

**Caregiving profiles in adolescent and adult early psychosis**

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**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## Overview

Part one presents a conceptual introduction reviewing the literature on factors related to wellbeing and distress in early psychosis caregivers. It considers factors relating to the caregiver, to the service-user and contextual factors. An evaluation of the type of methodology and approaches to analyses of the typical measurement of the appraisals of caregiving is given.

Part two is a quantitative, empirical study into whether caregiving profiles exist of types of appraisals and avoidant coping amongst carers in an early psychosis population. It further considers associations with these profiles and demographics and contextual factors and whether the profiles are related to the measures of wellbeing, depression and anxiety. It involves a secondary data-analysis of data originally collected from a group of caregivers of service users accessing support from an Early Intervention Service (EIS).

Part three is a critical appraisal of the process of undertaking this research described in parts one and two, as well as a reflection on the process of having to start on a new thesis project. It is inclusive of a series of reflections on various stages of the process, including the experience of conducting a piece of secondary data-analysis with complex analysis.

## Impact statement

The current study has some potential implications for both academic research and clinical work. Regarding academic research, to the best of the author's knowledge, this study presents a novel application of Latent Profile Analysis in the consideration of appraisals and avoidant coping amongst informal caregivers of those in early phase of psychosis. This has allowed for the consideration of a person-centered approach to a quantitative method in caregiving in psychosis, by looking at the patterns and co-occurrence of appraisals rather than variable-centered approaches used previously. Thus, this presents an important contribution to academic research within the area of caregiving research in psychosis. Further research is warranted to consider replication in a larger data set to consider reliability of the findings here and to test the relationship between potential profiles and distal outcomes (beyond the cross-sectional nature of the current study). It is intended to attempt to publish the findings in order to disseminate the academic findings.

In terms of the clinical implications, this study contributes to the growing literature on caregiving experiences in psychosis and specifically in considering factors that are related to caregiver distress and wellbeing. Thus, meeting previous calls for research to focus on caregiver support independent to solely focusing on caregivers in relation to service user outcomes. The fact that the current study has found three distinct profiles of caregiving appraisals may be useful to services for identifying caregivers who are at most risk of distress. Furthermore, the current findings may have implications for Early Intervention Services considering what *type* of support would be most beneficial (i.e. Family Intervention versus specific carer wellbeing intervention versus a group support group). Identifying profiles of key appraisals that are associated with distress or wellbeing may also help to identify particular targets for interventions and thus help to tailor treatments to caregivers.

The clinical implications could also apply to general service design within Early Intervention services. The current findings suggest that there exists a more 'positive' and 'engaged' group of caregivers who have been caring for briefer periods of time and this may support earlier findings that offering support to carers, even when they appear to be *doing well* can be important to maintain positive approaches to the role. Services may wish to consider offering information as soon as possible to provide awareness of available support and education around symptoms of psychosis. The findings and implications of this study will be presented to an Early Intervention Service that the author will be working with in attempt to disseminate the potential clinical implications.

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## **Part 1: Conceptual Introduction**

What does the research literature say about what predicts caregiver wellbeing and distress in Early Phase Psychosis?

## **Abstract**

It is well established that the impact of psychosis typically extends beyond the identified service user. Caregivers of those with mental illness report elevated rates of psychological distress, social isolation and poorer quality of life (Gupta, Isherwood, Jones, & Impe, 2015; Hayes, Hawthorne, Farhall, O’hanlon, & Harvey, 2015). Whilst the focus on caregiver experiences in First Episode Psychosis (FEP) has traditionally been concerned with improving service user outcomes, there are now calls to better understand caregiving experiences, providing specialist support that targets caregiver outcomes (Onwumere & Kuipers, 2017). This conceptual introduction presents a summary of the literature considering the predictors of caregiver distress in psychosis. The literature was collated from multiple sources, including empirical and theoretical articles and scholarly journals that are relevant to the topics of caregiving and psychosis. Additionally, a PsychINFO search was conducted with over 600 results returned. The introduction also focuses on the possible role that age of the service user may have in understanding the caregiving experience as a potential gap in the literature. The potential clinical implications of these factors are considered in relation to understanding carers who may present as the most in need.

## **Introduction**

The empirical paper of this project intended to further the understanding of caregiver experiences in Early Phase Psychosis (EP) by examining whether there are specific caregiver profiles and if these are a) associated with certain demographic factors and clinical factors and b) predict caregiver reports of wellbeing, depression and anxiety. In terms of service user characteristics, there was a particular focus on investigating the potential role of looking after an adult versus an adolescent with EP. The project reports on a secondary analysis of data collected in a cross-sectional study of caregivers of those accessing a First Episode in Psychosis (FEP) service. Caregivers were asked to complete standardised measures of burden, appraisals illness beliefs, wellbeing and proxy measures of distress of anxiety and depression. Whether profiles of caregivers' appraisals and coping exist may have useful clinical implications of identifying groups that have the highest need and could help consider suitable interventions and support. The following review will present the pivotal research and theoretical background motivating this study, including consideration of the methodological choices made.

### **Method of literature review**

#### *Reflexive position*

It is important to highlight the reflexive position of the author and how this may have contributed to the method of the review, such as defining search terms. Having previously worked within an Early Intervention in Psychosis service the experience of using the Cognitive Model of Caregiving in Psychosis (Kuipers, Onwumere & Bebbington., 2010) to inform clinical work is likely to have shaped the authors understanding of key psychological factors associated with caregiver distress (e.g. burden, appraisals, copying stypes). The theories associated with this model of caregiving in psychosis, such as expressed emotion (detailed below), are a key

factor in psychological interventions within psychosis and this too may have shaped the authors consideration of search terms and appraisals of the studies. In addition, the definition of search terms were influenced by an earlier systematic review (Jansen, Gleeson & Cotton., 2015) into predictors of caregiver distress.

### *Search terms*

In order to ensure the current review included a comprehensive coverage of the literature on caregiver and service user related factors associated with caregiver distress in psychosis, studies were identified using a number of sources. This includes a PsycINFO search (<https://ovidsp.ovid.com>), including the terms \*psychosis/ or exp schizophrenia/) AND (caregiver\* OR carer\* OR parent\* OR famil\*) AND (distress\* OR burden\* OR well-being OR well-being OR stress\* OR depress\* OR anxiety OR loss OR grief) AND (attribution\* OR coping OR attachment OR metacognition OR “metacognitive belief\*” OR “expressed emotion\*”). Over 500 results were returned and publications were reviewed for their relevance and additional papers were identified in citations included in these articles. Furthermore, other research was sourced from informal searches through the UCL online library catalogue and Google Scholar. The resources included peer-reviewed journals, book chapters and articles published by key researchers in the relevant areas. As this chapter represents a conceptual introduction to the topic rather than a systematic review (SR) of the literature, studies were not formally appraised using a quality appraisal tool and there was no exclusion criteria for ‘type’ of studies (i.e. RCT or qualitative).

### **Background concepts**

Key concepts that are important to this area are defined below before presenting the review of the literature.

### *Psychosis overview*

Individuals with psychoses-spectrum disorders face substantial levels of social disadvantage and disability (World Health Organisation, 1992). Psychosis represents one of the most severe psychiatric disorders, characterised by a range of symptoms including hallucinations, delusions, and cognitive difficulties (Mueser & McGurk, 2004). The disorder represents a life-changing event (Lavis, Lester, Everard, & 2015) associated with significant burden and distress for both the individual and their carers (Kuipers et al., 2006), in addition to a vast economic burden (Chong, Teoh, Wu, Kotirum, & Chiou, 2016). Lifetime risk of psychosis falls within 0.12% - 1.5%, with an estimation of a 7% chance of experiencing psychosis before the age of 75 (McGrath et al., 2016).

### *'Early' phase and First Episode Psychosis*

Psychosis can be categorised into 'early' phase (typically the first 3-5 years) and 'chronic' psychosis. Early phase psychosis, which a FEP occurs within, represents a key focus of research into prevention and intervention. The first three to five years following an initial episode are argued to be a 'critical period' in which there is rapid symptomatic and psychosocial deterioration (Birchwood, Todd, & Jackson, 1998). Early intervention is therefore considered vital for improving treatment outcomes during this period (Clarke et al., 2009; Craig et al., 2004; Correll et al., 2018) and there now exist specially designed services, 'Early Intervention Services' (EIS), that focus on the prodromal and early phase of psychosis. EIS services aim to reduce the 'duration of untreated psychosis' (DUP) (the 'time-lag' between onset of psychotic symptoms and access to treatment) to a service median of less than 3 months. The focus on targeting DUP is based on research finding modest associations between longer DUP and poorer outcomes regarding positive and negative symptoms, functioning, and quality of life (Marshall, et al, 2005; Penttilä, Jääskeläinen, Hirvonen, Isohanni & Miettunen, 2014).

## *Caregiving in psychosis*

### *Definition of a carer*

The move from admittance to institutional services to community-based care has placed much greater responsibility for care and management onto the families of individuals with mental health difficulties, including psychosis (Onwumere & Kuipers, 2017). Within psychosis, carers or caregivers are predominantly parents or partners (Jansen, Gleeson, & Cotton, 2015; Rethink, 2003; Sadath, Muralidhar, Varambally, Gangadhar, & Jose, 2017), however may also include siblings and close friends also. Non-professional carers may be either formal (i.e. can claim benefits) or informal. Whilst there are multiple definitions for carers, the Department of Health (DoH) broadly defines carers as:

“...anyone who spends time looking after or helping a friend, family member, who because of their health and care needs, would find it difficult to cope without this help...” (DoH, 2018, p.7).

### *Impact of caregiving in psychosis*

Caregivers and families play a pivotal role in the process of recovery in psychosis, particularly in the early stages (Jens Einar Jansen, Gleeson, et al., 2015). Service users often maintain close contact with families and informal carers (Onwumere, Hunter, & Kuipers, 2014) in EP with caregivers assisting in help seeking and access to mental health services (Tanskanen et al., 2011). Given their importance, support to caregivers is now considered in clinical recommendations (Galletly, Castle, & Dark, 2016) and national guidelines (National Institute for Health and Care Excellence [NICE], 2016). The focus on support to caregivers is due to the consistent finding of high levels of burden and emotional distress in this population (Martens & Addington, 2001; Nordstroem, Talbot, Bernasconi, Berardo, & Lalonde, 2017; Poon, Harvey, Mackinnon, & Joubert, 2017). The term ‘burden of care’ refers



to the experience of both 'objective' burden (e.g. the financial or time commitment implications of caring for a loved one with psychosis) and 'subjective' burden (e.g. the psychological reactions such as loss, grief or anxiety).

Early research focused on objective aspects of the burden of caregiving, finding burden reported across multiple areas, including needing to provide financial support (Ochoa et al., 2003), impact on work life and constraints to social activities (Baronet, 1999; Clausen & Yarrow Radke, 1995; Magliano et al, 2005). Recent studies have replicated this, reporting associations between caring for someone with mental health difficulties and financial constraints, such as restricted employment opportunities (Vaughan, Feinn, Bernard, Brereton, & Kaufman, 2013) and also poorer physical health of caregivers (Poon, Joubert, Mackinnon, & Harvey, 2018).

Much research has explored the subjective aspects of caregiver burden, including the psychological impacts, with studies reporting that between 30-40% of caregivers meet criteria for depression or anxiety (Hamaie et al., 2016; Sadath et al., 2017). Furthermore, the complex reactions caregivers experience in response to the illness have been linked to feelings of hopelessness (Shore, 2006) and loss regarding aspirations for their loved-one's future (Patterson, Birchwood, & Cochrane, 2005). Given the reported objective burden experienced by caregivers, it is unsurprising that caregivers also experience a significant sense of loss with regard to their own previous lifestyle (Magliano et al., 2005).

### *Expressed Emotion (EE) and Family Interventions in Psychosis*

Expressed Emotion (EE) has been the cornerstone of research into relapse and prevention in psychosis, as 'high' levels of EE in a family have been highlighted as a significant risk factor for relapse (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000; Weintraub et al., 2016). 'High' EE, considered as an interpersonal interaction, is defined as the presence of Critical Comments (CC), hostility and

emotional over involvement (EOI). The relationship between family environment and outcomes contributed to the development of Family Interventions in Psychosis (FiP). These interventions involve providing Psychoeducation to the family in a format that allows each family member the space to consider the impact of the illness on them. FiP are now recommended by relevant guidelines (e.g. NICE 2014). The predictive validity of EE specifically in FEP is less conclusive (e.g. Gleeson et al., 2010) although a recent systematic review found that FiP reduced the likelihood of relapse by targeting the different aspects of EE in FEP (Claxton, Onwumere, & Fornells-Ambrojo, 2017). The finding that targeting EE, which has implications for caregiving behaviours and experiences, has resulted in a growing interest in further understanding caregiving processes. Whilst this initially concerned improving service user outcomes it is now also considered vital to consider caregiver outcomes independently (Onwumere & Kuipers, 2017a).

### **Review of the literature**

The current caregiving literature highlights the experience as complex and one related to factors pertaining to both the caregiver and the clinical and demographic characteristics of the service user. Research has now moved beyond considering caregiving experiences in sole relation to the implication on service user outcomes, but as being important to the wellbeing and outcomes of caregivers themselves. Many studies assessing factors related to, and predictive of, caregiver outcomes considers their association to the following psychological, and subjective constructs: appraisals, illness beliefs and attributions, expressed emotion and the demographic and clinical factors of the service user. This review will consider factors related to caregivers and service users, in turn.

### **Caregiver related factors**

The following section will review the literature concerning the processes that may be linked to wellbeing or experiences of distress amongst caregivers. Within

the literature, distress has been conceptualised and measured in various ways. This review considers distress as including measures of depression, anxiety and distress.

### *Coping styles*

The distress caregivers experience in their role is thought to be related to both the illness-related difficulties and the manner of coping styles they employ (Kuipers, Onwumere, & Bebbington, 2010). Coping strategies that involve avoidance (e.g. through use of alcohol) are associated with greater levels of reported distress in caregivers, regardless of the length of illness of the service user (Onwumere et al., 2011). Avoidant coping is also linked to poorer overall functioning in caregivers (Raune, Kuipers, & Bebbington, 2004). In contrast, caregivers who engage in more active and 'problem-focused' coping strategies, are more likely to report higher levels of personal accomplishment, in recent onset psychosis caregivers (Onwumere, Lotey, et al., 2017).

Much of the research into coping styles has been based on cross-sectional studies and therefore it is difficult to determine the direction of the relationship between whether distress may lead to more avoidant forms of coping or vice versa. Folkman and Lazarus (1984) propose a reciprocal relationship between the two. Furthermore, as highlighted by others previously (e.g. Cotton et al., 2013), studies assessing coping styles of FEP caregivers have not reported on caregiver characteristics and symptomatology, which may be important to better understand the relationship between these factors. The authors suggested that it may be important to consider the dynamic of the patient-carer relationship, which may be different depending on the age of the service user or length of illness.

### *Caregiver appraisals and attributions*

Studies assessing caregivers' appraisals and attributions commonly consider how the perception of the impact of the illness, the extent to which caregivers attribute control to the service user and beliefs around consequences (e.g. timeline) of the illness relate to distress. Much of the literature into caregiving supports a stress-appraisal-coping framework within caregiving (e.g. Lazarus & Folkman, 1984), which proposes that in addition to the impact of the objective burden of caregiving, caregivers' distress and psychological wellbeing is affected by their subjective appraisals of the caring stressors and their own perceived ability to cope.

Appraisals concerning the negative consequences and illness chronicity (i.e. whether it is believed to be acute or chronic) are associated with greater level of distress and are predictive of poorer perceptions of perceived ability to cope at 6-month follow-up (Barrowclough, Gooding, Hartley, Lee, & Lobban, 2014; Juliana Onwumere et al., 2008). Caregivers' appraisals of loss are associated with reports of depression also (Patterson et al., 2005). Though younger service user age is linked to higher distress levels, appraisals make the greatest contribution to regression analyses and clinical symptoms, such as positive or negative symptoms, are not significantly related to caregiver distress (Addington, Coldham, Jones, Ko, & Addington, 2003). In addition to appraisals of future consequences of psychosis, caregivers who appraise their loved one as having poorer functioning are more likely to experience psychological distress and reduced social connection (Poon et al., 2018). The authors posit this could support a causative link between caregivers' perceptions of service users' inability to care for themselves leading them to dedicate more time to caregiving and less to personal social activities. .

### *Burnout*

Burnout is a complex construct, but is indicated by the key areas of *emotional exhaustion* (e.g. fatigue, feeling drained), *depersonalisation* (withdrawal, a negative attitude towards the person being cared for or the role of caring), and *decreased motivation and role effectiveness* (low appraisal of competence and achievement) (Schaufeli & Enzmann, 1998). Within FEP, caregiver burden is predictive of depersonalization and emotional exhaustion; a finding that reflects the fact that EP stages and its challenges present a setting in which caregivers feel emotionally exhausted and consequently lacking in positive affect towards the client (Onwumere, Lotey, et al., 2017). It is less clear whether the relationship between burden and burnout may be affected by the clinical characteristics of the service users, and this finding could help to further understand the context of caregiving.

### *Caregiver characteristics*

Research has focused on how caregiver characteristics may influence the relationship between psychological concepts, such as appraisals and caregiver distress in the broader caregiving literature. Caregiver gender in psychosis has been previously considered, with reports that females are more likely to be the primary caregiver than males (Jansen et al., 2015; Magaña, Ramirez Garcia, Hernández & Cortez, 2007; Juliana Onwumere et al., 2011). An early review of 28 studies (Baronet, 1999) found no relationship between gender of the caregiver and reports of burden and distress. Within the broader caregiving literature for severe mental illness, significant gender differences of burden are reported (Mulud & McCarthy, 2017), with females being significantly more likely to perceive themselves as having less social support and higher levels of burden (Hsiao, 2010). However, this relationship between gender and burden is mediated by resilience (defined as the ability of carers to adept to adversity) (Mulud & McCarthy, 2017). One study

assessing social characteristics associated with perceived burden (and distress) in FEP, found that female gender was significantly associated with higher levels of distress for caregivers of service users diagnosed with schizophrenia, but that males reported slightly higher levels of burden than females (Boydell et al., 2014). However, within the FEP population, a systematic review suggested that findings regarding gender are inconclusive (Jansen, et al., 2015).

The consideration of possible psychological factors that contribute to caregiver appraisals has emerged given the existing lack of understanding about what makes some caregivers more distressed than others (Jansen et al., 2015). One of the components of EE, EOI, alongside 'dysfunctional metacognitions' (e.g. caregivers having beliefs about needing to control thoughts) has been found to be a significant predictor of caregiver distress levels (Jansen, Harder, et al., 2015) with EOI mediating the relationship between metacognitions and distress. Psychological flexibility (defined as the ability to connect to the present moment fully, accepting any thoughts and sensations, and continuing to act in line with personal values) is also linked to caregiver distress in FEP (Jansen et al., 2017).

