208
IRAS project ID: 230357

Thank you for your letter of 24 January 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Appendix 4 & 5 – Information sheet for patients and carers (version 11 and 9)

UNDERSTANDING HOW CARERS THINK ABOUT PEOPLE EXPERIENCING PSYCHOSIS WITH NEGATIVE SYMPTOMS

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

WHAT ARE NEGATIVE SYMPTOMS?

The experience of psychosis can involve 'positive' and 'negative' symptoms. Positive symptoms are unusual experiences such as hearing voices or holding beliefs not shared by others. Negative symptoms reflect a loss or reduction in usual experiences or behaviour, for example diminished ability to pursue goals, to socialise or feel motivated. People experiencing negative

symptoms generally have a more difficult recovery and may be much less responsive to drugs or psychological therapy.

WHY IS HOW CARERS' THINK IMPORTANT?

It is important to understand how carers' think about people experiencing negative symptoms as it may help inform new treatment approaches and strategies. The exact cause of negative symptoms is still under investigation. However, one possibility is that these problems are related to difficulties with having complex thoughts about others. This difficulty may develop in response to interpersonal pressures or difficulty with coping. There is some evidence that as patients start to find it harder to think about their (or others) thoughts, they also develop negative symptoms.

WHY HAVE YOU BEEN ASKED TO TAKE PART?

You have been asked because you are (or have been) an inpatient in Glasgow or Edinburgh. You have experienced psychosis and been identified as someone experiencing negative symptoms.

WHAT IS INVOLVED?

If you provide written consent to take part, you will be asked to complete a questionnaire about your symptoms (this will take about 5 minutes). You will then be asked to choose one or two people who care for you (and either live with you or have weekly contact with you), to invite to take part in the research. For example, this could be a member of your family or a significant other. If you show the negative symptom profile we are examining, your carer(s) will be invited via letter delivered by a member of your healthcare team to take part in the study. Those who agree to take part will then be contacted by telephone. An interview about their experiences as a carer will be arranged at a time and place convenient to them, where they will also be asked to complete 3 questionnaires (taking approx. 1 hr). We will let your GP/psychiatrist know you are taking part.

DO I HAVE TO TAKE PART?

No. It is up to you whether you take part or not. If you do not agree (or agree and withdraw later) this will not affect the medical care you receive. If you agree but

your carer doesn't, we will still use your data. If you withdraw at a later point, your carer will still be able to independently decide if they want to take part.

CONFIDENTIALITY

All information collected will be kept confidential (unless the team are told anything that is worrying about your safety or someone else's and then this information will be passed onto your care team and your GP). We will keep your details and results from the study electronically in encrypted files for 10 years to ensure that it is available if necessary for representatives of the study sponsor to make sure the study was conducted correctly. Only the research team (or audit team) will access this data. We won't use names in the report or anything that could identify you. The information your carer provides will not be shared with you but we will ask you if you would like a summary of the results of the study at the end of your participation. The study will be used in scientific publications and as part of a doctoral thesis. **If you have any questions about the research, please contact: Amy Homes, researcher by email (a.homes.1@research.gla.ac.uk, Tel: 0141 211 0607); Hamish McLeod, supervisor (hamish.mcleod@glasgow.ac.uk); Tom McMillan, independent contact (Tom.mcmillan@glasgow.ac.uk). If you choose to raise a complaint about any part of this study, please call on 0141 201 4500 or email on complaints@ggc.scot.nhs.uk.**



UNDERSTANDING HOW CARERS THINK ABOUT PEOPLE EXPERIENCING PSYCHOSIS WITH NEGATIVE SYMPTOMS ¶



We would like to invite you to take part in a research study about how carers think about people experiencing the negative symptoms of psychosis. Before you decide to participate you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. ¶



WHAT ARE NEGATIVE SYMPTOMS? ¶

The experience of psychosis can involve 'positive' and 'negative' symptoms. Positive symptoms are unusual experiences such as hearing voices or holding beliefs not shared by others. Negative symptoms reflect a loss or reduction in usual experiences or behaviour, for example diminished ability to pursue goals, to

socialise or feel motivated. Patients experiencing negative symptoms generally have a more difficult recovery and may be much less responsive to drugs and psychological therapy. ¶



