The Impact of Coping Styles on Wellbeing in Older Adults with Severe and Enduring Mental Illness: A Systematic Review

and

From Powerless to Empowered: A Grounded Theory Approach to Chronic Psychosis in Middle Aged and Older Adults

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PORTFOLIO THESIS ABSTRACT

Aim: The aim of this thesis portfolio was to develop a preliminary, theoretical understanding of the experiences of middle-aged and older adults with chronic psychosis, their beliefs about illness and the impact on their self-identity. Additionally, it aimed to assess the impact of coping styles of middle-aged and older adults with severe mental illness (SMI) on overall wellbeing, and to identify if there was a certain type of coping style that had a more positive impact on outcomes.

Method: A systematic review of the literature was conducted assessing the impacts of coping strategies on wellbeing outcomes for adults over the age of 55 with severe mental illness. A search strategy was developed and carried out on PsychInfo, Web of Science, Ovid-Medline, EMBASE, CINAHL, ERIC and PubMed. From the 154 records identified, a narrative synthesis of 19 papers were included for review. For the empirical paper, interviews were conducted with middle-aged and older adults with chronic psychosis, with a grounded theory methodology applied to develop a theoretical understanding of their experiences of their mental health.

Results: Key findings from the systematic review indicated that active coping strategies (e.g. reinterpreting thoughts or seeking social contacts) were more beneficial than passive coping strategies (e.g. doing nothing or avoiding). A number of studies were divergent in their findings regarding which specific strategy led to better outcomes, but there appears to be slightly more consistent evidence that the use of cognitive strategies as opposed to behavioural strategies can lead to better wellbeing outcomes in people over the age of 55 with SMI. Within the empirical paper, the preliminary emerged model identified a core concept of “From Powerless to Empowered”, which was a key experience of all participants in relation to their experiences with mental health services, along with two major categories of “Stigma” and “Family/Community” which also influenced participants beliefs about illness.

Conclusions: Both the systematic review and the empirical study of this portfolio suggest that, along with traditional interventions of cognitive behavioural therapy, interventions with a focus on acceptance, mindfulness and compassion can be beneficial for middle-aged and older adults with chronic psychosis and severe mental illness. Formulation of the operation of institutional power should be considered when working with this population, and coping mechanisms encouraged and developed, with a focus on cognitive strategies where possible.

LAY PORTFOLIO THESIS ABSTRACT

Severe mental illness (for example Schizophrenia and Bipolar Disorder) are long term conditions that have a large impact on an individual’s life. They can also have a large impact on those around the individual, and the wider NHS health system. The term psychosis (a mental health condition that results in an individual experiencing reality differently to those around them, for example through hearing voices or holding unusual beliefs), has been used to described these difficulties in recent years. Psychosis has received increasing attention in terms of research. Understanding psychosis and severe mental illnesses, and how best to treat them, has been recognized as an area of focus within both clinical and research settings. However, most of the available research has been concerning adolescents and younger adults, with older adults often actively excluded from research. There is very little known about how older adults manage their illness and how they have made sense of this throughout their lives. Little is known about the impact this has had on how they view themselves.

Chapter 1 of this thesis looks at the evidence available on how people over the age of 55 with a severe mental illness cope with their illness. It also looks at what impact their coping has on their wellbeing. Additionally, it looks at if there are certain ways of coping (for example through doing something to keep busy or talking to someone; ways people think about problems or explain their mental health) that help people more. Chapter 2 looks at the experiences of people over the age of 55 with a long-standing psychosis. Interviews were carried out to gain a deeper understanding of what people had experienced during their first contacts with mental health services. It also looked at how they feel about themselves now following their experiences. It aimed to see if getting older whilst experiencing a long-standing mental health condition changed how people felt about their mental health and about themselves over the course of their lives.

The results of this study showed that the way people think about their mental health, and learning new ways of thinking about it, led to better wellbeing. This suggests that treatment which focuses on increasing people's willingness to accept their experiences and be kinder to themselves during their illness may be helpful. The experiences of people with a chronic psychosis were that in the past, services and other people around them made them feel powerless and not in control of their own health during the early stages of their illness. However, as people got older, they felt better able to manage their illness themselves by becoming familiar with it. People felt more able to make their own decisions and communicate these to professionals in a way that led to feeling more in control. It will be important for services to be mindful of the history behind older people with psychosis and schizophrenia's earlier mental health journeys. Working actively together with service users to increase trust and respect, whilst reducing stigma, is important. This again shows the need for treatment models that increase self-kindness and acceptance, and the importance of communication when working with older adults with long-standing psychosis.

CHAPTER 1: THE IMPACT OF COPING STYLES ON WELLBEING IN MIDDLE-AGED AND OLDER ADULTS WITH SEVERE AND ENDURING MENTAL ILLNESS: A SYSTEMATIC REVIEW

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ABSTRACT

Objective: This systematic review examined the literature that assessed the impact of coping strategies on overall wellbeing of middle-aged and older adults (aged 55+) with a severe mental illness (SMI). The specific aims of this review were to identify what impact coping styles have on wellbeing outcomes and identify if there is a specific coping style that leads to more positive outcomes in this population. Additionally, this review aimed to evaluate the quality of the studies identified.

Method: A narrative synthesis of the literature was conducted. A search strategy was implemented using PsychInfo, Web of Science, Ovid-Medline, EMBASE, CINAHL, ERIC and PubMed. Following review of inclusion criteria, 19 papers were identified for inclusion in the review.

Results: Studies varied in the depth of their description of coping variables and wellbeing outcomes, but overall, middle-aged and older adults were found to utilise some form of coping strategy when dealing with their mental health which had an impact on wellbeing outcomes. Active strategies (e.g. reinterpreting thoughts or seeking social contacts) were more beneficial than passive strategies (e.g. doing nothing or avoiding). A number of studies were divergent in their findings regarding which specific strategy led to better outcomes, but there appears to be slightly more evidence that the use of cognitive strategies as opposed to behavioural strategies can lead to better wellbeing outcomes in people over the age of 55 with a SMI.

Conclusions: Encouraging and supporting middle-aged and older adults with SMI to utilise any form of active coping strategy can be beneficial in increasing wellbeing. The use of cognitive strategies should be supported, as evidence suggests that as people age, interpretation of symptoms and illness can have a positive influence on wellbeing. This is encouraging for the use of interventions such as Acceptance and Commitment Therapy

(ACT) and Compassion Focused Therapy (CFT) alongside traditional cognitive behavioural interventions.

Key words: Severe Mental Illness; Psychosis; Coping; Older Adult; Wellbeing

INTRODUCTION

Severe and enduring mental illnesses (SMI) such as schizophrenia, bipolar disorder, schizoaffective disorders and other chronic functional disorder are, by definition, long term conditions (Hatfield and Dening, 2013). Research has shown that individuals with SMI are more likely to experience difficulties throughout their lifetime across several domains of functioning, including limited occupational opportunities, social segregation and reduced social support networks, poorer self-care and higher levels of overall psychological distress (MacDonald, Pica, McDonald, Hayes & Baglioni, 1998; McNeil and Galovski, 2015; Mueser, Rosenberg, Hamblen & Decamps, 2004; Peck and Scheffler 2002). It has been suggested that the prevalence of SMI in adults over the age of 65 is around 0.5% (Hatfield and Dening, 2013). Reports show that the UK health service spends 2.8% of total NHS budget on providing care for those with SMI (GGI, 2020). Therefore, understanding how individuals cope with illness and increasing the provision of services and interventions to support wellbeing, could lead to increased positive outcomes for both service users and the NHS.

The literature has shown that people with SMI report higher overall levels of stress than people without SMI in areas such as their domestic environment, driven behaviour and depressive symptoms (e.g. MacDonald et al, 1998). Individuals with SMI experience prolonged periods of coping with symptoms, side effects, and consequences (e.g. Davidson et al, 2005) and it has been suggested that episodes of acute mental health distress, often leading to hospitalisation and enforced medical treatment, can be experienced in and of themselves as traumatic events for the individual (Mazor, Gelkopf & Roe , 2018; Muser, Lu, Rosenberg, & Wolfe, 2010).

However, individuals with SMI can show improvements in their mental health and wellbeing, and illness do not always have to take a chronic course (e.g. Ridgway, 2001; Roe and Chopra, 2003). Reported rates of remission range from 3%-64% (in Auslander and Jeste, 2004; Torgalsboen & Rund, 2002), with the variability thought to be due to the definition of "remission" used within the literature. Irrespective, recovery can be achieved. The concept of personal growth and resilience within this population has become an increasing area of interest within the academic literature. How individuals cope with adversity can impact their outcomes, and beyond coping, individuals may actively find meaning within their experiences, leading to personal growth (e.g. Davis, 2005; Mazor et al, 2018; Arslan & Buldukoglu, 2018). However, Wesner et al (2015, 2019) suggested that resilience is symptom-dependent, in that less severe symptoms led to higher levels of resilience. Symptoms experienced by individuals with SMI may be more likely to be of greater intensity, and as such, potentially result in lower levels of resilience.

Due to the nature and possible frequency of traumatic experiences faced by individuals with SMI, this is an important factor to consider. If certain coping strategies can lead to positive outcomes and post traumatic growth (PTG, Tedeschi & Calhoun, 1995), understanding and supporting the utilisation of these strategies within this population may have an impact on functional outcome.

Theories of coping behaviour

There are an array of categorisations of coping behaviours reported within the literature, including adaptive and maladaptive behaviours (Zuckerman and Gagne, 2003), active and passive behaviours (Hertel, Rauschenbach, Thielgen & Krumm, 2015; Polanco-Roman, Danies & Anglin, 2016) and symptomatic and non-symptomatic coping (Carr, 1988). The most widely researched coping behaviours appears to be regarding problem focused or emotion focused coping. Problem focused coping is when an individual aims to change or manage the thing that is causing the distress (i.e. the “problem”), with emotion focused coping aiming to regulate or adapt the individuals emotional response to the problem itself (Lazarus and Folkman, 1984). The literature appears to be inconclusive in terms of the style of coping most prominently or effectively utilised by people with SMI, with opposing outcomes found. Although there are many categorisations of coping behaviours, these behaviours can, on the whole, be categorised into cognitive and behavioural strategies.

The stress-vulnerability model of schizophrenia (Zubin & Spring, 1977; Nuechterlein and Dawson, 1984) suggests that individuals with schizophrenia have a reduced ability to cope with life stressors, due to factors such as smaller social support networks, higher rates of familial stress resulting in higher environmental stress, and difficulties with information-processing, leading to difficulties in developing appropriate behavioural coping skills. Negative symptoms of psychosis may also lead to individuals withdrawing from social support, and perhaps utilising avoidant coping strategies. Therefore, the individual’s ability to cope with both major and minor stressors can have a major implication on distress.

Lazarus and Folkman (1984) used coping as the term to describe an individuals’ efforts to tolerate or reduce distress experienced through stressful transactions. These could be either cognitive or behavioural efforts. The aim of coping is to reduce negative affect prompted by stressful situations (Lazarus and Folkman, 1984; Compas et al, 2013). Coping styles are measured in terms of the type of behaviour used and the frequency of use (Fledderus, Bohlmeijer & Pieterse, 2010). Overall, coping may be viewed as a facet of Emotion

Regulation (Gross and John, 2003; Ong and Thompson, 2019), whereby the mechanism of cognitive reappraisal is aimed at reducing negative affect in relation to a stressor (e.g. Compas et al., 2013; Lazarus and Folkman, 1984).

When people employ problem focused coping strategies, these have been found to correlate to better outcomes such as increased mood and effective social skills (e.g. Malka et al, 2019; Yanos, West & Smith, 2010). McNeil and Galovski (2015) suggested that the proactive, solution focused nature of problem focused coping resulted in more positive outcomes overall, particularly if the stressor was changeable. Problem-focused coping for people with psychosis have been found to include the use of anti-psychotic medication and increased reliance on social support (e.g. Yanos et al, 2010). However, people with psychosis and other SMI’s have been found to use more emotion-focused and avoidant coping behaviours than people without SMI (Gumley, Taylor, Schwannauer & MacBeth, 2014; Macdonald et al, 1998; Van den Bosh, Van Asma, Rombouts & Louwerens, 1992). Emotion-focused coping has been found to be beneficial in circumstances where the “problem” cannot be fixed through problem-focused coping (Lazarus and Folkman, 1984). This suggests that emotion-focused coping may be more beneficial for people with SMI or chronic mental health conditions, where circumstances may not be able to be changed. Theories of attachment have been increasingly utilised to explain the increased use of avoidant coping in individuals experiencing psychosis, with evidence suggesting that individuals are more likely to adopt a “sealing over” approach (noted as an avoidant coping strategy) when they are less able to cope with stressors following an abusive or atypical relationship with their primary attachment figure (Tait, Birchwood & Trower, 2004).

Leventhal et al (1984) self-regulation model of illness perceptions suggests that the coping strategies employed by individuals to manage their illness are influenced by their cognitive representation of illness (illness beliefs). These beliefs can impact the way in which an individual makes sense of their illness, therefore impacting how they perceive and cope with this (e.g. Hagger and Orbell, 2003; Leventhal et al 2003). Research by Lobban and Barrowclough (2005) have shown this model fits with the experiences of people with schizophrenia. Although this was not studied in relation to older adults with a chronic illness, understanding how an individual perceives their illness may allow us more insight into which coping mechanisms can be effectively employed to reduce distress associated with this.

Furthermore, Chen and Miller (2012) proposed the concept of "shift and persist" as a style of coping. Here, an individual cognitively reappraises their experience and introduces an element of acceptance in unchangeable or unavoidable circumstances ("shifts") and subsequently strives to develop a different meaning or positive narrative within the newly accepted reality ("persist"). This strategy has been shown to be effective in coping with the impact of lower socio-economic status and inequalities on health outcomes (Chen and Miller, 2012; Christophe et al, 2019). This concept may be applicable within the SMI population due to the known links between SMI and lower SES, and the idea of SMI as a chronic illness.

Influence of coping styles

Boschi et al (2000) examined coping strategies employed by individuals recovering following hospital admission for first episode psychosis to assess if type of strategy used had an impact on psycho-social functioning at follow up. Individuals between the age of 15-60 were assessed using quantitative methods on the coping strategies most prominently used. Three categories of coping were endorsed: "active-behavioural"; "active-cognitive" and "avoidant" strategies. Individuals reported to use “active-cognitive” approaches most often, including strategies such as trying to see the positive, using past experiences, prayer and religious coping. Avoidant strategies (such as alcohol and substance misuse, ignoring problems or sleeping) were reported to be the least utilised. This is an interesting finding given the previous literature supporting the use of avoidant coping in this population. Participants rated active-behavioural strategies as the most helpful, primarily talking with a professional, followed by active-cognitive then avoidant strategies. The contrast between most commonly reported strategies and most helpful strategy highlights how supporting individuals to utilise active-behavioural strategies may lead to better outcomes. The authors suggest that it is the endorsed characteristics of the illness as opposed to demographics or illness onset that have the biggest impact on outcomes. Therefore, although the most common age range represented in this study was 18-22 years, the applicability of these findings to a mature and older adult population may be beneficial, with implication to encourage active-behavioural coping strategies.

Levy et al (2019) investigated the impact of coping in older adults with negative age stereotypes. Negative age stereotypes have been shown to be additional environmental stressors. Within the SMI population, cohort beliefs surrounding mental illness and ageing may potentially be present, with this environmental stressor a potential trigger. This study found that the use of active coping was associated with a reduction in the development of a psychiatric condition in older adults. Although focused on the development of a condition in later life as opposes to SMI, these results support the notion that active coping can have positive outcome for older people.

A systematic review on coping in psychosis by Philips, Francey, Edwards & McMurray (2009) suggested that people with psychosis employ at least one coping strategy to manage their distress, and that having an array of strategies can lead to better outcomes. Contrary to the work of Boschi et al (2000), there was not one strategy identified as more helpful than another over all of the studies assessed. However, neither of these studies explicitly address the influence of aging on the application of coping strategies.

The majority of the literature is focused on the coping behaviours of young people (eg Veerland et al, 2019; Christophe et al, 2019) or adults of working age. However, older adults who may have suffered from chronic SMI are relatively under-researched in terms of the coping mechanisms they apply. A document by the BPS Division of Clinical Psychology on Understanding Psychosis and Schizophrenia (DCP, 2014), did not make reference to the experience of mature or older adults with a psychotic illness, highlighting the neglected nature of this population in the literature. Experiences may substantially differ from the strategies utilised by younger adults, due to a number of factors such as longstanding cohort beliefs, increased stigmatisation from time of diagnosis and impact on social support networks. Subsequently, assessing coping mechanisms and their impact in middle-aged and older adults is important to identify areas for potential treatment support.

Objectives of current review

1) To review literature assessing the impact of coping strategies on overall wellbeing of middle-aged and older adults with a SMI.

Due to the very broad categorisation of wellbeing, it has been difficult to consistently measure this within the academic literature (Harvey & Taylor 2013; Cooke, Melchert &

Connor, 2016). As such, four main categorisations of wellbeing are generally accepted when it comes to measuring wellbeing outcomes (Cooke et al, 2016), and will be used at the basis for classification of wellbeing within the current review:

- Hedonic wellbeing (Ryan & Deci, 2001) in which wellbeing is measured on pleasure and happiness.
- Eudaimonic approaches (Lent, 2004) in which psychological health is measured through fulfilling one's potential as well as functioning to our "optimum level".
- Quality of Life (e.g. WHO, 1998), which encompasses physical, psychological and social functioning.
- Wellness (Rosecoe, 2009) which is broader and less clearly defined within the literature.

Research question (s)

1) What impact do coping styles have on wellbeing outcomes in people over the age of 55 with a SMI?

2) What style of coping (i.e. cognitive vs behaviour; emotion vs problem focused) leads to better wellbeing outcomes in people over the age of 55 with a SMI?

METHODS

Inclusion and exclusion criteria

Inclusion criteria were articles that 1) had a study population of individuals with a severe and enduring mental illness (SMI), which can encompass bipolar disorder, neurotic depression, psychosis (long standing and late onset), schizophrenia (and schizophrenia sub-types) as defined by recorded diagnosis fulfilling either DSM or ICD criteria; 2) that assessed ways of coping, defined as any way in which an individual is managing, or attempting to manage, their mental health; 3) focused on participants aged 55 and over.

Studies were not limited in methodology, including both quantitative and qualitative articles. Studies with both primary and secondary data were included in the review. Exclusion criteria were 1) letters to editors, conference abstracts and opinion pieces; 2) articles that are not written in English, or that do not have an adequate translation of the text available 3) review papers.

Search strategy

The review followed PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). See appendix 2. Following an initial scoping exercise, the electronic databases of PsycINFO, Web of Science, Ovid-MEDLINE, EMBASE, CINAHL, ERIC, PubMed and SCOPUS were searched for relevant literature. The literature search was first run on 11th February 2019, and subsequently repeated on 29th June 2020. Following adaptation of the search terms to ensure all possible relevant material was reviewed, the search was run again on papers up to including August 2020, with one final search conducted on 5th October 2020. Search terms were developed by the first author in consultation with the research team and refined with the assistance of an experienced librarian. The search terms applied were (schizo* or paranoi* or hallucinat* or bipolar or "bi polar") OR ("persistent* mental* ill*" or "chroni* mental* ill*" or "chronic* mental health" or "severe mental health" or "enduring mental health") OR ("severe* mental* ill*" or "enduring* mental* ill*") OR (psychosis or psychoses or psychotic*). These terms were then combined with the Boolean operator “AND” to include the terms ("older adult*" or geriatric* or "oldest old" or elderly); (“Coping”) and (“wellbeing or "well being" or "quality of life" or outcome*) OR ("subjective experience*" or functioning) OR “longitudinal) to complete the development of the search terms. Terms were truncated [*] to increase the reach and sensitivity of the search term.

Search engines such as Google Scholar were subsequently searched using the same key terms and databases containing unpublished material (PROQUEST Dissertation and Thesis Global) were also included. Following extraction of relevant studies, the references of included articles were hand searched for any additional studies not subsumed within the original search terms. Forward citation was carried out on the included studies to encompass articles which may have been missed by the original search terms. The author subsequently manually searched journals of relevance (Ageing and Mental Health and The Gentrologist) for any additional articles.

Study selection

Following completion of the search strategy, the inclusion and exclusion criteria were applied to title, abstract and full texts to assess for eligibility by the first author. For all papers where the first author was unsure of study eligibility (n= 8), a second member of the research team reviewed the study and a consensus was agreed. This led to 19 studies included in the review. Figure 1 (below) shows the full details of the extraction process and flow of study inclusion.

Data extraction

The characteristics of the identified studies were extracted and collated in a table by the first author. Data extraction included author, year of publication, title, sample demographics and sample size, study design, method, coping variable assessed, wellbeing/psychosocial variable assessed, measures used, data analysis and key findings. The extracted variables can be found in table 1 below.

Risk of bias tool

Each study was assessed for bias and quality appraised using the Joanna Briggs Institute (JBI) Critical Appraisal Tool. As most identified studies were cross-sectional in design, this was the most commonly applied appraisal tool (Moola et al, 2017). Cohort design (Moola et al, 2017), RCT (Tufanaru et al, 2017), qualitative (Lockwood, Munn & Porritt, 2015), case report (Moola et al, 2020) and appropriate mixed method appraisal tools were also utilised within the review. All studies were critically appraised by the first author. A selection of studies (35%) were independently appraised by a second rater not involved in the review to ensure reliability of ratings. Any discrepancies were discussed in depth by the first author and the second rater until consensus was agreed (2 points of clarity on one paper). The studies were rated on areas of appraisal specific for the identified design methodology, and included areas such as: the clarity of inclusion in the sample; the detail of the study subjects and setting described; if the exposure was measured in a valid and reliable way; if objective, standard criteria were used for measurement of the condition; if confounding variables (e.g. age, sociodemographic variables etc) were identified and subsequently controlled for; if the outcomes were measured in a valid and reliable way; if appropriate statistical analysis was used (i.e. for cross sectional design); if the methodology was congruent with the research questions (i.e. qualitative designs), randomisation (i.e. RCT designs) and how follow up data was handled (i.e. cohort designs). See appendix 3 for quality tools. There was 90% agreement between the raters regarding the quality assessments. Where there were divergences in ratings, the raters discussed these discrepancies in order to reach an agreed consensus.

The quality outcomes were appraised as “Yes”, “no”, “Unsure” or “not applicable”. The first author assigned a numerical score to each of the categories for interpretation of the appraisal tool (“yes” = 1; “Unsure” 0.5; “No” = 0), with a higher numerical rating indicating a stronger methodological quality.

As the review was conducted in an area with limited available research, studies which showed possible areas of bias (i.e. where the article had been given the scoring of “0.5 unsure”) were included in the review to allow for maximisation of study review. The areas of potential bias have been highlighted in the results sections and integrated within the overall narrative synthesis.

Data Synthesis

As the review encompassed both qualitative and quantitative studies, the heterogeneity of studies within the review resulted in a narrative synthesis of the data. Comparisons were made between studies regarding their classification of coping style and the measures used to quantify this. The measurements of wellbeing and the clinical implication for each coping style identified on participant wellbeing was compared across the studies. Where control or comparison groups were given, the wellbeing outcomes for each group were also compared, and differences and similarities in coping styles were reviewed. Due to the variability in the description of coping styles and the depth with which these were described within the studies (i.e. not always a primary variable; limited data availability or small sample size), it was not possible to generate effect sizes in the quantitative papers when these had not been reported by the author (n=7). The current review conclusions are therefore based on statistical inference of outcome where effect size is not reported, a major limitation of the studies reviewed in the current study. This is discussed further in the discussion section of this review.

Utilising the framework proposed by Lazurus and Folkman (1984), the first author identified and classified coping variables as any way in which the individual is attempting to tolerate and manage their mental health, keeping this definition broad to include qualitative descriptions of coping, as well as instruments which defined coping as a psychometric dimension. A full description of the coping variables identified can be found below.

Items of well-being were identified by the first author according to the four categories identified by Cooke et al (2016) as being the most commonly operationalised definitions of wellbeing within the literature (Hedonic wellbeing, Eudaimonic, Quality of Life and Wellness). Studies varied in terms of the depth and description of these variables.

PRISMA 2009 Flow Diagram

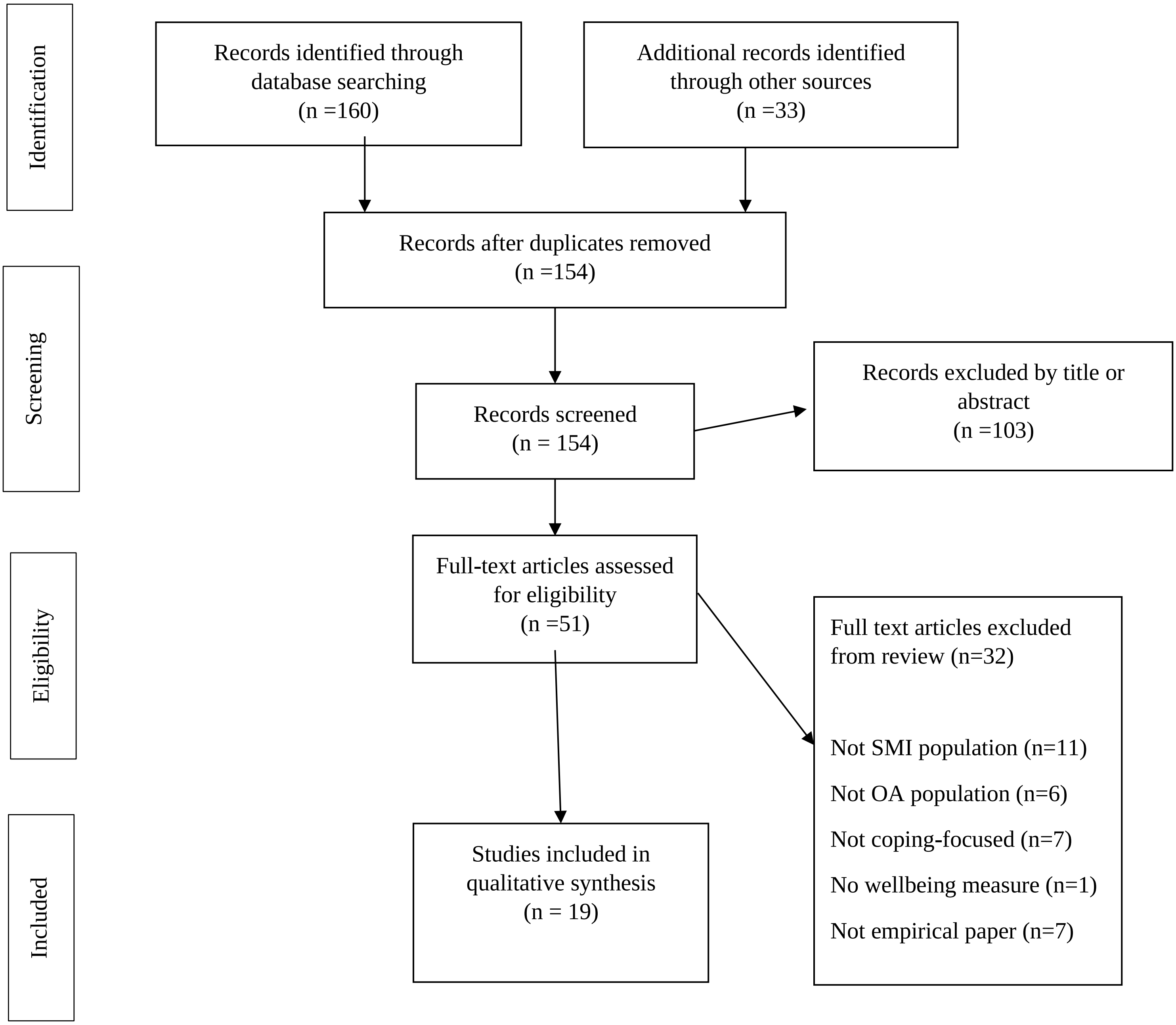

Figure 1: PRISMA flow chart

RESULTS

Methodological characteristics of included studies

Due to the methodological differences between the studies included in the review, a narrative synthesis of the results is presented. A total of 19 studies were included in the review. The characteristics of these studies are presented in table 1 (below). Eleven of the studies were cross-sectional design (Bankole, Cohen, Vahia, Diwan, Palkar, Reyes, Sapra, & Ramirez, 2008; Berry, Barrowclough, Byrne and Purandare, 2006; Cohen, 1993; Cohen, Jimenez & Mittal, 2010; Cohen, Hassamal & Begum, 2011; Cohen et al, 2014; Cukrowicz et al, 2007; Diwan et al, 2007; Ibrahim, Cohen & Ramirez, 2010; Patterson et al, 1997), four were qualitative designs (Meesters et al, 2019; Pentland, Miscio, Eastabrook & Krupa, 2003; Quin, Clare, Ryan and Jackson, 2009; Shepard et al, 2010;), one was mixed methods (Solan and Whitbourne, 2008), one was a cross-sectional longitudinal design (Cohen, Vengassery & Garcia Aracena, 2017), one was a case report (Nguyen, Truong, Feit, Marquett & Reisser, 2007) and one was an RCT (Granholm et al, 2015). Data was gathered from 1137 participants, with the sample sizes ranging from N= 6 to N=198 for the clinical group, and N=4 to N=113 for non-clinical comparison groups.

Participants had a range of diagnoses, with schizophrenia the most commonly reported (15/19 studies). Other diagnosis were schizoaffective disorder (3/19), psychosis (1/19), Delusional Disorder (2/19), Mood Disorder (3/19), Personality Disorder (3/19), schizophrenia spectrum disorders (2/19) and Very Late Onset-like Psychosis (1/19).

The mean age of clinical participants was 60.3 years, with a mean sample gender split of 50.7% female. For those with a non-clinical comparison group (Cohen et al, 2010; Cohen et al, 2011, Diwan et al, 2007; Granholm, et al, 2005; Ibrahim et al, 2010; Berry et al, 2006, Meesters et al, 2019*)*, the mean age for non-clinical controls was 63 years, 49% female.

Thirteen studies reported participant ethnicity (Bankole et al, 2008; Cohen et al, 2010; Cohen et al, 2011; Cohen et al, 1993; Cohen et al, 2014; Cohen et al, 2017; Cukrowicz et al, 2007; Diwan et al, 2007; Granholm et al, 2015; Ibrahim et al,2010; Nguyen et al, 2007; Shepard et al, 2010; Solan and Whitbourne, 2001) with the majority of participants reported as Caucasian. Five studies (Cohen et al, 2014; Granholm et al, 2005; Nguyen et al, 2007; Shepard et al, 2010; Stevenson et al, 2012) reported current employment status of participants. No demographic variables were found to be significant in any of the studies, however age between clinical and non-clinical comparisons in the studies within which this was reported were found to be statistically different (t=2.37, df= 306, p=0.02).
13 studies had no comparison group (Bankole et al, 2008; Cohen et al, 1993; Cohen et al, 2014; Cohen et al, 2017; Cukrowicz et al, 2007; Nguyen et al, 2007; Patterson et al, 1997; Pentland et al, 2003; Quin et al, 2009; Shepard et al, 2010; Solan and Whitbourne, 2001; Stevenson et al, 2012). Of those in which there was a comparison group (Berry et al, 2006; Cohen et al, 2010; Cohen et al, 2011, Diwan et al, 2007; Granholm et al, 2015; Ibrahim et al, 2010; Meesters et al, 2019), the demographics of the clinical and non- clinical samples were matched in four of the studies (Cohen et al, 2010; Cohen et al, 2011, Diwan et al, 2007; Granholm et al, 2015).

Study eligibility for diagnosis of a severe and enduring mental health condition was provided through eleven descriptions of confirmation: “Clinical diagnosis of Schizophrenia” (Pentland et al, 2003); “Chart diagnosis of schizophrenia meeting DSM-IV criteria” (Solan and Whitbourne, 2001); “Meet criteria for Very Late Onset-like Psychosis based on ICD criteria”

(Quin et al, 2009); "chart diagnosis of schizophrenia meeting DSM-IV criteria, supplemented by a Lifetime Illness Review" (Bankole et al, 2008; Cohen et al, 2010; Cohen et al, 2011; Cohen et al, 2014; Cohen et al, 2017; Diwan et al, 2007; Ibrahim et al, 2010) "Structured Clinical Interview for DSM-III" (Cohen, 1993; Cukrowicz et al, 2007; Granholm et al, 2015; Nguyen et al, 2008; Patterson et al, 1997; Stevenson et al, 2012); "structured assessment and confirmation from board certified psychiatrist or psychologist" (Shepard et al, 2010); or "satisfy criteria for any of the categories F20–29 in the International Classification of Diseases (ICD-10)" (Berry et al, 2006). One study did not have sufficient detail on confirmation of diagnosis, simply stating "diagnosed with severe mental illness" (Meesters et al, 2019).

Appropriate detail of selection and recruitment was not reported in Cohen's 1993 study, with the reader referenced to an earlier paper for details. However, despite best efforts, the researcher could not obtain a copy of the original research paper, and therefore this element for review could not be assessed. It appears that a number of the studies utilised the same sample, with reported recruitment procedures and methodology being identical for six of the 20 studies (30%) within the review. See Table 1 for results.

Quality review and clinical relevance of included studies

Studies included in the current review were appraised using the Joanna Briggs Institute quality appraisal tools (JBI, 2017). Each study was reviewed on the basis of inclusion of key quality indicators. The first author assigned values to each of the categories to produce a quantitative value to the appraisal of the studies. See Tables 2-5 for quality assessment of the included reviews.

Overall, the quality ratings of studies indicated good quality, with only Solan and Whitbourne’s (2001) mixed methods study and Nguyen et al’s (2008) case report having more than two points deducted. The most potentially influential methodological bias arose due to studies requiring further validation of the scales used to measure the exposure (e.g. in Cohen et al, 2010; Cohen et al, 2011). Further validation of scales measuring the outcome were also highlighted in Ibrahim et al’s (2010) study. Whilst found to be valid within the sample of these papers, generalisability of findings from those requiring further validation has to be approached with caution. However overall, studies used validated and reliable measures to assess wellbeing and quality of life indicators. The most common methodological issue was a lack of description in the time period within which the data was collected, with only three of the studies (Cohen et al, 2010; Cohen et al, 2017; Meesters et al, 2019) specifying this information. All other studies were given an assessment of 0.5 as opposed to 0 if other information regarding setting and subjects were adequately described.

Most studies had well described inclusion criteria, with the exception of Cukrowicz et al (2007) and Solan and Whitbourne (2001), who did not include any inclusion or exclusion criteria. Nguyen et al (2007) did not include sufficient inclusion or exclusion criteria for their study, providing very broad descriptions of their case reviews. Replicability and generalisability of results from these studies again require consideration, as the demographics for which the study conclusions are drawn are insufficient in detail. Appropriate statistical analysis was applied in relation to the specific study aims in all included studies. There were a number of studies which utilise a very similar methodology, resulting in the same methodological ratings.