### **Cognitive models of caregiving:**

The idea that caregiving in psychosis is related to both caregiver and illness-related factors and is transactional, is highlighted in a specific cognitive models of caregiving in caregiving (see Figure 1 Kuipers, Onwumere & Bebbington, 2010). This model provides a framework to consider how caregiver appraisals give rise to a set of cognitive and affective reactions that then manifest in certain behaviours towards the service user and was developed from evidence within the literature and has been supported by studies (Hesse & Klingberg, 2014).

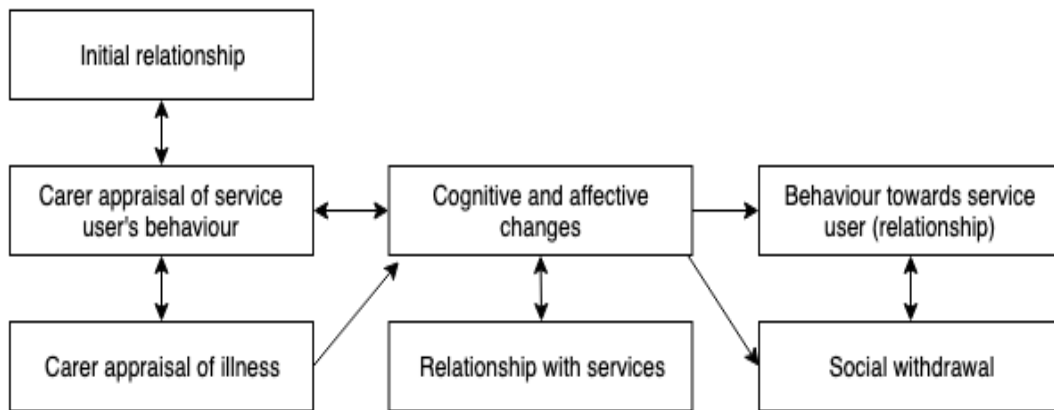


Figure 1: Adapted from Cognitive Model of Caregiving (Kuipers et al., 2010)

Within the model, the context of the relationship prior to the onset of psychosis is key to how the caregiving relationship unfolds, such that, a prior positive relationship will enable to caregiver to see the service user as a person, rather than a collection of behaviours that challenge. Thus, caregivers are more likely to appraise the service users' behaviours as unusual and not part of typical 'adolescent' behaviours and therefore requiring a different reaction. This model therefore highlights the importance of thinking about the context of the dynamic patient-carer relationship, which may vary depending on the developmental changes related to the age of the service user and length of illness (Cotton et al., 2013).

### Caregiving Behaviour

Research into FiP effectiveness provides some information on the relationship between aspects of caregiving behaviours (e.g. EE sub-constructs) and caregiver distress. Meta-analyses demonstrate no significant changes on caregivers' EOI post FiP (Claxton et al., 2017). This is important given that caregivers' presence of EOI and criticism is significantly associated with caregiver levels of distress (Lvarez-Jimnez et al., 2010; Patterson et al., 2005). EOI can be understood as a normal reaction to a crisis and could be considered as a coping strategy, as exhibiting behaviours associated with EOI (e.g. over-intrusiveness, self-

sacrificing and over-protective behaviours) may help caregivers feel more in control in the short-term, but is predictive of caregiver distress, even when controlling for clinical characteristics (such as severity) (Jansen et al., 2015).

CC, or criticism from caregivers, is considered as being associated with caregiver distress. CC are hypothesised to be related to caregiver attributions that service users are in control of symptoms (e.g. because of an inadequate understanding of the illness) and that criticism is used as an attempt to reduce to the behaviour (Weisman, Nuechterlein, Goldstein, & Snyder, 1998). One recent paper found that criticism was related to depressive symptoms within a FEP caregiver group (Hamaie et al., 2016). The authors found that both depression scores of caregivers and positive symptoms of the service users, when controlling for other variables, explained criticism scores. As a cross-sectional study, it is not possible to conclude whether caregiver levels of depression predict criticism necessarily, or vice versa, or is bi-directional, but the authors highlight that it fits with the idea that service user symptoms, along with caregiver factors, can evoke criticism as a response or attempt to cope with the behaviours. Caregiving behaviours, or responses, can be seen as perpetuating a 'vicious cycle', in which high levels of distress may lead to more CC or EOI, which may lead to worsening presentation and in turn may lead to increased levels of caregiving distress (Kuipers, 2002).

### **Interventions targeting caregiver distress**

Interventions focusing on the role of caregiver appraisals in distress are often Psychoeducation based, designed to improve understanding of psychosis (Sin et al., 2017). Whilst studies do not always include specific measures on psychological distress, they provide some further understanding on the associations and relationships between important caregiving experiences, such as burden and appraisals. Significant shifts in appraisals regarding illness consequences, attributions of blame and overall knowledge of psychosis are reported following a



Psychoeducation based interventions (Onwumere, Glover, et al., 2017). These findings are echoed in a literature synthesis focused on effectiveness on FiP specifically on caregiver outcomes (Hasan & Jaber, 2018) that additionally reported improvements to coping strategies and problem solving abilities.

The absence of intervention studies reporting specific caregiver outcomes of distress and wellbeing has been highlighted in a review and meta-analysis (Ma, Chien, & Bressington, 2018). However, given the established relationship between appraisals and distress in EP caregivers, it is plausible that positive shifts in appraisals may lead to reductions in distress in caregivers. Another plausible implication of Psychoeducation interventions improving understanding of psychosis is the impact on caregiver appraisals of blame and control (self or service users). The wider caregiving literature demonstrates self-blame attributions are predictive of, or significantly associated with, caregiver distress (Fortune, Smith, & Garvey, 2005; Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015) suggesting that understandings around potential 'causes' of psychosis are important to caregiver distress. Interventions targeting caregiving outcomes often include Psychoeducation that targets improving understanding around causes. Interestingly, studies that have considered 'explanatory models' of psychosis found that caregivers holding multiple models reported significantly lower levels of distress (Joy, Manoranjitham, Samuel, & Jacob, 2017).

Whilst most caregiving research has reported findings on negative appraisals, one RCT looking at the impact of a Psychoeducation intervention, found a specific advantage in caregiver appraisals (in the treatment arm) of a greater personal positive experience. However, these positive appraisals had no implication for caregivers' scores on a distress scale, suggesting that although positive appraisals may contribute to an overall positive experience, it is not related to overall distress. One systematic review and meta-analyses found no significant

improvements to positive appraisals of caregiving but significant changes (reduction) in appraisals of burden (Sin et al., 2017). The authors note however, the high heterogeneity in the studies in terms of geography and cultural implications and that most studies did not actually include a measure on the overall wellbeing of the caregivers. The results of both the RCT and SR do seem to suggest that interventions should not target improvements to positive appraisals alone, but that targeting negative appraisals is key to intervention for caregivers as it appears to be key predictors of caregiver distress.

Taken together, the above research highlights the importance that appraisals, attributions and beliefs about psychosis play in the manifestation of caregiver distress and wellbeing. It also highlights that what continues to be less clear, is why there are such differences in caregiving distress and the psychological factors that are associated or predict it. Some of the research is limited by cross-sectional designs and not considering the clinical characteristics of the service users, such as age or symptomatology. This is important as caregiving represents a transactional dynamic.

### **Service user and contextual factors in caregiver distress**

Research has highlighted that both caregiver appraisals and service user factors are associated with caregiver appraisals of burden and distress (e.g. Addington et al., 2003). Whilst reviews have suggested appraisals are more important than clinical characteristics for caregiver distress, it has been highlighted that studies have often not included measures of clinical characteristics or have perhaps been insufficiently powered to consider the interaction between these factors (Jansen, Gleeson, et al., 2015).

### *Stage of illness*

Elevated levels of distress in caregivers have been found in the early stages of psychosis (Sadath et al., 2017), a time when the illness itself and the related consequences are new and less understood (Boydell et al., 2014). Higher levels of burden in caregivers of chronic psychosis in terms of 'time dependence', physical and social burden but equal levels of emotional burden to carers of FEP service users have been reported (Sagut & Çetinkaya Duman, 2016). The authors argue the equitable levels of emotional burden in FEP caregivers, despite an average length of illness of only 11 months, suggest it is vital that interventions are mindful of the specific needs caregivers present with across different stages of an illness. Crucially, the association between caregiver distress and high EE variables (criticism and EOI) is particularly elevated in high-risk (those identified as being at risk of the onset of psychosis) and recent onset psychosis groups (Domínguez-Martínez, Medina-Pradas, Kwapil, & Barrantes-Vidal, 2017). It may be that the early stages of psychosis have an important impact on caregivers' psychological states, including burden, concern and sadness (Lvarez-Jimnez et al., 2010). The more intense and negative emotions, such as despair and concern, experienced in the early stages of psychosis, may decline in the 5-10 years during a phase of "gaining awareness regarding the chronic nature of the condition" (Sagut & Çetinkaya Duman, 2016, p. 769). Expectations and desires for loved ones experiencing a FEP reportedly change as caregivers gain a deeper understanding of the chronicity of the illness and allow for a closer and more positive relationship with their loved one (McCann, Lubman, & Clark, 2011). This research was qualitative and based on a small sample and therefore may not be generalisable to the wider FEP population, but it does offer a possible suggestion for why early stages of psychosis may result in high reporting of burden and distress in caregivers.

## **Service user age, caregiver appraisals and expressed emotion**

The potential relevance of service user age related factors and any association with caregiving experiences is important given the role illness beliefs and carer appraisals are thought to have in the manifestation of EE. Within the clinical literature, a study exploring one-year follow-up outcomes of children with depression and their caregivers' EE found that a) children returning to households with 'high EE' had poorer outcomes and b) the age of the child was significantly associated to levels of EE (Asarnow, Goldstein, Tompson, & Guthrie, 1993). Unfortunately, this paper does not report the direction of the relationship between age and EE but nevertheless suggests that age can be relevant in caregiving relationship. A review of the ARMS literature, including mostly studies with service users aged 17 and under, reported higher levels of the EE components of criticism and emotional over-involvement (EOI) compared to FEP groups (Izon, Berry, Law, & French, 2018). The finding that EOI is higher in ARMS groups is of interest when considering these studies largely included younger age children and adolescents. However, the association between service user age and EE has not been consistently replicated (Wearden et al., 2000).

### *Age of onset and clinical outcomes*

Typically age of onset can be considered in terms of 'early', 'youth', 'adolescent' onset or 'adult'/'late' onset. Definitions of the age groups within these terms vary in the literature, but early onset psychosis (EOP) is generally considered as onset before the age of 18 (Amminger et al., 2011; Díaz-Caneja et al., 2015). Age of onset is considered an important clinical characteristic and earlier age of onset, such as EOP, is linked to poorer outcomes (Addington & Addington, 2008; Langeveld et al., 2012; Reichart et al, 2008) with remission of positive symptoms being less likely to occur in those with adolescent onset (Golay et al., 2017; Veru, Jordan, Joobar, Malla, & Iyer, 2016). In one study that found earlier onset to be

associated with fewer symptoms and better functioning, the authors cited that a possible reason for this departure from the typical findings was that the EIS from which the participants were drawn had a beneficial impact, including the promotion of staying in education (Amminger et al., 2011). EOP may present as a more progressive illness and could be seen as a marker of distinct profiles of psychosis, rather than solely related to outcomes (Golay et al., 2017). The differences in service user outcomes depending on onset may also present differing demands and experiences for the caregivers of those with psychosis.

Research has also considered the relationship between age of onset and the DUP and duration of untreated illness (DUI), this being the sum of the prodromal period and DUP (Yıldızhan et al., 2015). The relationship between younger age of onset and poorer outcomes could be explained by the longer periods of DUP in younger onset individuals (Hardy et al., 2018). However, DUP is predictive of outcomes but the predictive validity in adolescent onset psychosis is less consistent but researchers have noted that often DUP missing data are higher in younger participants (Thomson et al., 2019). This may suggest that carers of those with EOP are more likely to be supporting a loved one with difficulties without support from services for a longer period of time and this may have implications for caregiver distress. Longer DUP has been found to be positively associated with components of EE in FEP caregivers (Lvarez-Jimnez et al., 2010), such as criticism (Patterson et al., 2005) and appraisals of stress (Sadath et al., 2017).

The poorer outcomes associated with the early-onset group suggest there may be worth in further investigation in childhood and adolescent onset groups. The mechanisms that may underlie these differences are unknown, but given the established role of family environment in outcomes more generally in FEP (e.g. the EE literature), it may be important to investigate potential differences in important caregiving factors that are known to relate to family environment.

### *Current Age of the service user*

There are several factors that concern the potential importance of age in relation to psychosis that can be considered. In the UK services for those with FEP, typically support those from the age of 14, but an individual aged between 14-18 may also be simultaneously seen within CAMHS to ensure the psychiatrist has specialist child and adolescent training, in accordance with NICE guidelines (NICE, 2016). Service users who are aged 18 or over, a legal adult, must self-present at a National Health Service (NHS) for medical support. Each of these scenarios presents caregivers with different potential challenges; managing multiple services for those with children under the age of 18 and struggling to negotiate and navigate support for a young adults (over 18) who may not have the insight into their condition. Furthermore, caring for someone aged 18 or over may produce additional complications regarding confidentiality to share information with families and caregivers. One meta-synthesis of qualitative research in caregiving experiences in FEP reported that caregivers of younger service users, who were still in school, reported that they felt well supported and experienced positive communication between services involved in the service users care (Cairns, Reid, & Murray, 2015). This is in contrast to a theme of 'fights with the system' in a qualitative study where caregivers of young adults with FEP described that issues of confidentiality and consent meant they were told information could not be shared with them, without the service users consent, which may be difficult to be given in the context of acute psychosis (Wainwright et al., 2015). Such factors represent important contextual implications to be considered when supporting both service users and carers.

Within quantitative research, caring for older service users with psychosis has been linked to better psychological health of carers (Poon et al., 2018), whilst high levels of service user and carer stigma has been found in those with younger age of onset (Phillips, Pearson, Li, Xu, & Yang, 2002). The role of age is

inconclusive, however, with a more recent study finding that the age of service users was not associated with caregiver burnout (Onwumere, Lotey, et al., 2017). Studies that have found age to be associated to caregiver distress conclude it plays a minor role in the appraisals of burden and wellbeing in the early stages of psychosis (Addington et al., 2003). Age is typically interpreted as being less important than appraisals (Jansen, Gleeson, et al., 2015) but research to date is possibly underpowered and has not been designed to look at differences between age groups. This review of the literature found that many studies into caregiver experiences had few carers who were caring for service users under the age of 18 and therefore further research maybe warranted.

#### *Family life cycle and psychosis onset*

The influence of unexpected life events, such as onset of psychosis, occurs within the context of parenting and family life cycles, which are characterised by the achievement of different goals at specific stages. Unpredicted events can therefore impact the achievement of the goals of the stage, (Carter & McGoldrick, & Garcia-Preto, 2010). In 'typically' developing parent-child relationships, there is a shift as the adolescent moves into adulthood, from one of dependence to one of mutuality and reciprocity of care (Nydgger, 1991). The presence of an illness, such as a disability or an episode of psychosis, may disrupt this process. The onset of psychosis represents a period of bewilderment and uncertainty that potentially presents particularly challenging violations to parental expectations that require parents' accommodation during adolescents (Collins & Russell, 1991). The 'launching stage' for families with children with disabilities can be associated with greater continuing responsibilities and the extension of the parental role beyond the 'usual' period (Seligman & Darling, 2017). Within the adult onset psychosis population, there may exist a reversal in parent-child relationships; the individual

may have previously been 'launched' and then returns to a relationship of greater dependence with the caregiver. Those caring for service users with adult-onset psychosis may have already achieved mutuality and reciprocity of care (Nydgger, 1991) in their parent-child relationship and consequently may make appraisals of loss associated with a potential reversal of this mutuality, especially given the finding that those with adult onset psychosis are less likely to return to premorbid levels of functioning (Golay et al., 2017).

For carers of those with onset during adolescence, the child may not have reached a stage of independence and consequently the caring associated with psychosis may be perceived as a more natural 'extension' of the caregiving role. However, other challenges may be associated with earlier-onset. Coping with the impact of the illness and having familial member showing this vulnerability from an earlier stage in life may cause caregivers to have worse expectations of chronicity of the illness. Research has demonstrated that caring for adolescents with disabilities is associated with dealing with issues of peer isolation and rejection that may arise from disruption to education and planning for vocational future during the 'adolescent' stages of family life (Turnball, Summers, & Brotherson, 1984). Furthermore, for parental caregivers, having 'successfully transitioned' (characterised by employment, cohabitation with others) adult children is associated with more positive parent-child relationships (Aquilino, 1997); the absence of such transitions could be potentially associated with additional challenges and conflict within the family. A recent systematic review found that caregivers of adolescents with mental health difficulties commonly report loss when adolescents fail to achieve the 'typical' progress associated with parental expectations (Rodríguez-Meirinhos, Antolín-Suárez, & Oliva, 2018). Consequently, the additional care required in supporting an adolescent child with severe mental health problems may be experienced in the context of ongoing emotional and financial strains associated



with the 'failure to launch', with a potentially greater impact on caregivers (Angold et al., 1998). Family life-cycle literature has considered that the dimension of 'time' becomes very important in relation to the presence of a disability in the family (Rolland, 2005) both in terms of dealing with loss in the present and in the future. Within the context of FEP, this may differ dependent on the age and stage a family is in when the onset of psychosis occurs.

The importance of providing support for caregivers for their own burden of care and distress is well established. Interventions delivered by services supporting those with psychosis work to both reduce caregiver distress but also as a way of reducing risk of relapse by reducing EE; this is done by targeting specific maintenance mechanisms, such as the aforementioned factors of caregiver appraisals of illness duration and control. Interventions that have attempted to target appraisals and beliefs (e.g. through Psychoeducation) have been found to produce changes to beliefs and increase caregiver's confidence in dealing with challenges (Juliana Onwumere, Glover, et al., 2017). It is relevant to consider whether the importance of appraisals identified in literature of adults with FEP, are applicable to caregivers of children and adolescents with FEP.