WHY IS HOW CAREGIVERS THINK IMPORTANT? ¶

It is important to understand how carers think about people with negative symptoms as it may help inform new treatment approaches and strategies. The exact cause of negative symptoms is still under investigation. However, one possibility is that these problems are related to difficulties with having complex thoughts about others. This difficulty may develop in response to interpersonal pressures or difficulty with coping. There is some evidence that as patients start to find it harder to think about their thoughts or those of others they also develop negative symptoms. We are interested in exploring what carers think about patients' negative symptoms. ¶



WHY HAVE YOU BEEN ASKED TO TAKE PART? ¶

You have been asked because you are a carer either living with (or who has weekly contact with) someone with a diagnosis of schizophrenia experiencing negative symptoms. They have already consented to take part in the study and have agreed for a member of their healthcare team to approach you. ¶

WHAT IS INVOLVED? ¶

If you agree, your contact details will be passed to the research team. You will be contacted by telephone and the researcher will organise an interview with you. At the interview you will be asked for written consent to take part in the study and questions (about the story of your family or relationship with the patient; whether you feel the person has a mental illness; how much this has influenced your life; how much being a carer controls your life and how you feel the patient's need for care will develop in the future.) You will also be asked to complete three questionnaires (about your experience as a caregiver). The interview will last an hour and will take place in a private room where the person you care for is staying/has stayed. This could be done at a time convenient to you such as before/after a visit. ¶

¶

DO I HAVE TO TAKE PART? ¶

No. It is up to you whether you take part or not, and you have until December 2018 to decide. If you do not agree (or agree and withdraw later) this will not affect the medical care the person you care for receives. If you agree and decide to withdraw from the study later, you can do [this](#) and we will not keep your data. The person you care for will still be able to independently decide if

they want to take part, although the purpose of the study is to include you both. ¶

CONFIDENTIALITY ¶

Your interview will be recorded and transcribed. All personal information will be removed from the transcript and the file will be encrypted and given a password. All information collected will be kept confidential (unless the team are told anything that is worrying about your safety or someone else's and then this information will be passed onto your GP and/or the healthcare team involved in the study as appropriate). Your GP will be notified you are taking part in the study but not given any confidential information. We will store all study data securely. Only the research team (or audit team) will access this data. We won't use names or anything that could identify you in the study report. If you choose, we will provide you with a summary of the results of the study at the end. The study will be used in scientific publications and as part of a doctoral study. ¶

If you have any questions about the research, please contact: Amy Homes, researcher by email (a.homes.1@research.gla.ac.uk, Tel: 0141 211 0607); Hamish McLeod, supervisor (Hamish.mcleod@glasgow.ac.uk); Tom McMillan, independent contact (Tom.mcmillan@glasgow.ac.uk). If you choose to raise a complaint about any part of this study, please call on 0141 201 4500 or email on complaints@ggc.scot.nhs.uk. ¶

Appendix 6 – Caregiver Consent Form (Version 7)



Institute of Health
& Wellbeing

Understanding how caregivers think about people experiencing psychosis with negative symptoms

CAREGIVER CONSENT FORM

(Version 7, 7th December 2017)

Chief Investigator: Dr. Hamish McLeod, Programme Director for Doctorate in Clinical Psychology and Senior Lecturer

Researcher: Amy Homes, Trainee Clinical Psychologist

Please carefully read each statement below and if you agree, write your initials in the box next to each statement.

1.	I have read and understand the Carer Information Sheet dated.....(Version....) for the above study.	
2.	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without interactions with NHS personnel, the patients' medical care or legal rights being affected.	
4.	I understand my GP will be notified I am taking part in this study, however they will not be told of the study title or aims, to protect the identity of the person I am caring for. They also will not be given any information regarding the content of the interview (unless safety at point 6 below is compromised).	
5.	The interview will be recorded and stored securely. It will be transcribed, all personal information will be removed from the transcript and the file will be encrypted and given a password. The transcript will only be used for the purposes of this study.	

6.	I understand that if I say anything that makes the researcher concerned about my safety or the safety of another person, this information may be passed onto a third party. I also understand that the researcher will attempt to discuss this with me, should this situation arise.	
7.	I agree to take part in the above study.	