For most, confounding variables were well highlighted and considered by the authors and were well controlled for in all but two studies, where this was less explicit and perhaps unclear to the reader (Bankole et al, 2008; Diwan et al, 2007). Therefore, consideration of the potential for confounding variables influencing the outcome in these studies was given. In studies were there was a comparison group, the recruitment and consideration of matched samples was documented in three studies. There was no documented description of the control sample in Patterson et al (1997). A statement of "against normal controls" was given within the paper, and once again the researcher could not access the original paper from which this was defined. Therefore, it is implied that these were not matched controls, and the differences between subject groups not clear for the reader to make concrete conclusions regarding the differences in outcomes.

Table 1: Article characteristics and data extraction

Author and Year	Design	Sample size/participants	Method	Coping variables assessed	Wellbeing/ psychosocial variables assessed	Measures Used
1. Cohen, Jimenez & Mittal (2010)	Cross sectional quasi-experimental design	Clinical group (N= 198); Diagnosis before the age of 45; Mean age= 61.5 (S.D= 5.6) Community comparison (N= 113); Mean age= 63 (S.D= 5.4)	One off interview with questionnaire completion	Religiousness; extent of use of cognitive coping; number of confidants	Measure of daily functioning, physical illness; financial strain; lifetime traumatic events; acute stressors; depression; Self-esteem; positive and negative symptoms	CESDS; PANSS; FSS; MAI; IADL; CCS; LTVS; SES; NAP; ASC; QoLI; RS
2. Cohen, Hassamel & Begum (2011)	Cross sectional quasi-experimental design	Clinical group (N= 198); Diagnosis before the age of 45; Mean age= 61.5 (S.D= 5.6) Community comparison (N= 113); Mean age= 63 (S.D= 5.4)	One off interview with questionnaire completion; respondents answering "yes or "no" to each of the 22 coping strategies presented	Cognitive coping strategies; instrumental coping strategies; avoidant coping strategies	Cognitive dysfunction, alcoholism, self-esteem, physical disorders, mental health services, residential status, sustenance network support, financial strain, acute trauma, lifetime traumatic events and psychiatric symptoms	PANSS; FSS; LTVS; SES; MAI; PSS; NAP; ASS; CAGE; MMSE; QoLI
3. Diwan, Cohen, Bankole, Vahia, Kehn & Ramirez (2007)	Cross sectional quasi-experimental design	Clinical group (N= 198); Diagnosis before the age of 45; Mean age= 61.5 (S.D= 5.6) Community comparison (N= 113); Mean age= 63 (S.D= 5.4)	2.5 hour interview to complete questionnaire battery	Copes by using medication; Cope with conflicts by keeping calm; Use of spiritualists or their products; Use of anti-depressants	Physical illness score; confidant variable; household income; daily living skills; cognition; psychotic symptoms; quality of life index and number of provoking stressors	MAI; PHS; IADL; ASS; DRS; NAP; PANSS; QoLI; PCS; CTS; CESDS
4. Ibrahim, Cohen & Ramirez (2010)	Cross sectional design	Clinical group (N= 198); Diagnosis before the age of 45; Mean age= 61.5 (S.D= 5.6 Community comparison (N= 113); Mean age= 63 (S.D= 5.4)	2.5 hour interview to complete questionnaire battery	Cognitive coping strategies; use of mental health services (as active coping); use of alcohol	Psychotic symptoms; quality of life index; frequency of medical support/use of MH services	CESDS; PANSS; FSS; AIMS; QoLI; DRS; MAI; PSMS; BADLS; IADLS; CCS; LTVS; CAE; NAP; SSAS; mean of sum of the frequency of mental health service use
5. Patterson, Shaw, Semple, Moscona, Harris, Kapplin, Grant & Jeste (1997)	Cross sectional design	N= 70 clinical group; Mean age= 58.2 (S.D= 9.2); Mean age of onset= 33.7 years. Comparison group; from another sample, of which	Not stated, but assume questionnaire completion as part of larger trial- **not well described**	Abbreviated Ways of Coping Questionnaire- Revised was utilised: but only looking at the use of avoidant and approach coping	Emotional support available; social adjustment; overall wellbeing; involuntary movement	PERI (+ additional identified variables); ESS; AWCQR; SAPNS; BSI-D; SAS; QWS; AIMS; Demographics

		there is no mention of demographic variables other than being "normal controls"				
6. Shepard, Depp, Harris, Halpin, Palinkas & Jeste (2010)	Qualitative	N=32 clinical sample; Mean age= 55.7 years; Mean symptom duration= 35 years. No comparison group	Semi structured interview and demographic questionnaire	Cognitive strategies (ignoring the voices, talking back to them, telling them to shut up; acceptance and reasoning); behavioural strategies (using the tv or radio to distract them, speak with peers/social contacts, adherence to medication; use of medical professionals); additional “escapism” strategies (use of substances and attempted suicide)	Finances; use of social network; use of medical professionals; subjective wellbeing; symptom management	Semi-structured interview format
7. Berry, Barrowclough, Byrne & Purandare (2006)	Cross- sectional design	Clinical group (N=48); Mean age= 72.71 Mean duration of illness= 31 years Mean age of onset= 41.96 years Control group (N=25); Mean age= 83.58	Semi-structured interviews completed and then categorised by the researchers into coping categories	Items on coping with: difficulties with others; reduced physical health; boredom; crime; miscellaneous stress. Classified as either problem focused or emotion focused coping	Social support (emotional and instrumental support available); depression scores; cognitive impairment	Interview to assess coping (rate each of the variables on an analogue scale from 0-100); PANS; Network NI; EISS; GDS; MMSE; NART; BI; Demographics
8. Solano & Whitbourne (2001)	Mixed methods- qualitative interviews and retrospective study?	Clinical group (N=15); Mean age= 58 (SD 3.52), range 50-62 No comparison group	Semi-stuctured interview based on Strauss, Hafez, Leberman and Harding (see tools for details); x2 sessions of 30-45 minutes over a 1 week period	Cognitive coping (i.e. fights back, suppression, ignore, remain calm) and behavioural coping (i.e. chores, pray, socialise, call doctor, take more meds, keep busy, exercise, smoke, listen to music, write, watch tv, use drugs, lay down/nap, relax, read, withdraw): do nothing (helpless); do nothing (accept) coping strategies	Employment, social relations, housing, treatment, symptom management	Semi-structure interview based on Strauss, Hafez, Liberman + Harding assessing symptoms, employment, social relations, housing, treatment, symptom management, ageing and coping; scale for coping compiled from Cohen and Berk (1985) and Carr (1988) on coping with schizophrenia
9. Cohen, Vengassery & Aracena (2017)	Longitudinal follow up study	Clinical group (N= 104) (Originally recruited N= 250, 146 lost to follow up); Mean age= 60.6 (SD 5.2) No comparison group	Completed battery of questionnaires, which were administered by project staff trained administers. Followed up to repeat battery of assessments. Follow up period ranged	CAGE questionnaire (for level of alcohol consumption); Cognitive Coping Scale; religiousness; network profile (indicative of social support and network); number of psychotropic medications and frequency of use of mental health services	Quality of Life Index measuring satisfaction and importance of domains of health and functioning, social and economic, psychological and spiritual, family	PANSS; CESDS; DRS; CAGE; CCS; MAIPSMS; IADLS; LTVS; SES; MSES; RS; NAP; FSS; PWvsOSS; QoLI; general questionnaire for demographic information and no. of psychotropic medications and mean frequency of psychological services usage

			from 12-116 months from baseline interview			
10. Meesters, Van Der Ham, Dominicus, Stek & Abma (2019)	Naturalistic qualitative approach	Clinical group (N= 10 for open interview; N= 4 for semi-structured interview); Mean age= 69.4 years (range 59-82). Non-clinical group N=4 (staff for semi-structured interview); No age demographic information about non-clinical staff group	Observations of participants across various tasks for approx. 1 month; open ended interview with N=10 service users; semi-structured interview with N= 8 (4 clinical service users, 4 activity co-ordinators)	The continued use of the facility as a behavioural coping mechanism	Social "recovery"/interpersonal functioning; increased experiences of "meaningful activity"; increasing self confidence and trust; adapting to change;	Qualitative data only (open interview followed by semi-structured interview)
11. Cohen, Izediuno, Yadack, Ghosh + Garrett (2014)	Cross sectional design	Clinical group (N= 198); Mean age= 61.5 (range= 55-82); Mean age at dx= 29.3 years No comparison group	2.5 hour interview to complete questionnaire battery	Psychiatric service usage higher than median; religiousness scale; Cognitive Coping Scale; No. of psychiatric medications; alcohol usage; no. of confidants	Symptoms (as endorsed in the PANSS); presence of auditory hallucinations	CESDS; PANSS; MAIPSMS; IADLS; NAP; DRS; RS; LTS; CCS; CAGE; SCI-PANSS
12. Granholm, McQuaid, McClure, Auslander, Perivoliotis, Pedrelli, Patterson., & Jeste (2005)	RCT	Clinical/ treatment group (N= 37); Mean age= 54.5 (range= 40-74); Age of onset= 26.4 Comparison/control group (N=39; Mean age= 54.5 (range= 40-74) Age of onset= 24.7	Measures administered at baseline, 3 months (mid treatment) and 6 months (end of treatment) time periods. Raters/ assessors were blind to trial condition	Cognitive and behavioural techniques provided/taught to participants in the treatment group (noticing and challenging thoughts; role playing to improve assertiveness; insight and conviction to dysfunctional beliefs); medication use	The use/frequency of social functioning behaviours (clothing and appearance; personal hygiene; health maintenance; transport use and arrangement of activities); PANSS scores/symptom severity; depression	ILSS; USCD performance-based Skills Assessment; PANSS; HDRS; BCIS; CMT
13. Cohen (1993)	Cross-sectional and exploratory	Clinical group (N=86); Mean age= 43 (range= 19-69) No comparison group	Measures administered over a 30 minute interview. Participants asked how they cope with 29 symptoms derived from Herz + Melville	Cognitive (fighting back; acceptance); increased behaviour (isolated diversion, social diversion, prayer); decreased behaviour (time out; drugs/alcohol); medical care (medication use; calling doctor; goes to hospital); Helpless (wants to do something but can't)	Levels of anxiety, depression, psychosis, interpersonal disturbances and substance abuse	Symptoms questionnaire derived from Hertz + Melvilles list of premorbid and acute symptoms (5 categories of Anxiety, Depression, Psychosis, Interpersonal Disturbances and Substance Abuse)
14. Pentland, Miscio, Eastbrook & Krupa (2003)	Qualitative	Clinical group (N= 6) Mean age= 55 (range 47-65) No comparison group	Two interviews per participant for development and consolidation of themes	Cognitive coping (looking at things differently; understanding themselves better; recognising and perceiving symptoms; distraction); Behavioural and social coping (through professionals, through family/friends,	Changes in psychotic symptoms, increase in engagement	Semi-structured interview schedule

				medication use); use of religion/spirituality		
15. Quin, Clare, Ryan & Jackson (2009)	Qualitative	Clinical group (N=7) Mean age= 76 years No comparison group	One-off semi-structured interview	Coping strategy style of solitary coping and avoidance; use of religion/spirituality	Changes in psychotic symptoms	Semi-structured interview schedule
16. Cukrowicz, Ekblad, Cheavens, Rosenthal & Lynch (2007)	Cross-sectional	Clinical group (N= 69) Mean age = 61.3 years No comparison group	Interview for administration of the SCID and HAM-D; completion of battery assessment measures	Cognitive coping styles (thought suppression); general coping style (emotional coping, avoidant coping, rational coping, detached coping)	Suicidality risk; hopelessness	SCID-II; HAM-D; WBSI; CSQ; ASIQ; BHS
17. Banokole, Cohen, Vahia, Diwan, Palekar, Reyes, Sapra & Ramirez (2008)	Cross sectional	Clinical group (N= 198) Mean age =61.5 No comparison group	One off interview with questionnaire comparison	Acceptance of situations/cognitive coping skills; total social contacts and mean proportion considered intimate contact; medication use	Measures of daily functioning; physical illness; depression, symptom rates; remission rates, financial strain; trauma; frequency of mental health treatment	QoL I; CESDS; IADL; MAI (physical illness and physical self-maintenance scale); NAP; FSS; DRS; PCS (acceptance scale); LTVS; MSES
18. Nguyen, Truong, Feit, Marquett & Reisser (2007)	Case report	Clinical group (N=2) Mean age= 59.5 No comparison group- from a wider study looking at CBT vs TAU, but no comparison made in current study	Pre and post group therapy outcome measure completion	Cognitive and behaviour coping skills taught through CBT	Levels of depression and mania, social adjustment; physical health	HDRS; YMRS; WSAS; HS-SF; IDS- SR
19. Stevenson, Brodaty, Boyce & Byth (2012)	Cross-sectional	Clinical group (N=104) Mean age= 76.23 Comparison groups (N=134). Age ranges= 18-64	Questionnaires administered at admission to and discharge from inpatient ward; follow up 6 months post discharge	Problem based coping; emotion based coping and dysfunctional coping skills	Global assessment of functioning; symptom severity; social support levels	COPE; MMSE; FAB; GPCOG; GAF; BPRS; SF12; SCL-90; GDS; SSQ6

Table 1 continued

Author and Year	**Data Analysis**	**Effect size measure**	**Key Findings**
1. Cohen, Jimenez & Mittal (2010)	Mann- Whitney U test; stepwise hierarchical linear regression mediation and moderation analysis	None reported	1) Higher levels of "formal" religiousness (i.e. attending church) in community sample but control group just as likely to use religion as a way to cope 2) No significant impact on PANSS scores; no mediating or moderating effect on the relationship between QoL and PANSS positive score 3) religiousness had no mediating or moderating effects on the four stressors found to be significantly associated with QoL, but did increase the explained variance in the QoL scores (independent additive effect on QoL rather than impact on stressors)

2. Cohen, Hassamel & Begum (2011)	T-test; hierarchical regression analysis; mediation analysis; Principle Component Analysis with Equamax Rotation	None reported	No difference between groups in the use of cognitive coping styles; community group used more avoidant coping; schizophrenia group more likely to use instrumental coping (schizophrenia= cognitive, instrumental, avoidant; control= cognitive, avoidant, instrumental). Stressor, financial strain and trauma associated with greater PANSS score; partial mediating effect of all coping strategies on psychopathology and QoL, but not on stressors and QoL; all coping strategies had a direct, independent effect on QoL
3. Diwan, Cohen, Bankole, Vahia, Kehn & Ramirez (2007)	Bi-variate analysis for independent and dependent variables (T-test and chi-square); logistical regression for associations with levels of depression	Odds Ratios	Significant difference between the control group and schizophrenia group in levels of depression. Coping was a significant variable in the regression model, with "lower number of confidants in social group"; "reliance on medication/professionals for support" and "greater use of keeping calm when in conflict" all identified as significant variables in levels of depression- coping strategies more commonly used in depressed people with schizophrenia, but directionality unknown
4. Ibrahim, Cohen & Ramirez (2010)	T-tests; chi-square; correlations; hierarchical regression analysis	None reported	Schizophrenia group had lower levels of "successful ageing" compared to community sample; coping did not predict successful ageing (only lower PANSS negative score and greater QoL index). Coping significantly correlated with successful ageing, but did not explain variance when added to model. 3/4 of variance unexplained by all 16 variables.
5. Patterson, Shaw, Semple, Moscona, Harris, Kapplin, Grant & Jeste (1997)	2 tailed T-test and chi-square analysis; path analysis for direct and indirect effects of multiple variables; multiple regression analyses.	Path co-efficients	Clinical group had higher levels of psychopathology and social maladjustment and decreased wellbeing; similar levels of avoidant coping in clinical and control groups, but less emotional support for clinical group; avoidance coping a significant variable (approach coping not). However coping was not found to be directly related to health related quality of wellbeing; avoidant coping related to depressive symptoms, and central in determining depressive symptoms; clinical group may benefit from interventions that aim to reduce avoidant coping
6. Shepard, Depp, Harris, Halpin, Palinkas & Jeste (2010)	Grounded Theory analysis	N/A	Ageing led to more developed active coping strategies; reported adapting social networks with peers and health professionals (with increased reliance on health professionals); cognitive appraisals regarding the future impacted wellbeing in the present; increase in acceptance and self-management skills, better medication adherence in later life and engagement with active strategies to defuse the impact of psychotic symptoms; key role of cognitions highlighted
7. Berry, Barrowclough, Byrne & Purandare (2006)	ANCOVA; bivariate correlations and then stepwise regression analysis	None reported	Same level of stress in both groups, but clinical group had increased use of problem- focused coping and described this as being less effective in managing the stress. Clinical also had higher levels of dysfunctional coping. Significant difference, even when controlling for age, CI and Depression. Clinical also had less friends and lower reported levels of emotional support. Significant correlation between higher PANS score and greater dysfunctional coping. Severity of symptoms predicted dysfunctional coping
8. Solano & Whitbourne (2001)	Categorisation of strategies from the interviews into either cognitive or behavioural, and descriptive of usage; tally of strategies endorsed on the self-report scale; some qualitative quotes/information used	N/A	People apply on average 10 coping strategies, mostly of behavioural focus. 100% of respondents endorsed watching tv and 93% endorsed seeking social support. Relaxing, using drugs and remaining calm were only endorsed by 1% of participants.

			Growing older and being more aware of "bizarre behaviour" and learning through experiences, keeping active and not blaming self for illness were learning points of sample
9. Cohen, Vengassery & Aracena (2015)	Use of individual effect size approach to assess any clinically meaningful change between time points; preliminary trimming of identified variables through correlations; linear regression analysis with resulting significant variables	Individual effect size	No significant difference between QLI at time 1 and time 2, instead fluctuating across time points in both positive and negative directions; no change in people being classed as higher QLI and lower QLI across time points; variables which predicted QLI at time 2 were lower depression score, higher religiousness, perceived wellbeing in relation to others/self, time from baseline interview and baseline QLI. No other coping variables were identified as retaining significance with QLI between time points.
10. Meesters, Van Der Ham, Dominicus, Stek & Abma (2019)	Iterative process of data collection and analysis following observation, open interviews and semi-structured interviews; feedback from participants and second rater themes throughout	N/A	The facility (a behavioural coping mechanism) led to increased personal and social recovery; environmental and care factors to recovery included the relationship with workers, striking a balance between autonomy and caring and accessibility of the environment
11. Cohen, Izediuno, Yadack, Ghosh + Garrett (2014)	Bivariate analysis- chi square for categorical, Mann Whitney-U test for continuous; logistical regression for predictor variables	Odds Ratio	36% of sample reported hallucinations, 32% were auditory. There was no difference between those with auditory hallucinations and those without on any of the coping variables. Increased depression score, PANSS delusional score <2; no. of psychiatric med; male; increased lifetime trauma all associated with auditory hallucinations, but only 3 retained significance in regression model (increased depressive symptoms, PANS <2, male). No coping variables were predictive of the presence of auditory hallucinations. However, OA were "more apt" to appraise and act upon the hallucinations as positive than younger adults
12. Granholm, McQuaid, McClure, Auslander, Perivoliotis, Pedrelli, Patterson., & Jeste (2005)	ITT analysis; t-test and chi square for demographic variables; ANCOVA; baseline scores for OM as covariate; treatment group and treatment site between subject variable; assessment time within-subject variable	Partial- Eta Squared	Good adherence and attendance for combined treatment group; combined treatment led to increase use of social functioning activities than TAU groups; combined treatment group showed great levels of increased awareness than TAU, leading to a significant relationship with reduction in positive symptoms. Increased reflectiveness/less resistance to feedback and more objectivity led to greater reduction in positive symptoms in combined group.
13. Cohen (1993)	Proportion of strategies used calculated and correlated with age and time since last hospitalisation; one tailed test	None reported	17.5 problems identified on average; the most commonly used strategy was cognitively "fighting back"; social diversion significantly associated with age; accepting and not fighting back may indicate increased tolerance of illness and oneself
14. Pentland, Miscio, Eastbrook & Krupa (2003)	Interviews coded thematically using an iterative process, seeking consensus amongst the research team	N/A	Both behavioural and cognitive coping strategies are used within this population, and that as individuals age, they become “veterans of schizophrenia and understanding themselves better”; use of others and professionals as a support and the need for medication as a behavioural coping mechanism a key conclusion, as was the used of prayer/religion.
15. Quin, Clare, Ryan & Jackson (2009)	Interpretative Phenomenological Analysis	N/A	People with very late onset-like psychosis tend to use a solitary coping strategy to manage their illness. Avoidance high in this population, with a “get one with it” attitude found and not discussing their mental health with others. Prayer and religion were also influential coping mechanisms.

16. Cukrowicz, Ekblad, Cheavens, Rosenthal & Lynch (2008)	Hierarchical Regression analysis, with gender as predictor and controlling from depression	None reported	Emotional coping, avoidant coping and thought suppression were all significant predictors of suicide risk composite (after controlling for depression), with avoidance coping negatively associated with suicide risk and emotional and thought suppression positively associated with suicide risk. Rational and detached coping not predictive of suicide risk composite. Avoidance coping was negative associated with suicide risk; emotional and thought suppression were positively associated with suicide risk.
17. Banokole, Cohen, Vahia, Diwan, Palekar, Reyes, Sapra & Ramirez (2008)	Independent t-tests; logistical regression analysis	Odds ratio	Remission is attainable in older people with chronic schizophrenia Rate of remission is positively associated with the size of kin network and formal contacts, but inversely with non-kin network size. Remission associated with a number of variables, but only 4 retain significance in regression model for prediction of remissions rates= fewer network contacts, increased proportion of intimates, lower number of lifetime traumatic events and increased dementia rating score. 3 out of 4 of the significant variables had only a modest effect.
18. Nguyen, Truong, Feit, Marquett & Reisser (2007)	Pre and post intervention comparison scores, but no detail of statistical analysis undertaken (Case study qualitative description of change)	None reported	Both cognitive and behavioural coping strategies had a positive effect in reducing post intervention outcome measures. Cognitive restructuring and behaviour strategies such as developing tools for controlling overstimulation reduced BP symptoms (depression and mania). Group-based CBT for OA with BD can be efficacious in reducing symptoms
19. Stevenson, Brodaty, Boyce & Byth (2012)	Chi-square and bivariate correlations; ANCOVA and hierarchical multiple regression. Age as a continuous variable in regression	None reported	There were more complex combinations of personality disorders found in younger patients than older adults. Dysfunctional coping was used most by OA's, followed by emotion-focused then problem-based (but problem based used more in OA than younger adult). All three styles were used less as people aged. Symptom distress was positively correlated with dysfunctional coping. PD had an effect on wellbeing and coping independently from age. Age only predicted use of problem-based coping

Note: CESDS: Centre for Epidemiologic Studies Depression Scale; PANSS: Positive and Negative Symptoms Scale; FSS: Financial Strain Scale; MAI: Multilevel Assessment Inventory; IADL: Instrumental activities of daily living scale; CCS: Cognitive Coping Scale; LTVS: Lifetime Trauma and Victimisation Scale; SES: Self-Esteem Scale; NAP: Network Analysis Profile; ASS: Acute Stressors Scale; QoLI: Quality of Life Index; RS: Religiousness Scale; CAGE: Alcohol Screening; MMSE: Mini-Mental State Exam; DRS: Dementia Rating Scale; PCS: Perlin Coping Scale; CTS: Conflicts Tactic Scale; AIMS: Abnormal Involuntary Movements Scale; BADLS: Basic Activities of daily living scale; SSAS: Subjective Successful Ageing Score; PERI: Psychiatric Epidemiology Research Interview; ESS: Emotional Supports Scale; AWCQR: Abbreviated Ways of Coping Questionnaire Revised; SAPNS: Scales for Assessment of Positive and Negative Symptoms; BSI-D: Brief Symptom Inventory- Depression; SAS: Social Adjustment Scale; QWS: Quality Wellbeing Scale; EISS: Emotional and Instrumental Supports Scale; GDS: Geriatric Depression Scale; NART: National Adult Reading Test; BI: Barthel Index; MSES: Medication Side Effects Scale; PWvsOSS: Perceived Wellbeing vs Others/Self-Scale; ILSS: Independent Living Skills Survey; HDRS: Hamilton Depression Rating Scale; BCIS: Beck Cognitive Insight Scale; CMT: Comprehensive Model Test; HAM-D: Modified Hamilton Rating Scale for Depression; WBSI: White Bear Suppression Inventory; CSQ: Coping Style Questionnaire; ASIQ: Adult Suicidal Ideation Questionnaire; BHS: Beck Hopelessness Scale; YMRS: Young Mania Rating Scale; WSAS: Weissman Social Adjustment Scale; HS-SF: Health Status Short Form; ISD-SR: Inventory of Depressive Symptomology- Self Report; COPE: Coping Orientation to Problems Experienced scale; FAB: Frontal Assessment Battery; GPCOG: General Practitioner Assessment of Cognition; GAF: Global Assessment of Functioning; SOFAs: Social and Occupational Functioning Assessment Scale; BPRS: Brief Psychiatric Rating Scale; SF12: Short Form Health Survey; SCL-90: Symptom Checklist; SSQ6: Social Supports Questionnaire

Granholm et al’s (2005) RCT was of the highest methodological quality, receiving full scoring of quality checks.

For the qualitative studies, these were overall of a high standard with explicit methods and reliability factors detailed within the study. However, there were no explicit statements of the researchers influence on research activity explicitly or statements regarding the attainment of ethical approvals in Shephard et al (2010), and statement of orientation culturally and theoretically in both Meetsters et al (2019) and Pentland et al (2009), and subsequently the articles were award a mark of 0.5 due to discussion regarding consent and the use of co-analysis to reduce researcher bias. Quin et al (2009) received full quality marking.

Solan and Whitbourne’s (2001) mixed methods study had the lowest overall quality rating. This paper was a pioneer for research in older adults with schizophrenia, being one of the first to address the question of coping styles. However, the level of analysis is poor in terms of statistical analysis and identification of confounding variables, lacking detail regarding inclusion criteria and valid measures. There is no representation of participants views or extracts of quotations pertaining to the essence of qualitative research or mention of efforts to increase reliability and validity of analysis. Whilst there has been some progress in the quality of research carried out in the field, the continued use of this paper as the benchmark for research in this field highlights the need for further, more methodologically rigorous research to be conducted in this neglected area.

Outcome measures

Across all 19 studies included within the review, 52 outcome measures were used to assess coping skills, wellbeing and general outcomes. In line with Lazarus and Folkman (1984), the first author classified a measurement of coping as any way in which the individual was attempting to manage their wellbeing. There were three measures used within studies which could be classified as measuring facets of both coping and wellbeing: The Network Analysis Profile; CAGE alcohol abuse screening tool; measurement of the frequency of mental health service usage. These measures can be seen as both coping strategies (e.g. the use of alcohol to cope with difficult experiences during a psychosis; use of mental health services as an active coping strategy for increased difficulties with mental health) or measures of wellbeing (e.g. increased alcohol use as indicative of decreased wellbeing; increase use of mental health services as indicative of decreased wellbeing), and therefore have been classified in relation to the research question applied within their respective study.

See table 1 for outcome measures used.

Table 2: Quality assessment of cross-sectional studies

Article Author and year	Clearly defined inclusion?	Study subjects and setting described in detail?	Exposure measure in valid and reliable way?	Objective, standard criteria used for measurement of condition?	Confounding factors stated?	Strategies to deal with confounding factors?	Outcomes measured in a valid and reliable way?	Appropriate statistical analysis?	Total score
Cohen, Jimenez & Mittal (2010)	Yes (1)	Yes (1)	Unsure (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	7.5/8
Cohen, Hassamel & Begum (2011)	Yes (1)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	Yes (1)	Unclear (0.5)	Yes (1)	7/8
Diwan, Cohen, Bankole, Vahia, Kehn & Ramirez (2007)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	7/8
Ibrahim, Cohen & Ramierz (2010)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Unclear (0.5)	Yes (1)	7/8
Patterson et al. (1997)	Yes (1)	No (0)	Yes (1)	Yes (1)	Not applicable	Not applicable	Unclear (0.5)	Yes (1)	4.5/6
Berry, Barrowclough, Byrne & Purandare (2006)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	7.5/8
Cohen, Izediuno, Yadack, Ghosh & Garrett (2014)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	Yes (1)	7/8
Cohen (1993)	Yes (1)	Unclear (0.5)	Unclear (0.5)	Yes (1)	Unclear (0.5)	Unclear (0-5)	Yes (1)	Yes (1)	6/8
Cukrowicz, Ekbald, Cheavens, Rosenthal & Lynch (2007)	No (0)	Unclear (0.5)	Yes (1)1	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	6.5/8
Solan and Whitbourne (2001) MM	No (0)	Unclear (0.5)	Unclear (0.5)	Yes (1)	No (0)	No (0)	Unclear (0.5)	Unclear (0.5)	3/8
Bankole, Cohen, Vahia, Diwan, Palekar, Reyes, Sapra & Ramirez (2008)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Unclear (0.5)	Unclear (0.5)	Yes (1)	Yes (1)	7/8
Stevenson, Brodaty, Boyce & Byth (2012)	Yes (1)	Yes (1)	Not applicable	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	7/7

Table 3: Quality assessment of qualitative studies

Article Author and year	Contingency between the stated philosophical perspective and research method?	Congruity between the research methodology and research question/objectives	Congruity between the research methodology and methods used to collect data?	Congruity between the research method and the representation of the data?	Congruity between the research methodology and interpretation of results?	Statement locating the researcher culturally and theoretically?	Statement of the influence of the researcher on the research, and vice-versa?	Are participants and their voices adequately represented?	Research ethical according to current criteria and evidence by appropriate bodies?	Do conclusions drawn flow from the analysis and interpretation of the data?	Total
Shepard, Depp, Harris, Halpain, Palinkas & Jeste (2010)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Unclear (0.5)	Yes (1)	Unclear (0.5)	Yes (1)	9/10
Meesters, Van Der Ham, Domincus, Stek & Abma (2014)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Unclear (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	9.5/10
Pentland, Miscio, Eastabrook & Krupa (2003)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	9/10
Quin, Clare, Ryan & Jackson (2009)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	10/10
Solan and Whitbourne (2001) MM	No (0)	Yes (1)	Yes (1)	Unclear (0.5)	Unclear (0.5)	No (0)	No (0)	No (0)	No (0)	Yes (1)	4/10

Table 4: Quality assessment of RCT articles

Article, Author and Year	Was true randomisation used for assignment to conditions?	Was allocation to treatment concealed?	Were groups similar at baseline?	Were participants blind to treatment assignment?	Were those delivering treatment blind to allocation?	Were outcome assessors blind to treatment assignment?	Were treatment groups treated identically other than the intervention of interest?	Was follow up completed, and if not, were differences in groups in terms of follow up adequately described and analysed?	Were participants analysed in the groups to which they were randomised?	Were outcomes measured in the same way for treatment groups?	Were outcomes measured in a reliable way?	Was appropriate statistical analysis used?	Was the trial design appropriate, and any deviations from RCT design accounted for in the conduct and analysis of the trial?	Total
Granholm, McQuaid, McClure, Auslander, Perivoliotis, Pedrelli, Patterson., & Jeste (2005)	Yes (1)	Yes (1)	Yes (1)	Not applicable	Not applicable	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	11/11

Table 5: Quality assessment of cohort study articles

Author and year	Were the two groups similar and recruited from same population?	Were the exposures measured similarly to assign people to both groups?	Was the exposure measured in a valid and reliable way?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were groups free of the outcome at the start of the study?	Were the outcomes measured in a reliable and valid way?	Was the follow up time reported and sufficient to be long enough for outcomes to occur?	Was follow up completed and if not, were reasons of loss to follow up explored?	Were strategies to address incomplete follow up utilised?	Was appropriate statistical analysis used?	Total score
Cohen, Vengassy & Aracena (2017)	Yes (1)	Not applicable (SMI)	Yes (1)	Yes (1)	Yes (1)	Not applicable (QoL)	Yes (1)	Unclear (0.5)	Yes (1)	Unclear (0.5)	Yes (1)	8/9

Table 6: Quality assessment of case report articles

Author and year	Were patient demographic characteristics clearly described?	Was the patient history clearly described and presented as timeline?	Was the current clinical condition of patient clearly described?	Were diagnostic tests or assessment methods and results clearly described?	Was the intervention (s) or treatment procedure (s) clearly described?	Was the post-intervention clinical condition clearly described?	Were adverse events or unanticipated events identified and described?	Does the case report provide take-away lessons?	Total score
Nguyen, Truong, Feit, Marquett & Reisser (2007)	Yes (1)	Unclear (0.5)	Yes (1)	Unclear (0.5)	Unclear (0.5)	Yes (1)	No (0)	Yes (1)	5.5/8

Impact of coping on wellbeing variables

In addressing the first research question of this review, the findings of the studies support that coping styles can have a positive impact on wellbeing outcomes for adults over the age of 55 with a SMI. Those who utilised an active coping strategy (i.e. “reinterpreting thoughts” or “seeking social support”) over a passive strategy (i.e. “doing nothing” or “avoiding”) tended to report more positive wellbeing outcomes (Bankole et al, 2008; Cohen, 1993; Cohen et al, 2011; Cohen et al, 2014; Cukrowicz et al, 2007; Granholm et al, 2005; Ibrahim et al, 2010; Meesters et al, 2019; Nguyen et al , 2007; Pentland, 2003; Shepard et al, 2010; Quin et al, 2009). Where effect sizes were known, the use of active strategies, such as seeking more intimate and close social relationships, were moderate in size (Bankole et al, 2008). Avoidant coping (both cognitive and behavioural) was found to be significantly associated with poorer wellbeing outcomes (Cohen et al, 2011; Cukrowicz et al, 2007; Patterson et al, 1997) and where effect size was reported (Patterson et al, 1997), this was also moderate. Qualitatively, avoidant coping was reported to impact on future wellbeing in Solan and Whitbourne, 2001. However, an interesting finding of Cohen et al’s (2011) study showed the control group was more likely to utilise avoidant coping than the clinical group, with the clinical group more likely to utilise active strategies, whilst all strategies had a positive impact on quality of life.

Based on the theoretical framework provided by Lazarus and Folkman (1984), the results were categorised into cognitive and behavioural coping strategies. All studies except one (Meesters et al, 2019) studied the impact of some form of cognitive coping on outcomes. Cognitive coping was found to be the most commonly used strategy in dealing with life stresses both in older adults with and without schizophrenia according to Cohen et al (2011), with cognitive coping having the strongest mediating impact on psychpathology and strongest direct impact on quality of life within the clinical sample ($\beta=0.17$, $t= 2.61$, $p= 0.01$).