### **'Profiles' and 'styles' of caregiving experiences and behaviours in psychosis**

Previous research has highlighted the need to better understand what support caregivers require in psychosis and why the experience of distress may differ amongst carers (Jansen et al., 2014 Onwumere & Kuipers., 2017). It is possible that the potential differences in wellbeing and distress of caregivers could relate to their existing different 'profiles' of carers, related to the patterns of appraisals and belief they hold, use of coping styles and caregiving response (behaviours). The cognitive model of psychosis (Kuipers et al., 2010) described above proposes three different 'styles' of carers: positive relationship style,

emotionally over involved style and critical and hostile style. These are posited to be related to the types of appraisals caregivers make and context of the relationship with the service user prior to illness onset but are based solely on theoretical assumptions from the literature and have not been empirically tested. The positive relationship style caregivers are more likely to use effective problem-solving and appraise illness-related behaviours as part of an illness as opposed to 'difficult' adolescent behaviours. This is in contrast to the 'critical and hostile' style, who the authors propose are more likely to make appraisals of 'blame' towards the service user and that they have little controllability over the illness and therefore exert pressure on services to 'fix' the problem. Given the relationship between caregiver appraisals and distress, such as control appraisals and anxiety (Fortune et al., 2005; Hesse & Klingberg, 2014) it may be that certain caregivers are more prone to distress and poorer wellbeing than others. The suggestion of caregiving profiles or 'styles' has important implications for caregiver outcomes and for the outcomes of service users, given the relationship between EE and relapse (Claxton et al., 2017; Weintraub et al., 2016). In the general population, 'positive' and 'negative' child outcomes have been associated with 'warmth/responsiveness' and 'control' based parenting styles, respectively (Nelson, Padilla-Walker, Christensen, Evans, & Carroll, 2011). Interestingly, these emerging parenting clusters in the general population are conceptually related to the caregiving literature in psychosis; including the role of beliefs about controllability of behaviours and the use of criticism as a method to manage behaviour (Weisman et al., 1998). The emotionally over involved 'style' caregiver, in psychosis, is posited to most likely be present in parents caring for younger children (Kuipers et al., 2010) and is not considered maladaptive when caring for this younger age group (Khafti, Yates, & Sher-Censor, 2015) or early psychosis populations (Domínguez-Martínez et al., 2017). Thus, the appraisals caregivers make that consequently influence the caregiving response or behavior may also be associated with the age of the service user or the relationship

to the service user. Though Kuiper's model offers a theoretical model of caregiving 'styles' it could be beneficial to understand whether styles or 'profiles' across the known factors linking to EE (appraisals and coping styles) exist as this has not been empirically tested.

## **Conclusions**

Based on the above literature, caregiver distress and wellbeing appear to be related, and predicted by, a number of complex factors. Notably, the way in which caregivers appraise the illness of their loved one and the coping strategies they employ is particularly important to the manifestation of distress. Some of the key appraisals include the controllability of the illness, perceptions regarding chronicity, blame and the most significant coping style predictor appears to be engagement in avoidant coping. It has also been pointed out that the research does not address why there are differences in how distressed some caregivers are compared to others (Jansen et al., 2017; Jansen, Gleeson, et al., 2015). The presence of different caregiver profiles across the identified key factors (e.g. certain appraisals, coping) might explain varying distress levels. This could perhaps contribute to the proposal of caregiving styles posited in the cognitive model of caregiving (Kuipers et al., 2010) by developing a more comprehensive formulation of the pattern of appraisals in caregiving. Given that interventions targeting caregiver distress are continually developing and often target some of the key variables or appraisals and coping, it may be helpful to identify whether certain combinations of important variables (e.g. variables or coping), or 'profiles' may lead to some caregivers being more likely to experience distress than others.

The evidence relating to whether, or how, service user characteristics and caregiver characteristics contribute to the manifestation of distress and wellbeing appears less conclusive. This may be due in part to small sample sizes and the cross-sectional nature of much of the research and also that some of the research

does not include specific measures of distress and necessitates the use of other factors, such as burden as a proxy. Given that the evidence shows this has important implications for outcomes for service users themselves, it may be relevant to consider its potential relevance for caregiving experiences, not least because caring for a child or adolescent with EP versus adult is likely to bring different challenges and levels of necessitated adjustments from the pre-illness role. Caregiving experiences in FEP are now considered vital to routinely recognise and support (Onwumere & Kuipers, 2017) and furthering our understanding of the factors important to distress may help us identify those most at risk. This could have clinical implications to developing effective interventions for carers and to influence the manifestation of EE and thus service user outcomes.

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## **Part Two: Empirical Paper**

Caregiving profiles in adolescent and adult early psychosis

## **Abstract**

**Background:** Early phases of psychosis present caregivers with uncertainty. Appraisals of the caregiving experience are associated with distress. Further understanding of the patterns of appraisals may help to identify carers most at risk and consider prevention strategies.

**Aims:** To determine if there are distinct caregiver profiles of appraisals and avoidant coping in early psychosis (EP). A further aim was to understand whether caregiving profiles relate to demographic and clinical features, and if they are associated with wellbeing.

**Methods:** The study represents a secondary data analysis of data collected from 254 caregivers within an Early Intervention Service. Appraisals, beliefs and coping styles were included into a Latent Profile Analysis (LPA) to explore possible latent profiles within the data. Profile memberships, alongside demographic factors, were then regressed onto caregivers' scores on wellbeing, depression and anxiety measures.

**Results:** LPA identified three caregiving profiles according to patterns of responses across the included indicator variables. The profiles are described as: Positive and Engaged, Avoidant and Helpless and High Carer Control. Profile membership was predictive of wellbeing, anxiety and depression scores in the mixed-linear regression models.

**Conclusion:** In line with the aims, profiles of caregiver appraisals and avoidant coping were identified and significantly associated with wellbeing, depression and anxiety. Clinical implications for identifying at-risk carers are considered in light of the limitations of the current study.

## Introduction

Psychoses-spectrum disorders include a broad-range of cognitive, perceptual, affective and social symptoms (American Psychiatric Association, 2013). The impact of psychosis on the individual and those providing support is vast and the move to community and home-based care has resulted in an increased responsibility on families to provide support (Onwumere & Kuipers, 2017). Given that the typical age of onset falls during adolescence to young adulthood (Kirkbride et al., 2012) it is unsurprising that service users in early stages of psychosis tend to have close contact with or live with caregivers (Gleeson et al., 2008; Lobban & Barrowclough, 2009). The experience of caregiving is associated with high levels of burden and distress (Kuipers et al., 2006; Poon, Harvey, Mackinnon, & Joubert, 2017) and trauma-like symptoms have been reported in around 30-40% of study populations (Kingston, Onwumere, Keen, Ruffell, & Kuipers, 2016; Loughland et al., 2009).

The co-occurrence of close caregiver involvement and high experiences of distress necessitates better understanding of caregiving processes and what support to provide. Studies suggest that between 30-40% of caregivers in psychosis meet criteria for depression or anxiety (Hamaie et al., 2016; Sadath, Muralidhar, Varambally, Gangadhar, & Jose, 2017). Furthermore, the way in which caregivers respond can have implications for recovery or relapse in service users (Wearden, Tarrrier, Barrowclough, Zastowny, & Rahill, 2000; Weintraub et al., 2016). The manner in which caregivers respond can contribute to the 'emotional climate' of the family, broadly known as 'Expressed Emotion' (EE). Sub-constructs of EE, such as criticism and over emotional involvement (EOI) have been linked to caregivers' perception of burden (Lvarez-Jimnez et al., 2010) and so better understanding of predictors of caregiver burden and distress may be important to both caregiver and service user outcomes. Family Interventions in Psychosis (FiP) have been found to

lead to reduction from 'high' (problematic) to 'low' levels of EE, improvements in service user outcomes and in carer wellbeing (leads to improvements in the EE of caregivers and better outcomes, such as fewer relapses (Claxton, Onwumere, & Fornells-Ambrojo, 2017)).

Early research into caregiving in psychosis considered the 'objective' burden placed on carers, such as hours per week caring. There has since been a move to focus on 'subjective' burden to understand how caregiving affects distress and wellbeing. Stress-appraisal-coping models posit that distress is dependent upon the appraisals of the caring experience, alongside the perceived ability to cope (Lazarus & Folkman, 1984). The cognitive model of psychosis (Kuipers, Onwumere, & Bebbington, 2010) has considered the interplay between caregiver related factors, such as appraisals, and relationship factors and has been successfully replicated in modelling studies in a First Episode in Psychosis (EIP) population (Hesse & Klingberg, 2014). What these models, and the wider literature, highlight is the importance of certain key factors, including coping, appraisals and beliefs, demographic factors and certain clinical characteristics.

## **Coping**

Coping styles are proposed to impact experiences of caregiver distress, alongside illness-related difficulties (Kuipers et al., 2010). Most studies assessing coping styles of psychosis caregivers, have considered the following broad categories: problem-focused coping, emotion-focused coping and avoidant coping. Avoidant coping strategies are consistently associated with greater levels of reported distress, independent of the length of illness of the service user (Gerson et al., 2011; Kingston et al., 2016; Onwumere et al., 2011). The employment of avoidant strategies that are aimed to reduce tension, (e.g. substance use), is the

most predictive indicator of distress in FEP population (Cotton et al., 2013) and is related to poorer overall functioning (Raune, Kuipers, & Bebbington, 2004). Interventions aimed at the familial or caregiver level consequently focus on considering more adaptive ways of coping through commonly using psychoeducation; reviews demonstrate caregivers do report improvements and use of more problem-focused coping (Hasan & Jaber, 2019).

### **Appraisals and beliefs**

Overall negative appraisals (frequently measured by the Experience of Caregiving Inventory: Szmukler Burgess et al., 1996) have been found to be predictive of caregiver distress, when controlling for socio-demographic factors, service user symptomatology and global functioning (Jansen et al., 2015). The level of 'control' that is attributed to the service user and carers' appraisals of the effectiveness of their behavioural responses is associated with distress (Jansen, Gleeson, & Cotton, 2015). More nuanced appraisal analysis has found that caregivers' specific perceptions of negative consequences and illness chronicity are associated with greater levels of distress (Onwumere et al., 2008) and are predictive of poorer functioning in caregivers at 6-month follow-up (Barrowclough, Gooding, Hartley, Lee, & Lobban, 2014). Caregivers' appraisals of impact and consequences, alongside service users of a younger age, have also found to be the best predictors of a wellbeing measure (Addington, Coldham, Jones, Ko, & Addington, 2003). The appraisal of 'loss' is significantly associated with experiences of negative burden (Patterson, Birchwood, & Cochrane, 2005) and may be in reference to loss of aspirations for their loved ones' future, or for their own pre-caring life-style (Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2005). For carers who make attributions of self-blame, significant associations with distress have been reported (Fortune, Smith, & Garvey, 2005; Wainwright, Glentworth, Haddock, Bentley, &

Lobban, 2015) and a key part of interventions is to provide psychoeducation around understanding of the complex causes of psychosis and thus impact some key appraisals. Further understanding of the causes and symptoms may help mitigate against the appraisals of stigma that can impact quality of life in FEP carers (Hasan & Jaber, 2019). Research has found that carers who hold multiple explanatory models do report significantly lower levels of distress (Joy, Manoranjitham, Samuel, & Jacob, 2017).

More recently there has been consideration of positive appraisals of caregiving, such as the experience of personal accomplishment (Shiraishi & Reilly, 2019). The presence of positive appraisals has been found to be unrelated to distress and wellbeing (Addington et al., 2003; Jens Einar Jansen, Gleeson, et al., 2015), though family based interventions do increase positive appraisals of caregiving (Gleeson, et al., 2010)

### **Caregiver and Service user-related factors**

As highlighted in the cognitive model of caregiving (Kuipers et al., 2010) it is useful to consider the interaction of the carer- service-user dynamic. Research into distress and wellbeing in early psychosis (EP) groups has considered both the role of caregiver and service user demographic factors. Primary caregivers in psychosis are typically parents (Lauber, Eichenberger, Luginbühl, Keller, & Rössler, 2003) with proportions of around 85% common across studies and reviews in EP (McCann, Lubman, & Clark, 2011; Onwumere, Zhou, & Kuipers, 2018). Carers are more likely to be female (Jansen, Gleeson, et al., 2015; Magaña, Ramirez Garcia, Hernández, & Cortez, 2007), with female gender associated with higher levels of distress; whilst male gender is predictive of higher burden scores (Boydell et al., 2014). Overall, reviews of the literature suggest that findings regarding gender and distress in FEP are inconsistent (Baronet, 1999; Jansen, Gleeson, et al., 2015) and warrant further

consideration.

The length of illness and the age of the service user, with the associated developmental stages, are thought to have implications for the carer-service user dynamic (Cotton et al., 2013). Research highlights elevated levels of caregiver distress in early stages of illness (Sadath et al., 2017) and equitable levels of 'emotional burden'. It has been deemed important to intervene early to support the difficulties experienced in patient-carer relationships in early phase psychosis (Tomlinson, Onwumere, & Kuipers, 2014). Specific caregiver needs may present and change at various stages of the illness (Sagut & Çetinkaya Duman, 2016). The age of the service user is a potential factor that may have specific implications for distress and needs of carers. Early onset psychosis, defined as onset before the age of 18 (Jackson et al., 2011), leads to poorer outcomes for service users (Golay et al., 2017; Langeveld et al., 2012) and younger age of onset is associated with high levels of reported stigma by service users and caregivers (Phillips, Pearson, Li, Xu, & Yang, 2002). Positive correlations have been reported between the age of service users and caregiver psychological health age (Poon, Joubert, Mackinnon, & Harvey, 2018). Possible differences in the experience and needs when caring for adolescents versus adults include the journey to and interaction with services. Those under 18 are often seen in liaison within Child and adolescent mental health service (CAMHS) for access to specialist child psychiatrists (NICE, 2016). Rules regarding confidentiality for those over 18 may reduce the involvement of parents in their son or daughter's care. These differences may present unique challenges to caregivers, including parents reporting 'fights with the system' to get adequate information regarding care when their child is over the age of 18 (Wainwright et al., 2015) that could have implications on their experience and wellbeing. Thus, the developmental characteristics that arise depending on service user age should be



taken into account when caring for adolescents or young adults and their families (Lenroot & Gibbs, 2019).

The onset of psychosis, and other unexpected life events, happens within the context of parenting and family life stages that are associated with specific goals. A recent review has found that parents of adolescents with mental health difficulties report loss when adolescents fail to reach 'typical' progress associated with parental expectations (Rodríguez-Meirinhos, Antolín-Suárez, & Oliva, 2018). An unpredicted event, like illness, can be considered as a disruption that impacts achievement of certain familial life-stages (Rolland, 2005). Given that adolescence to young adulthood is a time that typically sees a move from parent-child dependency to more mutuality and reciprocity (Nydegger, 1991) the onset of psychosis before adulthood may interrupt or reverse this process, giving rise to appraisals of loss and distress in caregivers. Conversely, caregivers to those with younger ages of onset may appraise the role as a natural extension of the parental caregiving role and therefore leading to less negative appraisals and distress. The impact of age of the service on caregiver appraisals of burden and burnout reports are inconclusive (Onwumere, Sirykaite, et al., 2018) and it has been found that although service user age is significantly related to caregiver distress, it is less predictive than appraisals (Addington et al., 2003). It has been noted that research into service user age (amongst other clinical characteristics) perhaps has been underpowered (Jansen, Gleeson, et al., 2015) and may require further consideration.

### **Current study**

Caregiver's appraisal or beliefs regarding their caring role are associated with wellbeing and distress. There is however less conclusive evidence regarding illness-related factors (e.g. length of caregiving), service-user factors, such as age, and specific caregiver factors, such as gender with regards to their association with

wellbeing and distress. This warrants further consideration. Better understanding of these factors may assist in the goal of understanding why some carers become more distressed than others (Jansen, Gleeson, et al., 2015; Onwumere & Kuipers, 2017) and help to identify possible risk needs-based factors. Developing an understanding of possible groups or 'types' of caregiver appraisal and coping styles, and their relationship to demographic or service-user related factors, could benefit approaches to identifying and supporting the high-need carers, as well as potential prevention-based interventions.

Much of the previous literature has focused on overall appraisals (e.g. positive or negative subscales) on caregiver distress or has considered the impact of specific individual appraisals beliefs and coping styles on distress, and to a lesser extent wellbeing. Earlier research has therefore used variable-centred approaches to explore these multi-dimensional constructs rather than person-centred approaches which might provide a better understanding of the interaction and co-occurrence of different constructs. The variable-centred approach limits the understanding of whether there exist distinct patterns across appraisals that impact the experience of distress in caregivers.

One type of analysis that is becoming increasingly popular for identifying sub-groups of individuals within social sciences is Latent variable mixture modelling, specifically latent class analysis, and its extension for using continuous variables, Latent profile analysis (LPA) (Saunders, Cape, Fearon, & Pilling, 2016). LPA is a statistical approach that evaluates unobserved heterogeneity in a population to consider whether it can be divided into meaningful subgroups based on observed data (Lubke & Muthén, 2005). This has potential to help us understand patterns of appraisals and avoidant coping across caregivers that could be used to consider in relation to the proxy distress measures of anxiety and depression and wellbeing.

Furthermore, once profiles have been identified one could explore the relationship to clinical or demographic factors, such as gender of caregiver and the age of the service user. By identifying profiles of appraisals and coping, and predictors of these profiles, preventative interventions can be targeted to reduce potential carer burden/burnout.

## **Research Aims**

In this context, the current secondary data study addressed the following research questions:

(a) Are there statistically different latent profiles (subgroups) of caregivers based on their appraisals (i.e., appraisals of timeline of illness, consequences, and difficult behaviours) and reported avoidant coping style of caring for someone with EP?

(b) What is the relationship between these latent profiles and demographic (caregiver gender, relationship to service user, ethnicity) and clinical factors (length of time caregiving and service user age)?

(c) Do (1) the identified latent caregiver profiles and (2) age group of the service user (adolescent or adult) predict caregiver health outcomes (wellbeing, anxiety, depression) when controlling for key demographics and the length of caregiving?

## **Method**

### **Participants**

Participants in this secondary analysis were identified as caregivers of service users accessing an Early Intervention in Psychosis Service (EIS) service in an NHS London Trust. The service accepts those experiencing a FEP, who are

aged between 14-35 years old and have a DUP of less than 21 months. For the purpose of the service and this study, those who were caring for a service user in an unpaid capacity (e.g. a parent, romantic partner, sibling, adult child) and who maintained weekly face-to-face contact (no minimum amount required) and over the age of 18, were eligible for inclusion. In some instances, more than one caregiver was enrolled in the study for a single service user (e.g. both parents, or a parent and a sibling); this reflected circumstances where there was similar involvement in providing care and support for the service user. However, this did not necessarily mean that service users with only one caregiver in the study did not have another carer providing support.

## **Ethics**

The data comprising this secondary data analysis were originally collected for service audit and evaluation purposes of routine caregiver assessments. Therefore, it was not necessary to obtain ethical approval for the evaluation, in line with NHS Research Ethics Committee Guidelines (Health Research Authority, 2013). See Appendix 1 for written communication from the Assistant Director of the NHS Research and Development department. Anonymised data provided from participants who refused to have their data published were not included (three participants).

## **Design**

A cross-sectional design was employed, with participants completing a selection of self-report measures. The current study conducted secondary data-analysis to explore the aforementioned research aims.

## **Measures**

*Socio-demographic questionnaire:* This included information about gender, ethnicity,

employment and relationship status of caregivers. Information regarding their relation to the service user, whether they lived with them and hours per week spent providing care was also collected.