Name of Caregiver

Date

Signature

Name of Person taking consent

Date

Signature

Appendix 7 – Service User Consent Form (Version 6)



Understanding how caregivers think about people experiencing psychosis with negative symptoms

SERVICE USER CONSENT FORM

(Version 6, 13th September 2017)

Chief Investigator: Dr. Hamish McLeod, Programme Director for Doctorate in Clinical Psychology and Senior Lecturer

Researcher: Amy Homes, Trainee Clinical Psychologist

Please carefully read each statement below and if you agree, write your initials in the box next to each statement.

1.	I have read and understand the Service User Information Sheet dated.....(Version.....) for the above study.	
2.	I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
4.	I understand that if I say anything that makes the researcher concerned about my safety or the safety of another person, this information may be passed onto a third party. I also understand that the researcher will attempt to discuss this with me, should this situation arise.	
5.	I agree to my Psychiatrist being informed of my participation in the study.	
6.	I agree to my GP being informed of my participation in the study.	

7.	I agree to take part in the above study and for my care team to approach my carer(s) to ask permission for their names and details to be passed onto the research team to organise an interview.	
8.	I understand that if I withdraw, this doesn't necessarily mean my caregiver has to withdraw and data collected up to that point can still be used.	

Name of service user

Name of Person taking consent

Date

Date

Signature

Signature

Appendix 8 - A table describing overview CCAT scoring of papers

	Onwumere et al. (2008)	Hjarthag et al. (2010)	Barrowclough et al. (2001)	Adeosun (2013)	Lerner et al. (2018)	Gomez-de-Regil et al. (2014)	Lowyck et al. (2004)	Sagut & Duman (2016)	Onwumere et al. (2011)	Koukia & Madianos (2005)
Preliminaries	5	4	5	4	4	4	4	5	4	4
Introduction	5	5	5	5	4	5	5	5	3	4
Design	5	3	4	4	4	3	4	4	3	4
Sampling	5	5	5	4	4	4	4	4	4	4
Data collection	5	4	3	3	4	4	4	4	3	2
Ethical matters	3	5	3	4	5	5	3	3	4	3
Results	5	4	4	4	4	4	4	3	4	3
Discussion	5	5	4	5	4	3	4	3	4	3
Total (maximum score = 40)	38	35	33	33	33	32	32	31	29	27
Total % score	95	88	83	83	83	80	80	78	73	68

Appendix 9 - A table describing illness duration features for the specified studies included in the Systematic Review

Study	Type of sample (persistent vs. persistent/FEP vs. heterogenous)	Chronicity of sample vs. variable
Gomez-de-Regil et al. (2014)	Persistent	Over 3 years illness duration since FEP
Koukia and Madianos (2005)	Persistent	
Sagut & Duman (2016)	Persistent vs. FEP	Over 2 years illness duration since FEP
Onwumere et al. (2011)	Persistent vs. FEP	
Barrowclough et al. (2001)	Persistent	
Hjarthag et al. (2010)	Persistent	
Lowyck et al. (2004)	Heterogenous	Presented data on subset of sample who had persistent symptoms
Adeosun. (2013)	Heterogenous	
Lerner at al. (2018)	Heterogenous	
Onwumere et al. (2008)	Heterogenous	

Appendix 10 - A table describing illness duration features for the specified studies included in the Systematic Review

Indiana Psychiatric Illness Interview - Version 3, 25.01.18

Participant ID: _____ **Date:** _____

*This interview should encourage participants to tell their story of being a carer as they will, with the interviewer asking the questions listed below. Comments may be necessary to cue the person that the interviewer is listening. These should be as reflective as possible, not introducing content that the participant has not mentioned. Do not ask the individual to fill in chronological gaps or probe about information that he/she did not mention in his /her initial telling of the story. Questions as listed below do not have to be asked in order and the interviewer should accommodate the participant's narrative. The over arching value should be to provide a setting in which the participant's narrative as it currently exists is able to emerge. The interview may be introduced as simply as: "The purpose of this interview is for me to understand as carefully as possible **your** story of being a carer including what has gone wrong and what has not gone wrong."*

Section I: General Free Narrative:

- *I'd like you to tell me the story of your family, in as much detail as you can, starting from around the birth of the child that currently receives treatment or from when you first met the person you care for. If it helps you to organize your story, you can divide it into chapters or sections. Any questions?*
-

Section II: Illness narrative

- *Do you think [X] has a mental illness (MI) and if so what do you think it is?*
 - *What is your experience of [X's] MI in the past?*
 - *What caused these problems?*
 - *How do you feel about [X] having this MI?*
 - *What is going to happen to [X's] MI in the future?*
-

Section III: What's wrong vs. what's not wrong

Since their MI, what about [X] has changed and what has stayed the same in their life in terms of work? Intimate relationships and friendships? The way [X] thinks, how they behave or the way they show their emotions? Probes could include:

- *Vocational function: Does [X] currently work? Is this the same/different to before?*
 - *Social function (family/romantic, friends/acquaintances): Does [X] have a partner? Friendships? If at all, how has this changed from before?*
 - *Personality: What is [X's] personality like? How, if at all, is it the same/different to before?*
 - *Cognition/emotion: What changes, if any, have you noticed in the way they think? Show their emotions?*
-

Section IV: Degree of influence of illness construct

how others influence their way of being caregivers.

- *To what extent and in what ways does being a caregiver of [X] control their life?*
- *To what extent and how well do you feel you cope with being a caregiver?*

- *How, if at all, have others been affected by you caring for [X]?*
 - *How, if at all, have others influenced your way of being a caregiver?*
-

Section V: The future, hopefulness and satisfaction?

- *How do you think [X's] need for care will develop in the future? Same level or different? what do you see ahead for [X] in the future?*

Appendix 11 – Screen shot of codeframe from NVIVO

- Coping strategies
- Experiences of services
- ▼ ● Feeling on high alert inc.unprocesse...
 - Feeling on high alert
 - Seeing difficult things
 - Unprocessed trauma or too much...
- ▼ ● Interpersonal themes
 - Abandonment for protection reasons
 - Can tell something is not right
 - Critical comments or hostile
 - Emotional over involvement
 - Protective
 - Resentment
- ▼ ● Key stress points
 - Concerns around meds
 - Not felt updated by services or list...
 - Promised discharges
 - Re-hospitalisations
- ▼ ● Making sense of the illness generally
 - ▼ ● Attributions
 - Attributions around relapse
 - Health of others
 - Symptom attributions
 - Their health
 - Treatment attributions
 - ▼ ● Causation
 - Biological
 - Cannabis
 - Trauma
- ▼ ● Reported impact on carer
 - Coping
 - Financially
 - Health
 - Impact on available time

- Losing contact with family
- Positives of caring
- ▼ ● Supports
 - Carers grp
 - Decision to get support staff
 - Talking or not talking to friends
- ▼ ● The future
 - Feelings of acceptance
 - Feelings of loss for the future
 - Loss of hope things will improve
 - Resignation
 - Worried about future after they pa...

Appendix 12 - Extract from interview using IPII, with MAS coding

“...but I still think they wouldn't have let them in the house anyway, a very good CPN I spoke to, I said [X] is 20 something now, does he get any money from anywhere, and they said yes, but [X] had gotten so proud when he said he could have a Social Worker, he said his Mum does that for him. And it was obviously someone with a list as long as there arm....I did get some help then....his rent was being sorted, but it was other things. We carried on, I found it v v stressful. I promise it was what made, it means there was an elephant in the room and you can't talk to your friends but I did join various carers groups....but some of them were filled with a generation older than me, who some, mostly, had obviously become ill a long time before and been on an older type of medication, and they were truly stuck and truly not making any progress...I had to stop going to those as I realised they were making me more ill than anything....it was dreadfully sad as I tried to be optimistic and positive and think I was going to fight this one...because initially I was told 1/3 of people who have a psychotic incident never have one again, 1/3 they might have another but it would be rare it stays for the rest of their days, but this seems to have done.....not psychotic now, no, the carers groups [pause] and then I...I think the next incident was 10 years ago when I discovered [her major illness], I walked straight from the [hospital], straight to another new CPN who was an innovative young man, who was trying to do his best, I didn't go anywhere, so I went straight from there to the unit where he was working, and he was expecting me.....and I said can I speak to him, I feel bad for him now, that is it I cannot do all this running around after [X], somewhere something has to be pulled out to support him becauseI am going to have to get my treatment done, and it is going to take a long time and I am not going to be up to it and it is going to take a long time, and I couldn't I could barely look after myself....I had quite rigorous treatment, and I am blessed, and because of research in the past, that is why I am still here talking so I will always support research, couldn't have been better supported by the western but they didn't know.....nowadays the first thing they ask is "are you a carer?", which is wonderful because they didn't do so in those days, it may seem a bit intrusive to some people but....it is a blessing for many to be able to say that now. So they supposedly tried to up the amount of support [X] got. His [sibling] by then, had gone [away], she had got married, she had children, and I don't blame her, she didn't want to take that on.....and there is no actual relatives round here and his old peer group disappeared like snow off a dyke.....but they all went off to go to university, to fancy jobs but they all set about their life, there is no contact from them, I am in contact with some of their parents, old friendships.”