Cognitive coping was found to be significantly associated with wellbeing in seven of the quantitative studies included (Bankole et al, 2008; Berry et al, 2006; Cohen et al, 2011; Cukrowicz et al, 2007; Diwan et al, 2007; Ibrahim et al, 2010; Patterson et al, 1997), qualitatively reported in Nguyen et al's (2008) study and was a factor in all qualitative studies (Shepard et al, 2010, Solan and Whitbourne, 2001; Pentland et al, 2003; Quin et al, 2009). However, in studies where a regression analysis was used to predict the impact of coping on wellbeing, cognitive coping only retained significance in three of the studies (Cukrowicz et al, 2007; Diwan et al, 2007; Patterson et al, 1997). This may suggest that whilst cognitive coping style is associated with wellbeing, there are other factors which are more predictive of outcomes (for example number of lifetime traumas, overall symptomology and reported financial strain). And in contrast to Cohen et al's (2011) study, Solan and Whitbourne (2001) found behavioural coping strategies more common within their sample of elderly schizophrenic participants. However, the quality rating of methodological rigour was poor in Solan and Whitbourne's (2001) study, indicating this conclusion should be generalised with a degree of caution. Coping style was not found to predict the presence of hearing voices in Cohen et al's (2014) study, however cognitive appraisals applied by older participants, such as interpreting auditory symptoms as friendly or more benevolent, was found to led to better outcomes and be more consistently applied by older participants than younger participants. In Granholm et al's (2015) RCT, the use of both cognitive and behavioural strategies, both active ways of coping, were found to have a positive impact on wellbeing outcomes, with a medium- large effect size.

In addressing the second research question, although there was variability between studies regarding the most helpful style of coping, there appears to be slightly more consistent evidence provided that cognitive coping has a greater influence on wellbeing than behavioural coping.

The use of religion as a coping strategy (which varies in its definition within the literature as either cognitive or behaviour based on the chosen expression of religiousness) was assessed explicitly in one study (Cohen et al, 2010), but was discussed as a coping strategy in four additional studies (Cohen et al, 2014; Cohen et al, 2017; Pentland et al, 2003; Quin et al, 2009). Although it did not have a significant impact on life stressors, higher levels of religiousness were found to have an independent additive effect on quality of life (Cohen et al, 2014). It was also found to be predictive of increased quality of life in a longitudinal study ($\beta = 0.24$, $t = 2.92$, $p = 0.005$), with a small- medium effect size (Cohen et al, 2017) and was reported in qualitative studies to be a beneficial strategy for the older adults involved. Religion was not a variable included in analysis in any other studies identified, and so raises the question of cultural differences in coping styles. Articles assessing religion were carried out in either one region of America or in Ireland, where the use of religion may have more cultural importance placed upon it.

Seven studies (Berry et al, 2006; Cohen et al, 2014; Cohen et al, 2017; Nguyen et al, 2008; Solan and Whitbourne, 2008; Shepard et al, 2010; Pentland et al, 2003) highlighted the role of interpretation of experiences (which may be categorised as a form of cognitive intervention) and the subsequent impact on wellbeing. Cohen (1993), Cohen et al (2014), Solan and Whitbourne (2001), Shepard et al (2010) and Pentland et al (2003) all found that as participants got older, they were better able to use cognitive strategies to reappraise interpretations of symptoms and illness, including hearing more pleasant voices in comparison to younger adults, reducing self-blame, perceiving symptoms differently, redirecting attention and applying acceptance and defusion thoughts in order to increase wellbeing. In Cohen et al's (2017) longitudinal study, the variable of "perceived wellbeing vs other/past self" was found to significantly predict quality of life at the second time frame (i.e. an individual's interpretation of how well they were doing in comparison with others influenced their reported quality of life), with a bi-directional relationship with a small-medium effect size found. Additionally, the findings of Berry et al (2006) that older adults who appraised their coping as less effective were more likely to have dysfunctional coping styles, which resulted in a significant correlation with higher PANSS scoring ($\beta= 0.654$, $t= 4.06$, $p< 0.001$), supports this conclusion also. Finally, the gold-standard RCT by Granholm et al (2015) found that the cognitive skills of noticing and reappraising thoughts led participants to have increased insight into their illness, resulting in increased self-awareness and openness to feedback, leading to increased social functioning decreased symptoms. The same was shown in Nguyen et al's (2008) study, where participants who applied techniques such as cognitive restructuring were found to have reduced symptoms of illness and improved functioning. Whilst the quality rating of Nguyen's study was lower than others in the review and therefore conclusions applied with a level of caution, the take home messages from the case-report were consistent with studies of a higher quality rating. Taken altogether, these outcomes suggest that the level of cognitive appraisal or reframing applied by middle-aged and older adults with SMI play an important role in subjective experiences of wellbeing.

Behavioural coping strategies were included as variables in 17 studies. The use of medication to manage symptoms were assessed in five of the studies (Cohen et al, 2014; Cohen et al, 2017; Diwan et al, 2007; Shepard et al, 2010; Solan and Whitbourne, 2001; Pentland et al, 2003), with mixed conclusions. Qualitatively, the use of medication led to decreased symptomology and increased subjective wellbeing (Shepard et al, 2010; Pentland et al, 2003).

However, quantitative studies suggested the use of medication was significantly associated with levels of depression in clinical sample (Diwan et al, 2007), with participants in this study who used medication as their coping strategy found to be twice as likely to experience depression (odds ratio= 2.12, 95% confidence interval= 1.08- 4.13, p=0.03). The use of medication could not predict the presence of auditory hallucinations (Cohen et al, 2014) nor did it result in any significant association with wellbeing over a longitudinal time period (Cohen et al, 2015). And in Granholm's (2015) RCT, there was no signification effect of medication in treatment outcomes. The difference in the objective and subjective results (i.e. between qualitative and quantitative results) once again highlight the role of individual interpretation of symptoms and subjective quality of wellbeing.

Although identified in the general adult literature as the most identified categories of coping, problem and emotion focused coping was only explicitly assessed in three older adult studies (Berry et al, 2006; Cukrowicz et al, 2007; Stevenson et al, 2012). Problem-focused coping may be defined as behavioural coping due to the focus on changing the problem itself, which usually occurs through some form of behavioural change. Berry et al (2006) found that older adults with psychosis use more problem-focused coping than age matched controls, producing higher levels of "dysfunctional coping" due to the discrepancy between problem focused strategies and level of actual control. Higher PANSS scores were found to be a significant predictor of dysfunctional coping (β= 0.654, t= 4.06, p< 0.001), highlighting the potential for a bidirectional relationship between coping and wellbeing variables. It is suggestive that behavioural coping may have a potentially negative effect on wellbeing through the creation of dysfunctional coping. Stevenson et al (2012) found concurrent evidence of this in their study comparing coping styles of older adults with those of working age. They found dysfunctional coping to be utilised more often in older adults than younger adults and that this was associated with increased symptomology. Older adults were also found to use problem-focused coping more than younger adults, with age a predictor of preferred coping style in their study population. Cukrowicz et al (2008) suggested that emotion focused coping was significantly positively associated with hopelessness and thoughts of suicide in older adults with personality disorder and depression. This suggests that neither emotion-focused nor problem-focused approaches are any more beneficial than the other for older adults with SMI. However, effect sizes were not reported for any of these three studies and so conclusions are reliant on statistical inference.

Instrumental coping, categorised as behaviours such as seeking out information, or asking health professionals or other social supports for help, was included in 11 of the studies (Berry et al, 2006; Cohen et al, 2011; Cohen et al, 2014; Cohen et al, 2017; Diwan et al, 2007; Granholm et al, 2005; Ibrahim et al, 2010; Meesters et al, 2019; Shepard et al, 2010; Solan and Whitbourne, 2001; Pentland et al 2003). Older adults with schizophrenia were found to utilise more instrumental coping strategies than controls (Cohen et al, 2011) with greater use of mental health service significantly associated with, but not predictive of, successful ageing (Ibrahim et al, 2010), reduced psychotic symptoms and increased subjective wellbeing (Shephard et al, 2010; Pentland et al, 2003). Older adults with severe and enduring mental health problems were found to have less social and emotional support than age matched peers (Berry et al, 2006; Patterson et al, 1997). This lack of social support occurs despite the finding that the number of intimate contacts an older adult with schizophrenia had, the lower their odds of developing depression (odds ratio= 0.03, 95% confidence interval = 0.01–0.39, p= 0.01; where <1 is associated with lower depression scores) (Diwan et al, 2007), highlighting the important impact social contact can have on wellbeing outcomes. Patterson et al (1997) also support the notion that social support can have an impact on symptoms of depression, however this was a relatively weak relationship (path co-efficient= -0.18). However, the same study found a strong negative link between rated social maladjustment and wellbeing variables (path co-efficient= -0.35), suggesting that those with poorer social interactions reported lower overall wellbeing. Bankole et al (2008) adds further weight to the use of social support as an important facet of coping through their finding that an individual's proportion of intimate contacts was significantly associated with remission from schizophrenia symptoms, with a modest effect size (odd ratio= 9.83, 95% confidence interval=1.44- 67.33, p=0.02; where >1 is associated with remission). In this study, total network size was not associated with remission (odds ratio= 0.82, 95% confidence interval= 0.74- 0.91, p= 0.00), suggesting that it is the quality of relationship that impacts remission as opposed to the overall number of social contacts.

Seeking social contact was shown to be the second most commonly used coping strategy in Solan and Whitbourne's (2001) study, with Cohen (1993) suggesting that as individuals aged, they were more likely to utilise social support as a means of diversion from symptoms than younger participants. Engagement with social supports was shown to lead to increased personal and social recovery (Meesters et al,2019), and participants in Granholm et al's (2015) study were found to be able to increase their social functioning through the use of behavioural training such as role-playing assertiveness skills. This suggests that increases in the successful socialising and the use of social support was more of an outcome achievement in itself as opposed to a coping mechanism.

DISCUSSION

The results of this systematic review indicate that middle-aged and older adults utilise a range of coping strategies when dealing with severe and enduring mental health issues, all of which have an impact on wellbeing. Active strategies were found to have a more positive impact on wellbeing than passive strategies or "doing nothing". Both these findings are consistent with past work in younger populations (Philips et al,2009; Boschi et al, 2000). It may be that positive symptoms experienced in psychosis or similar severe and enduring mental illnesses make it difficult for individuals to "do nothing", and more likely to try to attempt to combat the effects of distressing symptoms by applying an active coping strategy. Findings that control groups are more likely to use avoidant strategies (e.g. in Cohen et al, 2011) may suggest that it is easier for people with no active symptoms to simply "switch off", avoid or "do nothing" in comparison to those with unavoidable symptoms experienced as part of SMI (e.g. hallucination and/or distressing delusions). This is an interesting finding when considering the use of avoidant coping such as excess alcohol or substances in the general mental health population (e.g. Carr, 1988; Gregory et al, 2008). Although difficult to ascertain why these kinds of avoidant strategies may be less commonly used, it may perhaps be due to the individual with SMI having less access to substances (due to symptom severity inhibiting the sourcing of substances, or reduced social contact), or perhaps as a biproduct of SMI symptoms on inhibiting general functioning and financial resources.

Whilst there was evidence found for the use of both cognitive and behavioural coping strategies, there were more consistent reports on the benefits of the use of a range of cognitive strategies. Whereas successful behavioural strategies appeared to be primarily in the form of seeking and utilising social support. Results indicated that as individuals aged, they became better placed to interpret experiences such as hearing voices as more positive and helpful experiences as opposed to distressing, as well as how they interpreted their future impacting their wellbeing. This finding can be explained by Chen and Miller (2012) of "shift and persist" theory. Approaching SMI as something more difficult to radically change may cause a "shift" to occur through changing interpretations of symptoms and illness, to a new acceptance or "persist". This finding regarding cognitions may also align with the illness perceptions model proposed by Leventhal (1984), in that gaining a greater understanding of illness identity (e.g. increasing their sense of control over illness and subsequently reduced consequences), ageing adults are more likely to employ successful coping strategies. The role of cognition is further supported through, for example, the finding that medication use itself did not lead to increased quality of life over a longitudinal period, however participants did report the use of, and adherence to, their medication as being an important factor in their subjective wellbeing. Interpretation of symptoms appears to be a key factor in coping with illness in this population. The findings that indicate older adults with SMI can learn cognitive strategies such as cognitive restructuring and thought challenging (e.g. Granholm et al, 2005; Nguyen et al, 2008) should provide a sense of hopefulness to older adults with SMI. Learning can successfully occur in order to shift subjective wellbeing. It has previously been found the subjective and objective measures of wellbeing do not necessarily align (Kupper & Tschacher, 2008), however this may indicate that recovery should be the measure upon which "wellbeing" and "quality of life" are defined, and the role that psychosocial interventions may be able to have in impacting subjective wellbeing. A number of the studies in the review suggest there is a bi-directional relationship between symptomology and successful coping skills, therefore identification of the routes of intervention such as effective cognitive strategies and targeting interpretations are key.

Given the finding of this review in which social contact is greatly reduced within this population, despite seeking this contact as the primary means of behavioural coping, a particularly important need for older adults in building upon social supports is highlighted. This finding also supports the Stress Vulnerability Model of schizophrenia (Nuechterlein and Dawson, 1984), which has been primarily based on younger populations, as being evident in the ageing population. Aspects of the model (i.e. smaller social support networks) may be an even more prominent factor in older adults due to the physical restraints of ageing, and naturally diminished social networks. Findings indicate that it is the quality of a relationship that can have a more positive impact (i.e. more intimate reciprocity) as opposed to the overall number of contacts. Meester et al's (2019) study of a dedicated mental health facility for older adults with SMI highlighted the impact of increased social engagement on personal and social recovery and may provide evidence for the need in increasing the capacity of services to provide access to these forms of support. Such facilities can provide the opportunity for increased social connectedness with individuals with similar experiences and provide a sense of community and opportunity for relationship building within a secure and supportive environment.

There was discrepancy within the studies regarding the most commonly utilised strategy, with Cohen et al (2011) suggesting cognitive strategies were the most common, whereas Solan and Whitbourne (2001) reported behavioural strategies to be the most common. This is concurrent with the literature on younger populations. Potential reasons of this difference may lie within the methodology, with Solan and Whitbourne's (2001) mixed methods utilising a "tally" of strategies used by participants as opposed to stringent statistical analysis. The classification of different strategies across categories (i.e. overlap with some behavioural/cognitive/active/passive strategies across studies) may also account for mixed results, as comparisons. For example, in Solan and Whitbourne's (2001) study, "do nothing: accepting" and "do nothing: helpless" were classified as behavioural strategies, whereas one may argue that accepting and feeling helpless be classified as cognitive strategies, as "try to accept the situation" is cognitive within Cohen et al's (2011) study. This lack of clarity may lead researchers to become overly concerned with terminology, whilst the evidence suggests there is substantial overlap between the two. Results of cognitive and behaviour studies show that older adults with SMI can learn both cognitive and behaviour skills successfully and perhaps the inconsistent results of which one is utilised more frequently results from this. Perhaps emphasis should be on encouraging and teaching any form of active strategy that may be available for the individual.

Limitations and strengths

This review included papers from 1997 in order to allow the widest range of literature to be assessed and highlights the lack of research within this population regarding the review variables. In the included studies, the sample consisted of individuals who consented to research, and for the most part were recovered or coping well with their illness. This introduces a sampling bias, whereby an insight is not gained into those currently still struggling with their mental health, and the role of current coping on wellbeing. This is a common issue within empirical studies and the challenge of the appropriateness of participant's undertaking research.

With the majority of the included studies being cross-sectional in design, it is difficult to firmly define causality or direction between many of the associations found. Evidence from some longitudinal studies and designs of more complex nature (i.e. use of path analysis) can suggest some directional influences between the style of coping and outcomes, such that psychosocial factors (such as avoidant coping and reduced social support) were the product of increased symptoms (i.e. wellbeing). The relationship between these variable requires additional clarity using methods that allow more confidence in causality to be determined. It was not possible to conduct a meta-analysis due to the variability in the methodology of studies included in the review. The results are therefore narrative in nature. One of the most practical limitations of the current review is the lack of availability of effect size in the quantitative research reviewed. The author was unable to compute effect size due to insufficient data available on the variables being reviewed, as it was often not the primary variable in the research paper. Results are therefore based on statistical inference, which whilst indicative of a relationship between the variables, results in the real-life impact of each of the variables unknown.

It appears that a quarter of the studies in this review utilised the same sample, with reported recruitment procedures and methodology similar for five of the 19 studies within the review (26.3 %). These studies all took place in the same urban area of Northern America, and whilst culturally very similar to the UK and Europe, places greater emphasis on variables such as religion as a coping strategy and provides different levels of health care provision. Cultural differences where the studies took place should therefore be taken into consideration when comparing outcomes and variables. All five studies were included in the review due to the application of different research questions, aims and outcomes of the studies. Whilst having very similar samples within studies may be a limitation of the current review due to the lack of diversity of studies and potential lack of generalisability due to the demographic variables, this is indicative of the narrow field of research currently being conducted with older adults, and highlights the need for further development of this neglected field across the academic literature, over and above secondary analysis conducted within these studies.

Whilst inclusion of different methodologies meant there could not be a meta-analysis conducted, a strength of this narrative approach was that there were a large range of literature included from a qualitative perspective. This allowed a greater understanding of the processes involved in the managing illness by older adults with SMI. It highlighted the role of subjective experiences, which has shown to be a key facet of intervention in this population and which may not have been highlighted by the inclusion of quantitative literature alone. Being as inclusive as possible in the studies included in the review was aimed to widen our knowledge base of research in this neglected field. The inclusion of articles such as Solan and Whitbourne (2001) and Nguyen et al (2008), whilst methodologically weak in parts, highlighted the lack of methodologically rigours research in this field. More is required to progress our understanding and our ability to confidently and appropriately make generalisable conclusions on the role of different coping strategies on wellbeing outcomes in older adults with severe and enduring mental illness.

Clinical Implications and future research

Results that active strategies are more commonly used is a positive indication for the use of psychosocial intervention, and interventions to support individuals who may apply an avoidant or “sealing over” strategies to develop more active strategies. As the review has highlighted that cognitive coping and interpretation appears to have greater impact on wellbeing, this confirms that treatment of severe and enduing mental illness in middle-aged and older adults should focus on the development of cognitive skills in appraisal of symptoms and illness. Through the finding that acceptance and shifting of focus with illness in later life is a common experience of adults with SMI, the capacity for additional models of treatment such as Acceptance and Commitment Therapy (Hayes et al, 2006) or Compassion Focused Therapy (Gilbert, 2009) may be beneficial within this population, along with traditional cognitive behavioural methods. As a core component of these interventions, mindfulness may be beneficial in teaching individuals to “be” as way for tackling thoughts and symptoms. These interventions may also be able to address older adult’s tendencies to utilise problem-focused coping strategies, which has been shown to increase levels of dysfunctional coping. Through developing cognitive skills of acceptance, mindfulness and shifting of focus, it may be possible to encourage a move away from problem-focused and dysfunctional coping.

Future research should aim to provide more clarity on the directionality of the relationships of coping and wellbeing, utilising a method more stringent than cross-sectional analysis. Finally, consensus should be reached between academics and clinicians on the need for classification of coping strategies to ensure clearer conclusions can be drawn. At present, there is substantial overlap between cognitive and behavioural strategies within the literature, resulting in inconsistent conclusions. With results suggesting that older adults with SMI can develop both cognitive and behaviour strategies with good effect, focus should be shifted to developing and encouraging active strategies over passive strategies as the baseline intervention as opposed to losing focus on the nuisances between cognitive and behavioural.

Finally, when there is little information available around a topic of study, or where consensus is difficult to reach, qualitative methodologies may be helpful in order to develop an understanding of the divergent perspective from the view-point of the service user. This can be particularly useful for populations with limited empirical research available, such as middle-aged and older adults with long-standing mental health problems.

REFERENCES

Arslan, B.S., & Buldukoglu, K. (2018). The association of nursing care perception with coping skills and posttraumatic growth in mental disorders. *Journal Psychiatric Mental Health Nursing*, 25, 228-235.

Auslander, L.A., & Jeste, D.V. (2004). Sustaine Remmission in Schizophrenia Amongst Community Dwelling Older Outpatients, *Am J Psychiatry*¸ 161 (8), 1490- 1493

Berry, K., Barrowclough, C., Byrne, J., & Purandare, N. (2006). Coping strategies and social support in old age psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 41(4), pp.280-284.

Bankole, A., Cohen, C., Vahila, I., Diwan, S., Palekar, N., Reyes, P., Sapra, M., & Ramirez, P.M. (2008). Symptomatic Remission in a Multiracial Urban Population of Older Adults with Schizophrenia. *Am J Geriatr Psychiatry*, 16 (12), 966- 973.

Boschi, S., Adams, R.E., Bromet, E.J., Lavelle, J.E., Everett, E., & Galambos, N. (2000). Coping with Psychotic Symptoms in the Early Phases of Schizophrenia, *American journal of Orthopsychiatry*, 70 (2), 242- 252.

Carr, V. (1988). Patients’ techniques for coping with schizophrenia: An exploratory study. British Journal of Medical Psychology, 61, 339-352

Chen, E., & Miller, G.E. (2012). "Shift-and-Persist" Strategies: Why Low Socioeconomic Status Isn't Always Bad for Health. *Perspectives on Psychological Science*, 7 (2), 135-158

Christophe, N., Stein, G., Martin Romero, M., Chan, M., Jensen, M., Gonzalez, L., & Kiang, L. (2019). Coping and Culture: The Protective Effects of Shift-&-Persist and

Ethnic-Racial Identity on Depressive Symptoms in Latinx Youth. *Journal Of Youth And Adolescence*, *48*(8), 1592-1604. doi: 10.1007/s10964-019-01037-8

Cohen, C., Hassamal, S., & Begum, N. (2011). General coping strategies and their impact on quality of life in older adults with schizophrenia. *Schizophrenia Research*, 127(1-3), pp.223-228.

Cohen, C., Izediuno, I., Yadack, A., Ghosh, B., & Garrett, M. (2014). Characteristics of Auditory Hallucinations and Associated Factors in Older Adults with Schizophrenia. *The American Journal of Geriatric Psychiatry*, 22(5), pp.442-449.

Cohen, C., Jimenez, C., & Mittal, S. (2010). The Role of Religion in the Well-Being of Older Adults With Schizophrenia. *Psychiatric Services*, 61(9), pp.917-922.

Cohen, C., Vengassery, A., & Garcia Aracena, E. (2017). A Longitudinal Analysis of Quality of Life and Associated Factors in Older Adults with Schizophrenia Spectrum Disorder. *The American Journal of Geriatric Psychiatry*, 25(7), pp.755-765.

Compas, B. E., Jaser, S. S., Dunbar, J. P., Watson, K. H., Bettis, A. H., Gruhn, M. A., & Williams, E. K. (2013). Coping and emotion regulation from childhood to early adulthood: Points of convergence and divergence. Australian Journal of Psychology, 66(2), 71–81. doi:10.1111/ajpy.12043

Cooke, P., Melchert, T., & Connor, K. (2016). Measuring Well-Being. *The Counseling Psychologist*, *44*(5), 730-757. doi: 10.1177/0011000016633507

Cukrowicz, K., Ekblad, A., Cheavens, J., Rosenthal, M. and Lynch, T., 2008. Coping and thought suppression as predictors of suicidal ideation in depressed older adults with personality disorders. *Aging & Mental Health*, 12(1), 149-157.

Davidson, L., Borg, M., Marin, I., Topor, A., Mezzina, R., & Sells, D. (2015). Processes of Recovery in Serious Mental Illness: Findings from a Multinational Study, *American Journal of Psychiatric Rehabilitation*, 8 (3), 177-201.

Davis, G. (2005). Coping with Mental Illness. *Psychiatric Rehabilitation Journal*, 28 (3), 229- 302.

Division of Clinical Psychology. (2004). *Understanding Psychosis and Schizophrenia.* Leicester: British Psychological Society

Diwan, S., Cohen, C., Bankole, A., Vahia, I., Kehn, M., & Ramirez, P. (2007). Depression in Older Adults With Schizophrenia Spectrum Disorders: Prevalence and Associated Factors. *The American Journal of Geriatric Psychiatry*, 15(12), pp.991-998.

Fledderus, M., Bohlmeijer, E.T., & Pieterse, M.E. (2010). Does Experiential Avoidance Mediate the Effects of Maladaptive Coping Styles on Psychopathology and Mental Health? *Behaviour Modification*, 34 (6), 503-519

Good Governance Institute. https://www.good-governance.org.uk/wp-content/uploads/2020/05/COVID-19-blog-21-05-20.pdf

Granholm, E., McQuaid, J., McClure, F., Auslander, L., Perivoliotis, D., Pedrelli, P., Patterson, T., & Jeste, D. (2005). A Randomized, Controlled Trial of Cognitive Behavioral Social Skills Training for Middle-Aged and Older Outpatients With Chronic Schizophrenia. *American Journal of Psychiatry*, 162(3), pp.520-529.

Gregory, R. J., Chlebowski, S., Kang, D., Remen, A. L., Soderberg, M. G., Stepkovitch, J., & Virk, S. (2008). A controlled trial of psychodynamic psychotherapy for co-occurring borderline personality disorder and alcohol use disorder. Psychotherapy: Theory, Research, Practice, Training, 45, 28–41. doi:10.1037/0033-3204.45.1.28

Gross, J., & John, O. (2003). Individual differences in two emotion regulation processes: Implications for affect, relationships, and well-being. Journal of Personality and Social Psychology, 85, 348–362. doi:10.1037/0022-3514.85.2.348

Gumley, A.I., Taylor, H.E.F., Schwannauer, M. & Macbeth, A. (2014). 'A systematic review of attachment and psychosis: measurement, construct validity and outcomes', *Acta psychiatrica scandinavica*, 129 (4), 257-274. https://doi.org/10.1111/acps.12172

Hagger, M.S., & Orbell, S. (2003) A Meta-Analytic Review of the Common-Sense Model of Illness Representations, Psychology and Health, 18:2, 141-184, DOI: 10.1080/088704403100081321

Harvey, J., & Taylor, V. (2013). *Measuring Health and Wellbeing: Basic Concepts.* London: SAGE Publications

Hatfield, K., & Dening, T. (2013). Severe and Enduring Mental Illness. In Dening, T., & Thomas, A. (Ed). *Oxford Textbook of Old Age Psychiatry (2nd Ed).* London: Oxford University Press

Hertel, G., Rauschenbach, C., Thielgen, M.M., & Krumm, S. (2015). Are older workers more active copers? Longitudinal effects of age-contingent coping on strain at work. J. Organ. Behav. 36, 514–537. https://doi.org/10.1002/job.1995.

Ibrahim, F., Cohen, C., & Ramirez, P. (2010). Successful Aging in Older Adults With Schizophrenia: Prevalence and Associated Factors. *The American Journal of Geriatric Psychiatry*, 18(10), pp.879-886.

Kupper, Z., & Tschacher, W. (2008). Lack of concordance between subjective improvement and symptom change in psychotic episode. *British Journal of Clinical Psychology*, 47, 75–93

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Lent, R. W. (2004). Toward a unifying theoretical and practical perspective on wellbeing and psychosocial adjustment. Journal of Counseling Psychology, 51(4), 482-509. doi:10.1037/0022-0167.51.4.48

Leventhal, H., Nerenz, D.R., & Steele, D.F., (1984). Illness representations and coping with health threats. In A. Baum & J. Singer (Eds); A Handbook of Psychology and Health (pp. 219–252), Hillsdale, NJ: Erlbaum

Leventhal, H., Brissette, I., & Leventhal, E. (2003). The common-sense model of self-regulation of health and illness. In: Cameron, L.D., & Leventhal, H. (eds) The Self-Regulation of Health and Illness Behavior. London: Routledge, 42–65

Levy, B., Chung, P., Slade, M., Van Ness, P., & Pietrzak, R. (2019). Active coping shields against negative aging self-stereotypes contributing to psychiatric conditions. *Social Science & Medicine*, *228*, 25-29. doi: 10.1016/j.socscimed.2019.02.035

Lobban, F., & Barrowclough, C. (2005). Common Sense Representations of Schizophrenia in Patients and Their Relative. *Clinical Psychology and Psychotherapy*, 12, 134-141

Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc. 2015;13(3):179–187

MacDonald, E.M., Pica, S., McDonald, S., Hayes, R., & Baglioni, Jr, A.J. (1998) Stress and Coping in Early Psychosis. Role of Symptoms, self-efficacy and Social support in Coping with Stress. *British Journal of Psychiatry*, 172 (33), 122-127.

Malka, T., Hasson-Ohayon, I., Goldzweig, G., & Roe, D. (2019). Coping Style Is Associated With Parental Distress Beyond Having a Mental Illness: A Study Among Mothers With and Without Mental Illness. *Psychiatric Rehabilitation Journal*. Advance online publication. http://dx.doi.org/10.1037/prj0000381

Mazor, Y., Gelkopf, M., & Roe, D. (2018). Posttraumatic Growth among people with serious mental illness, psychosis, and posttraumatic stress symptoms. *Comprehensive Psychiatry*, 81, 1-9.

McNeil, S.A., & Galovski, T.E. (2015). Coping Styles Among Individuals with Severe Mental Illness and Comorbid PTSD. *Community Mental Health Journal*, 51, 663–673.

Meesters, P., van der Ham, L., Dominicus, M., Stek, M., & Abma, T. (2019). Promoting Personal and Social Recovery in Older Persons with Schizophrenia: The Case of The New Club, a Novel Dutch Facility Offering Social Contact and Activities. *Community Mental Health Journal*, 55(6), pp.994-1003.

Moher. D, Liberati. A, Tetzlaff. J, & Altman D.G, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/

Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/

Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/

Mueser, K. T., Rosenberg, S. D., Hamblen, J. L., & Decamps, M. (2004). A cognitive-behavioural treatment program for posttraumatic stress disorder in persons with severe mental illness. American Journal of Psychiatric Rehabilitation, 7, 107–146. doi:10.1080/1587760490476183.

Nguyen, T., Truong, D., Feit, A., Marquett, R., & Reisser, R. (2007). Response to Group-Based Cognitive Behavioural Therapy for Older Adults with Bipolar Disorder, *Clinical Gerontologist*, 30 (2), 103-110, DOI: 10.1300/J018v30n02_08

Nuechterlein, K. H., & Dawson, M. E. (1984). A Heuristic Vulnerability/Stress Model of Schizophrenic Episodes. *Schizophrenia Bulletin, 10*(2), 300–312. https://doi.org/10.1093/schbul/10.2.300

Ong, E., & Thompson, C. (2019) The Importance of Coping and Emotion Regulation in the Occurrence of Suicidal Behaviour. Psychological Reports, 122 (4), 1192-1210

Patterson, T., Shaw, W., Semple, S., Moscona, S., Harris, M., Kaplan, R., Grant, I., & Jeste, D. (1997). Health-Related Quality of Life in Older Adults with Schizophrenia and Other psychoses: Relationships Among Psychosocial and Psychiatric Factors. *International Journal of Geriatric Psychiatry*, 12(4), pp.452-461.

Peck, M. C., & Scheffler, R. M. (2002). An analysis of the definitions of mental illness used in state parity laws. Psychiatric Services, 53(9), 1089–1095. doi:10.1176/appi.ps.53.9.1089.

Pentland, W., Miscio., Eastabrook, S., & Krupa, T. (2003). Ageing Women and Schizophrenia, *Psychiatric Rehabilitation Journal*, 26 (3)

Philips, L.J., Francey, S.M., Edwards, J., & McMurray, N. (2009). Strategies used by psychotic individuals to cope with life stress and symptoms of illness: a systematic review, *Anxiety, Stress & Coping*, 22:4, 371-410, DOI: 10.1080/10615800902811065

Polanco-Roman, L., Danies, A., & Anglin, D. (2016). Racial discrimination as race-based trauma, coping strategies, and dissociative symptoms among emerging adults. *Psychological Trauma: Theory, Research, Practice, And Policy, 8*(5), 609-617. doi: 10.1037/tra0000125

Quin, R., Clare, L., Ryan, P., & Jackson, M. (2009). ‘Not of this world’: The subjective experience of late-onset psychosis. *Aging & Mental Health*, 13(6), pp.779-787.

Ridgway, P. (2001). Restoring psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24, 335–343.

Roe, D., & Chopra, M. (2003). Beyond Coping with Mental Illness: Towards Personal Growth. *American Journal of Orthopsychiatry,* 73 (3), 334-344

Roscoe, L. J. (2009). Wellness: A review of theory and measurement for counselors. Journal of Counseling and Development, 87(2), 216-226.

Ryan, R. M., & Deci, E. L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. Annual Review of Psychology, 52(1), 141-166.

Shepherd, S., Depp, C., Harris, G., Halpain, M., Palinkas, L., & Jeste, D. (2010). Perspectives on Schizophrenia Over the Lifespan: A Qualitative Study. *Schizophrenia Bulletin*, 38(2), pp.295-303.

Solano, N., & Whitbourne, S. (2001). Coping with Schizophrenia: Patterns in Later Adulthood. *The International Journal of Aging and Human Development*, 53(1), pp.1-10.

Stevenson, J., Brodaty, H., Boyce, P., & Blyth, K. (2012). Does Age Moderate the Effect of Personality Disorder on Coping Style in Psychiatric Inpatients? Journal of Psychiatric Practice, 18 (3), 187-198

Tait, L., Birchwood, M., & Trower, P. (2004). Adapting to the challenge of psychosis: personal resilience and the use of sealing-over (avoidant) resilience and the use of sealing-over (avoidant) coping strategies. *British Journal of Psychiatry,* 18 (5), 410-415

Tedeschi, R. G., & Calhoun, L. G. (1995). Trauma and transformation: Growing in the aftermath of suffering. Thousand Oaks, CA: Sage

Torgalsboen A.K., & Rund B.R. (2002). Lessons learned from three studies of recovery from schizophrenia. *Int Rev Psychiatry*; 14: 312–317

Tufanaru C, Munn Z, Aromataris E, Campbell J, Hopp L. Chapter 3: Systematic reviews of effectiveness. In: Aromataris E, Munn Z (Editors). Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/

Van Den Bosh, R.J., Van Asma, M.J.O., Rombouts, R., & Louwerens, J.W. (1992). Coping Style and Cognitive Dysfunction in Schizophrenic Patient. *British Journal of Psychiatry,* 161 (18), 123-128

Vreeland, A., Bettis, A., Reising, M., Dunbar, J., Watson, K., Gruhn, M., & Compas, B. (2019). Coping and Stress Reactivity as Moderators of Maternal Depressive Symptoms and Youth’s Internalizing and Externalizing Symptoms. *Journal Of Youth And Adolescence*, *48*(8), 1580-1591. doi: 10.1007/s10964-019-01033-y

Wesner, A. C., Gomes, J. B., Detzel, T., Guimarães, L. S., & Heldt, E. (2015). Booster sessions after cognitive-behavioural group therapy for panic disorder: Impact on resilience, coping, and quality of life. Behavioural and Cognitive Psychotherapy, 43(5), 513–525. https://doi. org/10.1017/S1352465814000289.