*Experience of Caregiving Inventory; ECI* (Szmukler Burgess et al., 1996) and *Brief Experience of Caregiving Inventory (BECI)* (O'Driscoll, Farrelly, Burgess, Szmukler, & Shaikh, 2018)): The ECI is a self-report measure, containing 66 items and assesses both the positive and negative appraisals of caregiving experiences. Respondents are required to answer how often they have considered a particular issue over the preceding month, on a five point likert scale ranging from 'never' to 'nearly always'. The measure is comprised of 10 subscales, with 8 subscales ('difficult behaviours'; 'negative symptoms'; 'stigma'; 'problems with services'; 'effects on family'; 'the need to provide back-up;'; 'dependency'; 'loss') assessing negative appraisals and two subscales ('rewarding personal experiences; 'good aspects of the relationship with the service user' measuring positive appraisals. The ECI constitutes two summary scores, reflecting the sum scores of the positive and negative subscales, respectively with higher totals indicative of higher levels of positive/negative caregiving experiences. The measure has been found to have good internal validity (Szmukler Burgess et al., 1996), construct validity (Joyce, Leese, & Szmukler, n.d.) and has been widely used in the caregiving in first episode psychosis population (e.g. Tennakoon et al., 2000; Tomlinson et al., 2014). The BECI has recently been developed and validated using a multidimensional item response theory approach with a large participant pool of caregivers (n= 626) of those with psychosis (O'Driscoll et al., 2018). The BECI utilises a sub-set of 19 items from the original questionnaire ECI, and has four-factors ('difficult behaviours'; 'problems with services'; 'stigma/Effects on the family'; and 'positive personal experiences'). The BECI has good psychometric properties, including good internal consistency (Cronbach's  $\alpha = 0.84$ ) and construct validity. Participants completed the

ECI (66 items, 10 subscales), but for the purposes of the current secondary analysis study the subset of items that form the BECI (19 items) were identified and the four BECI subscales calculated (Please see further details and rationale in the analysis section and details of retained items and factor loadings in Appendix 2).

*Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983):*

The HADS is a 14-item measure that detects clinical levels of anxiety and depression disorders. The full scale is comprised of two subscales for depression and anxiety, in addition to a total score. Respondents answer according to a four point-Likert scale ranging from 0 = 'as much as I ever did' to 4 = 'hardly at all'. The subscales scores range from 0-21, with a score of 11 or more indicating clinically significant levels of both anxiety and depression. The HADS has good psychometric properties (Zigmond & Snaith, 1983) and has been widely used in caregiving research (Onwumere, Sirykaite, et al., 2018; Thompson, Fernández de la Cruz, Mataix-Cols, & Onwumere, 2016).

*Illness Perception Questionnaire for Schizophrenia: Relatives' Version (IPQS-RV; Lobban, Barrowclough, & Jones, 2005):* The IPQS-RV is a measure that assesses the beliefs that relatives hold regarding the service users' illness. Five belief constructs are considered, including 'timeline' (how long relatives believe the illness would last/whether relatives believe the nature of the illness would be cyclical or chronic), 'consequences' (for service user and relative) and the controllability of the illness (for service user and relative). There are a total of 63-items grouped in 11 subscales. Each item is rated on a 5-point likert scale (where 1 = 'strongly disagree' and 5 = 'strongly agree'). Mean scores are calculated for the items on each subscale. The IPQS-RV has been found to be internally consistent and reliable over time with acceptable Cronbach's  $\alpha$  levels of between .43 -.83 (Lobban et al., 2005) and continues to be used frequently in the caregiving in psychosis literature (e.g.

Domínguez-Martínez, Medina-Pradas, Kwapil, & Barrantes-Vidal, 2017; Hesse & Klingberg, 2014). It is worth noting that 15 items on the IPQ scale refer to beliefs and appraisals caregivers hold about themselves (e.g. 'If I were a stronger person they would get better') representing a 'carer only' subscale. The remaining 48 items represent a 'service user only' subscale with items referring to beliefs and appraisals caregivers hold regarding the service user (e.g. If *they* were a stronger person they would get better'). Please see Appendix 3 for the full measure and indication of items on the respective 'carer' and 'service user only' subscale.

*COPE Inventory* (Carver, Scheier, & Weintraub, 1989). This is a multidimensional measure that contains 15 subscales, each representing a strategy employed by caregivers to cope with difficult situations. The subscales can also be grouped into 3 types of coping mechanisms: problem-focused coping (strategies that actively resolve or modify the stress), emotion-focused coping (less productive ways to alleviate emotional stress) and avoidant coping (coping by using avoidance strategies such as alcohol or drugs). There are 30 questions, rated on a 1-4 scale (1= 'I have never done this', 4= 'I have done this a lot'). Mean scores are calculated for each subscale and the three coping mechanisms. This measure is commonly used in caregiving research, with similar scale compositions (Onwumere, Lotey, et al., 2017; Raune et al., 2004) and has acceptable to good psychometric properties with Cronbach's  $\alpha$  ranging between 0.45 – 0.92 for the original subscales (Carver et al., 1989).

Psychological Wellbeing Scale (PGWB; Du Puy, 1984): This is a 22-item self-report measure that assesses an individual's view of their general wellbeing. The measure covers four dimensions of wellbeing: 'anxiety', 'depressed mood', 'positive wellbeing', 'self-control', 'general health' and 'vitality' using a 6 point Likert scale (where zero reflects most negative experience and 5 the most positive experience).

Scores are calculated for the subscales and for a global score for general wellbeing. Higher scores suggest more positive wellbeing.

### **Procedure**

All caregivers within the service are routinely identified by the teams admitting staff (e.g. care co-ordinators, psychologists, assistant psychologists) and offered a carer assessment. Carers were then routinely approached to complete the assessment by the team's Assistant Psychologist (AP). Data collection took place between 2011 and 2017. Data were only used in any subsequent publications outside of the audit where carers had given written informed consent for this purpose.

The AP had been trained in the engagement and administration of the reported measures and remained in the room for the duration of measure completion. Caregivers were usually assessed at the health centre, but occasionally at their homes. For those who did not speak English as a first language, interpreters were used as necessary to facilitate completion of the measures. In instances where there was more than one caregiver for a specific service user, they were instructed not to consult each other for opinions when answering the questionnaires.

At the time of original data collection, consent was obtained from the service user to collect information from their electronic records. This originally included information including demographic characteristics and clinical characteristics (e.g. illness length, diagnoses, and symptomatology) in addition to completion of measures related to the caregivers own experiences. Variables included in the study consequently represent a sub-set of data that were originally collected.



## Data analyses

The data were analysed using SPSS version 25, (SPSS Inc., 2017), Stata version 14 (StataCorp, 2015) for factor analyses and MPlus version 8 (Muthén & Muthén, 2017) was used for conducting the LPA.

### *Data screening:*

Prior to conducting the analyses, normality was checked for all study variables. Normality was assessed by visually inspecting histograms and Q-Q plots, calculating skewness and kurtosis statistics and identifying any extreme outliers. Extreme outliers were dealt with using the Winsorizing method on two cases for the subscales of the IPQ-R measure (service user blame and relative control subscales) (as outlined by Field, 2017). Analyses of the variables showed that the majority of IPQ-R and ECI subscales were either skewed or significantly skewed (positively). Unsuccessful attempts to transform the skewed data using log-transformations were undertaken. Consequently, the data was left untransformed and non-parametric tests (Kruskal-Wallis) were conducted where necessary.

### *Missing data*

A number of cases had missing data across the study variables. Missing data may have occurred because it was not possible to access relevant information regarding the service user at data collection (e.g. date of onset) or due to items of some questionnaires being non-applicable, for example asking about impact of psychosis on employment for those under 18. For each *demographic variable* included the number and percentage missing were: age of caregiver at assessment (n = 1 of 254, 0.4%), caregiver ethnicity (n= 2 of 254, 0.2%), length of time caregiving (since psychosis onset) (n=10 of 254, 3.9%), and hours per week caregiving (n= 9 of 254, 3.5%). These variables were utilised for preliminary analyses and only the completed cases were included in the analyses.

Missing data were also present in the *caregiving variables* that were included in subsequent analyses and are detailed in the descriptive tables. MPlus has excellent capabilities in dealing with missing values and uses full information maximum likelihood (Geiser, 2013). Analyses were conducted on complete cases for the mixed linear regression. An exception to this was for multiple imputations that were used for the purpose of a factor analysis (see below).

#### *Power calculation*

As this project was a secondary data analysis project, there was a pre-determined sample size and research aims with that required specific analysis. Therefore the literature was consulted to check sample size requirements before determining the analysis plan. There is limited research into the factors relating to statistical power needed to identify the correct number of latent variables using LPA, the statistical approach utilised. Research focusing on two commonly employed statistical tests to compare models with varying numbers of extracted classes: the bootstrap LR (BLR) difference test and the Vuong-Lo-Mendell-Rubin test (VLMR-LRT; Lo, Yungtai, Mendell, Nancy, Rubin, 2001) has considered necessary power and found that a sample size of 250 was adequate to correctly 'choose' the correct model that fitted the data (e.g. Tein, Coxe, & Cham, 2013). There is uncertainty in the literature regarding the number of appropriate number of 'indicator' variables (the variables to be included in an LPA) and therefore the decision was made to use data reduction techniques to arrive at a target of 10-11 variables.

#### *Variable selection and data reduction*

Though the previous literature has highlighted key variables thought to be predictive of, or associated with, caregiver distress, LPA represents an opportunity to assess the relationship between items by testing to see the presence of any a-priori unknown subpopulations (Geiser, 2013). As highlighted above, data reduction

techniques were utilised for the inclusion of appraisals and beliefs. The previous research highlights the respective importance of multiple appraisals and beliefs to caregiver wellbeing, but it was not possible to include all subscales into an LPA and thus the brief, but well validated, BECI was utilised alongside use of an exploratory factor analysis to reduce the number of variables from the IPQ (further detailed below). Furthermore, a decision was made to select only the subscale of avoidant coping. This decision was based on the consistency in the literature demonstrating avoidant coping being significantly associated with wellbeing and distress in caregiving.

#### *IPQ measure*

The IPQ measure consists of 10 subscales (Lobban et al., 2005). Exploratory factor analyses (EFA) were completed on items of the IPQ subscales (service user and carer), separately, in order to assess the possibility that the relationship between the items could be 'explained' by a smaller number of latent variables (or factors).

Key assumptions of EFA were considered; this included a consideration of the necessary sample size, with previous observations of the participant-item ratio varying from 3:1, 6:1 up to 20:1 (Worthington & Whittaker, 2006). The present study thus met the minimum requirement. The correlation matrix demonstrated that items were sufficiently correlated with each other. Variance Inflation Factor (VIF) and tolerance statistics were run to test for multicollinearity. Items were found to be sufficiently correlated and no items had VIF values surpassing 10, indicating that the assumption of collinearity was met (Allison, 1999). In order to prepare for the EFA an assessment of the missing data was undertaken in SPSS. The percentage of missing values per item varied from 0 – 14.2%. Whilst there is a lack of consensus on 'problematic' levels of missing data, it has been suggested that a value of over

10% may be an issue (Bennett, 2001). Two items were subsequently removed in line with Bennett's criterion. Given that excluding cases with any missing values across items from analyses can lead to difficulties, including loss of information and decreased statistical power (Dong & Peng, 2013), multiple imputations (MI) were carried out on the IPQ using the Markov Chain Monte Carlo Method (MCMC) (Schafer, 1997) using SPSS. MI represent a principled missing data method that acknowledges the uncertainty with imputed variables (Little & Rubin, 2002). MI use the following steps: 1) imputing missing data multiple times (here 100) to create complete data sets; 2) analyses each data set using statistical procedures (here regression); and 3) pools the estimates for each parameter to yield a single parameter and its corresponding standard error (SE) (Dong & Peng, 2013).

The EFA was subsequently run in Stata using the 'factor' command. Eigenvalues were first assessed in order to determine the amount of variance explained by the dimensions of principal factors (Field, 2017). Factor solutions with eigenvalues above 1.0 can be considered appropriate solutions, however selecting solutions based solely on eigenvalues may inaccurately represent the number of factors (Gorsuch, 1983). It is therefore recommended to also visually inspect the scree plot. Following the EFA the stata 'predict' command was used to obtain factor scores for identified factors; these factor scores use the factor loadings, which take the coefficient (i.e. weighting) for each variable and multiplies this by the participants score. The scores are standardised (centred) so that the mean factor score will be 0. This approach represents a refined method to factor score computation, which is more sophisticated and exact than non-refined methods (e.g. summing score by factors) (Distefano, Zhu, & Mîndrilă, 2009).

### *Experience of caregiving Inventory*

The original data collected using the ECI (Szmukler Burgess et al., 1996) - the 66-item 10-factor measure- was used to calculate scores for the briefer validated version of the measure, the BECI (O'Driscoll et al., 2018). The four factors 'difficult behaviours'; 'problems with services; 'stigma/effects on the family'; and 'positive personal experiences' were used as they provide a more nuanced detail of caregiving appraisals (beyond the positive and negative subscales) whilst meeting the pre-defined limit of indicator variables to be included the LPA. Please see appendix 2 for further information on the validation of the BECI (factor loadings and correlations).

### *Latent Profile Analysis (LPA)*

LPA was undertaken to assess the possibility of distinct profiles of caregivers based on their beliefs, appraisals and avoidant coping style. Following the identification of profiles, further analysis was conducted to explore whether these profiles are associated with differences in caregiver health (i.e anxiety, depression, wellbeing and burnout), demographic factors (e.g. gender) and service-user related characteristics (e.g. age). The variables included in the LPA are outlined in the results section. Given that the intention here was to test whether different psychological profiles of caregivers exist based on patterns of appraisals and beliefs, the decision was made not to include any demographic factors into the LPA. Due to sample size, it was not possible to split the data for the purpose of an independent sample to confirm the profile structure; this limitation is considered in the discussion. One assumption of LPA is independence of the data, which the presence of multiple caregivers speaking about the same service user may be in violation of. Methods used to tackle this in LPA include multilevel LPA (MLPA) (see Mäkikangas et al., 2018 for a comprehensive example). MLPA has not been chosen

in this instance due to a) inadequate sample size that may produce issues relating to statistical power and b) the presence of a second caregiver in the sample being circumstantial; 'sole' caregivers within the data may also have a second caregiver who did not complete the assessment and therefore the presence of two caregivers may be less meaningful. Furthermore, if the assessment had been concerned with rating the needs or experience of the *service user* in relation to the caregivers then there would likely be high dependence between multiple caregivers; however the focus here is on the caregivers' personal and subjective appraisals and beliefs; two caregivers of the same service user could have differing experiences.

LPA, an extension of Latent Class Analysis, allows for the inclusion of continuous (alongside categorical variables if required) (Hagenaars & McCutcheon, 2002). To establish the best fitting model, the VLMR-LRT (Mendell & Rubin, 2001) and the Bootstrap Likelihood Ratio Difference test (B-LRT) were compared (measures of 'relative model fit') alongside the information criteria (IC; descriptive indices) of Akaike Information Criterion (AIC), Bayesian Information Criterion (BIC) and entropy values. For the 'relative model fit' statistics the K model (the current model with 'K' number of profiles) is compared to K-1 model (indicating one less profile), with a significant p-value indicating the K model fits the data better than the model with one less profile. A non-significant finding (p-value  $\geq 0.05$ ) is suggestive that the model with one less profile provides a more parsimonious and 'better fit' for the data. The B-LRT has been found to be a more accurate indicator of the number of classes than the VLMR-LRT and should be preferred if discrepancies occur (Nylund, Asparouhov, & Muthén, 2007). These statistics should be considered alongside the IC indices; lower AIC and BIC values indicate a superior model fit and higher entropy values indicate a more accurate classification for the model. Given that there were no a-priori hypothesis on the exact number of caregiver profiles, analysis began with a two profile model and increased until either a) VLMR-LRT or

B-LRT became non-significant or b) if VLMR-LRT or B-LRT are significant but the AIC or BIC start to increase. This fits with recommendations to utilise BIC index for determining the number of classes in LCA (Nylund et al., 2007).

*Further analyses: Examining if profiles are associated with certain demographic and health factors*

Following the identification of latent profiles, the final step was to assess any associations between profiles and a) demographic details (of caregiver or service user and b) 'health' factors (e.g. scores on PGWB scale, HADS and the burnout measure). A series of chi-square analyses were conducted to assess associations between latent profiles and categorical demographic factors. For any significant result with an omnibus table larger than 2x2, post-hoc analyses were conducted following the standardised residual method (outlined by Beasley & Schumacher, 1995; Garcia-Perez & Nunez-Anton, 2003). The standardised residuals for each cell can be used to determine any discrepancies between observed and expected values that are larger than expected by chance by conversion to z-scores, with values over 1.96 considered significant (at 0.05 alpha level). Bonferroni corrections were used to adjust for increased risk of type 1 error. For continuous demographic or clinical characteristics, group differences were assessed using Kruskal-wallis (for non-parametric data); these results include post-hoc tests.

Finally, mixed-linear regression (MLR) analyses were conducted to explore the relationship between latent profile grouping and health outcomes (e.g. HADS score and wellbeing) when controlling for demographic and contextual factors (caregiver gender, length of caregiving and age grouping of the service user. MLR were chosen to account for possible dependency in the data due to correlations between the scores of multiple caregivers of one household. This approach has been utilised in previous FEP caregiver research (Jansen et al., 2017). Such models

are suited to data that is hierarchical and may have non-independence, as it allows for both *fixed* and *random* effects. In the current study, random effects measure the possible variance of caring for the *same* service user that predictor variables (e.g. latent profile, illness length) do not, by allowing for random intercepts.

In MLR the model is assessed using chi-square likelihood ratio test (LRT), which uses maximum likelihood estimation (MLE) to consider whether the fit of the model is improved by adding parameters (either predictors or random intercepts).

Information criteria, such as AIC, can be used to compare models if more than one parameter has been added. A null multi-level model is first run to determine the proportion of variance explained by random effects, calculated from the Intra-class correlations (ICC). Model 1 included the predictors of interest (e.g. latent profile grouping and age of service user) first as a fixed basic model only and then compared to a model allowing for random intercepts. Known predictors of wellbeing/distress (e.g. illness length) were then added in Model 2. All models used the default variance components option as the covariance structure and SPSS automatically assigns dummy coding to categorical predictor variables.

Interpretation of the b-values of fixed-effects are therefore in relation to the 'reference' group (labelled in the relevant tables).

### *Assumptions*

The assumptions for regression analyses include: linearity, independence of errors, homoscedasticity, and normal distribution of residuals (Field, 2017). Linearity was assessed by visually assessing continuous predictors plotted against dependent variables for any large deviations. With regard to independence of errors, MLR allows for violations of independence and the normality of residuals was visually inspected. The assumption of homoscedasticity (i.e. the variance in residuals does not differ as a function of the predictor variables) was checked by visually inspecting the predicted values and residuals plots. If assumptions were not



met (e.g. an instance of non-normality in residuals) and transformations did not help, then bootstrapping was performed as this can obtain more robust models (Field, 2017). SPSS was requested to pull 500 sample iterations in the bootstrapping. Bias-corrected and accelerated Confidence Intervals (CI) were selected, in line with recommendations (Field, 2017).