Appendix 13 – Detailed explanation of key themes from the thematic analysis

Theme 1: Caregiver causal attributions about the patients illness

There were mixed views from carers in relation to the causation of the illness. A couple of carers applied quite simplistic explanations for the illness, usually to genetics (despite not reporting other relatives with a similar illness) or relating it to taking illegal drugs. Others also focussed on a biological explanation, however they often supported this by explanations of other relatives with similar diagnoses. Otherwise, other reasons offered by caregivers (usually combined with some genetic component) included high levels of stress or trauma (such as sexual abuse or loss of a loved one which the person had found particularly difficult to deal with).

There were similar variations in the attributions made by caregivers about the patients' negative symptoms. A couple of participants reported how difficult they found these symptoms, but recognised they were negative symptoms and could be a part of the illness:

Gill: "He showed all his negative symptoms all the time in hospital, he would not join in things, he would not do anything, his hygiene was appalling."

Other participants seemed quite confused by their loved one's presentation, describing symptoms such as asociality and affective flattening, but not necessarily being aware these are negative symptoms. A couple of participants attributed a greater amount of control to the patient than was plausible, implying, or even stating, they viewed their relative as lazy and were obviously frustrated. These participants also made a higher number of statements about the consequences of the illness for themselves or other loved ones, in replacement of reflection of consequences for the patient.

Theme 2: Experiences of Services and Support by caregivers

Some participants reflected on how difficult the hospital environment had been for them when their loved one was (re-)hospitalised. Usually, they were keen to explain the differences they had observed in services over the years⁸. A few participants were able to reflect on the effect hospitalisations had on them, in relation to being traumatised by the experience, describing feeling “*on high alert*” as they never knew when they may get a phone call saying their relative had relapsed and needed to be re-hospitalised.

Other participants included less about hospitalisations in their narratives, deciding more to focus on recent contact with services, usually in the community. The decision as to which service to include in the narrative usually converged with the stage of illness of their relative, or where they patient was in their recovery journey. The few participants still living with their relative or still providing a lot of support to their relative, seemingly had less access to support services which is likely why they focussed more on recent experience with outpatients, Crisis teams or Community Mental Health Teams (CMHTs). Despite the different services mentioned by caregivers in their narratives, key themes throughout tended to be examples of service delivery where staff had not been as empathetic as caregivers would have liked; issues with understanding the explanation given by professionals or difficulties getting hold of necessary staff.

Experiences of support staff and/ or concerns for the future, were seemingly equally affected by stage of the recovery journey. Some participants were not at a stage where a decision had been made their relative needed increased care plan packages, which usually left these relatives concerned about what would happen to their loved ones should anything happen to them.

⁸ Some caregivers would have been reporting on service delivery in the 1980s, whereas others included more recent hospitalisations in their narratives.

Theme 3: Responses by the caregiver towards the patient

A few caregivers were able to reflect on how their response to their relative had changed over time. Some identified they used to be more emotionally invested, over intrusive and/or show more self-sacrificing behaviour. These caregivers were again usually those with patients further along their recovery journey, and those who also had less of a caregiving role in comparison to the one they used to have, with more support from external agencies. Those reporting the converse to this in their narrative, used more critical comments and hostile language than the former. A sub-theme of “acceptance/ integration of the illness into caregiver’s narrative vs. resentment” was also identified, in line with findings reported above. Those who seemed to have higher levels of acceptance in relation to the illness, and who seemed to have a better integrated narrative also reported less critical and hostile language towards the patient.