Wesner, A.C., Behenck, A., Finkler, D., Beria, P., Guimaraes, L.S.P., Manfro, G.G., Blaya, C., & Heldt, E. (2019). Resilience and coping strategies in cognitive behavioural group therapy for patients with panic disorder. *Archives of Psychiatric Nursing*, 33, 428- 433.

WHOQOL Group. (1998). The World Health Organization Quality of Life Assessment (WHOQOL): Development and general psychometric properties. Social Science & Medicine, 46(12), 1569-1585.

Yanos, P. T., West, M. L., & Smith, S. M. (2010). Coping, productive time use, and negative mood among adults with severe mental illness: A daily diary study. Schizophrenia Research, 124(1–3), 54–59. doi:10.1016/j.schres.2010.08.020.

Zubin, J., & Spring, B. (1977). Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology*, *86*(2), 103–126. https://doi.org/10.1037/0021-843X.86.2.103

Zuckerman, M., & Gagne, M. (2003). The COPE revised: Proposing a 5-factor model of coping strategies. Journal of Research in Personality, 37, 169–204. doi:10.1016/s0092- 6566(02)00563-9

CHAPTER 2: FROM POWERLESS TO EMPOWERED: A GROUNDED THEORY APPROACH TO CHRONIC PSYCHOSIS IN MIDDLE AGED AND OLDER ADULTS

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ABSTRACT

Aim: This empirical research paper aimed to develop and understanding of the experiences of middle-aged and older adults with a long-standing, chronic psychosis. It aimed to assess if an individual's illness beliefs impacted their experience of illness.

Method: The study followed a qualitative design, with semi- structured interviews conducted with six participants aged 55+ with chronic psychosis. Interviews were analysed using a Grounded Theory approach to develop a preliminary theoretical understanding of participant's experiences.

Results: The preliminary emerged model identified one core category which encapsulated all participant's experiences of their mental health: "From Powerless to Empowered". Additionally, the model identified two major categories that influenced the participants and how they made sense of their experiences: "Stigma" and "Family/Community".

Conclusion: The preliminary emerged model of the current study is consistent with the Power Threat Meaning (PTM) framework identified in younger adults with psychosis. Additionally, the preliminary model supports the Self-Regulation Model (SRM) of illness beliefs, in that illness identity, causes, consequences and level of control were influential in how middle-aged and older adults experienced their illness, and the impact this had on them. An awareness of the impact of historical influences and the operation of power at an institutional level were highlighted as key in the development of services, with active work to address stigmatisation required. Clinical interventions such as third wave Acceptance and Commitment Therapy and Compassion Focused Therapy could be beneficial in addition to traditional models of Cognitive Behavioural Therapy.

Key Words: Psychosis; Chronic Mental Health; Older Adult; Stigma; Illness Beliefs; Power

INTRODUCTION

Psychosis: Prevalence and need

Psychosis is a severe mental health condition which is now considered to be characterised by the presence of positive (e.g. voice hearing, delusional thoughts and persecutory beliefs) and negative (e.g. blunted affect and social withdrawal) symptoms, which significantly impairs an individual's ability to reality test (World Health Organisation, 2020). Psychosis can have a serious impact on an individual's wellbeing. Developing a greater understanding of psychosis has been an area of increasing interest in the academic literature, particularly around first episode psychosis and early intervention (e.g. Birchwood, Todd & Jackson, 1998). However comparatively, the experience of older adults who have lived with chronic psychosis (often primarily diagnosed in this population as schizophrenia) throughout their life has received considerably less focus in the literature.

Psychosis in old age has been viewed predominantly through a medical model utilising the diagnosis of Schizophrenia, with influences such as the stress vulnerability model (Zubin & Spring, 1977) and dopamine theory (Seeman, 1987) the prevalent understanding. Less evidence on the psychological understandings have been considered, despite ongoing debates in the literature regarding the validity of this diagnosis as a construct. Disagreement in key diagnostic manuals such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Disorders (ICD) regarding the criteria required for diagnosis of Schizophrenia, as well as a lack of evidence for consistent and reliable biological factors that contribute to and predict Schizophrenia as one valid concept have led to a move within literature and clinical practice to view Schizophrenia within a spectrum of psychosis (Jablensky, 2010), due to shared characteristics with other clinical presentations. This ongoing debate is important to consider given the historical and medically driven context within which older adults with a chronic illness would have received their diagnosis, and the implications of services understanding of this diagnosis at the time. The term “psychosis” is used throughout this study to reflect a broader understanding of the experiences of the individuals with this chronic illness.

Older adults with longstanding psychosis are likely to have received their diagnosis at a time where mental health difficulties were less understood and explored (i.e. 1970s/1980’s). The social-cultural context may have led to self-stigmatising beliefs and attributions of illness, perhaps further compounded through older adult cohort effects, and the differences in views of mental health at this time (Knight and Poon, 2008). Therefore, understanding the development of the individual’s cognitive representation of their illness is required in order to understand the meanings attributed and the resulting impact on recovery.

Individuals who experience psychosis in early adulthood can likely still be dealing with the symptoms and psychosocial impact in their later life (Parker, French, Kilcommons & Shiers, 2007). In the UK, it has been reported that the cost of caring for individuals with schizophrenia can be almost 2.8% of total NHS budget (GGI, 2020). Therefore, the impact of psychosis on the individual, their support systems, and the NHS suggests that this is an important area for developing our understanding.

Through provision of better health care, people are living increasingly longer lives, resulting in a progressively ageing population (BMA, 2016), including individuals diagnosed with psychosis in earlier life. Evidence suggests that individuals with psychosis can have a life span of almost 20 years less than individuals without, and the mortality rate can be two-three times higher in this population (Cohen, Meesters & Zhao, 2015; Saha et al, 2007; Tiihonen et al, 2009; Hendry et al, 2014). This is thought to be due to a number of biopsychosocial factors, e.g. increased risk of cardiovascular and respiratory issues, poorer health care, substance misuse and medication use (Jeste & Maglione, 2013; GGI, 2020).

In terms of policy contributions, the latest Mental Health Strategy (2017-2027) (Scottish Government, 2017) focuses on the provision of intervention for first episode psychosis and early intervention. Whilst encouraging that psychosis is a focus for government development, there is no mention of support and intervention for older adults with a chronic illness, and the availability or support of care for this group.

Most published literature focusing on older adults tends to consider the development and management of late onset psychosis (LoP), where first episode of psychosis occurs after the age of 45 (e.g Giblin et al, 2004; McCulloch et al, 2006), and lower life expectancy of individuals with chronic psychosis. The Oxford Handbook for Gentropsychology dedicates it’s chapter of “Psychosis in Older Adults” to the development of psychosis in later life, with a focus on psychosis in dementia and other LoP phenomenon (Ceglowski et al, 2014). LoP can have a significantly different origins to chronic psychosis, including the physical health co-morbidities discussed above, as well as evidence suggesting that social isolation, sensory deficits, polypharmacy and changes in cognition are predictors of LoP (Ceglowski et al, 2014). Existing literature regarding the experiences of chronic psychosis is limited in the academic field. However, of those who have explored this neglected issue (e.g. Araten-Bergman et al, 2015; Jeste et al, 2011; Shepard et al, 2010), there has been little focus on the exploration and maintenance of illness.

Berry and Barrowclough's (2009) review of the literature suggested that the needs of older adults with Schizophrenia are different to those of younger adults, for example in areas such as social support, cognitive functioning and experiences of symptoms. Providing participant's a way to express their thoughts, opinions and experiences of illness through qualitative methods allows for a richer understanding of often neglected topics, and develop a means of understanding phenomenon, meaning and processes in the context they occur (Godfrey, 2015). It is important to continue to develop our understanding of long-standing psychosis in an ageing population to ensure the development of appropriate evidence-based interventions.

Recovery and improvement in psychosis

Research has shown that individuals can make positive and meaningful improvements throughout the course of their illness (Ridgway, 2001; Roe and Chopra, 2003; Shepard et al, 2010) and reduce distress associated with symptoms. Eleven percent of the population will report to hearing voices in their lifetime, with two out of three individuals not being troubled or distressed by this (DCP, 2014). It therefore remains an important endeavour to understand the mechanisms through which individuals manage or interpret such experiences in order to reduce distress and ensure support to implement such strategies. Individuals may experience positive relationships with their symptoms and attribute coping to the positive meaning the individual derives from their diagnosis (e.g. Klapheck et al, 2012). This raises the issues of resilience in individuals who have longstanding illnesses, and how they have developed a self-identity that encompasses illness in a positive view. Exploring how these experiences may differ from those with negative self-identity in relation to illness could allow for development of interventions targeting distress maintenance.

Illness beliefs

The role of illness beliefs in health care have been well researched over the years, with a social cognition model proposed to understand these beliefs (Connor and Norman, 1995). How an individual makes sense of their illness, and the impact on how they cope with this, can be influential in determining outcomes. Leventhal's Self-regulation Model (SRM) (Leventhal, Naerenz and Steele, 1984) is one of the most widely used models in understanding illness beliefs, and proposes five key dimensions in the attribution of illness:

- perceived identity of the illness
- perceived consequences
- likely causes
- likely timeline (or sense of how long it will last)
- potential for control or cure of the illness (added latterly by Lau and Hartman, 1983)

A cognitive representation of illness is then developed through the evaluation of one's ability of coping with it (Leventhal et al, 1984). Weinman, Petrie, Moss-Morris & Horne, 1996 (and latterly Moss-Morris et al, 2002) developed a questionnaire based on these dimensions for assessing attributions of illness in physical health conditions called the Illness Perception Questionnaire. Lobban & Barrowclough (2005) suggested that this questionnaire, with some adaptations to language within the descriptions, and the dimensions associated with illness belief could be applied to how we understand illnesses such as schizophrenia. The same dimensions proposed in Leventhal's SRM were found to be present in individual's understandings of schizophrenia, suggesting they are represented in both physical and mental health conditions. However, this study was based on participants who had received a schizophrenia diagnosis within the last five years (n=19) and could not provide evidence on the experiences of individuals with a longstanding illness. Additionally, it did not include the views and experiences of older adults.

Theodore et al, (2012) assessed the effects of Illness beliefs on Quality of Life (QoL) outcomes in individual's with psychosis (n=81). Illness beliefs such as treatment control and consequences were found to have a significant association with QoL outcomes. This suggests that an individual's beliefs about their illness can impact how they experience their world, but the study did not explore how such beliefs came to be held and the subsequent impact on the individual's sense of self.

Power threat meaning framework

The British Psychological Society's Division of Clinical Psychology (DCP) recently proposed the Power Threat Meaning framework (Johnston & Boyle, 2018) aiming to re-address the way distressing experiences (such as those experienced during psychosis) are formulated. This framework may be beneficial in providing a way of understanding the experiences of people with psychosis over and above a historically medically driven, diagnostic-based perspective, taking into consideration the social, political and cultural environment within which events were experienced. Additionally, the PTM framework can encompass the role of trauma in the development of psychosis, with adverse childhood events a risk factor for developing a psychotic illness widely reported in the literature (e.g. Harder, 2014; LoPilato et al, 2019; MacBeth et al, 2011; Styla, Stolarski & Szymanowska, 2019; Varese et al, 2012; Wigman et al, 2012).

In utilizing this framework, we can begin to understand potential contributions to illness, and interpersonal and social implications of working with individuals experiencing psychosis.

Table 7: Power Threat Meaning (PTM) framework core concepts (Johnston &Boyle, 2018)

Concept	**Description**
Power	The operation of power within the individuals work, be that coercive, political, economic or social
Threat	What emotional distress or threat does this operation of power create for the individual, their social structures and communities? How is this threat mediated biologically?
Meaning	The meaning of this operation of power and subsequent threat, and how we understand and evaluate these experiences socially, culturally and primitively. How does this meaning shape the expression of power and threat and our response to this?
Threat response	Our reaction to the cultivation of the above factors. Can be utilised by an individual, family, community and so on in order to maintain emotional safety and survival. Can be automatic or consciously learned responses.

However, once again this document is largely focused on young adults and adults of working age, making brief reference to older adults as a demographic variable as opposed to identifying these factors in those with a chronic illness who have aged. This population may endorse a number of stigmatising factors (such as negative societal view of older people alongside a severe and enduring mental illness) and have experienced severe mental illness at a time of little acceptance. This framework may be beneficial in our understanding of their experiences, yet generational influences and cohort effects remain largely unaddressed.

Stigma

Research has shown that one the greatest challenges of recovery from psychosis is overcoming prejudice, discrimination and the expectations of other (BPS, 2014). The role of stigma and shame within mental health has been widely acknowledged to negatively impact on a range of psychosocial outcomes (e.g. Corrigon and Watson, 2006; Livingston & Boyd, 2010; Thornicroft et al., 2009; Vass et al., 2015; Wang et al, 2018). Meanings are derived from prior experiences and social interactions (including social groups, Tajfel, 1978) which may include biases and "hidden forces" (Roe & Middleton, 2010) and include societal views of mental health problems. It is important therefore to consider the impact of stigma on the development of self-identity in people with severe and enduring mental health conditions.

Pyle & Morrison (2014) conducted a qualitative study on individual's experiences of stigma in relation to a diagnosis of psychosis. Disclosure of illness to family and friends and the influence of negative, misrepresented media portrayals of people with psychosis were the main contributing factors to perceived stigmatisation. Again, this study failed to take into account the experiences of older adults, with the sample (N=9) ranging from 19-54 years, with adults aged 65+ excluded. A study on the attitude of community dwelling older adults towards individuals with mental health problems (Webb, Jacobs-Lawson & Waddell, 2009) found individuals with a diagnosis of schizophrenia were viewed as the most dangerous in the sample. This finding highlights the negative impact of our cultural representation of people with schizophrenia and alludes to the negative consequences of these attitudes on the individual.

Study Aims

Previous research brings light to the need for consideration of the experiences of middle-aged and older adults with psychosis. Most previous research were based on quantitative studies only, with no qualitative representation of the voices of participants and their experiences. Hence, this study aims to understand the experiences of middle-aged and older adults with a long-standing, chronic psychosis in terms of their illness beliefs and how these impacted their experiences of illness.

METHODS

Design

Given that a theoretical framework is needed to inform the development of complex interventions for middle-aged and older adults with chronic psychosis, the Medical Research Council Framework was applied (Möhler et al, 2015). A qualitative method with semi-structured interviews was conducted and data was analysed applying Grounded Theory (GT) approach to generate a theoretical understanding of participant experiences. GT is an inductive approach to research, generating theory through the data collected (Corbin & Strauss, 2008). This is achieved through the process of simultaneous data collection and analysis, where the development of subsequent interviews allows a constant comparison of the data collected. This systematic circularity allows the researcher to test out and develop emerging categories, integrating these into the resulting theory (Flick, 2018).

Ethical approval

Ethical approval was granted through the South East Scotland Research ethics committee 02 (reference number 19/SS/0046) and local NHS health board R&D department (reference 2019/0171). See appendix 4. All participants willing to take part in the study provided verbal and written consent (see appendix 5).

Sampling and recruitment

In line with GT methodology, purposeful sampling was conducted. The study followed two primary recruitment streams. **The first** involved recruitment from the Older Adults Community Mental Health Teams (CMHT), which comprised of seven local area teams, and a specialised psychosis service CMHT. The lead researcher attended team meetings for all localities. Participant Information Sheets (PIS) (see appendix 6) were left with the team for distribution to potential participants. In line with study protocol (see appendix 7), participants were initially identified by their key worker within the CMHT as eligible to take part. The key worker was the first to approach participants to introduce the study, providing the PIS.

The second stream of recruitment was through the Patient Council of the main psychiatric hospital within the health board the study took place. The lead researcher attended the weekly meeting of the council to introduce the study, answer study questions, and distribute the PIS to any potential participants. Members of the council self-identified as eligible to take part in the study, providing contact details through the co-ordinator of the council, who passed these to the researcher.

Eligibility criteria

Inclusion criteria were as follows:

1) participants had to be aged 55 and over; 2) have a diagnosis of a psychotic disorder (as diagnosed by an appropriate clinician using DSM or ICD criteria); 3) have had this diagnosis for 20 years or longer; 4) be fluent in the English language; 5) able to participate in a verbal interview; and 6) no active suicidality risk.

Exclusion criteria was:

1) A diagnosis of late on-set psychosis (first episode after the age of 60); 2) an established diagnosis of Dementia; 3) any active suicidality risk.

Capacity

Capacity to consent to the research was assessed initially by the key worker/care co-ordinator who had identified the participant as eligible for the research. However, as the researcher took written informed consent on the date of interview, the principles of capacity were reflected and reviewed by the researcher prior to commencing the interview. While the researcher did not conduct a formal assessment of participants' capacity to consent to research, they remained mindful of the principles of the Adults with Incapacity (Scotland) Act 2000 throughout the duration of the study (required as the ability to make decisions, communicate decisions, understand decisions, act on decision and retain the memory of decisions) and would halt the interview process if concerned about any participants ability during the interview process. Those identified through the patient council who were no longer under the direct care of the community mental team would be reviewed by the researcher in line with Adult's with Incapacity (Scotland) Act 2000 as above.

Sample Demographics

Demographic Questionnaire

Participants were provided a demographic information sheet (see appendix 8) to gather information including age, education, ethnicity, diagnosis, living arrangement, prescribed medication and previous treatment interventions.

Data analysis

In line with GT methodology, data collection and analysis occurred simultaneously (Corbin & Strauss, 2008). This allowed for the researcher to develop and shape the following interviews to expand on relevant topic areas, question and compare the responses and to inform further theoretical sampling.

Semi-structured interviews were conducted with participants (see appendix 9 for sample interview schedule). Interviews were audio recorded and transcribed verbatim. Validation and consensus of emerging categories was completed between members of the research team throughout analysis.

Coding was initially completed line by line, whereby the researcher developed an initial understanding of the data at a micro level (see appendix extract of coding). Following line by line coding, focused coding developed ideas paragraph by paragraph, with initial codes within each interview grouped together based on their similarities, and attention drawn to differences or divergence from previous items. A continued focus on these similarities and discrepancies allowed the researcher to identify codes requiring further validations and discussion, subsequently shaping the interview schedule for the next interview. Examples of changes to the schedule included focused questioning on the use of antipsychotics, explicit discussion regarding the influence of ageing, the experience of autonomy and choice, the influence of others in the social network and the participants take on “recovery”.

In-vivo coding was used to ensure the categories were developed from participants’ own words, and not driven by the preconceived notions of the lead researcher. Constant comparison between the interview ideas were made, generating a higher-level coding of similarities and differences between the emerging codes within the data. Theoretical coding was the final step of analysis, whereby lesser categories were subsumed into greater explanatory categories, with the relationships between the emerging categories developed.

Memos

Memos were used during the study as a means of assisting the researcher to monitor their own reflections and ideas about the data. A reflective journal was kept to ensure this process was identified and reflexivity maintained from the interview scenario e.g. emotion expressed during interview; participant reactions to initiation of comparative/theoretical questioning; spontaneous admissions of experience that had perhaps influenced the researcher.

Birk and Mill (2011) refer to how reflexive memos can assist the researcher in maintaining a stance congruent with the principles of GT. By allowing opportunity to consider the impact of self as researcher in relation to the research area, the researcher was better placed to consider the context of themselves in relation to participants, and the influence of reciprocal shaping. This centred on the researcher being a trainee clinical psychologist, relatively new to the field of psychosis, and the participant an older adult with extensive, personal experience of a psychosis. Memos kept by the researcher reference allowing for the rich experience that participants brought to the interview, with the researcher approaching from the stance of novice yet interested receiver of information. The memos and journal additionally made reference to monitoring of the need to command an interview situation (for the purpose of time management and reducing participant burden), whilst allowing the participants to feel heard and not once again directed by a “professional” in what and how they share their story. This balance was important to consider for the purposes of maintaining sensitivity to context during the study process.

Reflexive statement

The researcher did not have prior experience of working with people with psychosis over and above a small number of cases encountered during clinical training. However, the area has been of interest to the researcher prior to and throughout training, particularly given the researchers alignment to an older adult population and the impact of ageing on severe mental illness.

Triangulation

In order to ensure rigour and reliability of coding structures, a member of the research team with expertise in GT undertook coding of initial interviews separately prior to discussion with lead researcher to reach coding consensus. Additionally, the researcher and second member of the researcher team would routinely discuss the developing categories and structure in supervision to ensure commitment to the data. The use of supervision ensured the researcher took an analytical stance throughout each stage of analysis, and interpretation was driven through the data “grounded” in interviews only. **Subsequent triangulation** of the emerged model took place with five available participants, who were contacted by the researcher to discuss and confirm the emerged model as true to their experiences. Participant triangulation was conducted over the telephone due to COVID-19 restrictions on face-to-face meetings. All available participants agreed the model was an accurate depiction of their experiences, and discussions were centred around the bidirectional links and relationships between the emerging categories and the complexity of their experiences that this highlighted.

Due to the limited sample size, a preliminary theoretical model was developed. The model was gaining a level of theoretical saturation (the point in which no new or novel insights are produced by the data) through which similar and concurrent accounts of experiences were being discussed by interview six. However, there were slight divergences in interview 6, for example changes in managing symptoms of illness as more experience oriented than ageing, which require further validation. Due to the restrictions put in place due to the COVID-19 pandemic (see section on recruitment for further details), no further participants could be recruited to the current study for clarification. Hence the resultant theory if preliminary in nature.

Quality criteria

Ensuring adherence to, and reflection upon, quality principles throughout the research process is important for maintaining quality and rigour during qualitative research. Yardley (2000) proposes four characteristics of qualitative research that embodies good quality research: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance (see table 7). The lead researcher utilised these guiding principles throughout the analysis in combination with Corbin & Strauss methodology.

Table 8: Addressing quality criteria

Quality principle	**Addressing of key criteria**
Sensitivity to context	Introductory chapter lays out the current theoretical field, and the placement of the current study within this. Additionally, the social and cultural environment within which the study is taking place, and the relationship between the researcher and the participant (and subsequent reciprocal shaping that occurs) is reflected upon.
Commitment to the data and research	Prolonged engagement of the researcher with the data through continuous and at length re-evaluation of the materials; development of methodological skill through individual grounded theory tutorials. Rigour achieved through triangulation of the emerging categories and exploration of written transcripts from one participant, which served to strengthen the emerging categories. Transcripts and coding retained for proof of process should this be required.
Transparency	Participant quotations are used throughout the presentation of the results to evidence relevant coding of the emerged model was developed. The use of a reflective journal to ensure reflexivity of personal aspects of the process and potential influence of issues outwith the researchers control (e.g. difficulty with engaging recruitment). Cohesion with literature demonstrated through the discussion of the emerging categories in line with existing literature and framework for understanding psychosis, and how the current

	study can help expand our understanding of these frameworks.
Impact and importance of research	Links to the relative dearth of research on chronic psychosis in older adults. Increasing understanding of participants experiences leading to clinical implications for formulation and intervention within the field. Interest from clinicians in the teams where the research was conducted shows promising signs of clinical utility of the findings in practice.

RESULTS

Participants

A total of **six** participants consented to take part in the study (n= 3 female/ 3 male). A total of eleven interviews were conducted, including triangulation. Participants' average age was 68.7 years (range 59- 89) with the average length of illness 33.3 years (range 20 years- 58 years). Interviews averaged a length of 78 minutes (range 48- 105 minutes).

Table 9: Participant characteristics

Participant*	Age	Diagnosis	Chronicity of illness (years)	Marital Status	Member of patient council
Margaret	89	Schizophrenia	58	Divorced	No
John	62	Schizophrenia	37	Single	Yes
Joyce	63	Schizophrenia	24	Divorced	No
Tommy	59	Schizophrenia	41	Divorced	Yes
Carol	71	Bipolar Disorder with psychotic features	21	Divorced	Yes
Edward	68	Paranoid Schizophrenic	20	Married	No

*Pseudo-names provided to protect anonymity

Implications of recruitment in the context of COVID-19

During the course of this study, restrictions on recruitment were put in place due to the COVID-19 pandemic to maintain social and physical distance measures required to reduce the spread (ACCORD, 2020). In line with health and safety measures, recruitment to any research studies not directly linked to COVID-19 was halted. Recruitment was therefore halted following the completion of six participant interviews. Alternative arrangement for resumption of recruitment, whenever this may have been permitted, was also considered. Due to the population the study is involving, the lead researcher and wider members of the research team, felt that alternative methods of data collections (e.g. telephone interviews) would not be clinically appropriate at this time.

Preliminary Emerged Theoretical Model

The results of this study propose a model of experiencing a chronic psychotic illness from the view-point of older adults (figure 2). The results will be presented by introduction to the core category followed by major categories, with citations from participants to illustrate these. See appendix 11 for further quotations to support and illustrate the emerging categories. See Figure 2 to illustrate the emerged model.

1. Core category: 'From Powerless to Empowered'

The overall core category which emerged from the data was "From Powerless to Empowered" and encapsulated the experience of all participants in their journey through their illness. This category explained the experience of participants from the point of their first episode of psychosis. It encompasses their experiences of what their illness meant for them at the time of their diagnosis, how they managed their experiences and their interactions with mental health services. This was considered in terms of how this changed their view of themselves throughout their lives. Processes that appeared to underpin this core category included control, choice and communication (Powerless), and knowledge, active participation and the move to self-expert through the process of ageing and experience (Empowered).

> "*The whole problem is, you are not in a position of power [when entering mental health services]. You've not got the power." (Carol)*
>
> *"Like, you're being treated like you're a lab rat, you know, testing out all the like" (Joyce)*
>
> *"I've grown to see that I can have a say. Whereas initially I didn't…I'm more empowered now"(Edward)*

Experiences of feeling powerless over a number of factors regarding their mental health was a core category central to all participants, manifested in a number of ways. Most prominently was through the concept of control, with lack of control in the early days of illness leading participants to feel helpless in their own wellbeing.

> *"I felt overwhelmed with them* **telling me** *what was good for me" (Edward)*
> *"I did as I was told" (John)*

Lack of clarity, communication and information sharing meant participants struggled to make sense of what was happening for them, becoming almost passive bystanders in their own lives. Participants felt kept in the dark and misinformed, lacking information required to make choices or contribute to their wellbeing. Participants described often feeling dismissed by professionals, with a sense that professionals would not engage in transparent or collaborative communication, instead providing instructions to the participants. Lack of control, both over actions through illness and through lack of choice and autonomy in treatment, increased participants experiences of not feeling "safe" in their mental health, compounding feelings of powerlessness.

> *"It's just the way that it is, and you just have to accept that. Communication is just one way." (Edward)*
>
> *"There's no real communication. Because it is always top down" (Tommy)*

Clarity of information received by participants, including receiving their diagnosis and the impact this had on their ability to make sense of and process this information was found by all participants to be lacking, leading to confusion and compounding a feeling of helplessness. Five of the six participants reported to have been given a differential diagnosis when first experiencing their psychotic illness, and how it had taken some years to be given an accurate diagnosis.

Confusion led to increased uncertainty and strengthened further the participant's feeling that there was something intrinsically wrong with them that professionals could not identify what they were experiencing. This lack of clarity perhaps reflects the complex nature of the presentation of a psychotic illness, particularly considering the time of diagnosis for participants, in which both general and professional understanding was perhaps more limited. The experience of division and disconnect between participants and others (primarily medical professionals) strengthened the feeling of powerlessness in participants. The description of diagnosis for one participant where they felt professionals had "*branded me with schizophrenia*" (Tommy) highlighted how messages were communicated and interpreted. Reports of experiences of being "*caught*" in services suggests a feeling of powerlessness against this, unable to escape or move on from their experiences.

However, it is evident from the data gathered that as time goes on, the factors above that are integral in producing a sense of powerlessness reduced in intensity and frequency for people with chronic psychosis. Through the ageing process, the shift into empowerment emerges.

This developed through what appears in part to resemble behavioural learning. All participants shared the experience of understanding their illness and becoming more adept at responding to triggers, as well as having a repertoire of responses for scenarios, symptoms and the wider world that were more positive, proactive and helpful.

> *"But you try, and you try and you learn from it. You learn from it. That's what I'm saying about, as you get older, about getting older". (John)*

Ways of coping were developed and refined through ageing, and participants could use experience to test and inform both helpful and unhelpful coping strategies. The idea of gaining control over recognising and avoiding triggers leads to increased feeling of safety and security (a lack of which is a main contribution towards powerlessness). Keeping the mind busy and engaged helped all participants to manage some of their symptoms, often through reading and educating themselves. Two thirds of the participants took initiative to educate themselves to some extent on mental health, gaining knowledge and understanding of their condition in order to increase their sense of ownership and control.

> *"Because I found that that helps. Thinking, you know, "gosh if I can't make sense of eh… something you know, can I… (pause)… read something, or learn something. You know. I do strange things like to read New Scientist" (Joyce)*
>
> *"I did psychology for 2 years. I'm very interested in that area, and very motivated to read up about it"… "and I started reading of course about theories of schizophrenia" (Margaret)*

One participant took the opportunity to write down their experiences in the form of memoirs and engage in discussions at medical conferences. These acts of shifting role from passive bystander to active participant in their own journeys, shifting from "patient to expert", increased participant's empowerment through levelling out the power dynamic they had repeatedly come to experience.

From this experience, there grows evidence for the increasing and continuing importance of "experts by experience". This was something endorse by all participants, in that as ageing and experience increase, the individual themself becomes more likely to manage their illness appropriately rather than relying on others.

A number of the participants were members of a patient council at the main psychiatric hospital within which the study took place. Utilising this "experts by experience" stance allowed active seeking of opportunities to have a voice and advocate for patient rights. This fulfilled a role of counteracting the impacts of their experience of powerlessness, creating a more positive and powerful sense of self, contributing to both their own journeys and the journeys of others. Experiences reflected a feeling that role and responsibility of advocate bolstered their sense of self as being able to make decisions and choices to empower themselves and others, something which had been perceived as being taken away during their earlier experiences of illness.

> *"But things that I found… it's empowering again, things that I found with myself, and generally speaking, the voluntary work, I've made the right decisions and eh… its been good for me."* (John)

One participant who had received psychological therapy for their psychosis owed the learning gained through this as key to their recovery, and how a combination of experience of repeated patterns of illness, ageing and therapy had resulted in a feeling of empowerment and ownership over how they responded to others as well as how they responded to their symptoms.

However, one participant did not feel as though their shift from powerless to empowered was influenced by age, given that they had been relatively older than the other participants when first diagnosed (in their 40’s). They felt this shift was more attributable to increased exposure and experience in managing symptoms and illness, again supporting the notion of learning and experience as central to the shift in power.

In all participants, the idea of “recovery”, whilst attainable through the shift to empowerment, remained somewhat transient and fragile. Each participant made reference to taking it one day at a time, and the need to understand and monitor their illness day by day in order to prevent relapse.

> *I think it’s [recovery] an ongoing, day by day, step by step erm… ongoing process. Where eh… you have to… really be quite…inward looking. And think about yourself. And stop… thinking about other people.”* (Carol)

In addition to the core category above, two major categories were identified in the data: “**Stigma” and “Family/Community”**. The model discusses the core role of power and subsequent influence of the individual’s social network in both helping and hindering the shift into empowerment described above. The category of stigma describes how experience of this shaped individual’s likelihood to seek treatment and support, impacting the individual’s beliefs about themselves in relation to their mental health. The relationship between the categories appears to be intertwined and bi-directional, highlighting the complexity of experiences of older adults with chronic psychosis.

2. Major category: Stigma

Stigma was key experience of participants, shaping the way a number of participants thought about themselves in relation to their illness. Three participants attempted to address the impact of stigma through active work with psychology services, whilst all attempted to use common experiences of others as a way of negating the effect of stigma and normalising their experiences.

Differing dimensions of stigma were highlighted, with stigma experienced on the levels of other to self, from self to others and self to self (internalised). Stigma from others to the self was evident in participants' experiences of being viewed as a "psychotic" individual, and the meaning this held for participants. Stereotypical notions of psychosis as portrayed in the media and lack of understanding held by others led to the participants feeling segregated and rejected due to their mental health. This contributed to heightened experiences of isolation in their illness during the early stages of their journey.

> *"People think in terms of exclusion. They reject you because you are different" (Tommy)*
>
> *"It was quite isolating because of course at that time it was quite ill speaking [to have a mental health problem]" (Margaret)*

Stigma from self to others was also experienced by participants, with these societal views of psychosis so strongly held that even participants themselves could not openly identify with being “psychotic” or “schizophrenic”. Through not ‘aligning’ themselves to the idea of being someone with a mental illness, half of the participants rejected additional support in the form of day centres and social groups due to the “shame” associated in accepting they had common experiences.

> *“I mean even, I have to admit it… I myself, was probably stigmatising. I didn’t want to go to the day centres where the dirty old men might be. You know what I mean? Stigma. Erm… but, you know, the down and outs, and that kind of stuff. Erm… but… yeah, I think it does … stigma is… has… had a lot to answer for”* (Carol)

The socio-cultural context of mental health played a vital role in the pervasive experience of stigma within the participants. The influence of cohort beliefs regarding severe mental health conditions around the time the older adults within this sample were diagnosed appeared to have influenced not only other peoples’ interpretations of their diagnosis, but also participants interpretations and meanings of how they saw themselves (internalised stigma). Through self-stigmatisation came the experiences of guilt and shame, which contributed to the idea that participants had done something to be “deserving” of the negative associations they made with their mental health.

> *“That’s a… that was… that’s a theme of mine for a long time, shame. Shame as an adolescent, and then ehh… shame about the mental health difficulties, shame everything that came about… that was a big obstacle to me, and a difficult thing” (John)*

> *"what have I done to deserve this [stigmatising diagnosis]?"* (Joyce)
>
> *"you're going back to the 80's when this happened. We've come a long way, as far as the eh… stigma"… "I can't even describe it. You feel worthless"* (Carol)

Given the continued reinforcement of negative attitudes regarding their mental health, the participant's experienced remaining in a cycle of feeling powerless and rejected, stigmatised and 'different'.

3. Major Category: Family and Community

Searching for a meaning and a cause for illness was a process endorsed by all participants interviewed in this study, with all spontaneously offering their analysis of what had allowed their illness to develop. Participants identified feeling more contained in managing the course of their illness through developing this understanding of the cause. This sense making highlighted the role of family and community, with an interesting dichotomy generated in terms of both the precipitating and protective factors that it produces.

Family structures and the influence of family upbringing was something almost all participants attributed to their understanding of the development of their psychosis. Familial mental health was a common experience, however this had varying degrees of impact on the participants proposed understanding. Where other members of the participants family themselves had schizophrenia, the cause was primarily understood as biological, and appeared to hold less connotations of blame. Where the participant's family had provided abusive environments, the cause was overwhelming stress and resonated more with the actions of others as a contributory factor. Experiences of trauma and abuse felt inevitable in the development of the participants psychosis, with participants suggesting an almost expectant result from a powerless childhood. The lack of openness in discussion around mental health within family structures resulted in all participants feeling pressure and stress and lack of social support contributing to the development and management of their experiences. Ongoing negative interactions with family members, as well as reflections on this process, continued to contribute to a feeling of powerlessness for participants, highlighting the powerful contribution of these relationships to the reinforcement of ‘the self as powerless’.