## **Results**

This section is presented in three parts. The first section includes a descriptive analysis of the demographic and key variables in the study whilst the second section focuses on the results relating to the LPA (e.g. factor analysis for data reduction and the latent profiles). Finally, the identified latent profiles are considered in relation to descriptive information and associations with health related measures.

### **Descriptive information**

A total of 254 caregivers provided consent for their routine data to be used in subsequent studies. The details of the caregiver demographics are provided in Table 1. For 54 service users, more than one caregiver provided responses (e.g. a mother and father or parent and sibling) and results relating to the caregivers are presented for all 254 caregivers. For the demographics relating specifically to the service users (e.g. age) duplicates were identified from the data set and removed from the analyses.

#### *Caregiver demographics*

As shown in Table 1, most of the caregivers were parents and over half of the caregivers were mothers (n= 145, 57%), the vast majority of whom were living with the service user. Over half of the sample were in employment and of those not in employment, 20 (around 20% of unemployed caregivers) were retired.

### *Service user demographics*

The service user demographics have been calculated for the 198 service users cared for by the 254 carers included in the current study <sup>1</sup>. The majority of service users were male (61.6%, n = 122) with a mean age of 23.33 years (SD = 4.94 [14.02 – 36.44]) and mean age of onset of was 21.73 (5.02 [11.48 – 35.33]). At the time of assessment, 10% (n=20 8%, 2% missing data) were currently inpatients and 82% (n= 162) were currently unemployed.

### *Caregiving variables*

The caregiving variables are displayed in Table 2. The reduced subset of the caregiving variables (i.e. using BECI means) are presented here, but the descriptive statistics for the full ECI can be found in Appendix 4. This sample was found to be comparable to previous examples in the literature (Jansen, Gleeson, et al., 2015; Onwumere et al., 2008; Onwumere, Sirykaite, et al., 2018), with similar levels of negative experiences of caregiving reported across appraisals. Subscale and mean scores for health related measures (i.e. wellbeing) are presented in Table 2. The HADS scores were also recalculated to consider whether caregivers' met 'caseness' (defined as scoring 11 or above on each subscale) for clinical levels of anxiety and depression: 75 (30%) and 45 (18%) met caseness for anxiety and depression, respectively.

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<sup>1</sup> Any duplicated cases where multiple caregivers had completed the assessment were removed.

Table 1

## Caregiver demographics and characteristics

Demographic information	N = 254*
Gender (female) (%)	171 (67.3)
Age, mean (SD) [range, in years]	49.4 (10.95) [18 – 74.33]
Ethnicity (N= 252), n (%)	
Caucasian	84 (33.1)
Asian (Indian /Pakistani)	59 (23.2)
Black	50 (19.7)
Mixed-race/Other	59 (23.2)
Married/partner (N = 253) (%)	184 (72.4)
Employed (full or part-time) (%)	156 (61.4%)
Duration of self-reported caregiving in months, mean (SD) [range, in months]	18.24 (15.18) [1 – 72]*
Relationship to service user, n (%)	
Parent	209 (83.3)
Sibling	15 (5.9)
Partner	21 (8.3)
Other	9 (3.5)
Living with service user, n (%)	219 (86.2)

Table 2

Mean, standard deviations and ranges of caregiving appraisal variables

Caregiving Variables	Mean	SD	Range
<b>Caregiving Beliefs, IPQ <i>n</i>*</b>			
Timeline <i>acute/chronic n</i> = 250	17.68	4.82	6- 30
Timeline <i>cyclical n</i> = 253	14.53	2.96	6- 20
Consequences <i>service user n</i> = 247	39.23	7.35	19- 53
Consequences <i>relative n</i> = 228	27.60	6.41	10- 43
Personal Control <i>service user n</i> = 253	15.33	2.51	8- 20
Personal Control <i>relative n</i> = 253	14.78	2.73	6- 20
Blame <i>service user n</i> = 240	8.72	2.57	3- 15
Blame <i>relative n</i> = 252	7.78	2.28	3- 13
Treatment control <i>n</i> = 249	18.93	2.28	11- 25
Illness Coherence <i>n</i> = 250 (5- 25)	12.26	3.77	5- 21
<b>Appraisals of Burden, BECI <i>n</i></b>			
Difficult behaviours <i>n</i> = 252	10.66	6.70	0 - 16
Stigma/Effects on family <i>n</i> = 252	4.89	3.65	0- 16
Problems with services <i>n</i> = 252	7.19	4.53	0- 20
Positive personal experiences <i>n</i> = 253	10.22	4.03	0- 16
<b>Coping styles BCOPE <i>n</i></b>			
Problem-focused <i>n</i> = 247	27.46	5.44	10-39
Emotion focused <i>n</i> = 251	30.28	6.10	14 - 46
Avoidant focused <i>n</i> = 248	13.81	3.71	8- 25
Total Coping score <i>n</i> = 242	71.77	11.16	36- 100
<b>Anxiety and Depression HADS <i>n</i> = 245</b>			
Anxiety	8.36	4.79	0-21
Depression	6.43	4.61	0-21
<b>Psychological Wellbeing Scale (PGWB) <i>n</i> = 254</b>			
Positive wellbeing	9.95	4.55	0-20
Self-control	10.88	3.26	0-15
General health	9.36	3.44	0-15
Vitality	11.40	4.37	0-20
Total PGWB	41.58	13.64	0-70

\*Differences in *n* are due to missing data

## **Research Aim One: Are there profiles of psychological caregiving processes?**

### *IPQ-R data reduction*

As outlined in the methods section, two EFAs were conducted on the IPQ-R scale for data reduction purposes prior to the LPA. Appendix 5 includes information regarding the EFA and also specifies the items of both the 'service-user only' and 'carer-only' subscales referred to here. For the initial EFA for the 'service-user only' subscale (e.g. "If I were a stronger person they would get better") there were six factors with eigenvalues greater than 1.0, and it explained 82.41% of the variance. However, inspection of scree plot indicated a more parsimonious four-factor model. Thus, a four-factor solution was tested with varimax rotation; this accounted for 72.10% of the variance. This solution was selected, as it was the most parsimonious fit and met guidance of satisfactory (i.e. above 60%) total variance (Hair, Black, Babin, & Anderson, 2014). The details of the factors will be discussed below. For the initial EFA for the 'carer-only' subscale (e.g. 'if *they* were a stronger person they would get better') there was a three factors with eigenvalues greater than 1.0, however inspection of the factor loadings demonstrated weak unique variance of factor 3 (with only two items not accounted for by factor 1 and/or 2) and the scree plot indicated a more parsimonious two-factor model. This two-factor solution was tested with varimax rotation; this accounted for 83.2% of the variance. Please see Appendix 4 for IPQ-R item loadings on the four extracted factors for the service user only subscale and 'self' only subscale, respectively. Therefore there was a total of six factors to be included into the LPA. The factors are described below.

Factor 1 was labeled *Carer Emotional impact and Awareness of consequences (Carer Emotional Impact)* (accounting for 23.9% of the variance). The items on this factor largely corresponded to the original subscale of 'IR' and included items that concerned beliefs that the mental health problem of the service user was having a negative emotional impact. Some items also referred to consequences for the

service user regarding their relationships with others. Example items include: (a) *When I think about their mental health problems I get upset* (.71), and (b) *I get depressed when I think about their mental health problems* (.68). Higher scores on this factor would indicate a belief that the mental health problem causes greater emotional impact.

Factor 2 was labeled *Timeline* (accounting for 23.4% of the variance). Items on this factor concerned perceptions of the timeline of the illness (e.g. it being permanent over temporary) and some items that endorsed negative consequences for the service user. Example items include: (a) *Their mental health problems will last a long time* (.71) and (b) *Their mental health problems will pass quickly* (.69). Higher scores on this item would indicate a perception of greater negative consequences, particularly in terms of the illness timeline or course.

Factor 3 was labeled *Understanding of illness and treatment effectiveness* (accounting for 16% of the variance). This factor contained items that relate to the individuals sense of coherence regarding the illness and beliefs and understanding about whether it is possible for treatment to have any effect on symptoms. Example items include: (a) *I feel I don't know anything about their mental health problems* (.61), and (b) *I don't have any understanding of their mental health problems* (.67). Higher scores would indicate the caregiver has less of a coherent understanding of the mental health problems

Factor 4 was labeled *Service User Control* (accounting for 9% of the variance). This factor included items that related to the service user having control over the illness, including some items that originally were on the service user blame scale. This included item such as: (a) *To some extent what they do can affect whether their mental health problems get better or not* and (b) *If they tried harder they could control their symptoms*.

Factor 5 was labeled *Caregiver Consequences* (accounting for 49.4% of the variance of the separate EFA). The items on this factor corresponded to the original IPQ-R subscale for consequences and included items such as: (a) *Their mental health problems have messed up my social life* (.68), and (b) *Their mental health problems make it more difficult for me to do day-to-day things* (.65).

Factor 6, *Carer Control* (CC) accounted for 33.4% of the variance. Items loading highest onto this factor include: *To some extent what I do can determine whether their mental health problems get better or worse* (.64).

#### LPA

The final selection of indicators that were included in the LPA were the following: the six factor scores computed from the EFA of the IPQ-R, four BECI subscale scores and the total score on the COPE, avoidant coping subscale.

Model comparison statistics for the LPA are presented in Table 3. The LPA showed significant p-values on the VLMR-LRT for successive models ranging from a two to three-profile solution and became non-significant at the four-profile solution ( $p=0.5763$ ). In addition to the significant VLMR-LRT result indicating that the three-profile model was a superior fit to the two-profile model, the AIC and BIC values also decreased. The entropy value for the three-profile model was acceptable (0.782), where values closest to 1 indicate high classification accuracy. The B-LRT was then performed on the three-profile solution, with a significant finding between the two and three profile models ( $p<0.001$ ).

Table 3:  
Information criteria for the different class solutions

<b>Model</b>	<b>AIC</b>	<b>BIC</b>	<b>aBIC</b>
Two classes	11078.970	11199.239	11091.452
Three classes	<b>11002.650</b>	<b>11165.368</b>	<b>11019.358</b>
Four classes	10969.213	11174.378	10990.506

#### *Description of the Latent Profiles*

Descriptive statistics for the full sample and the distribution of the key variables for each latent profile are displayed in Table 4. Figure 1 presents a graphical representation of each profile (with LP means converted to Z-scores to allow for comparison across the indicators). In order to understand the characteristics of each profile, the caregiver profiles can be compared to the full sample means.

Profile one, '*Positive and Engaged profile*' (PEP) scored lower than the mean on avoidant coping, suggesting less frequent engagement with coping strategies such as alcohol use. Across most of the variables this profile scored lower than the average, suggesting this group appraised fewer negative consequences for themselves. In particular, PEP was much lower than average for reporting of difficult behaviours, indicating these caregivers appraised their service user in less critical ways (e.g. being unpredictable or inconsiderate). For positive personal experiences, this profile scored slightly above the mean, suggesting they gave higher endorsements on items such as discovering strengths. This profile scored below the mean for perceptions that the service user has control and on the mean that they did. This is a group that overall could be seen as appraising less impact of caregiving across variables and as taking more positive experiences.



Profile two, '*Avoidant and Helpless profile*' (AHP) had a higher mean on avoidant coping, suggesting more engagement in avoidant strategies, such as alcohol and substance use. The scores on difficult behaviours and stigma/effects on family were both the *highest* across the groups and much higher than the overall mean (17.33 for AHP versus 8.303 overall mean). Compared to the other groups, Avoidant and Helpless profile scored lower on the caregiver control factor, indicating they felt their behaviours had less control over the illness (e.g. Nothing I do will affect their mental health problems at all). They scored higher than average on the factor relating to understanding, suggesting they had a poorer understanding of psychosis. They also had a lower group mean on positive personal experiences, scoring less on items such as '*I have discovered strengths in myself*'.

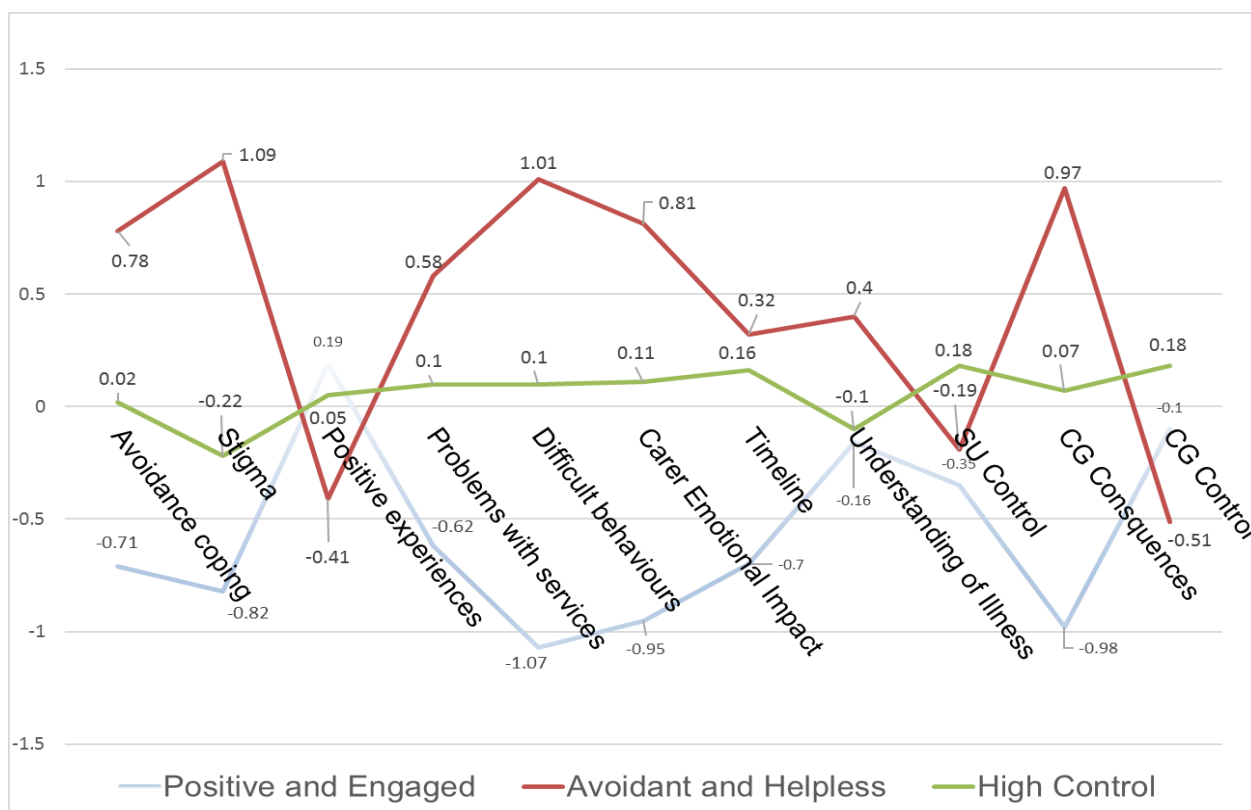
Profile three, '*High Control, Average Coping and Consequences profile*' (HCACC) (*High Control*) in comparison to the other two groups were most representative of the overall means. This group had the highest mean on *caregiver control*, suggesting they perhaps appraised themselves as believing themselves to have more control over the symptoms and illness than the other groups. They were also the only group that had the same mean across both caregiver control and service user control, indicating that compared to the overall mean they perceived themselves and the service user to have equal capacity to control the illness.

There is a large variation between the sizes of the caregiver profiles. HCACP represents the highest share of the presented population (61.4%), followed by PEP and then AHP with 21.3% and 17.3%, respectively.

Table 4:  
Latent profiles and full sample means for included indicator variables

	Full Sample	Positive and Engaged (21.3%)	Avoidant and Helpless (17.3%)	High control (61.4%)
<b>Indicator variable M (SD)</b>				
Avoidant coping –	13.86 (3.7)	11.182(3.49)	16.681(6.16)	13.82(4.55)
Stigma/Effects on family	4.89 (3.64)	1.89(2.32)	8.86(8.94)	4.81(4.59)
Positive Personal experiences	10.23 (4.0)	11.01(5.98)	8.61(4.43)	10.43(4.80)
Problems with services	7.19 (4.53)	4.38(4.45)	9.84(5.70)	7.44(6.45)
Difficult behaviours	10.66 (6.7)	3.30(6.3)	17.45(7.20)	11.27(8.0)
Illness representations	0 (.94)	-0.95(1.21)	0.81(1.42)	0.11(1.95)
Timeline	0 (.95)	-0.7(1.72)	0.32(1.37)	0.16(2.93)
Understanding	0 (.93)	-0.16(1.31)	0.4(1.01)	-0.10(2.23)
Service User control	0 (.93)	-0.35(1.64)	-0.19(1.12)	0.18(2.79)
Consequences	0 (.89)	-0.98(1.12)	0.97(1.08)	0.07(1.90)
Caregiver control	0(.83)	-0.1(1.30)	-0.51(1.36)	0.18(2.21)

Figure 1:  
Identified latent profiles and means on indicator variables. All means have been converted to Z-scores to allow for comparison across variables.



## **Research Aim Two: Caregiver profiles and their relationship to demographic and clinical characteristics:**

In order to consider any associations between the profiles and any demographic clinical characteristics, descriptive statistics were computed and a series of chi-square (for categorical characteristics) and Kruskal-Wallis tests were conducted. Table 5 reports the results of all tests run, with only significant differences reported below.

There was a significant difference between the profile of caregivers and relationship to the service user (being a parent/step-parent versus *other* relationship) ( $\chi^2(2) = 6.33, p = 0.04$ ). Post-hoc chi-square analyses were conducted and found that the standardised residuals for two cell (both relating to latent profile two) significantly contributed to the omnibus chi-square statistic with adjusted  $p$ -values for bonferroni corrections for type 1 error. Caregivers of AHP were the parent or step-parent of a service user significantly *more* than expected ( $p=0.01$ ) and therefore logically were *other* relatives (e.g. grandparent, sibling) significantly less likely than the other two profiles ( $p= 0.01$ ).

Non-parametric Kruskal-Wallis was utilised to assess differences between length of caregiving reported (in months) between the three profile groups. There was a significant difference in length of time caregiving between the three profiles groups ( $H(2) = 9.78, p = 0.008$ ). Pairwise comparisons with adjusted  $p$ -values showed no significant differences between Positive and Engaged and High Control profiles ( $p= 0.122, r = 0.14$ ) and High Control and Avoidant and Helpless profiles ( $p=0.206, r = 0.13$ ). There was a significant difference between length of time caregiving between Positive and Engaged and Avoidant and Helpless profile ( $p= .006, r = 0.32$ ), with those in latter reporting significantly longer periods of caregiving to the Positive and Engaged profile.