Theme 4: Current and past coping strategies

In line with a stress-appraisal-coping framework, caregivers exhibited a variety of coping strategies. Despite not identifying them as coping strategies, several caregivers adopted positive strategies for helping them handle the stressors of their role. These included talking to friends, using a carer’s group, trying to change/ alter ‘the system’ to improve experiences for other families or focussing on spending time with their loved one. Some of these caregivers could identify their coping strategies had changed from earlier in the illness trajectory to the ones they used currently.

Others had not reached this acceptance and described using more emotionally focused coping strategies. Caregivers described themselves as having a need to keep busy so they do not “*think about [the patient]*” or distancing themselves from the patient. For others, it was apparent they were still using the coping strategies they had used for years, which tended to involve trying to educate the relative of how to do things, for example, go shopping, cook etc. with an apparent lack of understanding as to why these techniques did not seem to be successful. Carers using

these emotion focussed strategies tended to report increased levels of hostility and criticism in their interpersonal response with patients. These carers also seemed to have less additional support, both from friends and family as well as from external agencies.

Appendix 14 – Quantitative data, descriptive statistics and correlations

Patient/Carer dyad	Patient measures	Caregiver measures				
		<i>ECI negative</i> <i>(n=8)</i>	<i>ECI positive</i> <i>(n=8)</i>	<i>EOI</i> <i>(n=7)</i>	<i>GHQ-30</i> <i>(n=7)</i>	<i>MAS-A</i> <i>(n=9)</i>
	<i>SNS (n=9)</i>					
Charlotte/Amanda	15	66	20	32	99	18
Tony/Gill	15	123	36	28	3	21
Will/Tim	13	65	21	99	0	23.5
Will/Natasha	13	97	38	29	0	20.5
Steve/Theresa	99	102	36	25	14	15.5
George/Hannah	27	115	41	33	7	9
Bruno/Helen	28	116	40	25	3	10.5
Chris/Jessica	22	99	99	99	99	18
Ryan/Daniel	18	86	12	26	4	15.5
Mean	18.88	96.25	30.5	28.29	4.43	16.83
Range	13-28	65-123	12-41	25-33	0-14	9-23.5
Standard deviation	6.08	22.32	11.08	3.25	4.86	4.78

Correlations							
		<i>SNS_total</i>	<i>ECI neg</i>	<i>ECI pos</i>	<i>EOI</i>	<i>GHQ-30</i>	<i>MAS total</i>
<i>SNS_total</i>	Pearson Correlation	1	0.579	0.486	-0.025	0.420	-0.915**
	Sig. (1-tailed)		0.66	0.111	0.479	0.174	0.000
	N	9	8	8	7	7	9
<i>ECI Negative</i>	Pearson Correlation	0.579	1	0.793**	-0.215	0.300	-0.376
	Sig. (1-tailed)	0.066		0.009	0.322	0.257	0.179
	N	8	8	8	7	7	8
<i>ECI positive</i>	Pearson Correlation	0.486	0.793**	1	-0.003	0.233	-0.251
	Sig. (1-tailed)	0.111	0.009		0.497	0.308	0.274
	N	8	8	8	7	7	8
<i>EOI_total</i>	Pearson Correlation	-0.25	-0.215	-0.003	1	-0.609	0.110
	Sig. (1-tailed)	0.479	0.322	0.497		0.100	0.407
	N	7	7	7	7	6	7
<i>GHQ-30 total</i>	Pearson Correlation	0.420	0.300	0.233	-0.609	1	-0.470
	Sig. (1-tailed)	0.174	0.257	0.308	0.100		0.143
	N	7	7	7	6	7	7
<i>MAS_total</i>	Pearson Correlation	-0.915**	-0.376	-0.251	0.110	-0.470	1
	Sig. (1-tailed)	0.000	0.179	0.274	0.407	0.143	
	N	9	8	8	7	7	9
** Correlation is significant at the 0.01 level (1-tailed)							