> *“I’m not quite sure how they [siblings] see me. Like, I almost don’t exist”… “Yeah… it’s quite… no wonder I was sick. You know! (sigh)”… “it hasn’t been an easy one, and it still isn’t. But just… I feel as though I’m the only one that’s been caught, somehow, like into the… sort of psychiatric realm you know? And they [family]* are *all kinda weird. But just ah…” (Joyce)*

> *“There’s obviously a genetic link...but my family were just (pffft)! You know, I’m not the worthless one, they are the worthless ones, you know? And that’s what you have to learn, the hard way”* (Carol)

However, whilst most of the participants experiences of family networks were alluded to as a contributory factor in their illness, the development of social networks and systemic support as a positive in the illness journey also applied. Social connections could be viewed as positives that helped counteract and reduce the impact of the earlier defined categories of stigma and powerlessness. Furthermore, and perhaps on the contrary to the “self-other” stigma category, the notion of a mental health community experienced by participants was important in providing positive support in the journey to empowerment. This was not just within the ‘patient’ population, but within the wider mental health community including professionals. Continued development of a shared understanding and providing a counteract to the stigma of psychosis through shared experiences, allowed the older adults in this sample to develop a more active stance in their journey and reduce feelings of shame and guilt in their understanding of illness.

> *“Yeah, my so… ehhh my social network is eh… a lot of … people who have also had lived experience of mental health issues. Ehh… and… but it’s a healthy thing. We don’t talk about… well we’re doing other things. We’re a community, a mental health community. But you don’t need to talk about the mental health difficulty” (*John)

> *“Patients, the nurses, the doctors, the psychologists, the psychiatrist, the occupational therapists really have to work together. Because we are together, we’re a community” (*Tommy)

The importance of moving from the powerless/powerful dichotomy to one of a genuine shared community was felt to be a process crucial in increasing empowerment and developing sustained recovery.

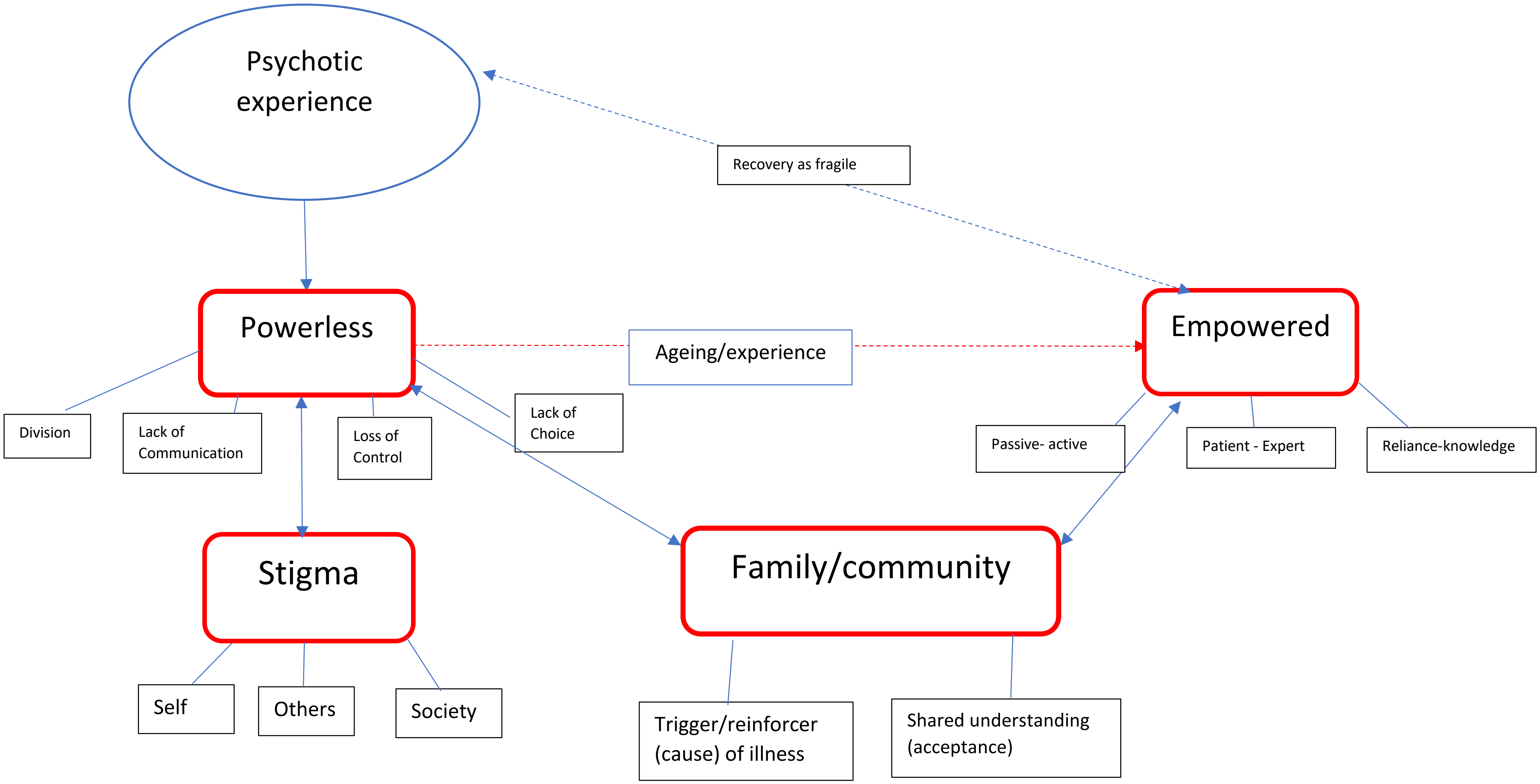

Figure 2: Preliminary theoretical model of psychosis in Older Adults

DISCUSSION

From the data gathered in this study, it appears that for people over the age of 55 with a psychotic illness, the experience of feeling powerless can be generated through interactions with professionals in where communication, choice and connection are lacking. This feeling of powerlessness is compounded through stigma experienced from others, and at times from themselves, with the influence of family and community playing a complex role of either reducing blame or as triggering and reinforcing. Through the process of ageing and repeated experiences, middle-aged and older adults with psychosis have found a shift in their ability to control and influence both their symptoms of illness and their role in their life, over and above that of an individual with a psychotic illness, developing into the role of empowered individual. However, the finding also highlight that a sense of “recovery” is fragile, and a continued sense of day by day management.

The findings of this study fits with both the **Power Threat Meaning Framework (PTM)** (Johnston and Boyd, 2018) and the **Self-Regulation Model** (Leventhal, 1984), with overlap between models represented in the current findings. However, the pervasive and central experience of power found within the emerged model for middle-aged and older adults alludes to stronger identification with the PTM framework in this population, where the operation of power is fundamental in how individuals with psychosis experience and manage their illness. The current preliminary model identified how social structures (such as services) can unintentionally support the operation of power differentials, and the experience of threat to individuals through a feeling of not being taken seriously, a focus on biological factors and poor communication. The current emerged model proposes the manifestation of power at an institutional level, which was a common and pervasive experience for participants of the study. This is especially important for the older adult population, where this operation of power appears ingrained in the historical context of mental health services and the lasting impact this has had. Older adults with mental health conditions can often be differential towards the use of services (Hatfield, 1999), and this can be compounded further when the diagnosis of one of severe mental illness. The discrepancy, confusion and negative impact for participants in the current study of receiving their Schizophrenia/Bipolar diagnosis supports the need for contextualising experiences in a formulation driven approach that underpins the core ethos of PTM framework, highlighting this as applicable to middle-aged and older adults with chronic psychosis. This may allow for a reduction in the focus and conceptualisation of a psychopathology, and provide individuals with a sense of hopefulness, which was lacking for the participants in the current sample.

Meyers & Ziv (2016) discussed the idea of a loss of autobiographical power for people with psychosis through such experiences with services. Participants reclaimed this power through “telling ones own story”, which compliments the findings of the current study in which gaining ownership over experiences improved a sense of empowerment. Furthermore, meaning and distress must be understood at the wider systemic level through the integration of social, community and cultural impacts within an individual’s experience (Johnstone and Boyle, 2018; Salvatore et al, 2012). This systemic understanding is the cornerstone of the PTM framework’s view of psychosis, with the current study supporting this stance as integral in the experiences of a middle-aged and older adult psychosis population.

In line with Corrigan and Watson (2002) the current study identified stigma on distinct levels (societal and internalised), as well as introducing the idea of “self to other” stigma. The current model proposes that middle-aged and older adults with chronic psychosis experience shame and stigma from others. This stigma can be viewed as the threat of social rejection, which once again mirrors the various potential levels of threat response triggered in individuals as described in the PTM framework. This idea of stigma in people with psychosis has been well documented in the literature (e.g. Brohan, Elgie, Sartorius & Thornicroft, 2010; Loch et al, 2013; Thronicroft et al, 2009). Judge, Estroff, O'Perkins & Penn (2008) found individuals would avoid seeking help from professionals due to the stigma they experienced. This was found to be true in the older adults within the current study, through a reduction in attendance and support seeking in day centre supports and social clubs. This barrier to support is a vicious cycle through which individuals do not allow themselves the opportunity to counteract their stigmatised views through relationship building with others who share a common experience. This highlights the severity of the potential impact of threat response experiences in this population.

In their study on the experiences of stigma in people with psychosis, Pyle and Morrison (2009) discuss the idea of a possible exit from stigma encompassing normalisation and peer support. The current study supports this idea, through the identification of "community" and advocacy within the preliminary model. The category of a mental health community as a supportive aspect in the journey to empowerment highlights its role in reducing the felt sense of stigmatisation and powerlessness and increasing the sense of belonging. With the evidence that self-stigmatisation can increase loneliness in individuals with psychosis (Chrostek et al, 2016), and high levels of self-stigma within the population (Kardini et al, 2010), this is an important aspect to consider in the development of future treatment focus, with the role of increasing social belonginess a key consideration. It is within this area of intervention that individuals can begin to challenge the stigmatised and power-focused "meaning" of their mental health diagnosis and shape an understanding that promotes inclusions and recovery.

However, there appears to be two stances identified in the emerging model, with the introduction of the “self to other” stigma. This may be more prominent in an older adult population where cohort and socio-cultural beliefs surrounding severe mental health problems are even more ingrained and where associated threat-responses are more highly sensitised.

The cause of illness in the current study was thought in most cases to be due to the influence of family or trauma in childhood, with the role of trauma in the development of psychosis, and subsequent potential role of attachment, highlighted. A number of participants felt familial mental health played a role in the development of their illness, suggesting they felt more vulnerable to illness given their familial history. As trauma is often experienced in stressful environments, the current findings are in line with the stress vulnerability model of schizophrenia (Zubin & Spring, 1977; Neuchterlein & Dawson, 1984). The influence of family and trauma further supports the operation of power and threat (in this instance threat experienced at a young age) as within the PTM framework as a key force in the experience and maintenance of psychosis.

The emerging model can also be understood by mapping onto the framework for understanding illness beliefs as proposed by Leventhal, Naerenz & Steele’s (1984) self-regulation model (SRM), and influence how individuals perceive themselves in relation to their illness. The most influential aspect is the perceived identity of illness, impacting participants thoughts about themselves and those around them, with the major category of stigma capturing this. The preliminary model builds upon previous work by Lobban and Barrowclough (2005) in which the SRM could be used to understand the experiences of people with schizophrenia through highlighting the role of this model within an older adult population. Various facets of cohort beliefs and historical influences do impact how middle-aged and older adults made sense of their illness identity and consequences in the context of their illness beliefs. Interestingly, both the current study and Lobban and Barrowclough (2005) did not find spontaneous endorsements of individuals in terms of the chronicity/timeline dimension of Leventhal et al's (1984) SRM in people with psychosis. There was a clear "here and now" focus as opposed to consideration of the longevity of illness. The current model did identify the notion that recovery was fragile and an acceptance that there may be relapse (cyclical timeline), however the chronicity was not a focus for the middle-aged and older adults in this study. This is important when considering interventions within this population, and the sufficiency of a "here and now" focus. The lack of emphasis on the timeline of illness within a psychosis population may be due to the repeated experiences of symptoms and illness. Individuals reported learning to manage and recover from periods of illness, perhaps rendering a focus on the longevity of illness unhelpful and not necessary. Consideration of the length of illness may also require a level of insight, which may be unobtainable for some individuals when experiencing symptoms of illness.

The positive impact of ageing found within the current study supports the limited research available regarding ageing and schizophrenia in which symptoms reduce in intensity as the individual grows older (e.g. Shepard et al 2010; Jeste et al, 2011, Folsom et al, 2009). In the present study, the repeated learning experiences of individuals and the process of reflection, hindsight, awareness and adjustment were identified as key in managing illness. This is an interesting finding, given previous research on the influence of negative age stereotypes on ageing (e.g. Levy et al, 2019) and the role of cohort beliefs and stigma regarding mental health in old age (e.g. Angermeyer et al, 2004; Hatfield, 1999). The positive impact of ageing in chronic psychosis provides an opportunity for services to promote coping and instil hope potentially at an earlier stage of illness journey, in order to tackle various aspects of the illness beliefs and PTM framework to encourage empowerment in those with a recurrent illness.

Limitations and strengths of current study

The main limitation of the current study is the small sample. Therefore, the proposed emerging model is preliminary. The researcher took steps to address this issue through triangulation of the data with participants, with the proposed model indicative of the experiences and processes experienced by older adults with chronic psychosis. No new concepts were spontaneously proposed in the final interviews, potentially suggesting a level of theoretical saturation. However additional participants would be required to confirm some divergent ideas proposed from participant six and subcategories for illness beliefs and trauma in old age to confirm the emerged model.

Recruitment to the study was a difficulty prior to the restrictions put in place due to the COVID-19 pandemic due to the difficult to reach population. Key workers of potential participants on numerous occasions made judgements as to the participants lack of willingness to consent, in essence refusing to allow the choice to participate to be made by the participant themselves. Whilst this judgement was at times necessary given questions of capacity and clinical appropriateness to take part in research, there were instances when key workers would refuse this choice as their opinion would be that the participant would not like to take part. This removal of personal choice and autonomy fits within the theoretical model proposed within the study regarding the dynamics of power and control. The researcher believes there to be a distinction between lack of capacity to consent to research, and lack of choice and option to take part in research.

As with many aspects of research, the current theoretical model is hinged upon those who opt to take part in research, and perhaps therefore represents a biased sample. Half of the sample were advocates and members of a patient council, suggesting their innate sense of increasing empowerment and shared vision of a mental health community. However, half of the sample were still being seen regularly within the community mental health teams for ongoing treatment, so provided a balanced view of those recovered and those still seeking treatment.

Strengths acknowledged are that to the authors knowledge this is the first study to address the impact of illness beliefs on the experience of older adults with a chronic psychosis, and the influence this may have on the individual's life. Understanding this influence is key in ensuring services are appropriately addressing these issues, highlighting opportunity for engagement with psychological therapy that may have been missing for this population. An important finding from the current study is the stark experience of power within the older adults' experiences of chronic psychosis. The role of power, threat, meaning and threat response encompassed in the PTM framework as applicable and a highly pervasive experience of this older adult population is important to contextualise and understand an individual's experiences, in order to encourage empowerment and shift in sense of self.

Future directions and implications for clinical practice

The results of the current study suggest that as individuals age, people living with psychosis develop ways of managing their illness through familiarity with its identity and belief that they can exhibit control over symptoms. However, key aspects in the experiences of those within the study was the operation of power, stigma and community. Service response and awareness of this process is important in providing a safe and effective service to older adults with chronic psychosis, in order to re-address the historical influences and focus on increasing empowerment, autonomy and sense of control for the individual. Increased focus should be placed on communication between NHS services and service users in order to achieve this. As noted above, additional participants would be required to clarify the emerged model, and this is an area of future development. Additionally, it may be beneficial to replicate the interview structure given in the current study in a younger population (matched for chronicity of illness) to allow a comparison between groups to provide further clarity on the role of aging as opposed to the role of purely repeated exposure in the shift in sense of self to empowered that occurred in the current sample.

Until recently, access to psychological therapies for older adults with chronic psychosis was limited. Understanding that individuals can learn to identify triggers and manage positive symptoms should ensure these options are provided as routine, multidisciplinary care for this population, and services should ensure access to these interventions. When working with older adults, the current study suggests that engagement with potential issues of stigma which may impede an individual's ability to access support networks is an area for focused improvement. Alongside direct cognitive work and evidence-based interventions for symptoms reduction (e.g. Cognitive Behavioural Therapy for Psychosis), the findings that older adults can become more accepting of their illness and adjust expectations of the self, suggests the importance of providing therapies such as Acceptance and Commitment Therapy or Compassion Focused Therapy, and the importance of providing trauma informed care within this population. Interactions and therapeutic relationship should be utilised to reduce implicit stigma, power differentials and impact of these interactions on the individual's sense of self, with communication, psychoeducation and active empowerment a key intervention.

Finally, the current COVID-19 pandemic should be considered in terms of the influence of this experience on the population the study was conducted with. The pandemic will have a number of implications for this population when considering the impact and influence of one's social network and access to shared communities as both a perpetuating and protective factor. Considering the impact of isolation in the contribution of feelings of powerlessness for the participants of this study, and the subsequent sustained periods of isolation being enforced upon the population as a whole (reduced sense of choice and control), services need to consider and appropriately respond to the potential vulnerability this has enhanced. Taking active steps to connect, support and provide a "community" to this population should be considered and prioritised by services, with the known impacts of this a risk services need to actively work to avoid.

Preliminary Conclusion

This study has highlighted a preliminary emerged model of the experiences of middle-aged and older adults with chronic psychosis. Participants may be somewhat sceptical about the role of mental health services, with historical influences of stigma and power differentials contributing to an underlying division. There has been an increased movement towards patient centred care and the development of advocacy work within mental health services in recent years, which are indicative of services aims to re-address the power imbalance. The development and discussion around the PTM framework has been prominent movement towards a more empowering stance for individuals who experience psychosis, and the current study highlights the applicability, importance and relevance of extending this to explicitly encompass an older adult population.

REFERENCES

ACCORD. (2020). COVID-19 Clincal Research Plan and Guidance. Version 3. Available: http://www.accord.scot/about-accord/accord-news/covid19-planning-and-guidance-research-0

Angermeyer, M.C., & Matschinger, H. (2004). The Stereotype of Schizophrenia and Its Impact on Discrimination Against People With Schizophrenia: Results From a Representative Survey in Germany. *Schizophrenia Bulletin,* 30 (4), 1049-1061

Araten-Bergman, T., Avieli, H., Mushkin, P., & Band-Winterstein T. (2015). How ageing individuals with Schizophrenia experience the self-etiology of their illness: a reflective lifeworld research approach. *Ageing and Mental Health*. 20 (11), 1147-1156, DOI: 10.1080/13607863.2015.1063110

Auslander, L.A., & Jeste, D.V. (2004). Sustaine Remmission in Schizophrenia Amongst Community Dwelling Older Outpatients, *Am J Psychiatry*¸ 161 (8), 1490- 1493

Berry, K., & Barrowclough, C. (2009). The Needs of Older Adults with Schizophrenia. *Clinical Psychology Review*, 29, 68-76.

Birchwood, M., Todd, P., & Jackson, C. (1998). Early Intervention in Psychosis: The Critical Period Hypothesis. *The British Journal of Psychiatry*, 172 (33), 53-39

British Medical Association. (2016). *Older Peoples Mental Health and Wellbeing.* London: BMA Hous

Brohan, E., Elgie, R., Sartorius, N., & Thornicroft, G. (2010). Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study. *Schizophrenia Research*, *122*(1–3), 232–238. https://doi.org/10.1016/j.schres.2010.02.1065

Ceglowski, J., Vergel de Dios, L., & Depp, C.A. (2014). Psychosis in Older Adults. In The Oxford Handbook of Clinical Geropsychology, Ed.

Chrostek, A., Grygiel, P., Anczewska, M., Wciorka, J., & Switaj, P. (2016). The intensity and correlates of the feelings of loneliness in people with psychosis. *Comprehensive Psychiatry,* 70, 190- 199.

Cohen, C.I., Meesters, P.D., & Zhao, J. (2015). New perspectives on schizophrenia in later life: implications for treatment, policy, and research. *Lancet Psychiatry,* 2, 340- 350.

Connor, M., & Norman, P. (1995). The role of social cognition in health behaviours. In M. Connor, & P. Norman (Eds), Predicting health behaviour: Research and practice with social cognition models (pp. 1–22). Oxford: Oxford University Press.

Corbin, J. & Strauss, A. (2008). *Basics of Qualiative Research: techniques and procedures for developing Grounded Theory*. London: Sage Publications

Corrigan, P., & Watson, A. (2002). The impact of stigma on people with mental health problems. *World Psychiatry,* 1:1, 16-20.

Division of Clinical Psychology. (2004). *Understanding Psychosis and Schizophrenia.* Leicester: British Psychological Society

Flick, U. (2018). Doing Grounded Theory (Qualitative Research Kit). Second Ed. London: SAGE Publications.

Folsom, D.P., Depp, C., Palmer, B.W., Mausbach, B.T., Golshan, S., Fellows, I., Cardenas, V., Patterson, T.L., Kraemer, H.C., & Jeste, D.V. (2009). Physical and mental health- related quality of life among older people with Schizophrenia. *Schizophrenia Research,* 108, 207–213.

Giblin, S., Clare, L., Livingston, G., & Howard, R. (2004). Psychosocial correlates of late-onset psychosis: Life experiences, cognitive schemas, and attitudes to ageing. *International Journal of Geriatric Psychiatry*, *19*(7), 611–623. https://doi.org/10.1002/gps.1129

Godfrey, M. (2015). Qualitative research in Age and Ageing: enhancing understanding of ageing, health and illness. *Age and ageing*, 44. 726-727.

Good Governance Institute. https://www.good-governance.org.uk/wp-content/uploads/2020/05/COVID-19-blog-21-05-20.pdf

Harder, S. (2004). Attachment in Schizophrenia- implications for research, prevention and treatment. *Schizophrenia Bulletin*, 40 (6), 1189- 1193.

Hatfield, A.B. (1999). Barriers to serving older adults with a psychiatric disability. *Psychiatric Rehabilitation Journal*, 22 (3), 270- 276.

Hendry, H.C., Tu.W., Tabbey, R., Purnell, C.E., Ambuehl, R.J., & Callahan, C.M. (2014). Health Outcomes and Cost of Care Among Older Adults with Schizophrenia: A 10 year study Using Medical Records Across the Continuum of Care. *American Journal of Geriatric Psychiatry*, 22 (5)

Jeste, D. V., & Maglione, J. E. (2013). Treating older adults with schizophrenia: Challenges and opportunities. *Schizophrenia Bulletin*, *39*(5), 966–968. https://doi.org/10.1093/schbul/sbt043

Jeste, D. V., Wolkowitz, O. M., & Palmer, B. W. (2011). Divergent trajectories of physical, cognitive, and psychosocial aging in schizophrenia. *Schizophrenia Bulletin*, *37*(3), 451–455. https://doi.org/10.1093/schbul/sbr026

Jeblensky, A. (2010). The diagnostic concept of schizophrenia: its history, evolution, and future prospects. *Dialogues in Clinical Neuroscience*, 12 (3), 271-287

Johnstone, L. & Boyle, M. with Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D. & Read, J. (2018). *The Power Threat Meaning Framework: Overview*. Leicester: British Psychological Society

Judge, A.M., Estroff, S.E., O'Perkins, D., & Penn, D.L. (2008). Recognizing and Responding to Early Psychosis: A Qualitative Analysis of Individual Narratives. *Psychiatric Services,* 59 (1), 96- 99.

Karidi, M.V., Stefanis, C.N., Theleritis, C., Tzedaki, M., Rabavilas, A.D., & Stefanis, N.C. (2010). Perceived social stigma, self-concept and self-stigmatisation of patient with Schizophrenia. *Comprehensive Psychiatry*, 51, 19–30.

Klapheck, K., Nordmeyer, S., Cronjäger, H., Naber, D., & Bock, T. (2012). Subjective experience and meaning of psychoses: The German subjective sense in psychosis questionnaire (SUSE). *Psychological Medicine*, *42*(1), 61–71. https://doi.org/10.1017/S0033291711001103

Knight, B.G., & Poon, C.Y.M. (2008). The Socio-cultural context in understanding older adults: contextual adult lifespan theory for adapting psychotherapy. In Woods, R., & Clare, L. (Eds). *Handbook of the Clinical Psychology of Ageing* (439-456). Chichester: Wiley & Sons

Leventhal, H., Nerenz, D.R., & Steele, D.F., (1984). Illness representations and coping with health threats. In A. Baum & J. Singer (Eds); A Handbook of Psychology and Health (pp. 219–252), Hillsdale, NJ: Erlbaum

Levy, B., Chung, P., Slade, M., Van Ness, P., & Pietrzak, R. (2019). Active coping shields against negative aging self-stereotypes contributing to psychiatric conditions. *Social Science & Medicine*, *228*, 25-29. doi: 10.1016/j.socscimed.2019.02.035

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science and Medicine*, *71*(12), 2150–2161. https://doi.org/10.1016/j.socscimed.2010.09.030

Lobban, F., & Barrowclough, C. (2005). Common Sense Representations of Schizophrenia in Patients and their Relatives. *Clinical Psychology & Psychotherapy*, *12*(2), 134–141. https://doi.org/http://dx.doi.org/10.1002/cpp.443

Loch, A.A., Guarniero, F.B., Lawson, L.F., Hengarten, M.P., Rossler, W., Gattaz, W.F., & Wang, Y.P. (2013). Stigma towards Schizophrenia: do all psychiatrists behave the same? Latent profile analysis of a national sample of psychiatrists in Brazil. *BMC Psychiatry*, 13 (92), 1-10, http://www.biomedcentral.com/1471-244X/13/92

LoPilato, A.M., Goines, K., Addington, J., Bearden, C.E., Cadenhead, K.S., Cannon, T.D., Cornblatt, B.A., Mathalon, D.H., McGlashan, T.H., Seidman, L., O.Perkins, D., Tsuang, M.T., Woods, S.W., & Walker, E.F. (2019). Impact of childhood adversity of corticolimbic volumes in youth at clinical high- risk for psychosis. *Schizophrenia Research*, 213, 48- 55.

MacBeth, A., Gumley, A., Schwannauer, M., & Fisher, R. (2011). Attachment states of mind, mentalization, and their correlates in a first-episode psychosis sample. *Psychology and Psychotherapy: Theory, Research and Practice*, 84, 42–57.

Martins, M. J. R. V., Castilho, P., Carvalho, C. B., Pereira, A. T., Santos, V., Gumley, A., & De Macedo, A. F. (2017). Contextual Cognitive-Behavioral Therapies across the psychosis continuum a review of evidence for schizophrenia, schizoaffective and bipolar disorders. *European Psychologist*, *22*(2), 83–100. https://doi.org/10.1027/1016-9040/a00028

McCulloch, Y., Clare, L., Howard, R., & Peters, E. (2006). Psychological processes underlying delusional thinking in late-onset psychosis: A preliminary investigation. *International Journal of Geriatric Psychiatry*, *21*(8), 768–777. https://doi.org/10.1002/gps.1561

Möhler, R., Köpke, S., & Meyer, G. (2015). Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare: Revised guideline (CReDECI 2). *Trials*, *16*(1), 1–9. https://doi.org/10.1186/s13063-015-0709-y

Myers, N.A.L., & Ziv, T. (2016). "No one even ever asked me that before": Autobiographical Power, social defeat, and recovery among African Americans with Lived experiences of Psychosis. *Medical Anthropology Quarterly*, 30 (3), 395-413.

Nuechterlein, K. H., & Dawson, M. E. (1984). A Heuristic Vulnerability/Stress Model of Schizophrenic Episodes. *Schizophrenia Bulletin*, *10*(2), 300–312. https://doi.org/10.1093/schbul/10.2.300

Overall, J.E., & Gorham, D.R. (1962). The Brief Psychiatric Rating Scale. *Psychological Reports*,10, 799- 812

Parker, S., French, P., Kilcommons, A., & Shiers, D. (2007). Report on early detection and intervention for young people at risk of psychosis. CSIP North West and CSIP West Midlands. Available: http://www.iris-initiative.org.uk/silo/files/early-detection-report.pdf

Pyle, M., & Morrison, A. P. (2014). "It's just a very taboo and secretive kind of thing": Making sense of living with stigma and discrimination from accounts of people with psychosis. *Psychosis*, *6*(3), 195–205. https://doi.org/10.1080/17522439.2013.834458

Ridgway, P. (2001). Restorying psychiatric disability: Learning from first person recovery narratives. Psychiatric Rehabilitation Journal, 24, 335–343

Roe, D., & Chopra, M. (2003). Beyond Coping with Mental Illness: Towards Personal Growth. *American Journal of Orthopsychiatry,* 73 (3), 334-344

Roe, J., & Middleton, H. (2010). Symbolic interaction: a theoretical approach to understanding stigma and recovery. *Mental Health Review Journal,* 15 (1), 31-38

Saha S, Chant D, McGrath J. (2007). A systematic review of mortality in schizophrenia. Arch Gen Psychiatry 2007; 64: 1123–31.

Salvatore, G., Lysaker, P.H., Popolo, R., Procacci, M., Carcione, A., & Dimaggio, G. (2012). Vulnerable self, poor understanding of others' minds, threat anticipation and cognitive biases as triggers for delusional experience in Schizophrenia: A Theoretical Model. *Clinical Psychology and Psychotherapy,* 19, 247- 259.

Scottish Government. (2017). Mental Health Strategy 2017-2027. Available at www.gov.scot.

Seeman, P. (1987). Dopamine Receptors and The Dopamine Hypothesis. *Synapse.*1 (2). 133-152.

Shepherd, S., Depp, C.A., Harris, G., Halpain, M., Palinkas, L.A., & Jeste, D.V. (2010). Perspectives on Schizophrenia over the lifespan: A qualitative study. *Schizophrenia Bulletin, 38 (2),* 295-303

Styla, R., Stolarski, M., & Szymanowska, A. (2019). Linking childhood adversity with schizophrenia: A mediating role of the balanced time perspective. *Schizophrenia Research,* 209, 281- 283.

Tajfel, H. (1978). *Differentiation between social groups: studies in the social psychology of* *intergroup relations.* London: European Association of Experimental Social Psychology by Academic Press

Theodore, K., Johnson, S., Chalmers-Brown, A., Doherty, R., Harrop, C., & Ellett, L. (2012). Quality of life and illness beliefs in individuals with early psychosis. *Social Psychiatry and Psychiatric Epidemiology*, *47*(4), 545–551. https://doi.org/10.1007/s00127-011-0360-1

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M., & Study, I. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia : a cross-sectional survey. *The Lancet*, *373*(9661), 408–415. https://doi.org/10.1016/S0140-6736(08)61817-6

Tiihonen J, Lönnqvist J, Wahlbeck K, et al. (2009). 11-year follow-up of mortality in patients with schizophrenia: a population-based cohort study (FIN11 study). *Lancet*, 374: 620–27. 103

Torgalsboen A.K, & Rund B.R. (2002). Lessons learned from three studies of recovery from schizophrenia. *Int Rev Psychiatry*, 14: 312–317

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., Read, J., Van Os, J., & Bentall, R. (2012). Childhood Adversities Increase the Risk of Psychosis: A Meta-analysis of Patient-Control, Prospective- and Cross-sectional Cohort Studies. *Schizophrenia Bulletin*, 38 (4), 661- 671.

Vass, V., Morrison, A. P., Law, H., Dudley, J., Taylor, P., Bennett, K. M., & Bentall, R. P. (2015). How stigma impacts on people with psychosis: The mediating effect of self-esteem and hopelessness on subjective recovery and psychotic experiences. *Psychiatry Research*, *230*(2), 487–495. https://doi.org/10.1016/j.psychres.2015.09.042

Wang, K., Link, B. G., Corrigan, P. W., Davidson, L., & Flanagan, E. (2018). Perceived provider stigma as a predictor of mental health service users' internalized stigma and disempowerment. *Psychiatry Research*, *259*(October 2017), 526–531. https://doi.org/10.1016/j.psychres.2017.11.036

Webb, A.K., Jacobs-Lawson, J.M., & Waddell, E.L. (2009). Older Adults Perceptions of Mentally Ill Older Adults¸ *Ageing and Mental Health*, 13 (6), 838- 846.

Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. Psychology and Health, 11(3), 431–445.

Wigman, J.T.W, van Winkel, R., Ormel, J., Verhulst, F.C., van Os, J., & Vollebergh, W.A.M. (2012). Early trauma and familial risk in the development of the extended psychosis phenotype in adolescence. *Acta Psychiatr Scand*, 126, 266–273.

World Health Organization (2019). International statistical classification of diseases and related health problems (11th ed.). https://icd.who.int/

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Zubin, J., & Spring, B. (1977). Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology*, *86*(2), 103–126. https://doi.org/10.1037/0021-843X.86.2.103

PORTFOLIO THESIS REFERENCE LIST

ACCORD. (2020). COVID-19 Clincal Research Plan and Guidance. Version 3. Available: http://www.accord.scot/about-accord/accord-news/covid19-planning-and-guidance-research-0

Angermeyer, M.C., & Matschinger, H. (2004). The Stereotype of Schizophrenia and Its Impact on Discrimination Against People With Schizophrenia: Results From a Representative Survey in Germany. *Schizophrenia Bulletin,* 30 (4), 1049-1061

Araten-Bergman, T., Avieli, H., Mushkin, P., & Band-Winterstein T. (2015). How ageing individuals with Schizophrenia experience the self-etiology of their illness: a reflective lifeworld research approach. *Ageing and Mental Health*. 20 (11), 1147-1156, DOI: 10.1080/13607863.2015.1063110

Arslan, B.S., & Buldukoglu, K. (2018). The association of nursing care perception with coping skills and posttraumatic growth in mental disorders. *Journal Psychiatric Mental Health Nursing*, 25, 228-235.

Auslander, L.A., & Jeste, D.V. (2004). Sustaine Remmission in Schizophrenia Amongst Community Dwelling Older Outpatients, *Am J Psychiatry*¸ 161 (8), 1490- 1493

Bankole, A., Cohen, C., Vahila, I., Diwan, S., Palekar, N., Reyes, P., Sapra, M., & Ramirez, P.M. (2008). Symptomatic Remission in a Multiracial Urban Population of Older Adults with Schizophrenia. *Am J Geriatr Psychiatry*, 16 (12), 966- 973.

Berry, K., & Barrowclough, C. (2009). The Needs of Older Adults with Schizophrenia. *Clinical Psychology Review*, 29, 68-76.