In summary, there were significant associations between profiles and the relationship between caregiver and service user and the length of time spent caregiving. Caregivers of the Avoidant and Hopeless profile were more likely to be parents and had been caring for a significantly longer period than the Positive and Engaged profile.

Table 5:

Results of the chi-square test of independence between latent caregiving profiles and demographic factors

<b>Characteristic</b>	<b>LP1</b>	<b>LP2</b>	<b>LP3</b>	<b>Chi-Square test</b>
<b>Caregiver gender <i>n</i> (expected count)</b>				$\chi^2 = .89$
Female	39 (36.4)	28(29.6)	104	$p = .640$
Male	15(17.6)	16(14.4)	52	
<b>Ethnicity <i>n</i> (expected count)</b>				
White	18 (18)	15 (14.7)	51 (51.3)	
Asian	11 (12.6)	12 (10.3)	36 (36.1)	$\chi^2 = 6.22$
Black	16 (10.7)	5 (8.7)	29 (30.6)	$p = .399$
Mixed/other	9 (12.6)	12 (10.3)	38 (36.1)	
<b>Caregiver relationship status <i>n</i> (expected count)</b>				
Single	11(14.7)	10 (12)	48 (42.3)	$\chi^2 = 2.82$
With a partner*	43 (39.3)	34(32)	107 (112.7)	$p = .244$
<b>Employment status <i>n</i> (expected count)</b>				
Employed	34 (33.4)	29 (27.2)	93(95.3)	$\chi^2 = .475$
Unemployed	20(20.6)	15(16.8)	61(58.7)	$p = .789$
<b>Service user age group <i>n</i> (expected count)</b>				
Adolescent (<18)	6 (7.2)	10 (5.9)	18 (20.9)	$\chi^2 = 4.01$
Adult (>18)	48 (46.8)	34 (38.1)	138 (135.1)	$p = .135$
<b>Service user gender <i>n</i> (expected count)</b>				
Female	24(18.9)	14(15.4)	51(54.7)	$\chi^2 = 2.68$
Male	30 (35.1)	30(28.6)	105 (101.3)	$p = .262$
<b>Relationship to service user <i>n</i> (expected count)</b>				
Parent or step-parent	43 (44.4)	42 (36.2)	124 (128.4)	$\chi^2 = 6.34$
Other (grandparent, sibling, partner)	11 (9.6)	2 (7.8)	32 (27.6)	$p = .04$

### **Research Aim Three: Are the caregiving profiles predictive of caregiver reports on health outcomes?**

#### *General wellbeing measure*

Caregivers overall general wellbeing scores (PGWB) were regressed onto the predictor variables and to the random effects of multiple caregivers (referred to from now as 'caregiving household'<sup>2</sup>). A null-mixed linear regression (with random intercept only) was run first and the ICC was calculated at 0.20, suggesting around 20% of the variance in wellbeing score occurred across caregiving households. Findings of between 0.5 – 0.20 are common in cross-sectional data in social sciences (Peugh, 2010). The next step was to include the predictor variables of latent profile group (with High Control assigned as the dummy/reference variable) and service user age group as a basic fixed effect model only (without random intercept). Comparing the AIC values from the null-model to model 1 resulted in an improvement in model fit (indicated by lower value). Allowing for random effects (random intercept) further reduced AIC values indicating better fit of the model, although this was not found to be statistically significant (chi-squared<sub>(1)</sub> = 1.35,  $p > 0.05$ ).

Caregiving profiles remained significantly predictive of PGWB scores ( $F(2, 238.08) = 46.88, p < 0.001$ ) in model 2 (where demographic and clinical factors were included). In model 2, gender also significantly predicted wellbeing scores ( $F(1, 174.72) = 23.02, p < 0.001$ ), whilst length of caregiving was found to be non-significant ( $F(1, 212.09) = .93, p = 0.938$ ). Caregiver ethnicity was found to be approaching significance ( $F(3, 202.29) = p = 0.07$ ). Table 6 presents the betas ( $\beta$ ) for each effect and confidence intervals and allows for interpretation of the direction of relationship

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<sup>2</sup> Note 'caregiving household' refers to instances where there are more than one caregiver answering the questionnaires about the *same* service user which could lead to dependency in the data.

between predictors and the outcome. Being female ( $\beta = -7.00$ , 95% CIs = -9.88 to -4.12,  $p < 0.001$ ) and of the Avoidant and Helpless Profile ( $\beta = 11.33$ , CI = -15.20 to -7.47,  $p < 0.001$ ) were both significantly associated with lower scores on the wellbeing scale (indicating poorer wellbeing). The Positive and Engaged profile was significantly associated with higher wellbeing ( $\beta = 12.08$ , CI = 8.50 – 15.65,  $p < 0.001$ ). Though not reaching significance, caregivers identifying as black scored higher on the wellbeing measure ( $\beta = 3.97$ , CI = -0.41 – 8.35,  $p = 0.07$ ).

### *Depression*

As an assumption for parametric regression was violated (normality of residuals) bootstrapping was performed for the outcome of depression. The null mixed-linear regression (with random intercept only) was run and the ICC was calculated to be 0.29, suggesting around 29% of the variance in depression scores varied across caregiving households. Model 1, including predictor variables latent profile group and age group was subsequently run and the AIC values demonstrated an improvement in model fit. Allowing for the random intercept, significantly improved the fit of the model ( $\chi^2_{(1)} = 3.84$ ,  $p < 0.05$ ). Caregiving profiles remained significantly associated with HADS depression scores in model 2 ( $F(3, 222.615) = 33.64$ ,  $p = .001$ ). Table 7 demonstrates the  $\beta$  for each effect and bias-corrected and accelerated confidence intervals (Bca). Being of Positive and Engaged profile ( $\beta = -3.59$ , BCaCI = 2.18 – 4.93),  $p = < .004$ ) was associated with lower scores on the depression subscale whilst Avoidant and Helpless profile scored significantly higher than the other two profiles ( $\beta = 3.55$ , BCa CI = 1.49 – 5.20). Ethnicity overall was not significant ( $F(3, 197.115) = 2.56$ ),  $p = 0.056$ , but white ethnicity was significantly ( $\beta = -1.85$ , BCaCI = -3.29 - -0.49,  $p = 0.012$ ) associated with lower scores on the depression subscale. Gender was not a significant predictor ( $\beta = 1.67$ , BCa CI = .27 to -.49,  $p = 0.100$ ).

Table 6:  
Mixed linear regression of predictor variables onto the dependent variable of 'wellbeing' score with information criteria included.

Predictors <sup>b</sup>	Models <sup>a</sup>					
	Model 1			Model 2		
	$\beta$	95%CI	<i>P</i> *	$\beta$	95%CI	<i>P</i> *
<b>Profiles</b>						
Positive and Engages	12.68	9.07 – 16.28	<b>.001</b>	12.08	8.50 – 15.65	<b>.001</b>
Avoidant and Helpless	-10.89	-14.76- -7.03	<b>.001</b>	-11.33	-15.20 - -7.47	<b>.001</b>
<b>Age grouping (adult age)</b>	-3.43	-7.78 – 0.93	.122	-3.06	-7.62 -1.50	.187
Gender (female)	-	-	-	-7.00	-9.88 - -4.12	<b>.001</b>
<b>Ethnicity<sup>c</sup></b>						
White	-	-	-	1.95	-1.93 – 5.84	.323
Asian	-	-	-	-1.68	-5.90 – 2.54	.433
Black	-	-	-	3.97	-0.41 – 8.36	.070
Length of CG <sup>d</sup>	-	-	-	0.05	-0.05 – 0.12	.334
Information criteria: AIC*	1963.085			<b>1865.184</b>		

<sup>a</sup>All models include results from inclusion of random intercept; <sup>b</sup>SPSS coded Grp 3 (largest) as the reference group; <sup>c</sup> SPSS coded 'Other' as the reference group; <sup>d</sup>CG = caregiving for psychosis; \*Significant results highlighted in bold; Lowest AIC highlighted bold



Table 7:  
Mixed linear regression of predictor variables onto dependent variable of 'depression' subscale with information criteria and BCa CI and *p* values presented

Predictors <sup>b</sup>	Models <sup>a</sup>					
	Model 1			Model 2		
	$\beta$	95%CI	<i>P</i> *	$\beta$	95% BCa <sup>e</sup> CI	BCa adjusted <i>p</i>
<b>Profiles</b>						
Positive and Engaged				-3.59	-5.24 - -1.82	<b>.004</b>
Avoidant and Helpless				3.55	1.49 – 5.20	<b>.016</b>
<b>Age grouping (adult age)</b>				.65	-.586 – 1.62	.224
Gender (female)	-	-	-	1.65	.270 – 2.84	1.00
<b>Ethnicity<sup>c</sup></b>						
White	-	-	-	-1.85	-3.29 – -.488	<b>.012</b>
Asian	-	-	-	-.411	-1.92 - .697	.503
Black	-	-	-	-1.31	-3.05 - .278	.116
Length of CG <sup>d</sup>	-	-	-	-0.01	-.074 - .058	.633
Information criteria: AIC*		1320.978			<b>1314.48</b>	

<sup>a</sup>All models include results from inclusion of random intercept; <sup>b</sup>SPSS coded Grp 3 (largest) as the reference group; <sup>c</sup> SPSS coded 'Other' as the reference group; <sup>d</sup>CG = caregiving for psychosis; <sup>e</sup>BCa= Bias corrected (bootstrapping)\*Significant results highlighted in bold; Low est AIC highlighted in bold

## *Anxiety*

First, the null mixed-linear regression (with random intercept only) was run and the ICC was calculated to be 0.29, suggesting around 29% of the variance in anxiety scores varied across caregiving households. The basic, fixed-effect model was then run, which included the predictor variables of interest of profile group and age group was then run. AIC values for this model were smaller, suggesting an improvement in model fit. Including the random intercept did result in a smaller AIC value, but did not significantly improve the model (chi-squared<sub>(1)</sub> = 0.662,  $p > 0.05$ ). Caregiving profiles remained significantly predictive of anxiety scores in model 2, when controlling for gender, length of caregiving and ethnicity ( $F(2, 216.510) = 52.764$ ,  $p < 0.001$ ). As seen in Table 8 Positive and Engaged caregiver b-values demonstrated significantly lower scores on the anxiety subscale ( $\beta = -4.40$ , CI = -5.62 - -3.18,  $p = 0.001$ ) whilst Avoidant and Helpless status was significantly associated with higher anxiety scores ( $\beta = 4.06$ , CI = 2.72 – 5.40,  $p = < .001$ ). Again, gender was a significant predictor, with female gender associated with higher anxiety scores ( $\beta = 2.70$ , CI = 1.80 – 3.79),  $p = 0.001$ . Caregivers coded as black ethnicity were the only ethnicity to be significantly predictive and scored lower ( $\beta = -2.06$ , CI = -3.59 to -.533),  $p = 0.008$ ) on anxiety.

Table 8: Mixed linear regression of predictor variables onto the dependent variable of 'anxiety' subscale with information criteria included.

Predictors <sup>b</sup>	Models <sup>a</sup>					
	Model 1			Model 2		
	$\beta$	95%CI	<i>P</i> *	$\beta$	95%CI	<i>P</i> *
<b>Profiles</b>						
Positive and Engaged	-4.63	-5.89- -3.37	<b>.001</b>	-4.04	-5.62- -3.18	<b>.001</b>
Avoidant and Helpless	3.833	2.45 – 5.21	<b>.001</b>	4.06	2.72- 5.40	<b>.001</b>
<b>Age grouping (adult age)</b>	0.41	-1.43- 1.71	.859	0.60	-1.03- 2.23	.468
Gender (female)	-	-	-	2.80	1.80 – 3.79	<b>.001</b>
<b>Ethnicity<sup>c</sup></b>						
White	-	-	-	-7.14	-2.09 - 0.66	.306
Asian	-	-	-	-7.32	-2.20- 0.74	.328
Black	-	-	-	-2.06	-3.59- -5.33	.008
Length of CG <sup>d</sup>	-	-	-	-0.03	-0.06- -0.06	.103
Information criteria: AIC*	1370.617			<b>1273.568</b>		

<sup>a</sup>All models include results from inclusion of random intercept; <sup>b</sup>SPSS coded Grp 3 (largest) as the reference group; <sup>c</sup> SPSS coded 'Other' as the reference group; <sup>d</sup>CG = caregiving for psychosis; \*Significant results highlighted in bold; Low est AIC highlighted in bold

## **Discussion**

To the author's knowledge, this study is the first to identify latent profiles of caregiver appraisals and avoidant coping in an EP population. The relationship between profiles and demographic factors were explored, finding significant associations between relationship to the service user and the length of time caregiving. Finally, profiles' relationship to caregiver wellbeing and scores on a depression and anxiety measure were explored indicating profile membership was a significant predictor, with the Avoidant and Helpless profile predicting poorer scores across all three measures.

### **Are there caregiving profiles in Early Psychosis?**

The LPA identified three statistically reliable profiles of caregivers' appraisals, beliefs and avoidant coping. The profiles had similarities and differences that can be considered in reference to existing literature and their potential implications for identifying more 'at-risk' caregivers.

Profile one, 'Positive and Engaged', is a sub-group who are managing well and are characterised by lower use of avoidant coping, less appraisals of consequences for themselves and more positive appraisals. It is a positive finding that 21.3 percent of the current study population formed this profile, highlighting that a modest proportion of these caregivers are reporting positive experiences.

'Avoidant and Helpless', profile two, potentially represents the highest need group and although represented the smallest proportion, accounted for 17.3 percent. This supports the wider literature that caring for someone in EP can be a highly difficult and distressing experience (Barrowclough et al., 2014; Dillinger & Kersun, 2019; Jansen, Gleeson, et al., 2015; Wainwright et al., 2015). Avoidant coping strategies were highly endorsed in this group, alongside higher means across a

combination of appraisals linked to distress in a systematic review, including control, consequences and symptoms (here 'difficult behaviours') (Jansen, Gleeson, et al., 2015). Finally, High Control was the largest profile (61.4%). This reflects the majority of caregivers supporting those in EP stages. Appraisals of control, both for themselves and for the service user, were high, and identical in this group. This group appears to experience some autonomy and ability to impact symptoms.

The profiles share some overlaps between aspects of the caregiving styles proposed in the Cognitive Model of Caregiving in psychosis (Kuipers et al., 2010) as well as some differences. Firstly, Kuiper and colleagues discuss the 'positive relationship style': caregivers who make 'positive' appraisals and see behaviours as symptomatic of an illness and not 'normal adolescent bad behaviour' (pp. 261). These caregivers are engaged in effective coping, by asking for help from social networks and responding positively to services. This reflects responses of the Positive and Engaged profile. In particular, the combination of low avoidance coping and low reports of stigma/effects on family may equate to a group more engaged in effective problem-solving, such as working with services and seeing support from social networks, which is linked lower burden amongst caregivers (Magliano et al., 2005). This group had the lowest mean on 'difficult behaviours', perhaps in line with Kuiper's argument that these caregivers are less likely to see it as 'negative' behaviours but as symptoms. It is interesting that this pattern has emerged within a profile who appraised service users as having 'less control': perhaps viewing service users as having less control contributes to lower appraisal of behaviours as difficult. Alternatively, this profiles' service users may have fewer symptoms or 'behaviours that challenge'. The current study has no indication of symptomatology and this is a limitation. Implications in Kuiper's model are that although less in need, these carers should still be offered information and support. This finding supports the suggestion that 'preventative' interventions should be considered to help carers who

engage in low avoidant strategies to maintain the positive responses (Gerson et al., 2011).

Kuiper and colleagues also propose the 'Emotionally Overinvolved' group' who appraise their loved ones as needing to be buffered against stressors and are more likely to dedicate vast periods of time to caregiving. The High Carer Control profile of this study, may match onto the Emotionally Overinvolved group. The pattern of average (in this study) use of avoidant coping paired with high caregiver control may suggest a group who perceive themselves as being able to effect change in some way. However, this was the sole profile who perceived both themselves and the service user to have equal levels of control and this is in contrast to the cognitive model of caregiving. The High Carer Control group scored higher on the consequences for services users and timeline (greater chronicity) and lower on perceptions of consequences for themselves than Avoidant and Helpless group. This could be hypothesized as a group that although appraises negative consequences, may be more concerned with the service user consequences than for themselves. This group continues to take some positive experiences: perhaps indicative of likely previously positive relationships highlighted by Kuipers in the Emotionally Overinvolved Style. High Carer Control groups may benefit from support to help problem-solve and to allow service users to take more control over their care.

The Avoidant and Helpless profile presented with a pattern of the highest appraisals of 'difficult behaviour', lowest control and the greatest endorsement of avoidant coping. It may be that when caregivers feel they have little or no control they are *more* likely to engage in avoidant coping strategies. This may present a profile of caregivers who could benefit from more intensive interventions, such as FiP, as caregivers report this aids engagement in more adaptive coping styles

(Hasan & Jaber, 2019) and also is likely to facilitate greater understanding of behaviours and symptoms of psychosis.

The current study represents findings of caregiver profiles from empirical data, beyond the theoretical suggestions as in the cognitive model of caregiving in psychosis (Kuipers et al., 2010). The cognitive model and this study both highlight three profiles and the patterns of appraisals and avoidant coping across them have some similarities. Though requiring further replication, the findings have some potential implications to help consider what might work for whom.

### **Caregiver profiles and wellbeing**

Profiles were significantly related to wellbeing and the HADS. The Positive and Engaged profile was significantly associated with higher wellbeing scores and lower scores on anxiety and depression. This finding is positive and fits with reviews of the previous literature, demonstrating that lower engagement in avoidant coping and appraisals of less consequences has a positive impact on wellbeing and distress (Jansen et al., 2015). Due to the cross-sectional design, it is not possible to infer causality or direction between the positive and engaged profile but nonetheless perhaps support the idea that caregivers exhibiting positive reactions should be offered preventative interventions to maintain such responses (Gerson et al., 2011; Kuipers et al., 2010). The Avoidant and Hopeless caregivers could be considered as the most 'at risk' group. The combination of appraisals of difficult behaviours, negative consequences, stigma, low control and higher average endorsement of avoidant coping link to burden and distress in the wider literature (Darmi, Bellali, Papazoglou, Karamitri, & Papadatou, 2017; Hesse & Klingberg, 2014; Magaña, Ramirez Garcia, Hernández & Cortez, 2007; Patel, Chawla, Krynicki, Rankin, & Uptegrove, 2014). Indeed, caregivers of this profile scored significantly lower on a wellbeing measure and higher on depression and anxiety measures compared to

the other profiles in this study. This fits with research that has found associations between some of these independent appraisals and distress measures and wellbeing (Addington et al., 2003; Barrowclough et al., 2014). Unfortunately, service user symptomatology was not measured in this study, but the wider literature does report that appraisals are more predictive of distress and wellbeing than illness-related factors (Addington et al., 2003; Hegde, Chakrabarti, & Grover, 2019).