Berry, K., Barrowclough, C., Byrne, J., & Purandare, N. (2006). Coping strategies and social support in old age psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 41(4), pp.280-284.

Birchwood, M., Todd, P., & Jackson, C. (1998). Early Intervention in Psychosis: The Critical Period Hypothesis. *The British Journal of Psychiatry*, 172 (33), 53-39

Boschi, S., Adams, R.E., Bromet, E.J., Lavelle, J.E., Everett, E., & Galambos, N. (2000). Coping with Psychotic Symptoms in the Early Phases of Schizophrenia, *American journal of Orthopsychiatry*, 70 (2), 242- 252.

British Medical Association. (2016). *Older Peoples Mental Health and Wellbeing.* London: BMA Hous

Brohan, E., Elgie, R., Sartorius, N., & Thornicroft, G. (2010). Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study. *Schizophrenia Research*, *122*(1–3), 232–238. https://doi.org/10.1016/j.schres.2010.02.1065

Carr, V. (1988). Patients' techniques for coping with schizophrenia: An exploratory study. British Journal of Medical Psychology, 61, 339-352

Ceglowski, J., Vergel de Dios, L., & Depp, C.A. (2014). Psychosis in Older Adults. In The Oxford Handbook of Clinical Geropsychology, Ed.

Chen, E., & Miller, G.E. (2012). "Shift-and-Persist" Strategies: Why Low Socioeconomic Status Isn't Always Bad for Health. *Perspectives on Psychological Science*, 7 (2), 135-158

Christophe, N., Stein, G., Martin Romero, M., Chan, M., Jensen, M., Gonzalez, L., & Kiang, L. (2019). Coping and Culture: The Protective Effects of Shift-&-Persist and

Ethnic-Racial Identity on Depressive Symptoms in Latinx Youth. *Journal Of Youth And Adolescence, 48*(8), 1592-1604. doi: 10.1007/s10964-019-01037-8

Chrostek, A., Grygiel, P., Anczewska, M., Wciorka, J., & Switaj, P. (2016). The intensity and correlates of the feelings of loneliness in people with psychosis. *Comprehensive Psychiatry,* 70, 190- 199.

Cohen, C., Hassamal, S., & Begum, N. (2011). General coping strategies and their impact on quality of life in older adults with schizophrenia. *Schizophrenia Research*, 127(1-3), pp.223-228.

Cohen, C., Izediuno, I., Yadack, A., Ghosh, B., & Garrett, M. (2014). Characteristics of Auditory Hallucinations and Associated Factors in Older Adults with Schizophrenia. *The American Journal of Geriatric Psychiatry*, 22(5), pp.442-449.

Cohen, C., Jimenez, C., & Mittal, S. (2010). The Role of Religion in the Well-Being of Older Adults With Schizophrenia. *Psychiatric Services*, 61(9), pp.917-922.

Cohen, C., Vengassery, A., & Garcia Aracena, E. (2017). A Longitudinal Analysis of Quality of Life and Associated Factors in Older Adults with Schizophrenia Spectrum Disorder. *The American Journal of Geriatric Psychiatry*, 25(7), pp.755-765.

Cohen, C.I., Meesters, P.D., & Zhao, J. (2015). New perspectives on schizophrenia in later life: implications for treatment, policy, and research. *Lancet Psychiatry,* 2, 340- 350.

Compas, B. E., Jaser, S. S., Dunbar, J. P., Watson, K. H., Bettis, A. H., Gruhn, M. A., & Williams, E. K. (2013). Coping and emotion regulation from childhood to early adulthood: Points of convergence and divergence. Australian Journal of Psychology, 66(2), 71–81. doi:10.1111/ajpy.12043

Connor, M., & Norman, P. (1995). The role of social cognition in health behaviours. In M. Connor, & P. Norman (Eds), Predicting health behaviour: Research and practice with social cognition models (pp. 1–22). Oxford: Oxford University Press.

Cooke, P., Melchert, T., & Connor, K. (2016). Measuring Well-Being. *The Counseling Psychologist*, *44*(5), 730-757. doi: 10.1177/0011000016633507

Corbin, J. & Strauss, A. (2008). *Basics of Qualiative Research: techniques and procedures for developing Grounded Theory*. London: Sage Publications

Corrigan, P., & Watson, A. (2002). The impact of stigma on people with mental health problems. *World Psychiatry,* 1:1, 16-20.

Cukrowicz, K., Ekblad, A., Cheavens, J., Rosenthal, M. and Lynch, T., 2008. Coping and thought suppression as predictors of suicidal ideation in depressed older adults with personality disorders. *Aging & Mental Health*, 12(1), 149-157.

Davidson, L., Borg, M., Marin, I., Topor, A., Mezzina, R., & Sells, D. (2015). Processes of Recovery in Serious Mental Illness: Findings from a Multinational Study, *American Journal of Psychiatric Rehabilitation,* 8 (3), 177-201.

Davis, G. (2005). Coping with Mental Illness. *Psychiatric Rehabilitation Journal*, 28 (3), 229- 302.

Division of Clinical Psychology. (2004). *Understanding Psychosis and Schizophrenia.* Leicester: British Psychological Society

Diwan, S., Cohen, C., Bankole, A., Vahia, I., Kehn, M., & Ramirez, P. (2007). Depression in Older Adults With Schizophrenia Spectrum Disorders: Prevalence and

Associated Factors. *The American Journal of Geriatric Psychiatry*, 15(12), pp.991-998.

Fledderus, M., Bohlmeijer, E.T., & Pieterse, M.E. (2010). Does Experiential Avoidance Mediate the Effects of Maladaptive Coping Styles on Psychopathology and Mental Health? *Behaviour Modification*, 34 (6), 503-519

Flick, U. (2018). Doing Grounded Theory (Qualitative Research Kit). Second Ed. London: SAGE Publications.

Folsom, D.P., Depp, C., Palmer, B.W., Mausbach, B.T., Golshan, S., Fellows, I., Cardenas, V., Patterson, T.L., Kraemer, H.C., & Jeste, D.V. (2009). Physical and mental health- related quality of life among older people with Schizophrenia. *Schizophrenia Research*, 108, 207–213.

Giblin, S., Clare, L., Livingston, G., & Howard, R. (2004). Psychosocial correlates of late-onset psychosis: Life experiences, cognitive schemas, and attitudes to ageing. *International Journal of Geriatric Psychiatry*, *19*(7), 611–623. https://doi.org/10.1002/gps.1129

Godfrey, M. (2015). Qualitative research in Age and Ageing: enhancing understanding of ageing, health and illness. *Age and ageing,* 44. 726-727.

Good Governance Institute. https://www.good-governance.org.uk/wp-content/uploads/2020/05/COVID-19-blog-21-05-20.pdf

Granholm, E., McQuaid, J., McClure, F., Auslander, L., Perivoliotis, D., Pedrelli, P., Patterson, T., & Jeste, D. (2005). A Randomized, Controlled Trial of Cognitive Behavioral Social Skills Training for Middle-Aged and Older Outpatients With Chronic Schizophrenia. *American Journal of Psychiatry*, 162(3), pp.520-529.

Gregory, R. J., Chlebowski, S., Kang, D., Remen, A. L., Soderberg, M. G., Stepkovitch, J., & Virk, S. (2008). A controlled trial of psychodynamic psychotherapy for co-occurring borderline personality disorder and alcohol use disorder. Psychotherapy: Theory, Research, Practice, Training, 45, 28–41. doi:10.1037/0033-3204.45.1.28

Gross, J., & John, O. (2003). Individual differences in two emotion regulation processes: Implications for affect, relationships, and well-being. Journal of Personality and Social Psychology, 85, 348–362. doi:10.1037/0022-3514.85.2.348

Gumley, A.I., Taylor, H.E.F., Schwannauer, M. & Macbeth, A. (2014). 'A systematic review of attachment and psychosis: measurement, construct validity and outcomes', *Acta psychiatrica scandinavica*, 129 (4), 257-274. https://doi.org/10.1111/acps.12172

Hagger, M.S., & Orbell, S. (2003) A Meta-Analytic Review of the Common-Sense Model of Illness Representations, Psychology and Health, 18:2, 141-184, DOI: 10.1080/088704403100081321

Harder, S. (2004). Attachment in Schizophrenia- implications for research, prevention and treatment. *Schizophrenia Bulletin,* 40 (6), 1189- 1193.

Harvey, J., & Taylor, V. (2013). *Measuring Health and Wellbeing: Basic Concepts.* London: SAGE Publications

Hatfield, A.B. (1999). Barriers to serving older adults with a psychiatric disability. *Psychiatric Rehabilitation Journal,* 22 (3), 270- 276.

Hatfield, K., & Dening, T. (2013). Severe and Enduring Mental Illness. In Dening, T., & Thomas, A. (Ed). *Oxford Textbook of Old Age Psychiatry (2nd Ed).* London: Oxford University Press

Hendry, H.C., Tu.W., Tabbey, R., Purnell, C.E., Ambuehl, R.J., & Callahan, C.M. (2014). Health Outcomes and Cost of Care Among Older Adults with Schizophrenia: A 10 year study Using Medical Records Across the Continuum of Care. *American Journal of Geriatric Psychiatry*, 22 (5)

Hertel, G., Rauschenbach, C., Thielgen, M.M., & Krumm, S. (2015). Are older workers more active copers? Longitudinal effects of age-contingent coping on strain at work. J. Organ. Behav. 36, 514–537. https://doi.org/10.1002/job.1995.

Ibrahim, F., Cohen, C., & Ramirez, P. (2010). Successful Aging in Older Adults With Schizophrenia: Prevalence and Associated Factors. *The American Journal of Geriatric Psychiatry*, 18(10), pp.879-886.

Jeblensky, A. (2010). The diagnostic concept of schizophrenia: its history, evolution, and future prospects. *Dialogues in Clinical Neuroscience*, 12 (3), 271-287

Jeste, D. V., & Maglione, J. E. (2013). Treating older adults with schizophrenia: Challenges and opportunities. *Schizophrenia Bulletin*, *39*(5), 966–968. https://doi.org/10.1093/schbul/sbt043

Jeste, D. V., Wolkowitz, O. M., & Palmer, B. W. (2011). Divergent trajectories of physical, cognitive, and psychosocial aging in schizophrenia. *Schizophrenia Bulletin*, *37*(3), 451–455. https://doi.org/10.1093/schbul/sbr026

Johnstone, L. & Boyle, M. with Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D. & Read, J. (2018). *The Power Threat Meaning Framework: Overview*. Leicester: British Psychological Society

Judge, A.M., Estroff, S.E., O'Perkins, D., & Penn, D.L. (2008). Recognizing and Responding to Early Psychosis: A Qualitative Analysis of Individual Narratives. *Psychiatric Services*, 59 (1), 96- 99.

Karidi, M.V., Stefanis, C.N., Theleritis, C., Tzedaki, M., Rabavilas, A.D., & Stefanis, N.C. (2010). Perceived social stigma, self-concept and self-stigmatisation of patient with Schizophrenia. *Comprehensive Psychiatry*, 51, 19–30.

Klapheck, K., Nordmeyer, S., Cronjäger, H., Naber, D., & Bock, T. (2012). Subjective experience and meaning of psychoses: The German subjective sense in psychosis questionnaire (SUSE). *Psychological Medicine*, *42*(1), 61–71. https://doi.org/10.1017/S0033291711001103

Knight, B.G., & Poon, C.Y.M. (2008). The Socio-cultural context in understanding older adults: contextual adult lifespan theory for adapting psychotherapy. In Woods, R., & Clare, L. (Eds). *Handbook of the Clinical Psychology of Ageing* (439-456). Chichester: Wiley & Sons

Kupper, Z., & Tschacher, W. (2008). Lack of concordance between subjective improvement and symptom change in psychotic episode. *British Journal of Clinical Psychology*, 47, 75–93

Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

Lent, R. W. (2004). Toward a unifying theoretical and practical perspective on wellbeing and psychosocial adjustment. Journal of Counseling Psychology, 51(4), 482-509. doi:10.1037/0022-0167.51.4.48

Leventhal, H., Brissette, I., & Leventhal, E. (2003). The common-sense model of self-regulation of health and illness. In: Cameron, L.D., & Leventhal, H. (eds) The Self-Regulation of Health and Illness Behavior. London: Routledge, 42–65

Leventhal, H., Nerenz, D.R., & Steele, D.F., (1984). Illness representations and coping with health threats. In A. Baum & J. Singer (Eds); A Handbook of Psychology and Health (pp. 219–252), Hillsdale, NJ: Erlbaum

Levy, B., Chung, P., Slade, M., Van Ness, P., & Pietrzak, R. (2019). Active coping shields against negative aging self-stereotypes contributing to psychiatric conditions. *Social Science & Medicine, 228,* 25-29. doi: 10.1016/j.socscimed.2019.02.035

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science and Medicine*, *71*(12), 2150–2161. https://doi.org/10.1016/j.socscimed.2010.09.030

Lobban, F., & Barrowclough, C. (2005). Common Sense Representations of Schizophrenia in Patients and their Relatives. *Clinical Psychology & Psychotherapy*, *12*(2), 134–141. https://doi.org/http://dx.doi.org/10.1002/cpp.443

Loch, A.A., Guarniero, F.B., Lawson, L.F., Hengarten, M.P., Rossler, W., Gattaz, W.F., & Wang, Y.P. (2013). Stigma towards Schizophrenia: do all psychiatrists behave the same? Latent profile analysis of a national sample of psychiatrists in Brazil. *BMC Psychiatry*, 13 (92), 1-10, http://www.biomedcentral.com/1471-244X/13/92

Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc. 2015;13(3):179–187

LoPilato, A.M., Goines, K., Addington, J., Bearden, C.E., Cadenhead, K.S., Cannon, T.D., Cornblatt, B.A., Mathalon, D.H., McGlashan, T.H., Seidman, L., O.Perkins, D., Tsuang, M.T., Woods, S.W., & Walker, E.F. (2019). Impact of childhood adversity of corticolimbic volumes in youth at clinical high- risk for psychosis. *Schizophrenia Research,* 213, 48- 55.

MacBeth, A., Gumley, A., Schwannauer, M., & Fisher, R. (2011). Attachment states of mind, mentalization, and their correlates in a first-episode psychosis sample. *Psychology and Psychotherapy: Theory, Research and Practice,* 84, 42–57.

MacDonald, E.M., Pica, S., McDonald, S., Hayes, R., & Baglioni, Jr, A.J. (1998) Stress and Coping in Early Psychosis. Role of Symptoms, self-efficacy and Social support in Coping with Stress. *British Journal of Psychiatry,* 172 (33), 122-127.

Malka, T., Hasson-Ohayon, I., Goldzweig, G., & Roe, D. (2019). Coping Style Is Associated With Parental Distress Beyond Having a Mental Illness: A Study Among Mothers With and Without Mental Illness. *Psychiatric Rehabilitation Journal*. Advance online publication. http://dx.doi.org/10.1037/prj0000381

Martins, M. J. R. V., Castilho, P., Carvalho, C. B., Pereira, A. T., Santos, V., Gumley, A., & De Macedo, A. F. (2017). Contextual Cognitive-Behavioral Therapies across the psychosis continuum a review of evidence for schizophrenia, schizoaffective and bipolar disorders. *European Psychologist, 22*(2), 83–100. https://doi.org/10.1027/1016-9040/a00028

Mazor, Y., Gelkopf, M., & Roe, D. (2018). Posttraumatic Growth among people with serious mental illness, psychosis, and posttraumatic stress symptoms. *Comprehensive Psychiatry,* 81, 1-9.

McCulloch, Y., Clare, L., Howard, R., & Peters, E. (2006). Psychological processes underlying delusional thinking in late-onset psychosis: A preliminary investigation. *International Journal of Geriatric Psychiatry*, *21*(8), 768–777. https://doi.org/10.1002/gps.1561

McNeil, S.A., & Galovski, T.E. (2015). Coping Styles Among Individuals with Severe Mental Illness and Comorbid PTSD. *Community Mental Health Journal*, 51, 663–673.

Meesters, P., van der Ham, L., Dominicus, M., Stek, M., & Abma, T. (2019). Promoting Personal and Social Recovery in Older Persons with Schizophrenia: The Case of The New Club, a Novel Dutch Facility Offering Social Contact and Activities. *Community Mental Health Journal*, 55(6), pp.994-1003.

Moher. D, Liberati. A, Tetzlaff. J, & Altman D.G, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Möhler, R., Köpke, S., & Meyer, G. (2015). Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare: Revised guideline (CReDECI 2). *Trials, 16*(1), 1–9. https://doi.org/10.1186/s13063-015-0709-y

Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/

Mueser, K. T., Rosenberg, S. D., Hamblen, J. L., & Decamps, M. (2004). A cognitive-behavioral treatment program for posttraumatic stress disorder in persons with severe mental illness. American Journal of Psychiatric Rehabilitation, 7, 107–146. doi:10.1080/1587760490476183.

Myers, N.A.L., & Ziv, T. (2016). “No one even ever asked me that before”: Autobiographical Power, social defeat, and recovery among African Americans with Lived experiences of Psychosis. *Medical Anthropology Quarterly,* 30 (3), 395-413.

Nguyen, T., Truong, D., Feit, A., Marquett, R., & Reisser, R. (2007). Response to Group-Based Cognitive Behavioural Therapy for Older Adults with Bipolar Disorder, *Clinical Gerontologist*, 30 (2), 103-110, DOI: 10.1300/J018v30n02_08

Nuechterlein, K. H., & Dawson, M. E. (1984). A Heuristic Vulnerability/Stress Model of Schizophrenic Episodes. *Schizophrenia Bulletin*, *10*(2), 300–312. https://doi.org/10.1093/schbul/10.2.300

Ong, E., & Thompson, C. (2019) The Importance of Coping and Emotion Regulation in the Occurrence of Suicidal Behaviour. Psychological Reports, 122 (4), 1192-1210

Overall, J.E., & Gorham, D.R. (1962). The Brief Psychiatric Rating Scale. *Psychological Reports,*10, 799- 812

Parker, S., French, P., Kilcommons, A., & Shiers, D. (2007). Report on early detection and intervention for young people at risk of psychosis. CSIP North West and CSIP West Midlands. Available: http://www.iris-initiative.org.uk/silo/files/early-detection-report.pdf

Patterson, T., Shaw, W., Semple, S., Moscona, S., Harris, M., Kaplan, R., Grant, I., & Jeste, D. (1997). Health-Related Quality of Life in Older Adults with Schizophrenia and

Other psychoses: Relationships Among Psychosocial and Psychiatric Factors. *International Journal of Geriatric Psychiatry*, 12(4), pp.452-461.

Peck, M. C., & Scheffler, R. M. (2002). An analysis of the definitions of mental illness used in state parity laws. Psychiatric Services, 53(9), 1089–1095. doi:10.1176/appi.ps.53.9.1089.

Pentland, W., Miscio., Eastabrook, S., & Krupa, T. (2003). Ageing Women and Schizophrenia, *Psychiatric Rehabilitation Journal*, 26 (3)

Philips, L.J., Francey, S.M., Edwards, J., & McMurray, N. (2009). Strategies used by psychotic individuals to cope with life stress and symptoms of illness: a systematic review, *Anxiety, Stress & Coping*, 22:4, 371-410, DOI: 10.1080/10615800902811065

Polanco-Roman, L., Danies, A., & Anglin, D. (2016). Racial discrimination as race-based trauma, coping strategies, and dissociative symptoms among emerging adults. *Psychological Trauma: Theory, Research, Practice, And Policy*, *8*(5), 609-617. doi: 10.1037/tra0000125

Pyle, M., & Morrison, A. P. (2014). “It’s just a very taboo and secretive kind of thing”: Making sense of living with stigma and discrimination from accounts of people with psychosis. *Psychosis*, *6*(3), 195–205. https://doi.org/10.1080/17522439.2013.834458

Quin, R., Clare, L., Ryan, P., & Jackson, M. (2009). ‘Not of this world’: The subjective experience of late-onset psychosis. *Aging & Mental Health*, 13(6), pp.779-787.

Ridgway, P. (2001). Restoring psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24, 335–343.

Roe, D., & Chopra, M. (2003). Beyond Coping with Mental Illness: Towards Personal Growth. *American Journal of Orthopsychiatry*, 73 (3), 334-344

Roe, J., & Middleton, H. (2010). Symbolic interaction: a theoretical approach to understanding stigma and recovery. *Mental Health Review Journal*, 15 (1), 31-38

Roscoe, L. J. (2009). Wellness: A review of theory and measurement for counselors. Journal of Counseling and Development, 87(2), 216-226.

Ryan, R. M., & Deci, E. L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. Annual Review of Psychology, 52(1), 141-166.

Saha S, Chant D, McGrath J. (2007). A systematic review of mortality in schizophrenia. Arch Gen Psychiatry 2007; 64: 1123–31.

Salvatore, G., Lysaker, P.H., Popolo, R., Procacci, M., Carcione, A., & Dimaggio, G. (2012). Vulnerable self, poor understanding of others' minds, threat anticipation and cognitive biases as triggers for delusional experience in Schizophrenia: A Theoretical Model. *Clinical Psychology and Psychotherapy*, 19, 247- 259.

Scottish Government. (2017). Mental Health Strategy 2017-2027. Available at www.gov.scot.

Seeman, P. (1987). Dopamine Receptors and The Dopamine Hypothesis. *Synapse.*1 (2). 133-152.

Shepherd, S., Depp, C., Harris, G., Halpain, M., Palinkas, L., & Jeste, D. (2010). Perspectives on Schizophrenia Over the Lifespan: A Qualitative Study. *Schizophrenia Bulletin*, 38(2), pp.295-303.

Solano, N., & Whitbourne, S. (2001). Coping with Schizophrenia: Patterns in Later Adulthood. *The International Journal of Aging and Human Development*, 53(1), pp.1-10.

Stevenson, J., Brodaty, H., Boyce, P., & Blyth, K. (2012). Does Age Moderate the Effect of Personality Disorder on Coping Style in Psychiatric Inpatients? Journal of Psychiatric Practice, 18 (3), 187-198

Styla, R., Stolarski, M., & Szymanowska, A. (2019). Linking childhood adversity with schizophrenia: A mediating role of the balanced time perspective. *Schizophrenia Research,* 209, 281- 283.

Tait, L., Birchwood, M., & Trower, P. (2004). Adapting to the challenge of psychosis: personal resilience and the use of sealing-over (avoidant) resilience and the use of sealing-over (avoidant) coping strategies. *British Journal of Psychiatry,* 18 (5), 410-415

Tajfel, H. (1978). *Differentiation between social groups: studies in the social psychology of intergroup relations.* London: European Association of Experimental Social Psychology by Academic Press

Tedeschi, R. G., & Calhoun, L. G. (1995). Trauma and transformation: Growing in the aftermath of suffering. Thousand Oaks, CA: Sage

Theodore, K., Johnson, S., Chalmers-Brown, A., Doherty, R., Harrop, C., & Ellett, L. (2012). Quality of life and illness beliefs in individuals with early psychosis. *Social Psychiatry and Psychiatric Epidemiology*, *47*(4), 545–551. https://doi.org/10.1007/s00127-011-0360-1

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M., & Study, I. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia : a cross-sectional survey. *The Lancet*, *373*(9661), 408–415. https://doi.org/10.1016/S0140-6736(08)61817-6

Tiihonen J, Lönnqvist J, Wahlbeck K, et al. (2009). 11-year follow-up of mortality in patients with schizophrenia: a population-based cohort study (FIN11 study). *Lancet*, 374: 620–27. 103

Torgalsboen A.K, & Rund B.R. (2002). Lessons learned from three studies of recovery from schizophrenia. *Int Rev Psychiatry*, 14: 312–317

Tufanaru C, Munn Z, Aromataris E, Campbell J, Hopp L. Chapter 3: Systematic reviews of effectiveness. In: Aromataris E, Munn Z (Editors). Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/

Van Den Bosh, R.J., Van Asma, M.J.O., Rombouts, R., & Louwerens, J.W. (1992). Coping Style and Cognitive Dysfunction in Schizophrenic Patient. *British Journal of Psychiatry*, 161 (18), 123-128

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., Read, J., Van Os, J., & Bentall, R. (2012). Childhood Adversities Increase the Risk of Psychosis: A Meta-analysis of Patient-Control, Prospective- and Cross-sectional Cohort Studies. *Schizophrenia Bulletin*, 38 (4), 661- 671.

Vass, V., Morrison, A. P., Law, H., Dudley, J., Taylor, P., Bennett, K. M., & Bentall, R. P. (2015). How stigma impacts on people with psychosis: The mediating effect of self-esteem and hopelessness on subjective recovery and psychotic experiences. *Psychiatry Research*, *230*(2), 487–495. https://doi.org/10.1016/j.psychres.2015.09.042

Vreeland, A., Bettis, A., Reising, M., Dunbar, J., Watson, K., Gruhn, M., & Compas, B. (2019). Coping and Stress Reactivity as Moderators of Maternal Depressive Symptoms and Youth's Internalizing and Externalizing Symptoms. *Journal Of Youth And Adolescence*, *48*(8), 1580-1591. doi: 10.1007/s10964-019-01033-y

Wang, K., Link, B. G., Corrigan, P. W., Davidson, L., & Flanagan, E. (2018). Perceived provider stigma as a predictor of mental health service users' internalized stigma and disempowerment. *Psychiatry Research, 259*(October 2017), 526–531. https://doi.org/10.1016/j.psychres.2017.11.036

Webb, A.K., Jacobs-Lawson, J.M., & Waddell, E.L. (2009). Older Adults Perceptions of Mentally Ill Older Adults¸ *Ageing and Mental Health*, 13 (6), 838- 846.

Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. Psychology and Health, 11(3), 431–445.

Wesner, A. C., Gomes, J. B., Detzel, T., Guimarães, L. S., & Heldt, E. (2015). Booster sessions after cognitive-behavioural group therapy for panic disorder: Impact on resilience, coping, and quality of life. Behavioural and Cognitive Psychotherapy, 43(5), 513–525. https://doi. org/10.1017/S1352465814000289.

Wesner, A.C., Behenck, A., Finkler, D., Beria, P., Guimaraes, L.S.P., Manfro, G.G., Blaya, C., & Heldt, E. (2019). Resilience and coping strategies in cognitive behavioural group therapy for patients with panic disorder. *Archives of Psychiatric Nursing*, 33, 428- 433.

WHOQOL Group. (1998). The World Health Organization Quality of Life Assessment (WHOQOL): Development and general psychometric properties. Social Science & Medicine, 46(12), 1569-1585.

Wigman, J.T.W, van Winkel, R., Ormel, J., Verhulst, F.C., van Os, J., & Vollebergh, W.A.M. (2012). Early trauma and familial risk in the development of the extended psychosis phenotype in adolescence. *Acta Psychiatr Scand*, 126, 266–273.

World Health Organization (2019). International statistical classification of diseases and related health problems (11th ed.). https://icd.who.int/

Yanos, P. T., West, M. L., & Smith, S. M. (2010). Coping, productive time use, and negative mood among adults with severe mental illness: A daily diary study. Schizophrenia Research, 124(1–3), 54–59. doi:10.1016/j.schres.2010.08.020.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Zubin, J., & Spring, B. (1977). Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology*, *86*(2), 103–126. https://doi.org/10.1037/0021-843X.86.2.103

Zuckerman, M., & Gagne, M. (2003). The COPE revised: Proposing a 5-factor model of coping strategies. Journal of Research in Personality, 37, 169–204. doi:10.1016/s0092- 6566(02)00563-9

APPENDIX 1- Author guidelines: Journal of Mental Health and Ageing

Journal of Mental Health and Aging is an interdisciplinary research journal that encourages original research work in all major disciplines of neurology, psychology and gerontology. Review articles on current topics will also be included. Psychologists and gerontologists are encouraged to contribute research articles.

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- The margins should be set at one inch all around.
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- Do not use headers or footers.
- The font used should be Times New Roman, 12 point (with the size exceptions mentioned below for quotes, tables, and references).
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- Title of the paper must be in ALL CAPITAL LETTERS, bolded, centered and in 18 point font.
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- Main Headings in the document should be in ALL CAPITAL LETTERS, bolded and centered in the default 12 point font. Subheadings should be in Initial Capital Letters, bolded and left justified. Pay attention not to orphan a heading from the text that follows at the bottom of a page. More information on headings can be found in the sections below.
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- References should be in 10 point font, single spaced between references, with hanging indents (see section below for more instructions).

Guidelines for Article types

Research Articles

Research articles are articles written based on the empirical/secondary data collected using a clearly defined research methodology, where conclusion/s is drawn from the analysis of the data collected. The information must be based on original research that adds to the body of knowledge in Mental Health and Aging. Article/s should provide a critical description or analysis of the data presented while adding new and rapidly evolving areas in the field. Include an abstract of at least 300 words with 7 to 10 important keywords. The abstract should be divided into Objective, Methods, Results, and Conclusion. Research articles must adhere to a format constituting the introduction followed by a brief review of relevant literature, methodology applied (to collect the data), discussion and References, Tables, and

Figure Legends.

Review Articles

Review articles are written based mostly on secondary data that is falling in line with the theme of the journal. They are brief, yet critical discussions on a specific aspect of the subject concerned. Reviews generally start with the statement of the problem with a brief abstract of 300 words and few key words. Introduction generally brings the issue forward to the readers followed by analytical discussion with the help of necessary tables, graphs, pictures and illustrations wherever necessary. It summarizes the topic with a conclusion. All the statements or observations in the review articles must be based on necessary citations, providing complete reference at the end of the article.

Commentaries

Commentaries are opinion articles written mostly by the veteran and experienced writers on a specific development, recent innovation or research findings that fall in line with the theme of the journal. They are very brief articles with the title and abstract that provides the gist of the topic to be discussed, with few key words. It straight away states the problems and provides a thorough analysis with the help of the illustrations, graphs and tables if necessary. It summarizes the topic with a brief conclusion, citing the references at the end.

Case Study

Case studies are accepted with a view to add additional information related to the investigative research that advances in the field of Neurology, Psychology and Gerontology. It should add value to the main content/article submitted, by providing key insights about the core area. Cases reports must be brief and follow a clear format such as Cases and Methods Section (That describe the nature of the clinical issue and the methodology adopt to address it), discussion section that analyzes the case and a Conclusion section that sums up the entire case.

Editorials

Editorials are concise commentaries on a currently published article/issue on Neurology, Psychology and Gerontology. Editorial office may approach for any such works and authors must submit it within three weeks from the date of receiving invitation.

Clinical Images

Clinical Images are nothing but photographic depictions of Neurology, Psychology and Gerontology and it should not exceed more than 5 figures with a description, not exceeding 300 words. Generally no references and citations are required here. If necessary, only three references can be allowed. Do not add separate figure legends to clinical images; the entire clinical image text is the figure legend. Images should be submitted with the manuscript in one of the following formats: .tiff (preferred) or .eps.

Letters to the Editor/Concise Communications

Letters to the editor should be limited to commentaries on previous articles published with specific reference to issues and causes related to it. It should be concise, comprehensive and brief reports of cases or research findings. It does not follow a format such as abstract, subheads, or acknowledgments. It is more a response or the opinion of the reader on a particular article published and should reach the editor within 6 months of article publication.

Acknowledgement

This section includes acknowledgement of people, grant details, funds, etc. #Note: If an author fails to submit his/her work as per the above instructions, they are requested to maintain clear titles namely headings, subheading.

Tables These should be used at a minimum and designed as simple as possible. We strongly encourage authors to submit tables as .doc format. Tables are to be typed double-spaced throughout, including headings and footnotes. Each table should be on a separate page, numbered consecutively in Arabic numerals and supplied with a heading and a legend. Tables should be self-explanatory without reference to the text. Preferably, the details of the methods used in the experiments should be described in the legend instead of the text. The same data should not be presented in both table and graph form or repeated in the text. Cells can be copied from an Excel spreadsheet and pasted into a word document, but Excel files should not be embedded as objects.

#Note: If the submission is in PDF format, the author is requested to retain the same in .doc format in order to aid in completion of process successfully.

Figures

The preferred file formats for photographic images are .doc, TIFF and JPEG. If you have created images with separate components on different layers, please send us the Photoshop files. All images must be at or above intended display size, with the following image resolutions: Line Art 800 dpi, Combination (Line Art + Halftone) 600 dpi, Halftone 300 dpi. See the Image quality specifications chart for details. Image files also must be cropped as close to the actual image as possible. Use Arabic numerals to designate figures and upper case letters for their parts (Figure 1). Begin each legend with a title and include sufficient description so that the figure is understandable without reading the text of the manuscript. Information given in legends should not be repeated in the text.

Figure legends:

These should be typed in numerical order on a separate sheet.

Tables and Equations as Graphics

If equations cannot be encoded in MathML, submit them in TIFF or EPS format as discrete files (i.e., a file containing only the data for one equation). Only when tables cannot be encoded as XML/SGML can they be submitted as graphics. If this method is used, it is critical that the font size in all equations and tables is consistent and legible throughout all submissions.

Supplementary Information

All Supplementary Information (figures, tables and Summary diagram/, etc.) is supplied as a single PDF file, where possible. File size within the permitted limits for Supplementary Information. Images should be a maximum size of 640 x 480 pixels (9 x 6.8 inches at 72 pixels per inch).

Proofs and Reprints

Electronic proofs will be sent as an e-mail attachment to the corresponding author as a PDF file. Page proofs are considered to be the final version of the manuscript and no changes will be made in the manuscript at the proof stage. Authors can freely download the PDF file. Hard copies of the documents are available on request.

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Submit Manuscript

The Journal publishes high-quality original articles, reviews, editorials, and case reports addressing all aspects of Neurology, Psychology and Gerontology. It delivers timely interpretations of key scientific developments in psychology, aging, and related areas of study.
Known personalities with expertise and published studies in a specific field are invited to write reviews and editorials in our journal. Un-invited reviews will also be accepted if written by experts with publications in the field.

Manuscripts submitted to the journal will be accepted on the understanding that the author has not previously submitted the paper to another journal or had the material published elsewhere. We recommend the authors to read the formatting guide completely as it describes how to prepare manuscript for submission.