The finding regarding the 'at-risk' Avoidant and Helpless profile may have potential implications beyond outcomes for caregivers. Though this study did not include measures of EE, the patterns of appraisals in the profile, such as 'difficult behaviours' potentially reflect the presence of critical views, such as seeing symptoms as 'inconsiderate', or 'reckless'. The 'criticism' sub-construct of EE is associated with avoidant coping and low self-esteem in EP caregivers (Kuipers et al., 2006) and EE is linked to increased relapse risk in service users (Weintraub et al., 2016). The Avoidant and Helpless profile has a high scoring pattern across appraisals that are commonly targeted, and positively impacted, in FiP and other caregiver interventions. This includes the fact this profile exhibits poorer understanding of psychosis, higher avoidant coping strategy use, and low positive experience, which are all found to improve post FiP (Hasan & Jaber, 2019; Ma, Chien, & Bressington, 2018) and in a brief cognitive interventions (Onwumere, Glover, et al., 2017). Perhaps caregivers presenting with appraisals similar to this profile could particularly benefit from FiP or cognitively focused interventions. This might mitigate the risk of engaging in caregiving behaviours linked to EE and relapse, as posited in the cognitive model of caregiving. Future research could consider profiles in relation to more specific measures of EE and caregiver outcomes.



### **Profiles, demographics and 'contextual' factors.**

Across all profiles female gender was a significant predictor for scoring lower on the wellbeing measures and higher on anxiety. Previous literature is inconclusive regarding the role of gender in relation to burden and distress (Baronet, 1999; Boydell et al., 2014). The current study suggests that regardless of caregiving profile being female represents a consistent predictor of lower wellbeing and higher depression and anxiety scores. Role-theory (Biddle, 1986) has been referenced in explaining possible gender differences in caregiving, positing that traditional expectations of the roles of females may contribute to them taking on greater levels of objective burden (Mulud & McCarthy, 2017). Female caregivers have reported greater 'time' and 'physical' burdens (Patel et al., 2014). Early intervention services should perhaps consider female gender as a risk factor for negative caregiving experiences.

Significant associations between profiles and relationship to service users were found. Avoidant and Helpless caregivers were more likely to be parents over siblings, partners or grandparents. Thus, parents may be more prone to appraisal patterns associated with distress and arguably they may have greater caring responsibilities. Little research exists into differences between parents and non-parental caregivers but the component of guilt has been found to be an aspect of parental distress (Young, Murata, McPherson, Jacob, & Vandyk, 2018). In particular, guilt over the posited hereditary component of psychosis and about their child's developmental experiences (Huang, Hung, Sun, Lin & Chen, 2009; Wiens & Daniluk, 2009). Parental caregivers may have multiple concerns, including caring for other children. Perceptions of negative impacts on families is a key appraisal related to negative experiences in the literature (Blomgeren, Muhli, & Siouta, 2016). Appraisals of stigma and effects on family were highest in the Avoidant and Helpless group, where caregivers were most likely to be parents. This poses a question of

why non-parental caregivers were more common to Positive and Engaged and High Carer Control profiles. Older siblings are found to take more proactive approaches to coping and report positive appraisals in EP, including thoughts that it has made them a better person and brought family closer together (Dillinger & Kersun, 2019; Sin, Moone, Harris, Scully, & Wellman, 2012). These perhaps highlight 'positive personal experiences' that were found in two other profiles here. The demography of this study was mainly parents and future research could consider experiences and needs of non-parental caregivers more, including the roles they play and the needs they have.

The finding that the profile with the lowest wellbeing were more likely to be parents is of potential interest given the lack of association found between service user age and caregiver wellbeing. The study sought to consider age, in particular whether caring for an adult or adolescent with psychosis. It is important to highlight that the current study had a substantially larger number of caregivers to adult service users (n= 220) to adolescent (n= 34). The regression analyses may have consequently had insufficient power to find an effect. It seems plausible to speculate that caring for an adolescent may increase the likelihood of being a parental caregiver, who in the current study were more likely to be of Avoidant and Helpless profile. Future research could consider recruitment of more caregivers of adolescents to further consider contextual factors related to age and family life-stage and the caregiving experience.

Length of time caregiving was not related to overall scores of wellbeing, anxiety or depression in the regression analyses. This is perhaps consistent with previous research findings of no differences in emotional burden between EP and chronic phase psychosis caregivers (Sagut & Çetinkaya Duman, 2016). However, differences were found between the profiles, with the Positive and Engaged profile

caregiving for significantly shorter periods of time than the Avoidant and Helpless profile. This finding could suggest that the pattern of less 'negative' appraisals across the Positive and Engaged profile are more likely given the shorter period of caring. It is plausible that those caring for longer periods of time may appraise more negative consequences for the service user or may be more questioning of the possibility of recovery. The current study could have benefited from considering other clinically related factors, including number of relapses or hospital admissions throughout the caregiving experiences and this reflects a limitation of the cross-sectional design of the current study. Though, as highlighted above, this finding may echo the need to provide support to caregivers as early as possible to ensure maintenance of positive appraisals and effective coping strategies (Boydell et al., 2014; Gerson et al., 2011).

### **Strengths and limitations**

This study presents a novel way of considering caregiver experiences in an ethnically diverse EP caregiving population. A strength of the study includes the finding of three statistically distinct profiles using LPA. This is in addition to the caregiving literature as it considers the pattern of responses across the known key appraisals and avoidant coping EP carers. This offers a potential to identify important co-occurring appraisals to identify a) those most in need of support and b) tailoring of information to target specific appraisals in interventions.

There are a number of limitations to be discussed. Potentially the most important is the cross-sectional design and the implication on any causal inferences. Whilst the analyses identified significantly different profiles, that in turn were 'predictive' of wellbeing, anxiety and depression, we did not have any indication of baseline or historical wellbeing or mental health problems. Consequently, existing

wellbeing or depression, may have contributed to the patterns of profiles. This is important to consider in light of the research that is now exploring how individual psychological factors (e.g. cognitive flexibility and resilience) may have implications for caregiver distress (Jansen et al., 2017; Jansen, Harder, et al., 2015). Regarding the use of measures, no specific measure of distress was utilised and the subscales of HADS were used as 'proxy measures' to compare to the previous literature. Furthermore, there is some overlap between the HADS with the general wellbeing scale. Research into caregiving also considers other important indicators of 'health' of carers, including physical health outcomes and quality of life: their absence is a potential limitation of this study.

Another limitation concerns the absence of other potentially important factors. Information pertaining to what, if any, support or interventions had been provided to the caregivers was not possible to obtain. Given that interventions are found to have implications for appraisals and coping styles (Claxton et al., 2017; Thompson et al., 2016) having completed an intervention could be a possible confounding variable not accounted for here. Similarly, the lack of information on service user symptomatology presents a further caution to the interpretation and generalisability of the study, such that caregivers for someone well or recovered could have impacted appraisals. Finally, information was also missing regarding how many caregivers were offered the baseline assessment and it is therefore important to interpret the results with caution as they may not be generalisable to the general caregiving in EP populations due to sampling bias.

The final limitation concerns analyses. In LPA, the identified subgroups can be highly dependent on the choice of indicator variables included, having implications for the generalisability of the findings (Lanza & Rhoades, 2013). This study attempted to include variables based on systematic principles (e.g. EFA for data

reduction) but the process of selecting variables for inclusion may have impacted the results. It is advisable to split the dataset to confirm findings in LPA to ensure results are consistent, unfortunately due to the sample size of the current study, this was not possible.

### **Future research**

The results of this study require further replication to consider the generalisability of findings. Future research could benefit from looking at profiles of caregivers across time to consider implications for wellbeing and distress as distal factors. It would be beneficial to include measures of EE in order to understand the relationship between potential profiles and relationship to caregiving styles and consequently service user outcomes. Furthermore, as highlighted by previous reviews of the literature, inclusion of service user symptomatology, would be beneficial to consider implications of both caregiver and service-user related factors (Jansen, Gleeson, et al., 2015).

### **Clinical implications**

Despite the limitations, the findings here do have some useful clinical implications. As suggested in the cognitive model of caregiving (Kuipers et al., 2010) dynamic relationships between service user and caregiver appraisals and coping styles may manifest in different 'styles' or profiles. The findings here present a way to identify caregivers who perhaps are most 'at-risk' in terms of wellbeing and of appraisals linked to EE. Given that offering assessments is recommended to all caregivers (NICE, 2016) the clinical implications of the study could include identifying appraisals common to the differing profiles which may suggest the need for immediate FiP versus identifying the Positive and Engaged caregivers who would benefit from briefer interventions, such as a carer support group. Although requiring further research, these findings suggest an initial understanding of

caregivers and the types of interventions that may be suitable. It can be considered as contributing to the calls for research into better understanding the differences in responses and needs of caregivers in EP (Jansen, Gleeson, et al., 2015; Onwumere & Kuipers, 2017).

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## **Part Three: Critical Appraisal**

## **Introduction**

This critical appraisal will consider aspects of the research process, including a discussion of some conceptual and methodological challenges and limitations encountered in this exploration into caregiving experiences in early psychosis. I will also consider the context of conducting secondary data and the associated challenges. I will begin by outlining my interest in this area and the journey to the project presented in part two, including a reflection on my experience of having to change research projects.

## **Journey to the project**

Prior to training I had worked as a support worker at a homeless shelter, where a considerable number of service users experienced psychosis. I often had conversations with service users about their families; I heard stories of continuing support over sustained periods, but also of the impact of psychosis on familial relationships and wellbeing. The notion that the impact of psychosis expands to beyond the service user was mirrored in my first year placement in an Early Intervention Service (EIS). I had the privilege of working with caregivers and families, in addition to service users, as part of a carer wellbeing intervention and Family Intervention in Psychosis (FiP). Caregivers and families were integral to the cases I worked with, the discussion of cases as a team, and more broadly in the effort of the service to actively seek to engage and support caregivers. I frequently felt moved by the variety of reactions, both emotional and practical, of caregivers and generally of the great personal sacrifices families made to support and try to understand the changes exhibited by their loved one. I became interested in the difference in reactions to caregiving experiences and often found myself using space in supervision to consider the caregiver-service user dyad and relationship. My interest into factors that may impact caregiver wellbeing developed having completed a qualitative Service Related Research Project (SRRP) into caregiving

experiences of a wellbeing intervention. Although only on a small number of caregivers, I noticed that contextual aspects such as the age of onset and age of the service user had implications for caregiver experiences – including practical differences in accessing services (i.e. those under the age of 18 being seen in liaison with Child and Adolescent Mental Health Services). For those with ‘adult’ children, there were frustrations reported in a sense of being ‘locked-out’ of care decisions if the service user did not want them informed. Whilst it is undoubtedly vital to honour the wishes of service users, I found myself feeling empathetic to the distress this causes parents and loved ones.

Providing support and interventions at the family level is premised on the fact that most service users experiencing a First Episode of Psychosis (FEP) will live with family members (Boydell et al., 2014; Fisher et al., 2008) and that the ‘emotional climate’ of familial environments, coined ‘Expressed Emotion’ (EE) has an implication for relapse rates (Cechnicki, Bielańska, Hanuszkiewicz, & Daren, 2013). Interventions often target the key variables thought to manifest in the sub-constructs of EE (e.g. critical comments, hostility and over emotional involvement). More recently there has been a call for services to focus more on, and target, outcomes for caregivers themselves, as opposed to being secondary to outcomes of the service users (Onwumere & Kuipers, 2017a). Therefore, I was drawn to the idea that research into a caregiving experiences could be important way to contribute to the literature.

### **Practical difficulties in NHS ethics**

The research presented in chapter two of this thesis was not the original project I worked on across my first and second year of training. Although the original study into caregiving experiences in psychosis is not presented, I feel that it has been important and helpful to reflect on what represented a time-consuming and

important part of my research experience: co-designing a study and applying for National Health Service (NHS) ethics. The initial study aimed to consider whether the concept of EE was a valid and reliable construct amongst British South Asian FEP caregivers. I was interested in the cultural sensitivity or, rather, potential insensitivity, of EE conceptualisations. Given that EE was developed in white, western populations, there is a risk of pathologising 'typical' cultural variations and a recent meta-analysis has argued that cultural considerations *should* be made when interpreting EE and its relationship to relapse rates (O'Driscoll, Sener, Angmark, & Shaikh, 2019).

I was aware that the NHS ethics process was likely to be lengthy and began the application at the earliest opportunity, holding in mind that doctoral theses can often take twice as long as you think, with unexpected delays that can be beyond the control of the trainee (Barker, Pristrang, & Elliot, 2016). Ultimately, I was left extremely disappointed when I had to make the difficult decision to give up on the first study due to time constraints and factors that did feel partly beyond my control, including what I perceived to be some inefficiency on the parts of the system. This disappointment left me thinking about the undeniable importance of NHS ethical approval process, but of the pitfalls and ways in which the process may inadvertently do a disservice to potentially important research and to service users. I was disappointed, but not surprised, to find that others, including trainees and student researchers, had similar experiences. The NHS ethical application process underwent an overhaul in 2009, following reports of criticisms and concern. Despite these changes, there continue to be reports of failures in consistency and streamlined approaches (Thompson & France, 2010). It has been highlighted previously that the NHS governance process can be a barrier to student research (Oakeshott & Yadava, 2006; Tan, 2004) and my personal experiences have helped me consider such positions of caution. NHS Research Ethics Committees apply the



same standards to student research as to studies that carry significant possible risk to service users, such as complex clinical trials (Wilkinson, 2008). This was reflected in my experience in completing much of the paperwork, that questions were geared towards clinical trials. Unfortunately, partly due to issues beyond my control (an admin error), the ethics application ended up going to three separate ethics boards, all of which had different views on ethical considerations and necessary amounts of Participant Patient Involvement (PPI). This inconsistency across ethics boards reflects earlier criticisms regarding the lack consistency in decision-making in ethics applications (Tully, Ninis, Booy, & Vinner, 2000). Although the study was finally given provisional approval it was not possible continue due to time constraints to carry out the further PPI requirements. The board had asked as to test the questionnaires on between 10-30 service users or caregivers in an EIS service and after discussions with the trust it was clear that achieving this prior to approval would be difficult as a PPI service was not set-up. This experience was also held by another trainee who consequently completed their thesis on trainee experiences of NHS ethics applications (Brindley, 2012). This qualitative research presented themes that felt very familiar to mine, including: anxiety, powerlessness and isolation in navigating the process. The introduction of proportionate review (ethical consideration by a sub-committee) has gone some way to improving experiences regarding timelines (House of Commons Science and Technology Committee, 2013) but carries the negative of not being able to answer concerns and defend decisions made due to not being present. My experience of the proportionate review was of feeling powerlessness, a sentiment also shared by others (Brindley, 2012; Tan, 2004). In spite of the difficulties regarding timelines, the feedback from ethics committees was thoughtful and helpful in the consideration of the possible sensitivity of conducting research looking at cultural and ethnic variations of caregiving experiences.

The importance and necessity of ethical approval is paramount, however I was left with some concerns. The experience of applying to NHS ethics left me wondering whether future trainee Clinical Psychologists and/or researchers may be cautious regarding applications. I was aware anecdotally that the number of trainees completing NHS approved studies was decreasing and within the adult social care educational field it has been reported that universities actively discourage studies requiring NHS ethics due to the complexity and time constraints (Woolham, 2011). This has since made me consider my own relationship to the scientist practitioner-role, which some have suggested identification with is important to clinical psychology trainees publishing research (Newman & McKenzie, 2011). I do hope that trainees continue to be able to have the experience of designing and conducting research in NHS-settings during training, given that this is where many will work post-qualification.

### **Conceptual introduction**

In carrying out a literature review, I expanded my knowledge base regarding caregiving experiences in early psychosis and what factors relate to wellbeing and distress. Whilst I had a good grounding into concepts related to this current study, such as EE, it was a beneficial experience to further explore the caregiving literature, across a range of methodologies. It was evident in the literature, that often the focus in early psychosis studies that have considered the experience of carers has been in relation to service user outcomes but that there has been a move to focusing specifically on caregiver outcomes (Onwumere & Kuipers, 2017b). The literature on caregiving in psychosis provided me with a knowledge into the caregiver related factors and the importance of the key appraisals of stigma, loss, consequence and control in relation to distress (G., C., Lee, Barrowclough, & Lobban, 2014; Jansen, Gleeson, & Cotton, 2015; Onwumere et al., 2008). Despite

the popularity of The Cognitive Model of Caregiving in psychosis (Kuipers, Onwumere, & Bebbington, 2010) and its consideration of the dynamic between carer and service user, I was surprised about the scarcity of literature regarding 'contextual' factors that impact caregiving appraisals and behaviours (e.g. age of service user or family stage) and this was important in considering exploring the age of the service user in the current project.

The conceptual introduction highlighted to me that much of the analyses in the literature utilised regression analyses to explore relationships between a) positive *and* negative appraisal subscales or b) individual appraisals (e.g. *consequences of illness*) and caregiver related outcomes. This was important in the consideration of the choice of approach of analyses used in the current study, Latent profile Analysis (LPA), as an analysis method that would contribute something new to the literature and provide potentially useful clinical 'groupings' of caregivers.

### **Experience of conducting secondary data-analysis**

As I had not intended to complete a secondary data project, my appraisals of the challenges and choices of using this methodology have been interesting to reflect on. Within other disciplines, such as economics, secondary data analysis is extremely common yet that within social sciences, the associated stages and benefits are less well understood (Jones, 2010). The main difference between primary and secondary data analysis is in the set of steps included to complete the research (Elder & Taylor, 2009; Zaitzow & Fields, 2006). Both begin with the process of identifying a broad research aim and then ensues a period of refining the research question (including finding specific measures, research sample etc) and collecting data for primary research, whereas secondary data projects involve searching for an appropriate existing data set and refining questions in light of this.

Jones (2010) notes a common misconception of secondary data analysis in psychological research of it being 'too easy', when in reality it can involve different and equally challenging steps. I too, found it an extremely challenging process. Firstly, it was difficult to accept the limitations of 'joining' a research project past the period of design. An extensive amount of time during the first thesis project was in considering the positive and negatives of certain choices, including measurement selection for particular aspects of the caregiving experience that met my research aims and hypotheses. During this project I felt that the refinement of the research questions were somewhat limited by absence of certain measures I would have liked to include. In particular, in the research log during the second project, I reflected on my desire for measurements of EE, in order to consider the LPA in relation to caregiving behaviours (e.g. criticism or emotional over involvement), as theoretically considered in the Cognitive Model of Caregiving in Psychosis (Kuipers et al., 2010). In addition to difficulties regarding the available measures, it was also a challenge, the absence of information on important clinical variables and possible moderators for the analysis. For example, the fact that I did not have data regarding the symptomatology of the service users to consider in association to caregiving profiles and their relationships to wellbeing, depression and anxiety. Again, this is something that has been called for in previous reviews of the caregiving in early psychoses populations (Jansen et al., 2015). Additionally, the data set did not record whether caregivers had been completed any interventions (e.g. psychoeducation-based or FiP). Given the fact that interventions are found to impact caregiver outcomes and appraisals (Claxton, Onwumere, & Fornells-Ambrojo, 2017; Onwumere et al., 2017) this could have been a potential extraneous variable impacting the relationship between profiles and reports of wellbeing, depression and anxiety. Though my first thesis project was not completed, on reflection the experience of designing and applying for ethics combined with conducting a secondary-data analysis project has offered a rich learning experience.