You may submit manuscripts online at www.scholarscentral.org/submissions/mental-health-aging.html or You may submit manuscripts as an email attachment to editor@alliedacademies.org

APPENDIX 2- PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	

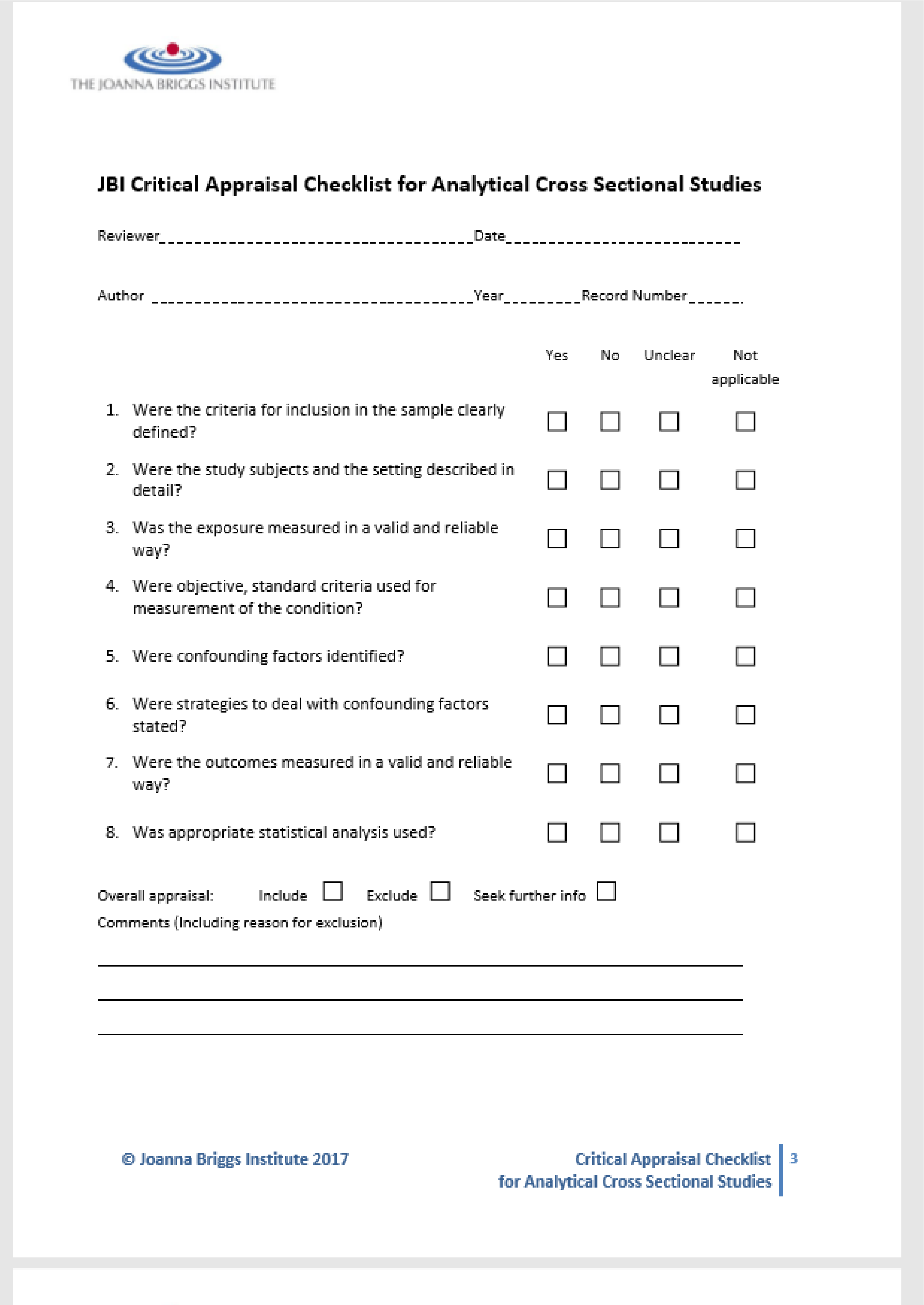
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

APPENDIX 3- Quality Assessment Tools

Analytical Cross-Sectional Appraisal Tool:



THE JOANNA BRIGGS INSTITUTE

JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies

Reviewer______________________________________Date_____________________________

Author _______________________________________Year_________Record Number______.

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	☐	☐	☐	☐
2. Were the study subjects and the setting described in detail?	☐	☐	☐	☐
3. Was the exposure measured in a valid and reliable way?	☐	☐	☐	☐
4. Were objective, standard criteria used for measurement of the condition?	☐	☐	☐	☐
5. Were confounding factors identified?	☐	☐	☐	☐
6. Were strategies to deal with confounding factors stated?	☐	☐	☐	☐
7. Were the outcomes measured in a valid and reliable way?	☐	☐	☐	☐
8. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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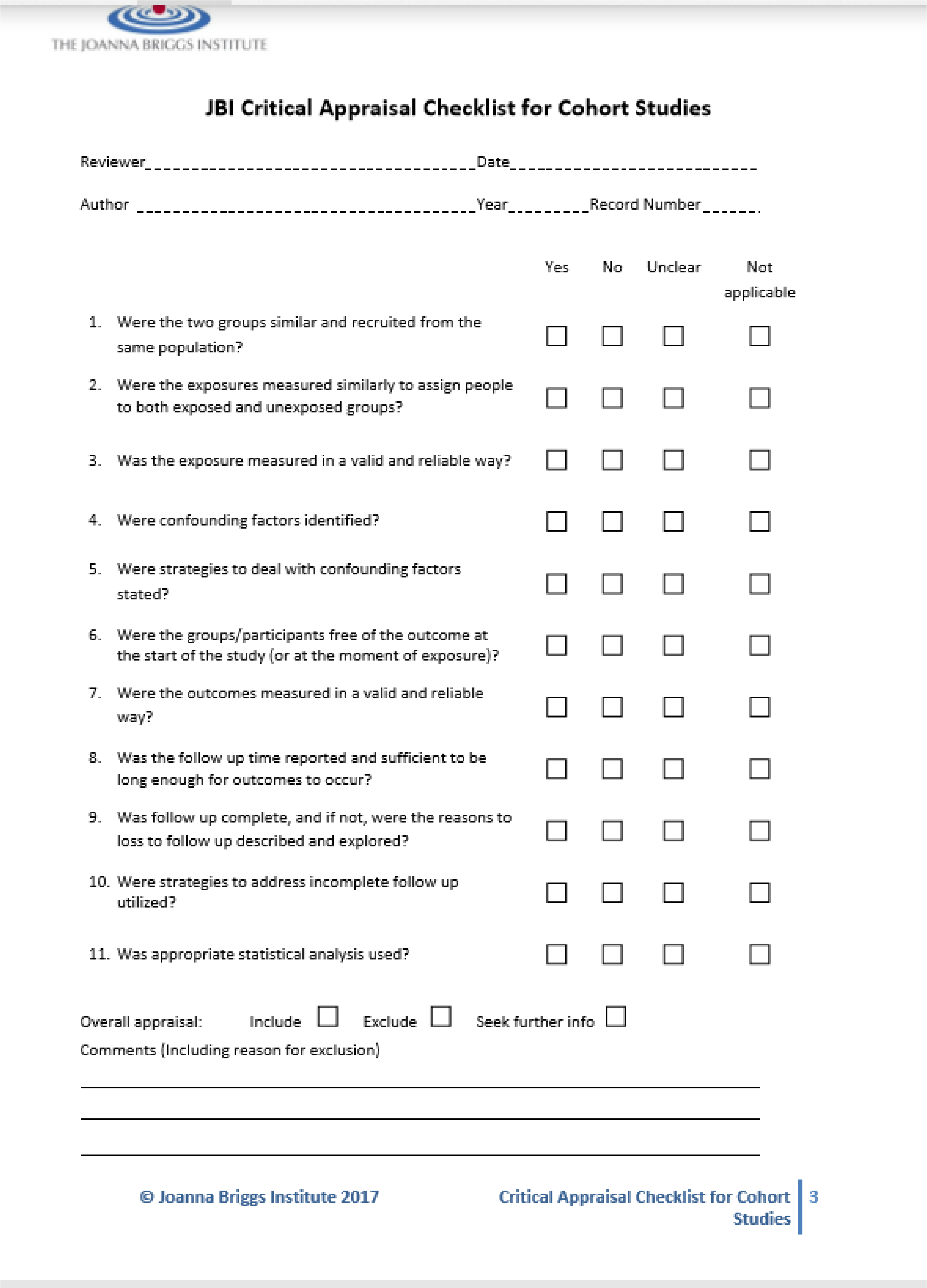
Cohort Study Appraisal Tool



THE JOANNA BRIGGS INSTITUTE

JBI Critical Appraisal Checklist for Cohort Studies

Reviewer_________________________________Date_________________________

Author __________________________________Year_________Record Number______

	Yes	No	Unclear	Not applicable
1. Were the two groups similar and recruited from the same population?	☐	☐	☐	☐
2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	☐	☐	☐	☐
3. Was the exposure measured in a valid and reliable way?	☐	☐	☐	☐
4. Were confounding factors identified?	☐	☐	☐	☐
5. Were strategies to deal with confounding factors stated?	☐	☐	☐	☐
6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	☐	☐	☐	☐
7. Were the outcomes measured in a valid and reliable way?	☐	☐	☐	☐
8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	☐	☐	☐	☐
9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	☐	☐	☐	☐
10. Were strategies to address incomplete follow up utilized?	☐	☐	☐	☐
11. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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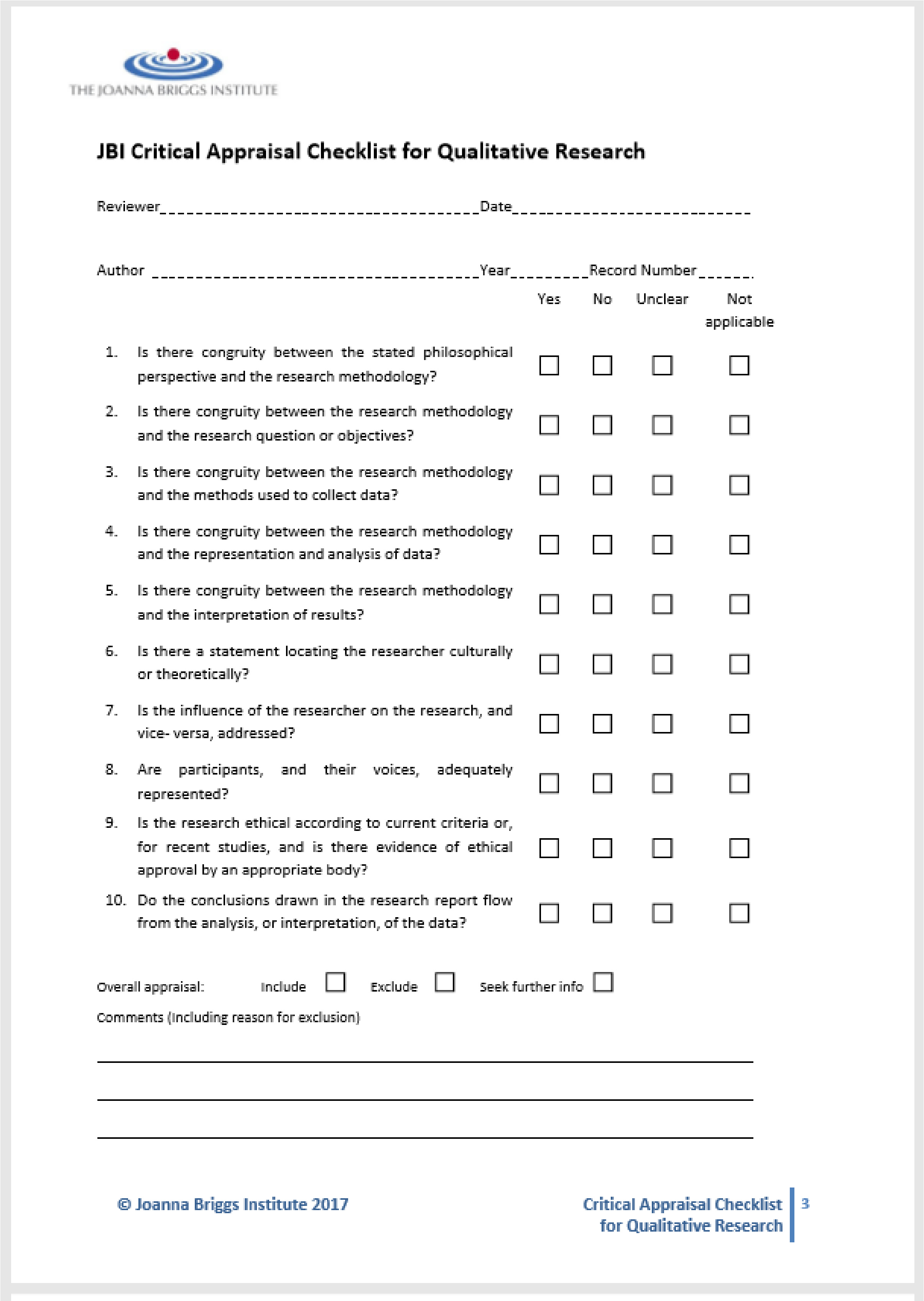
Qualitative Appraisal Tool



THE JOANNA BRIGGS INSTITUTE

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer______________________________________Date_____________________________

Author ______________________________________Year_________Record Number______

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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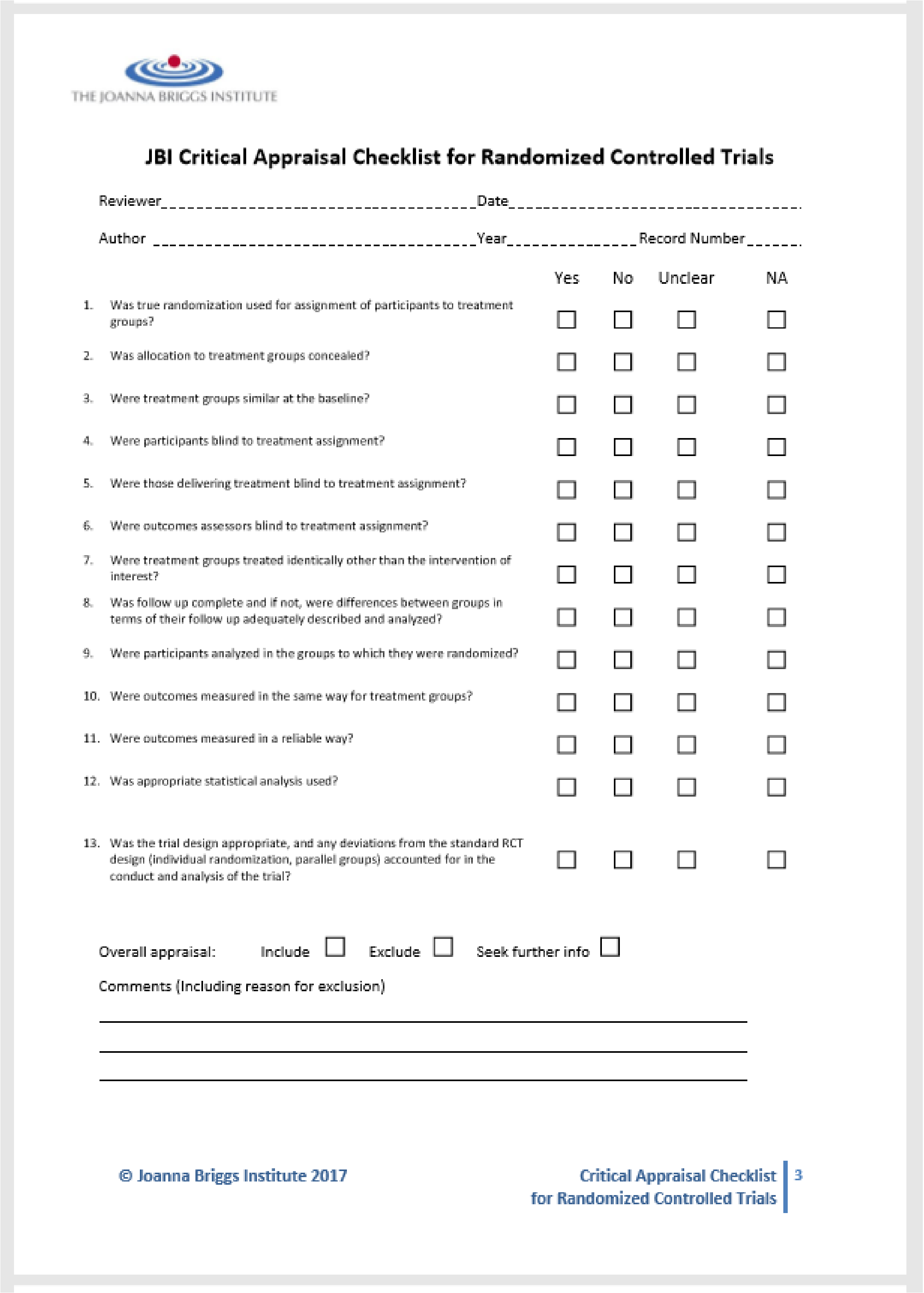
RCT Appraisal Tool



THE JOANNA BRIGGS INSTITUTE

JBI Critical Appraisal Checklist for Randomized Controlled Trials

Reviewer____________________________________Date__________________________________

Author ____________________________________Year______________Record Number______

	Yes	No	Unclear	NA
1. Was true randomization used for assignment of participants to treatment groups?	☐	☐	☐	☐
2. Was allocation to treatment groups concealed?	☐	☐	☐	☐
3. Were treatment groups similar at the baseline?	☐	☐	☐	☐
4. Were participants blind to treatment assignment?	☐	☐	☐	☐
5. Were those delivering treatment blind to treatment assignment?	☐	☐	☐	☐
6. Were outcomes assessors blind to treatment assignment?	☐	☐	☐	☐
7. Were treatment groups treated identically other than the intervention of interest?	☐	☐	☐	☐
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	☐	☐	☐	☐
9. Were participants analyzed in the groups to which they were randomized?	☐	☐	☐	☐
10. Were outcomes measured in the same way for treatment groups?	☐	☐	☐	☐
11. Were outcomes measured in a reliable way?	☐	☐	☐	☐
12. Was appropriate statistical analysis used?	☐	☐	☐	☐
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

____

____

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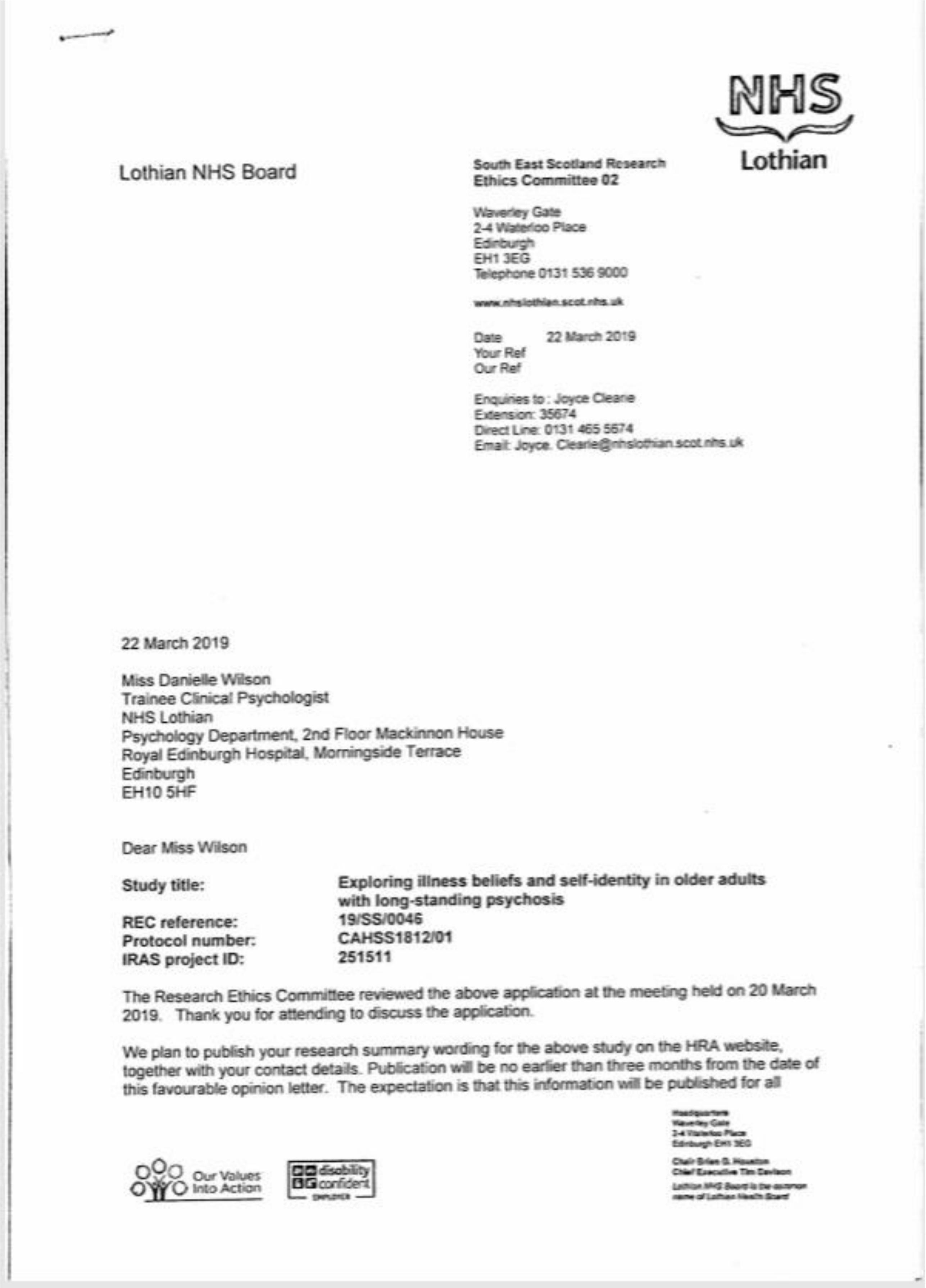
APPENDIX 4- Ethical Approval and NHS R&D



Lothian NHS Board

NHS
Lothian

South East Scotland Research
Ethics Committee 02

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000

www.nhslothian.scot.nhs.uk

Date 22 March 2019
Your Ref
Our Ref

Enquiries to : Joyce Clearie
Extension: 35674
Direct Line: 0131 465 5674
Email: Joyce. Clearie@nhslothian.scot.nhs.uk

22 March 2019

Miss Danielle Wilson
Trainee Clinical Psychologist
NHS Lothian
Psychology Department, 2nd Floor Mackinnon House
Royal Edinburgh Hospital, Morningside Terrace
Edinburgh
EH10 5HF

Dear Miss Wilson

Study title:	**Exploring illness beliefs and self-identity in older adults with long-standing psychosis**
REC reference:	**19/SS/0046**
Protocol number:	**CAHSS1812/01**
IRAS project ID:	**251511**

The Research Ethics Committee reviewed the above application at the meeting held on 20 March 2019. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all

studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request.
Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

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

1. The following changes/revisions should be made to the Participant Information sheets.
   Participant PIS
    a. Revise wording so more understandable to a lay person. E.g. reconsider terms such as emerging themes. Do typographical check of participant documentation.
    b. ✓ Revise wording so clear that all interviews will be held on NHS premises.
    c. ✓ Add statement making clear that anonymised quotes will be published.
    d. ✓ Needs to make it clearer about audio recording (including security and destruction arrangements.
    e. ✓ Needs to be explicitly clear what arrangements are regarding any disclosures of criminality or matters relating to child protection.
    f. Need contact phone numbers for CI and other key contacts provided e.g. Independent advisor
    g. ✓ Consider using larger font size for ease of readability
    h. Confirm time to complete BPRS should be adequate
2. The following changes/revisions should be made to the consent forms
    a. ✓ Need additional bullet points added to allow for use of audio recordings and for anonymous quotes to be published.
    b. ✓ Need bullet point and tick box to allow for lay feedback.

3. Please provide semi-structure interview plan particularly initial part.

Points for note

a. An appropriate GDPR information sheet should be used no longer DPA.
b. Please consider registering the research on a public database.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please do not hesitate to contact me if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		12 February 2019
GP/consultant information sheets or letters [GP letter]	1.0	12 February 2019
IRAS Application Form [IRAS_Form_25022019]		25 February 2019
IRAS Application Form XML file [IRAS_Form_25022019]		25 February 2019
IRAS Checklist XML [Checklist_25022019]		25 February 2019
IRAS Checklist XML [Checklist_06032019]		06 March 2019
Letters of invitation to participant [Appointment letter to participant]	1.0	12 February 2019
Non-validated questionnaire [Participant Demographics Questionnaire]	1.0	12 February 2019
Other [Sponsor insurance and indemnity]		24 July 2018
Other [Sponsor insurance/indemmity form]		31 July 2018
Other [Sponsor insurance/indemnity]		31 July 2018
Participant consent form [Participant Consent Form]	1.0	12 February 2019
Participant information sheet (PIS) [Participant Information Sheet]	1.0	12 February 2019
Research protocol or project proposal [Study Protocol]	1.0	12 February 2019
Summary CV for Chief Investigator (CI) [CI research CV]	1.0	12 February 2019
Summary CV for supervisor (student research) [Academic supervisor CV]	1.0	13 February 2019
Validated questionnaire [BPRS form]	1.0	12 February 2019

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

NHS
Lothian

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/SS/0046	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Mr Lindsay Murray
Chair

E-mail: joyce.clearie@nhslothian.scot.nhs.uk

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments*
	"After ethical review – guidance for researchers
Copy to:	*Ms Charlotte Smith*

Lothian NHS Board **South East Scotland Research Ethics Committee**
02

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000

www.nhslothian.scot.nhs.uk

Date 18 June 2019

Your Ref Our Ref

Enquiries to : Joyce Clearie

Extension: 35674

Direct Line: 0131 465 5674 Email: Joyce. Clearie@nhslothian.scot.nhs.uk

18 June 2019

Miss Danielle Wilson

School of Health in Social Science

The University of Edinburgh

Medical School, Teviot
Place EH8 9AG

Dear Miss Wilson

Study title: **Exploring illness beliefs and self-identity in older adults with longstanding psychosis**

REC reference: **19/SS/0046**

Protocol number: **CAHSS1812/01**

IRAS project ID: **251511**

Thank you for your letter received 18th June 2019. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 March 2019

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Initial semi-structured Interview Plan]	1.0	12 June 2019
IRAS Checklist XML [Checklist_17062019]		17 June 2019
Other [Response to the REC-conditions]	1.0	12 June 2019
Participant consent form [Consent Form]	2.0	12 June 2019
Participant information sheet (PIS) [Participant Information Sheet]	2.0	12 June 2019

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		12 February 2019
GP/consultant information sheets or letters [GP letter]	1.0	12 February 2019
Interview schedules or topic guides for participants [Initial semi-structured Interview Plan]	1.0	12 June 2019
IRAS Application Form [IRAS_Form_25022019]		25 February 2019
IRAS Application Form XML file [IRAS_Form_25022019]		25 February 2019
IRAS Checklist XML [Checklist_17062019]		17 June 2019

Letters of invitation to participant [Appointment letter to participant]	1.0	12 February 2019
Non-validated questionnaire [Participant Demographics Questionnaire]	1.0	12 February 2019
Other [Sponsor insurance and indemnity]		24 July 2018
Other [Sponsor insurance/indemnity form]		31 July 2018
Other [Sponsor insurance/indemnity]		31 July 2018
Other [Response to the REC-conditions]	1.0	12 June 2019
Participant consent form [Consent Form]	2.0	12 June 2019
Participant information sheet (PIS) [Participant Information Sheet]	2.0	12 June 2019
Research protocol or project proposal [Study Protocol]	1.0	12 February 2019
Response to Additional Conditions Met [Response to Additional conditions met]		
Summary CV for Chief Investigator (CI) [CI research CV]	1.0	12 February 2019
Summary CV for supervisor (student research) [Academic supervisor CV]	1.0	13 February 2019
Validated questionnaire [BPRS form]	1.0	12 February 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

19/SS/0046	**Please quote this number on all correspondence**

Yours sincerely

Joyce Clearie

SESREC 2 Manager

E-mail: joyce.clearie@nhslothian.scot.nhs.uk

Copy to: *Miss Danielle Wilson*
Ms D Aitken, NHS Lothian

Lead Nation
Scotland: nhsg.NRSPCC@nhs.net

Lothian NHS Board

01 October 2019

Miss Danielle Wilson
School of Health in Social Science
The University of Edinburgh
Medical School, Teviot Place
EH8 9AG

Dear Miss Wilson

Study title:

REC reference:
Protocol number:
Amendment number:
Amendment date:
IRAS project ID:

South East Scotland Research Ethics Committee 02

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000

www.nhslothian.scot.nhs.uk

Date 1 October 2019

Your Ref Our Ref

Enquiries to : Joyce Clearie
Extension: 35674
Direct Line: 0131 465 5674
Email: Joyce. Clearie@nhslothian.scot.nhs.uk

Exploring illness beliefs and self-identity in older adults with longstanding psychosis 19/SS/0046
CAHSS1812/01
1
13 September 2019
251511

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved Documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Notice of Substantial Amendment (non-CTIMP) [Notice of SA 1]	1	13 September 2019
Participant consent form [PCF]	3	18 September 2019
Participant information sheet (PIS) [PIS]	3	18 September 2019
Research protocol or project proposal [Protocol]	2.0	18 September 2019

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/SS/0046: Please quote this number on all correspondence

Yours sincerely

Mr Lindsay Murray
Chair
E-mail: joyce.clearie@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

South East Scotland REC 02

Attendance at Sub-Committee of the REC meeting on September 2019

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Balkishan Agrawal	General Practitioner	Yes	
Mr Lindsay Murray	Health & Safety Manager	Yes	Chair
Professor Lindsay Sawyer	Professor Emeritus	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Joyce Clearie	REC Manager

University Hospitals Division
Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ
FM/CK/approval

NHS
Lothian

Research & Development

Room El.16
Tel: 0131 242 3330

Email:
accord@nhslothian.scot.nhs.uk

Director: Professor Tim Walsh

23 July 2019

Miss Danielle Wilson
Psychology Department, Mackinnon House

Royal Edinburgh Hospital
Edinburgh

EH10 5HF

Dear Miss Wilson

Lothian Project No: 2019/0171 REC No: 19/SS/0046

Title of Research: Exploring illness beliefs and self-identity in older adults with long-standing psychosis

Participant Information Sheet:
Version 2.0, dated 12 June 2019

Consent Form:
Version 2.0, dated 12 June 2019

Protocol: Version 1.0, dated 12 February 2019

I am pleased to inform you this letter provides Site Specific approval for NHS Lothian for the above study and you may proceed with your research, subject to the conditions below.

We note that this study has obtained Caldicott approval for the use of a portable device for audio recording. You are responsible for informing the NHS Lothian R&D Office if there are any changes to the study that impact the terms of this approval.

Please note that the NHS Lothian R&D Office must be informed of any changes to the study such as amendments to the protocol, funding, recruitment, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please keep this office informed of the following study information, which is a condition of NHS Lothian R&D Management Approval:

1. Date you are ready to begin recruitment, date of the recruitment of the first participant and the monthly recruitment figures thereafter.

2. Date the final participant is recruited and the final recruitment figures.
3. - Date your study / trial is completed within NHS Lothian.

I Wish you every success with your study.

Yours sincerely

yours sincerely

Fiona McArdle.

Ms Fiona McArdle
Deputy Director

Cc: Ms Tracey McKigen, Services Director, Royal Edinburgh Hospital, NHS Lothian
Ms Kaye Skey, Clinical Service Development Manager, MCH, NHS Lothian

Mr Nick Clater, Senior Service Manager MHMT, NHS Lothian

Ms Nicola Cochrane Service Manager Adult & Old Adult Mental Health, NHS Lothian

APPENDIX 5 – Written Consent Form

CONSENT FORM

Participant ID: ☐

Chief Investigator: Danielle Wilson, Trainee Clinical Psychologist, Lothian Older Peoples Psychology Service, Royal Edinburgh Hospital.

Please initial box

1. I confirm that I have read and understand the information sheet V2.0 (Date 12/06/2019) and the Data Protection Information Sheet (V1.0, 12/02/2019) for the above study and have had the opportunity to consider the information and ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsors (NHS Lothian and the University of Edinburgh) or from the/other NHS Board(s) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records ☐

4. I agree to my General Practitioner being informed of my participation in this study. ☐

5. I agree to the researcher having access to my clinical notes in order to confirm study eligibility criteria. ☐

6. I agree to my interview being audio recorded for the purpose of accurate data collection ☐

7. I agree to anonymous quotations from my interview being publish as part of the write-up of this study. ☐

8. I agree to take part in the above study. ☐

Optional consent point

9. I agree to be contacted following my interview to give my feedback on the ideas developed from my interview. ☐

__________________________	__________________	__________________
Name of Participant	Date	Signature
___________________________	__________________	__________________
Name of Person taking consent	Date	Signature

APPENDIX 6- Participant Information Sheet

Exploring the impact of illness beliefs on the self-identity of older adults with long-standing psychosis

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. The researcher can be contacted if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study aims to increase our understanding of people's experiences of living with psychosis throughout their lives, and how their experiences may have impacted them. Psychosis can be described as a mental health condition that results in a person experiencing reality differently to those around them, for example through hearing voices or holding unusual beliefs. Currently, there is very little known about the impact of long-standing psychosis in later life, with the majority of research focusing on a psychosis occurring for the first time in later life or experiences in early adulthood. These experiences are potentially significantly different, and therefore so may be aspects of the treatment required to reduce psychological distress.

Why have I been asked to take part?

You have been asked to take part as you are over the age of 55 and have either previously been, or are currently, receiving care through your community mental health team and have a diagnosis of psychosis that you have dealt with throughout your life. We asked your health care workers to put forward people who may be suitable to take part in this research and they asked you if you would agree to reading the following information.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form to show that you agree to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive now or in the future.

What will happen if I take part?

If you decide to take part in this study, you will be contacted by the researcher to arrange a suitable time to meet. All interviews will take place at the NHS site you are familiar with attending. The researcher (Danielle Wilson, Trainee Clinical Psychologist) will go through this information sheet with you and give you the opportunity to ask any questions you may have about taking part in the study. The researcher will then ask you to sign a written consent form to agree to take part. You will be asked at the same time if you consent to being contacted after your interview to give feedback on the ideas gathered from your interview. You do not have to consent to doing this to take part in the study.

You will be asked to complete 2 brief questionnaires. One will ask some general information about you and the other about any current symptoms of psychosis. These questionnaires should take no longer than 30 minutes to complete. The researcher will then ask you some questions about your experience of psychosis, including how you felt about your diagnosis and how this may have impacted your life so far. The interview will last between 30-60 minutes and will be audio recorded with your consent for the purpose of accurate data collection. Once the researcher has been able to gather initial ideas from your interview, you will be contacted to arrange a second meeting for you to give feedback on the findings, and if they accurately reflect your experience. This will only happen if you have consented to being contacted.

You will have to give up a maximum of an hour and a half of your time to attend the interview appointment.

Any care you currently receive from your clinical team will not be affected in any way by agreeing or not agreeing to take part in this study.

What are the possible benefits of taking part?

You may not get a direct benefit from taking part in this study. However, the results of this study aim to help our understanding of long-standing psychosis in adults over the age of 55, and hope to therefore inform on the future healthcare of other patients.

What are the possible disadvantages and risks of taking part?