## The process of complex data analysis

Completing a secondary data analysis project requires the inclusion of a certain level of complexity in the approach to analysis in order to meet the course criteria. This required me to take on the new challenge of familiarising myself with novel statistical techniques and software. LPA was not something I had much awareness or knowledge of, but I quickly became interested in the potential it provided to consider caregiving experiences by looking at *patterns* of appraisals as opposed to individual impacts of appraisals. This presented a benefit in comparison to alternative techniques, such as moderation analysis, in that it allows for multiple variables to be included in analyses, without increasing the likelihood of type 1 errors. However, the disadvantage was in learning to use a novel (and complicated) new software, MPlus. The main appraisal I have made on the *process* of conducting this type of analysis is the invaluable use of supervision from the statistics demonstrator and my supervisor throughout this period. It made me reflect on being in the stage of 'consciously incompetent' and reminded me of my first year experiences of being the 'incompetent novice' as a therapist (Thériault & Richardson, 2009) working with caregivers for the first time. Just as in my clinical work, effectively using supervision and being aware of my limitations was vital during the learning period.

In addition to becoming familiar with new types of analysis and software, I was struck by the frequent small, but critical decisions, that were necessitated by both the data I had (e.g. missing data) and the type of analysis I had chosen. For example, the process of starting with a given number of participants (here 254) and considering the necessary power to conduct LPA. Whilst it is clear in the literature that for VLMR analysis (the significance test) around 250 participants are needed (Tein, Coxé, & Cham, 2013), there is less consistency regarding the number of

indicator variables to be included. The suggestion of around 10-11 was available in the literature and given as guidance by the statistics demonstrator and this required utilising data reduction techniques. As highlighted in the limitations section of chapter two, a criticism of LPA is that it can be sample specific and limited by the variables included (Lanza & Rhoades, 2013). With this in mind, I attempted to be as systematic as possible in the choice of included variables, including using exploratory factor analysis (EFA) as a data reduction technique. Following EFA, it is common for factor scores to be calculated for inclusion in further analyses (here LPA) with refined and non-refined approaches as the two broad approaches to calculation (Distefano, Zhu, & Mîndrilă, 2009). This demonstrates one of many of the small but critical choices of the analysis process: choosing non-refined approaches that offer more interpretable (i.e. easily comparable to the original measure) but less statistically sophisticated scores versus the more statistically valid but less interpretable refined methods. These experiences made me part with some (naïve) assumptions regarding statistics: that there would be a 'right' or 'wrong' choice, when in reality it was more about taking time to balance the positive and negatives of each decision.

The data analysis process presented me with a steep learning curve, in a short time-frame. With hindsight, I would have perhaps decided to go onto some statistical courses to familiarise myself more with the types of analysis.

### **Reflections on choice of methodology**

Throughout the process of conducting this research project I have often found myself returning to thinking about the types of methodology, broadly speaking: quantitative and qualitative approaches. My experience of having completed a qualitative SRRP, into the area of caregiving in FEP, was a rewarding experience

and highlighted the benefits of the methodology. For example, considering the epistemology of approaches within qualitative research as being concerned with the in-depth examination of an individual's lived experience (Smith, Jarman, M., & Osborn, 1999) and the potential limitations of the quantitative measures in the current study to capture the very complex experience of caring for a loved one with psychosis. Whilst within the qualitative areas of research, there may be lots of space and time given to what the researcher may be bringing to the research (i.e. own experiences and assumptions) this is perhaps less considered in quantitative forms of research. However, on reflection I believe that due to my own clinical experience and the experience of the previous qualitative SRP I completed, I did bring an assumption related to the potential importance of the age of the service user to the caregiving experience. This has been previously discussed in terms of being a tension between 'clinical knowledge' and 'scientific psychology' (Miller, 1998). The current study found that the age group of the service user (adolescent versus adult) was not a significant predictor of carer reports of wellbeing, depression and anxiety. This finding did come as a surprise to me, although as considered within chapter two, may be an implication of the small sample size of the younger age group and more generally of the conceptualisation of the age groups (above and below 18 years of age).

Caregiving in psychosis is a complex phenomenon and as the quantitative research shows, is shaped by the appraisals and beliefs of the experience. Given that qualitative research is generally interested in meaning-making (Willig, 2016), I am unsurprised, and encouraged, by the wide-range of studies that consider caregiving in psychosis from across both types of methodology. It is possible that a more qualitative approach could have provided more nuanced, rich data that explored the lived experience and individual perspective.

## **Personal reflections**

The thesis journey has presented an intellectually and emotionally challenging experience. The sense of disappointment I felt regarding my initial project and loss of the time dedicated to what I felt was valuable research took time for me to accept and move forward from. The current project presented many intellectual challenges to my statistical experience and knowledge. However, I have appreciated at each stage my continued interest into the area of caregiving in psychosis and the impetus the project has provided me with to pursue continuing working in early psychosis post qualification. The opportunity to expand my understanding of the clinical psychologist role as a scientist-practitioner as conducting relevant research, alongside working clinically has been invaluable. I appreciated that this project represented working with exploratory research aims, rather than specific hypotheses that helped me to remain open-minded and curious about the findings presented in the current study. Furthermore, it has been exciting to consider the current project in relation to the previous literature and what this informs us about important areas for future research.



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## Appendices

## **Appendix 1 – Confirmation of status as 'evaluation and audit'**

**From:** Lewis, Lynis [Lynis.Lewis@camdenpct.nhs.uk]  
**Sent:** 08 February 2011 10:36  
**To:** Raune David (CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST)  
**Subject:** Publishing work

Dear David

I would like to confirm that when publishing audit or service evaluation it is not necessary to obtain ethical. In the guidelines attached from NRES it clearly states that audit and service evaluation do not require ethical review by an NHS Research Ethics Committee and do not require approval from NHS R&D offices; therefore publishing anything as a result of this work would not have to go through IRAS.

As you state in your email when writing up for publication you will adhere to the usual ethical conventions of publishing; in particular, anonymity, and where patients/carers scores could conceivably be guessed by the other group members, written informed consent will be sought from the patient/carer to publish - if any patient/carer does not give this then their data would not be used in any paper.

If you or any trainees are in doubt whether a study is an audit or self evaluation the attached guidance should help. Otherwise please feel free to contact me or NRES (queries@nres.npsa.nhs.uk, subject: is my project research?) to confirm.

Best wishes

Lynis

**NHS Camden Provider Services**

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**Lynis Lewis**

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**Appendix 2 – Additional information on the Brief Experience of Caregiving Inventory**



Supplementary Table 1: Factor loadings, factor correlations and reliability for the BECI

	Difficult behaviours	Pos personal exp	Problems with services	Stigma/Effects on Family
14 (54) Unpredictable	0.86			
17 (61) Irritable	0.81			
18 (62) Inconsiderate	0.79			
19 (63) Behaving in a reckless way	0.72			
15 (56) Uncommunicative	0.68			
16 (57) Not interested	0.63			
12 (44) I have discovered strengths in myself		0.89		
4 (20) I have become more confident dealing with others		0.84		
5 (23) I have become more understanding of others with problems		0.71		
7 (22) He/she is good company		0.49		
8 (36) How health professionals do not understand your situation			0.84	
6 (26) How to deal with mental health professionals			0.88	
2 (10) How mental health professionals do not take you seriously			0.83	
3 (16) Dealing with psychiatrists			0.83	
11 (42) How to make complaints about his care			0.64	
9 (39) How to explain his illness to others				0.59
10 (40) Others leaving home because of the effects of the illness				0.65
13 (47) The illness causing a familybreakup				0.58
1 (02) Feeling unable to tell anyone about his illness				0.71
<b>Factor Correlations</b>				
Difficult Behaviours (F1)		Positive personal exp -0.12	Problems with services 0.53	Stigma/effects on family 0.48
Positive Personal Experiences (F2)			-0.20	-0.19
Problems with Services (F3)				0.47
Cronbach's $\alpha$	0.87	0.76	0.87	0.69

## **Appendix 3 – Illness Perception Questionnaire – Relatives Version**

Illness Perception Questionnaire- Relatives version. Items in **bold** highlight items relating to the 'caregiver only' subscale. All other items form part of the 'service user only' scale.

	<b>Views about their mental health problems</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
IP1	Their mental health problems will last a short time					
IP2	Their mental health problem is a serious condition					
IP3	There are some things which they can do to control their symptoms					
<b>IP3X</b>	There are some things I can do to control their symptoms					
IP4	There is little treatment available that can improve their mental health problems					
IP5	I get depressed when I think about their mental health problems					
IP6	I feel very puzzled by their mental health problems					
IP7	Their mental health problems are likely to be permanent rather than temporary					
IP8	Their mental health problem does not have much effect on their life					
<b>IP8X</b>	Their mental health problem does not have much effect on MY life					
IP9	To some extent what they do can determine whether their mental health					

	problems get better or worse					
<b>IP9X</b>	To some extent what I do can determine whether their mental health problems get better or worse					
IP10	When I think about their mental health problems I get upset					
IP11	Their treatment will be effective in managing their mental health problems					
IP12	I don't have any understanding of their mental health problems at all					
IP13	Their mental health problems will last for a long time					
IP14	Their mental health problems have financial consequences for them					
<b>IP14X</b>	Their mental health problems have financial consequences for me					
IP15	Their mental health problems make it more difficult for them to do day to day things					
<b>IP15X</b>	Their mental health problems make it more difficult for me to do day to day things					
IP16	Nothing they do will affect their mental health problems at all					
<b>IP16X</b>	Nothing I do will affect their mental					

	health problems at all					
IP17	Their mental health problems make me feel angry					
IP18	The negative effects of their mental health problems can be prevented (avoided) by their treatment					
IP19	I feel that I don't know anything about their mental health problems					
IP20	Their mental health problems will pass quickly					
IP21	Sometimes they have more symptoms than other times					
IP22	Their mental health problems cause difficulties for those who are close to them					
IP23	Their actions will have no effect on the outcome of their mental health problems					
<b>IP23X</b>	My actions will have no effect on the outcome of their mental health problems					
IP24	Their mental health problems do not worry me					
IP25	Their mental health problems make no sense to me at all					
IP26	I expect them to have these mental health problems for the rest of their life					
IP27	They don't get on as well with our family since their					

	mental health problems					
<b>IP27X</b>	I don't get on as well with our family since their mental health problems					
IP28	If they tried harder they could control their symptoms					
<b>IP28X</b>	If I tried harder I could control their symptoms					
IP29	Their mental health problems make me feel anxious					
IP30	Their treatment can control their mental health problems					
IP31	I have a clear picture or understanding of their mental health problems					
IP32	They have times when they are well and times when they are not so well					
IP33	Their mental health problems have messed up their social life					
<b>IP33X</b>	Their mental health problems have messed up my social life					
IP34	They could do more to help themselves					
<b>IP34X</b>	I could do more to help them					
1P35	Their mental health problems mean that they are valued less by other people					
<b>IP35X</b>	Their mental health problems mean that I am valued less by other people					

IP36	Their mental health problems make me feel afraid					
IP37	There is no treatment that can help with their condition					
IP38	Sometimes the symptoms of their mental health problems are worse than other times					
IP39	Their mental health problems make working very difficult for them					
<b>IP39X</b>	Their mental health problems make working very difficult for me					
IP40	If they were a stronger person they would get better					
<b>IP40X</b>	If I were a stronger person they would get better					
IP41	Their mental health problems make me feel worthless					
IP42	Some of their symptoms will be there all the time but others will come and go					
IP43	They have lost important relationships as a result of their mental health problems					
<b>IP34X</b>	I have lost important relationships as a result of their mental health problems					
IP44	I get very frustrated by their mental health problems					

IP45	Their mental health problems have had some positive effects on their life					
<b>IP45X</b>	Their mental health problems have had some positive effects on my life					
IP46	Their mental health problems will improve in time					
IP47	I feel a sense of loss due to their mental health problems					



## **Appendix 4 – Means for the full Experience of Caregiving Inventory**

Supplementary Table 2: Descriptive Statistics of the full Experience of Caregiving Inventory (prior to re-calculation into the BECI)

<b>Caregiving Variables</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>
Appraisals of Burden, ECI n= 245*			
Difficult behaviours <i>n</i> = 252	12.82	8.51	0 - 32
Negative symptoms <i>n</i> =250	12.13	7.22	0- 24
Stigma <i>n</i> =251	7.21	5.10	0 -20
Problems with services <i>n</i> = 247	12.60	7.07	0- 32
Effect on family <i>n</i> = 247	9.70	6.38	0- 26
Need to back up <i>n</i> = 248	11.77	5.40	0- 24
Dependency <i>n</i> = 251	11.70	4.65	0- 20
Loss <i>n</i> = 252	11.27	5.61	0 - 26
Total Negative Burden <i>n</i> =239	89.36	35.94	7-176

## **Appendix 5 – Further information on the Exploratory Factor Analysis**

Supplementary Table 3: Factor analysis item loadings for rotated pattern matrix for service user related questions. Items larger than .4 are highlighted with corresponding original factor on left and loadings below .3 were suppressed in the output

Original subscale	Item	*Factor 1	Factor 2	Factor 3	Factor 4
Timeline acute/chronic	1. Their mental health problems will last a short time <sup>r</sup>		<b>0.68</b>		
	7. Their mental health problems are likely to be permanent rather than temporary		<b>0.62</b>		
	13. Their mental health problems will last for a long time		<b>0.71</b>		
	20. Their mental health problems will pass quickly		<b>0.69</b>		
	26. I expect them to have these mental health problems for the rest of their life		<b>0.60</b>		
	46. Their mental health problems will improve in time <sup>r</sup>		0.32		
Timeline cyclical	21. Sometimes they have more symptoms than other times		<b>0.49</b>		
	32. They have times when they are well and times when they are not so well				<b>0.42</b>
	38. Sometimes the symptoms of their mental health problems are worse than other times		<b>0.55</b>		
	42. Some of their symptoms will be there all the time but others will come and go		<b>0.49</b>		
Consequences for patient	2. Their mental health problem is a serious condition		0.39		
	8. Their mental health problem does not have much effect on their life		<b>0.40</b>		
	14. Their mental health problems have financial consequences for them		<b>0.42</b>		
	22. Their mental health problems cause difficulties for those who are close to them	<b>0.48</b>	<b>0.47</b>		
	15. Their mental health problems make it more difficult for them to do day to day things	<b>0.40</b>	<b>0.43</b>		
	27. They don't get on as well with our family since their mental health problems	0.37			
	33. Their mental health problems have messed up their social life	0.35	0.34		
	35. Their mental health problems mean that they are valued less by other people	0.36			
	39. Their mental health problems make working very difficult for them	<b>0.40</b>	<b>0.44</b>		
	43. They have lost important relationships as a result of their mental health problems	0.33	0.38		
Personal control - patient	9. To some extent what they do can determine whether their mental health problems get better or worse				<b>0.42</b>
	16. Nothing they do will affect their mental health problems at all <sup>r</sup>			<b>-0.50</b>	
	23. Their actions will have no effect on the outcome of their mental health problems <sup>r</sup>			<b>-0.44</b>	
Personal blame - patient	28. If they tried harder they could control their symptoms				<b>0.42</b>
	34. They could do more to help themselves				<b>0.49</b>
Tx control	4. There is little treatment available that can improve their mental health problems <sup>r</sup>			-0.31	
	11. Their treatment will be effective in managing their mental health problems <sup>r</sup>			<b>-0.50</b>	
	18. The negative effects of their mental health problems can be prevented (avoided)			<b>-0.40</b>	

Original subscale	Item	*Factor 1	Factor 2	Factor 3	Factor 4
	by their treatment <sup>r</sup>				
	30. Their treatment can control their mental health problems			-0.36	
	37. There is no treatment that can help with their condition			<b>-0.45</b>	
<b>Illness coherence</b>	6. I feel very puzzled by their mental health problems	<b>0.58</b>			
	12. I don't have any understanding of their mental health problems at all			<b>0.61</b>	
	19. I feel that I don't know anything about their mental health problems			<b>0.61</b>	
	25. Their mental health problems make no sense to me at all			<b>0.55</b>	
	31. I have a clear picture or understanding of their mental health problems <sup>r</sup>			<b>0.48</b>	
<b>Emotional representation</b>	5. I get depressed when I think about their mental health problems	<b>0.68</b>			
	10. When I think about their mental health problems I get upset	<b>0.71</b>			
	17. Their mental health problems make me feel angry	<b>0.54</b>			
	29. Their mental health problems make me feel anxious	<b>0.66</b>			
	36. Their mental health problems make me feel afraid	<b>0.60</b>			
	41. Their mental health problems make me feel worthless	<b>0.55</b>			
	44. I get very frustrated by their mental health problems	<b>0.65</b>			
47. I feel a sense of loss due to their mental health problems	<b>0.56</b>				

\*Factor 1= Carer Emotional impact and Awareness of consequences; Factor 2= Timeline; Factor 3= Understanding of illness and treatment effectiveness; Factor 4= Service User Control

Supplementary Table 4: EFA loadings for IPQ-R for rotated pattern matrix for questions to related to caregiver questions. Items larger than .4 are highlighted with original corresponding factor indicated on the left. Loadings below .3 were suppressed in the output.

<b>Original subscale</b>	<b>Item</b>	<b>*Factor 5</b>	<b>Factor 6</b>
<b>Personal control</b>	3x. There are some things which I can do to control their symptoms		<b>0.60</b>
	9x. To some extent what I do can determine whether their mental health problems get better or worse		<b>0.64</b>
	16x. Nothing I do will affect their mental health problems at all		<b>0.50</b>
	23x. My actions will have no effect on the outcome of their mental health problems		<b>0.52</b>
	14x. Their mental health problems have financial consequences for me	<b>0.54</b>	
	15x. Their mental health problems make it more difficult for me to do day to day things	<b>0.65</b>	
	27x. I don't get on as well with our family since their mental health problems	<b>0.59</b>	
<b>Consequences</b>	33x. Their mental health problems have messed up my social life	<b>0.68</b>	
	35x. Their mental health problems mean that I am valued less by other people	<b>0.55</b>	
	43x. I have lost important relationships as a result of their mental health problems	<b>0.56</b>	

\*Factor 5; Caregiver Consequences; Factor 6 = Caregiver Control