It is not anticipated for there to be many disadvantages of taking part. However, it is possible that discussing some of your experiences of your mental health may be distressing or upsetting for you. If this is the case, you can discuss this with either the researcher or a member of your usual clinical team following your interview. You can also opt to stop the interview whenever you need to. The researcher will be able to discuss this with you and there is no impact on your usual care should you withdraw from the study.

The time taken to take part in the study may also be a disadvantage, as you will have to give up a maximum of an hour and a half of your time to attend the interview appointment.

What if there is a problem?

If you have a concern about any aspect of this study please contact the researcher, who will do their best to answer your questions (see contact details below). If you remain unhappy and would like to complain formally, you can do this through the NHS Complaints Procedure. Contact details can be found below.

What happens when the study is finished?

At the end of the research study, the findings will be written up for publication of a doctoral research project, and for publication in a scientific journal. You will be asked if you would like to receive the study results once this is completed.

The anonymised data gathered during your time in the study (e.g interview write-up) will be kept for approximately 3 years. Following this time period, it will be removed and destroyed by NHS Lothian trust and The University of Edinburgh.

Will my taking part in the study be kept confidential?

All of the information that is collected during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

Once your data has been collected, all identifiable information will be removed from the data and you will be assigned an anonymous research study number. All attempts will be made to remove any identifying information. All audio recordings will be made on a securely protected recorder, which only approved members of the research team will have access to. Transcriptions (write ups) of interviews will be made on secure NHS computer systems and will only be accessed by approved members of the research team. The audio recording of your interview will be destroyed immediately after the researcher has written up your interview. Once anonymised, quotes from your interview may be published in the write up of the study. These will not be identifiable.

With your consent we will inform your GP that you are taking part. This will only be to inform them that you are participating, and your answers will not be shared with your GP.

All efforts will be made to ensure participant confidentiality throughout the study. Please note that if there are any disclosures relating to criminal offences or the safety of yourself or others (including that of a young person), the researcher has a legal obligation to share this information with relevant professionals.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the regulatory authorities and from the Sponsors (NHS Lothian and the University of Edinburgh) to access the data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

We will also ask you for your consent to access your medical notes. The purpose of this will be to confirm that you are eligible to take part in the research study by meeting inclusion criteria.

What will happen to the results of the study?

The study will be written up as part of a doctoral research thesis, as well as for publication in a scientific journal. We do not expect the results to be available until after the end of the study (2020). You will not be identifiable in any published results. The results of the study will be made available for you in a non-scientific format, should you wish to receive this. The researcher will discuss with you how you would like to receive these results.

Who is organising the research?

This study has been organised and sponsored by The University of Edinburgh and is funded by NHS Lothian.

Who has reviewed the study?

The study proposal has been reviewed by The University of Edinburgh's Doctorate in Clinical Psychology academic team. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. A favourable ethical opinion has been obtained from The South East Scotland 02 REC. NHS management approval has also been obtained.

If you have any further questions about the study please contact:

Danielle Wilson

Trainee Clinical Psychologist

Lothian Older People's Psychology Service

Royal Edinburgh Hospital

Morningside

Edinburgh

EH10 5HF

Telephone number: 0131 537 6901

If you would like to discuss this study with someone independent of the study please contact:

Dr Clara Calia

Lecturer in Clinical Psychology

The University of Edinburgh

School in Health and Social Science

Medical School (Doorway 6), Room 1M.3

Teviot Place

Edinburgh, EH8 9AG

Telephone number: 0131 651 3762

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team

2nd Floor

Waverley Gate

2 - 4 Waterloo Place

Edinburgh

EH1 3EG

Tel: 0131 465 5708

complaints.team@nhslothian.scot.nhs.uk.

Thank you for taking the time to read this information sheet.

APPENDIX 7- Study Protocol

Study Protocol

Exploring illness beliefs and self-identity in older adults with long-standing psychosis

	The University of Edinburgh School of Health in Social Science Medical School Teviot Place Edinburgh EH8 9AG
Protocol authors	**Danielle Wilson**
Chief Investigator	**Danielle Wilson, Trainee Clinical Psychologist**
Sponsor number	CAHSS1812/01
REC Number	
Version Number and Date	**Version 1.0 (12/02/2019)**

CONTENTS

INTRODUCTION

BACKGROUND

The field of psychosis and early intervention has been gaining increasing attention within the academic literature (e.g Braehler & Schwannauer, 2012; Langdon et al, 2013). However, psychosis in older adults who have experienced it recurrently throughout life has received much less consideration. The impact of psychosis on the individual, their support systems, and the NHS suggests that this is an important area for developing our understanding. Individuals who experience psychosis in early adulthood can likely still be dealing with the symptoms and psychosocial impact in their later life (Parker et al, 2007).

Through provision of better health care, people are living increasingly longer lives, resulting in a progressively ageing population (BMA, 2016), including individuals diagnosed with psychosis in earlier life. Evidence suggests that individuals with psychosis have a life span of 20 years less than individuals without due to a number of biopsychosocial factors, e.g increased risk of cardiovascular and respiratory issues, poorer health care, substance misuse and medication use (Jeste & Maglione, 2013). Most published literature focuses on the development and management of late onset psychosis (LoP), first episode of psychosis occurring in later life (e.g Giblin et al, 2004; McCulloch et al, 2006). Currently the management of longstanding psychosis appears to be a frequently neglected topic of academic research.

Illness attribution

The role of illness beliefs in health care have been well researched over the years, with a social cognition model adopted to understand these beliefs (Connor and Norman, 1995). Leventhal's Self-regulation Model (SRM) (Leventhal, Naerenz and Steele, 1984) is one of the most widely used models in understanding illness beliefs, and proposes 5 key dimensions in the attribution of illness:

- The perceived identity of the illness
- It's perceived consequences
- It's likely causes
- It's likely timeline (or sense of how long it will last)
- The potential for control or cure of the illness (added latterly by Lau and Hartman, 1983)

A cognitive representation of illness is then developed through the evaluation of one's ability of coping with it (Leventhal et al, 1984). These dimensions were developed into a questionnaire for assessing attributions of illness in physical health conditions called the Illness Perception Questionnaire (Weinman et al, 1996; latterly Illness Perception Questionnaire- Revised, Moss-Morris et al, 2002). Lobban & Barrowclough (2005) studied whether this questionnaire, with some adaptations to language within the descriptions, and the dimensions associated with illness belief could be applied to how we understand mental health problems, specifically schizophrenia. The same dimensions proposed in Leventhal's SRM were present in individual's understandings of schizophrenia, suggesting they are represented in both physical and mental health conditions. This studies participants (n=19) had received their schizophrenia diagnosis within the last 5 years, and therefore lacked investigation into the experiences of individuals with a longstanding illness. It did not include the views and experiences of older adults.

Theodore et al, (2012) used quantitative methods to investigate the effects of Illness beliefs on Quality of Life (QoL) outcomes in people with psychosis (n=81). Using regression analysis, the authors found that illness beliefs such as treatment control and consequences had a significant association with and influence on QoL outcomes ($r(80) = 0.29$, $p = 0.009$). Additionally, in a hierarchical multiple regression model, illness beliefs were found to contribute a significant proportion of variance explained in the model when QoL outcomes were the dependant variable (from 12 to 22% (F (3, 73) = 3.04, p\0.05, R2 = 0.22, adjusted R2 = 0.16)). This suggests that an individual's beliefs about their illness can impact how that individual experiences their world. However, the study did not explore how such beliefs came to be held and the subsequent impact on the individual's sense of self.

It is important to consider the wider socio-cultural contexts of the experiences of older adults with long-standing mental health difficulties, particularly the influences of cohort effects and the differences in the views and understanding of mental health as recently as 20 years ago (Knight and Poon, 2008). From the researcher's point of view, there is a strong likelihood that older adults with long standing psychosis may have received their diagnosis at a time where understanding of mental health difficulties was limited or misunderstood. This may have led to self-stigmatising beliefs and attributions of illness, perhaps compounded through the cohort beliefs and attitudes. Therefore, understanding the development of the individual's cognitive representation of their illness is required in order to understand the meanings attributed and the resulting effects on the self.

Stigma in mental health

The role of stigma and shame within mental health has been widely acknowledged to negatively impact on a range of psychosocial outcomes (e.g Corrigon et al, 2006; Thornicroft et al., 2009; Vass et al., 2015; Wang et al, 2018). A meta-analysis by Livingston & Boyd (2010) on the relationship of internalised stigma in people with mental health difficulties found a strong negative relationship between internalised stigma and a range of psychosocial factors. Correlation coefficients were calculated between studies and showed strong and consistent findings between high levels of internalised stigma and poorer self-esteem (r= -.55, p <.001), lower self-efficacy (r= -.54, p< .001), weakened social support/integration (r= -.28, p< .001) and decreased QoL (r= -.47, p<.001). This study also found a positive association between internalised stigma and psychiatric symptom severity (r=.41, p< .001). Watson, River and Corrigon (2005) proposed the socio-cognitive model of self-stigmatisation, within which they attribute awareness and agreement of stereotypes within the public to the development of internalised beliefs and negative evaluations. This could lead an individual to withdraw from social support and reduce levels of self-efficacy and self-esteem (Tzouvara et al, 2018; Brohan et al, 2010).

Pyle & Morrison (2014) conducted a qualitative study using Interpretive Phenomenological Analysis investigating individual's experiences of stigma in relation to a diagnosis of psychosis. Superordinate themes found to contribute to stigmatisation were those of "Judgement", '"Disclosure" and "Psychological Distress". Disclosure of illness to family and friends and the perceived negative judgements of social supports following this disclosure was felt by participants to be heavily influenced by negative, misrepresented media portrayals of people with psychosis, which led to felt stigmatisation by the participants of the study. . A constraint of this study was the age of the sample population. It failed to take into account the experiences of older adults, with the sample (n=9) ranging from 19-54 years, with adults aged 65+ excluded.

Individuals may experience a positive relationship with the symptoms of their illness (e.g. hallucinations) and attribute coping to the positive meaning they derive from their diagnosis (Klapheck et al, 2012). This raises the issues of resilience in individuals who have longstanding illnesses, and how they have developed a self-identity that encompasses their illness in a positive view. Exploring how these experiences may differ from those with negative self-identity in relation to illness could allow for development of interventions targeting distress maintenance.

Stigma and self-identity

Identity processes in adulthood as proposed by Whitbourne (1986;2002) reflects the work of Piaget (1975) and Erikson (1963), in that identity assimilation and accommodation can define how an individual makes sense of, and adapts the self to, new experiences associated with aging throughout adulthood (Whitbourne et al., 2002). Stryker (1980) proposed structural symbolic interactionism as a means for understanding how social structures affect the self and vice versa, and that as human beings we make sense of the world based on the social meanings prescribed to objects and situations (e.g Blumer, 1969; Mead 1934). Meanings are derived from prior experiences and social interactions (including social groups, Tajfel, 1982) which may include biases and "hidden forces" (Roe & Middleton, 2010) and include societal views of mental health problems.

The Division of Clinical Psychology recently proposed the Power Threat Meaning framework (Johnston & Boyle, 2018) aiming to re-address the way distressing experiences (such as those experienced during psychosis) are formulated. This framework may be beneficial in addressing some of the aforementioned issues of stigma and identity processes through taking into account the social, political and cultural environment within which these events are experienced. Table 1 details the proposed framework.

Table 10: Power Threat Meaning (PTM) framework core concepts (Johnston &Boyle, 2018)

Concept	**Description**
Power	The operation of power within the individuals work, be that coercive, political, economic or social
Threat	What emotional distress or threat does this operation of power create for the individual, their social structures and communities? How is this threat mediated biologically?
Meaning	The meaning of this operation of power and subsequent threat, and how we understand and evaluate these experiences socially, culturally and primitively. How does this meaning shape the expression of power and threat and our response to this?
Threat response	Our reaction to the cultivation of the above factors. Can be utilised by an individual, family, community and so on in order to maintain emotional safety and survival. Can be automatic or consciously learned responses.

The social-cognitive model of identity formation would sit within this framework. However generational influences are unknown, as the experiences of older adults are neglected within this document. Given that the population within the current study may endorse multiple "stigmatising" factors, (e.g negative societal view of older people alongside a severe and enduring mental illness) this framework may be beneficial in our understanding.

RATIONALE FOR STUDY

Overall there is a dearth of research in the area of longstanding mental illness in older adults. The development of psychological interventions appears to be hinged on the application of therapies developed for those of working age who may differ in cognitive attributions and appraisals, likely accounted for by cohort effects and subsequent beliefs. Multiple factors may make the experiences of older adults qualitatively different than younger adults (e.g cognitive decline; loss of social support through bereavement; transitional life stages, multiple physical health co-morbidities; cohort beliefs), and the research should reflect this. Therefore, following the Medical Research Council Framework (Möhler et al, 2015) a theoretical framework is needed to inform the development of a complex interventions to meet the needs of older people living with psychosis.

This study aims to contribute to the field of older adult psychology in light of the lack of current understanding regarding the experiences of older people with a long-standing illness, and their exclusion from the majority of research studies. The results aim to provide an understanding for services regarding the experience of individuals often-neglected from the research, and some of the factors that may influence how people respond to their illness. The results can be used to explore if the models of understanding illness currently discussed within the literature (eg SRM and PTM framework) fit with the study population to adequately explain their experiences, or if the emerged theoretical model requires consideration of other factors and the adaptation of the existing frameworks, to assist in directing future clinical research on the potential psychosocial interventions that may target some of these factors and improve patient outcomes.

STUDY OBJECTIVES AND AIMS

STUDY AIMS:

1) To understand how older people make sense of their mental health through the use of varying appraisals and cognitive representations of their illness (such as the perceived identity and chronicity of the illness, and other factors endorsed in the SRM model)
2) To understand the impact of the socio-culturally driven experiences of mental health and the subsequent impact on the self, to allow us to consider relevant psychological interventions for longstanding psychotic experiences

OBJECTIVES

Primary Objective

To explore the impact of long-standing psychosis on the self-identity of older adults.

Secondary Objectives/research questions

Does an individual’s cognitive representation of their illness (illness belief) impact upon their self-identity, either positively or negatively?

STUDY DESIGN

A qualitative research design applying Grounded Theory (Corbin & Strauss, 2008) with semi-structured open-ended questions will be applied. This approach will allow the researcher to investigate in depth the way that individuals make sense of their illness, and how this may have impacted them throughout their lives, and begin to establish an understanding of the needs of this population in terms of future interventions. Participants will take part in semi-structured interviews which will last approximately between 30-60 minutes and will take place within the participants preferred setting (e.g. within their care unit or NHS outpatient department). Interviews will be audio-recorded for the purpose of transcription and analysis and will be securely stored in accordance with local NHS and university procedures. Data will then be transcribed verbatim and analysed using a Grounded Theory methodology. Participants will also be asked to complete a short questionnaire regarding their current experiences of their illness for the purpose of study demographic information.

The study will last for approximately 1 year and 3 months from participant recruitment through to write up and completion. Recruitment will continue simultaneously with analysis, as per Grounded Theory protocol, until sufficient data is obtained for generation of a theoretical framework. The study completion date is estimated for May 2020.

Participants will be involved in the study for a maximum of approximately 75 minutes (including interview time and questionnaire completion). Following analysis, and in line with grounded theory methodology, available participants will be asked for their feedback on the emerged theoretical framework generated from their interviews to ensure accurate reflection of their experiences.

STUDY POPULATION

NUMBER OF PARTICIPANTS

For the current study, a sample size of 15 has been deemed appropriate and feasible for the study aims. See section 8.1 for a detailed description of sample size calculation, justification and confidence in achieving the required sample.

PARTICIPANT POPULATION

Older adults living with longstanding psychosis will be recruited (see section 4.3 below for inclusion/exclusion criteria). The study will take into account the experiences of individuals living with psychosis, schizophrenia and bipolar disorder. The sample will include adults over the age of 55. The likely cognitive and social impacts of long standing psychosis in adults of this age will be comparative to the functioning of an older adult without a diagnosis of psychosis (Jeste et al, 2011). For the purpose of this study, the term long standing has been operationalised to include illness over the length of 20 years or more. As research has shown that most first episodes of psychosis occur most frequently between puberty and mid-late 20’s (Jones, 2013), participants aged 55 and over may likely have had their illness for 20 years or more if recurrent in nature.

INCLUSION CRITERIA

To take part in the study individuals will need to meet the following inclusion criteria:

- Be an adult over the age of 55
- Have been given a diagnosis of a psychotic psychiatric disorder (such as psychosis, schizophrenia, bipolar disorder) prior to the age of 55, as diagnosed by an appropriate clinician based on DSM and ICD criteria
- Have evidence, as noted within medical records, of experiencing psychotic symptoms for 20+ years
- Be fluent in the English language in order to take part in a one-to-one semi structured interview
- Be able to provide written consent

EXCLUSION CRITERIA

Exclusion criteria:

- Be experiencing acute mental health difficulties at the time of recruitment
- Be actively expressing suicidal intent
- Have an established diagnosis of Dementia

PARTICIPANT SELECTION AND ENROLMENT

IDENTIFYING PARTICIPANTS

Participants will be recruited primarily from within the community setting of the NHS board that the study is taking place. Participants will be living either independently within the community or within supported accommodation. Individuals residing in Hospital Based Complex Clinical Care (HBCCC) units within the NHS board and individuals who have had previous inpatient treatment will also be approached for recruitment

Recruitment will take the form of 2 streams.

In stream 1, participants will be identified through their clinical team, primarily their named clinician (community psychiatric nurse, psychiatrist, psychologist, AHP). Participants will be approached by their clinical team member in the first instance and told about the research study. Participants will then be given the participant information sheet to read at their leisure and encouraged to ask questions should they wish to do so. Participants may be seen on an outpatient basis, or they may reside in long-term care (e.g HBCCC units). Participants may be at a variety of stages in terms of their treatment within the teams, including having completed a course of psychological therapy, be on the waiting list for therapy or only receiving medication management. This will be noted as part of the study demographics.

In stream 2, the chief investigator (CI) will attend meetings of the Royal Edinburgh Hospital Patient Council to discuss the study. Eligible members of the council (as defined by the inclusion criteria) will be given participant information sheets to read at their leisure and the contact details of the CI should they have any additional questions or if they wish to consent to taking part. If the individual is currently under the care of the community mental health team and has an ongoing keyworker/ case holder, study eligibility will be confirmed through the case holder. If the individual is not currently under the care of the community mental health team and subsequently has no named keyworker, the individual will sign a written consent form allowing the researcher access to their notes in order to confirm study eligibility.

See appendix 1 for recruitment procedure details

Recruitment will continue until write up of the study findings begins, approximately around 1 year. Recruitment will continue simultaneously with data analysis, as proposed in grounded theory methodology. Once identified through either of the above streams, participants will agree an approximate date for their interview to take place

Convenience sampling will be utilised for recruitment to the study.

CONSENTING PARTICIPANTS

Once participants have been given the information sheet by a member of their clinical team, or following the CI's attendance at the patient council meetings, participants will be given a minimum of 24 hours to consider taking part in the research. The CI's contact details will made available to the participants and the CI will be available to answer any questions participants may have regarding the study prior to consenting to taking part in the study.

The CI will collect informed consent from participants using a written consent form. These will be available within the study area for participants to read prior to meeting with the CI to give their consent, to allow participants time to think of any questions they may have and consider their consent.

WITHDRAWAL OF STUDY PARTICIPANTS

Participants are free to withdraw from the study up until the point of data analysis. A participant can also be withdrawn by the Investigator. If the participant chooses to withdraw from the study prior to data analysis, then any data collected up until that point will be removed from the study. Due to the analysis process of the chosen methodology (simultaneously with data collection and building on theoretical sampling), removal of data following anonymised data analysis will not be possible.

Participants will not have to give reason for withdrawing from the study. The only “discontinuation criteria” will be if the participant is feeling particularly overwhelmed or distressed during their interview and if continuing to take part is deemed by the CI to be impacting negatively on their mental health.

STUDY ASSESSMENTS

STUDY ASSESSMENTS

The main method of data collection within the study is through audio-recorded semi-structured interviews, however participants will be asked to complete a short demographics questionnaire and symptom severity screening questionnaire prior to their interview.

These questionnaires will be given to the participants by the CI directly before their interview for a one-off completion.

The screening measures are as follows:

1) A demographics questionnaire will be given to participants to complete which will collect information on: age; gender; length/duration of psychosis (from first episode to present day); education; occupation; ethnicity; the number of episodes of psychosis experienced in the last 5 years; brief history of substance use and any current/ongoing use (if applicable); length of stay in current place of residence; type of treatment (if applicable) they have received in the past (medical management only/psychological intervention/social); current medication.
2) A brief screening questionnaire regarding psychotic symptoms will be completed with the participants to screen for any current psychotic experiences. The Brief Psychiatric Ratings Scale (BPRS) is an 18 item 7 point-ordered category rating scale (Overall and Gorham, 1962), assessing main characteristics of psychotic symptoms (positive and negative symptoms). The questionnaire has been developed for instances where efficiency and speed in assessing these symptoms is important (Overall and Gorham, 1962) and would therefore be appropriate for use within the current study to ensure participant burden during the study remains low, whilst providing demographic information regarding the study population.

DATA COLLECTION

Data will be collected using a semi-structured interview. An interview schedule will be prepared to assist with this. Although Grounded Theory is used to produce themes from emerging data and guide the development of theory, the use of an interview schedule can be beneficial to novice researchers (Birks and Mills, 2011) and will allow for flow of interview and establishment of rapport.

The interview will aim to explore the development of the participant's view of their self-identity, and whether or not this is linked to their illness. The participant's beliefs about their illness and their experiences of perceived or self-stigmatisation will be explored.

Examples of potential interview questions include the following:

Can you tell me about when you received your diagnosis of psychosis?

How did you feel when you were told this?

What was your reaction to and understanding of your diagnosis?

What information were you given about your diagnosis at the time?

Questions will be asked to address the illness beliefs individuals have around their condition, based on Lobban et al's (2005) Illness Perception Questionnaire for Schizophrenia to ensure these concepts are being explored, and the impact this has had on the individual. Concepts within the PTM framework may also guide interview conversation if required. Although semi-structured to ensure key themes are addressed within the interview, the direction of the interview will follow that initiated by the participant to allow for discussion of key features of their experiences and reflection of their lived experiences.

Following the Grounded Theory methodology, data collection and analysis will be completed simultaneously. This allows for early identification of initial theoretical frameworks with which to explore throughout the study. Further details of the analytical process can be found in section 8.3.

It is intended that interviews will be completed in a single session with participants. However, should participants feel unable to complete the interview in one session, the CI will arrange to meet with the participant for additional sessions. Due to the nature of the study, no follow up data will be collected. However, participants will be asked if they would be willing to give their feedback on the initial proposed theoretical framework to allow for accurate reflection of their lived experiences, which will require meeting with the CI on one further occasion to give this feedback.

SOURCE DATA DOCUMENTATION

Data will be gathered in the form of audio recordings and two brief questionnaires (demographic information and screening questionnaire. The audio recordings will be stored securely on NHS computers for transcription and only accessed by the CI and approved members of the research team (academic and clinical supervisors). Once transcribed, the data will be anonymised through assigning each participant a randomised study number. Transcribed files will be stored in a securely locked cabinet only access by the chief and principle investigators. The anonymised raw data may also be kept in a locked case when required for transportation purposes. The CI may be required to take anonymised data (ie transcription extracts) outwith NHS premises for analysis purposes. This will be kept securely in locked cases and contain no identifiable information.

The demographic information and brief screening questionnaires will be paper based records, and will be stored in the locked filing cabinet within NHS premises that only approved members of the research team will have access to. Hard copies of participant consent forms will be kept in a separate locked filing cabinet within the CI's base within NHS premises that only approved members of the research team will have access to.

STATISTICS AND DATA ANALYSIS

SAMPLE SIZE CALCULATION

As the study takes a qualitative design, it is not applicable to calculate a study sample size for the purpose of power. However, a sample size of 15 has been deemed appropriate to the study aims and feasibility. Previous research in health care settings that have utilised a Grounded Theory methodology appear to have ranging sample sizes, perhaps reflecting the developmental nature of the research questions and the sufficient sample size for theoretical saturation to occur (Harper and Thompson, 2011; Green and Thorogood, 2018). Published work was found to range from n=11 to n=32 (Fourie, 2009; Kartalova-O'Doherty et al, 2012 respectively).

Theoretical sampling (a proponent of grounded theory) suggests that recruitment and sampling continue until key theoretical concepts are achieved, and it is therefore difficult to predict pre-completion. However, the practicality of an open-ended sampling is not feasible for the current project (e.g constraint in study time). Additionally, the small number of individuals with longstanding psychosis who have reached older adulthood and who may be in contact with services regarding this, may limit this open-ended recruitment further.

CONFIDENCE IN SAMPLE SIZE

General prevalence rates of psychosis in older adults has been reported to be less than 3% in the UK (BMA, 2016). Exact figures for the number of older adults attending mental health services for treatment of psychosis has proven difficult to define. This may in part reflect the hard to reach nature of this population, and something the current study would hope to gain an understanding of. However, professionals currently working in the psychology services within the health board where the study will take place indicate that between 10-15 participants could be realistically recruited for the study, based on clinical experience and service provision in this board.

The Scottish government published a consensus paper in 2017 looking at the number of people in Hospital Based Complex Clinical Care (HBCCC) and long stay units. Overall, there were 1884 people receiving care in HBCCC and long stay units. According to this report, 79% of individuals were receiving this care for mental health reasons. 47% of the study population were aged 65+ and a third had input from a consultant within Old Age Psychiatry. The NHS board within which the current project will take place was found to provide care to 334 people in HBCCC units (Scottish Government, 2017), speculating that a sample size of 15 should be achievable. However, there was no information available on the breakdown of mental health conditions served within the units, so the number of older adults residing in these areas with longstanding psychosis is relatively unknown.

PROPOSED ANALYSES

1) Demographic and screening variables will be analysed with descriptive statistics using SPSS to inform readers of the participant demographics, in order to understand the population within which the theoretical framework is built upon.
2) Semi-structured interviews will be analysed in line with Grounded Theory methodology (Corbin and Strauss, 2008). Interviews will be transcribed verbatim and the data anonymised for the purpose of analysis. Grounded theory can be used in areas of study where there is little known about the phenomenon or experience being investigated and where researchers wish to elaborate in understandings of this. Through the use of grounded theory, researchers can begin to develop a consistent set of concepts that provide a thorough theoretical understanding of the event being studied (e.g Corbin and Strauss, 2008; Charmaz, 2006). Corbin and Strauss (2008) discuss the idea of the influence of symbolic interaction in their grounded theory framework. This would appear to match the proposed research questions regarding identity formation, and Blumer's (1969) proposed framework for understanding the process of meaning making based on socially prescribed meanings, and therefore is a good fit for the study aims.

Simultaneous data collection and analysis will help to guide the process of data collection in order to accumulate data for emerging key themes (Charmaz, 2006). This process leads to theoretical sampling, an important component of grounded theory (Corbin and Strauss, 2008), which allows for richer development of the theory. Theoretical sampling reflects the aim of grounded theory in obtaining a "good fit" between data and emerging theory. Memo keeping throughout the process of data collection and analysis is key in developing and clarifying categories within the data.

Supervision will also be sought from the academic supervisor regarding the emerging themes throughout the process of analysis, and their validity within the data. This will ensure the integrity of the themes emerging from the data. The emerged theory will be fed back and discussed with participants to ensure those developed are a true reflection of participant experiences.

If participants choose to withdraw from the study before the end of the data collection period, their data previously collected will be destroyed and not used within the analysis of the study.

RISKS

There are no immediate risks identified with undertaking this study. However, consideration of the emotional impact of the nature of the study has been given. The process of undertaking an interview regarding a long-standing illness and the potentially negative impact this has had on an individual's life has the possibility of being distressing for the participant. Ways for managing this risk will need to be taken into consideration. A protocol will be followed in instances where participants may become distressed during interviews. Participants can choose to terminate the interview whenever they wish to do so. The participant can discuss how they are feeling with the CI, who will be conducting the interview and has experience with dealing with distressed individuals in the role of a Trainee Clinical Psychologist, and will in the first instance be familiar with the health board's protocol for handling risk and risk assessments. The main care provider for the participant will be notified and the participant can choose to discuss it with them if they would prefer to do so. Support from the clinical team will be given as usual to aid in helping the participant manage any distress they are experiencing.

Participants will have consented to taking part in the research after sufficient time for reading the Participant Information Sheet and being able to ask the researcher any questions they may have regarding this. They are able to withdraw at any time throughout the study. Throughout the process, the researcher will use clinical judgement to assess any levels of distress the participant may be experiencing and check this with them, and remind them that they are free to withdraw at any time should they feel this necessary.

The researcher will receive clinical supervision throughout the recruitment process from a qualified clinical psychologist within the health board.

A range of out of hours/emergency contact numbers will be made available to the participants should this be required, and can be found in appendix 2.

OVERSIGHT ARRANGEMENTS

INSPECTION OF RECORDS

Investigators and institutions involved in the study will permit trial related monitoring and audits on behalf of the sponsor, REC review, and regulatory inspection(s). In the event of audit or monitoring, the Investigator agrees to allow the representatives of the sponsor direct access to all study records and source documentation. In the event of regulatory inspection, the Investigator agrees to allow inspectors direct access to all study records and source documentation.

RISK ASSESSMENT

A study specific risk assessment will be performed by representatives of the co-sponsors, ACCORD monitors and the QA group, in accordance with ACCORD governance and sponsorship SOPs. Input will be sought from the Chief Investigator or designee. The outcomes of the risk assessment will form the basis of the monitoring plans and audit plans. The risk assessment outcomes will also indicate which risk adaptions (delete if no adaptations were possible) could be incorporated into to trial design.

STUDY MONITORING AND AUDIT

The ACCORD Sponsor Representative will assess the study to determine if an independent risk assessment is required. If required, the independent risk assessment will be carried out by the ACCORD Quality Assurance Group to determine if an audit should be performed before/during/after the study and, if so, at what frequency.

Risk assessment, if required, will determine if audit by the ACCORD QA group is required. Should audit be required, details will be captured in an audit plan. Audit of Investigator sites, study management activities and study collaborative units, facilities and 3rd parties may be performed.

GOOD CLINICAL PRACTICE

ETHICAL CONDUCT

The study will be conducted in accordance with the principles of the International Conference on Harmonisation Tripartite Guideline for Good Clinical Practice (ICH GCP).

Before the study can commence, all required approvals will be obtained and any conditions of approvals will be met.

INVESTIGATOR RESPONSIBILITIES

The CI is responsible for the overall conduct of the study at the site and compliance with the protocol and any protocol amendments. In accordance with the principles of ICH GCP, the following areas listed in this section are also the responsibility of the CI. Responsibilities may be delegated to an appropriate member of study site staff.

Delegated tasks must be documented on a Delegation Log and signed by all those named on the list prior to undertaking applicable study-related procedures.

INFORMED CONSENT

The CI is responsible for ensuring informed consent is obtained before any protocol specific procedures are carried out. The decision of a participant to participate in clinical research is voluntary and should be based on a clear understanding of what is involved.

Participants must receive adequate oral and written information – appropriate Participant Information and Informed Consent Forms will be provided. The oral explanation to the participant will be performed by the CI and will cover all the elements specified in the Participant Information Sheet and Consent Form.

The participant must be given every opportunity to clarify any points they do not understand and, if necessary, ask for more information. The participant must be given sufficient time to consider the information provided. The participant may withdraw their consent to participate at any time without loss of benefits to which they otherwise would be entitled.

The participant will be informed and asked to agree to their medical records being inspected by regulatory authorities and representatives of the sponsor(s).

The CI and the participant will sign and date the Informed Consent Form(s) to confirm that consent has been obtained. The participant will receive a copy of this document and a copy filed in the Investigator Site File (ISF) and participant's medical notes (if applicable).

STUDY SITE STAFF

The CI will be familiar with the protocol and the study requirements. It will be the CI's responsibility to ensure that all staff assisting with the study are adequately informed about the protocol and their trial related duties.

DATA RECORDING

The CI is responsible for the quality of the data recorded in the CRF at each Investigator Site.

INVESTIGATOR DOCUMENTATION

- The CI will ensure that the required documentation is available in local Investigator Site files (ISFs).

CONFIDENTIALITY

All records must be identified in a manner designed to maintain participant confidentiality. All records (such as signed consent forms and interview audio recordings) will be kept in a secure storage area with limited access. Clinical information will not be released without the written permission of the participant. The CI and study site staff involved with this study may not disclose or use for any purpose other than performance of the study, any data, record, or other unpublished, confidential information disclosed to those individuals for the purpose of the study. Prior written agreement from the sponsor or its designee must be obtained for the disclosure of any said confidential information to other parties.

DATA PROTECTION

All Investigators and study site staff involved with this study must comply with the requirements of the Data Protection Act 2018 with regard to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles. Access to collated participant data will be restricted to individuals from the research team treating the participants, representatives of the sponsor(s) and representatives of regulatory authorities.

Computers used to collate the data will have limited access measures via user names and passwords.

Published results will not contain any personal data that could allow identification of individual participants.

STUDY CONDUCT RESPONSIBILITIES

PROTOCOL AMENDMENTS

Any changes in research activity, except those necessary to remove an apparent, immediate hazard to the participant in the case of an urgent safety measure, must be reviewed and approved by the Chief Investigator.

Amendments will be submitted to a sponsor representative for review and authorisation before being submitted in writing to the appropriate REC, and local R&D for approval prior to participants being enrolled into an amended protocol.

MANAGEMENT OF PROTOCOL NON COMPLIANCE

Prospective protocol deviations, i.e. protocol waivers, will not be approved by the sponsors and therefore will not be implemented, except where necessary to eliminate an immediate hazard to study participants. If this necessitates a subsequent protocol amendment, this should be submitted to the REC, and local R&D for review and approval if appropriate.

Protocol deviations will be recorded in a protocol deviation log and logs will be submitted to the sponsors every 3 months. Each protocol violation will be reported to the sponsor within 3 days of becoming aware of the violation. All protocol deviation logs and violation forms should be emailed to QA@accord.scot

Deviations and violations are non-compliance events discovered after the event has occurred. Deviation logs will be maintained for each site in multi-centre studies. An alternative frequency of deviation log submission to the sponsors may be agreed in writing with the sponsors.

SERIOUS BREACH REQUIREMENTS

A serious breach is a breach which is likely to effect to a significant degree:

(a) the safety or physical or mental integrity of the participants of the trial; or

(b) the scientific value of the trial.

If a potential serious breach is identified by the Chief investigator, Principal Investigator or delegates, the co-sponsors (seriousbreach@accord.scot) must be notified within 24 hours. It is the responsibility of the co-sponsors to assess the impact of the breach on the scientific value of the trial, to determine whether the incident constitutes a serious breach and report to research ethics committees as necessary.

STUDY RECORD RETENTION

All study documentation will be kept for a minimum of 3 years from the protocol defined end of study point. When the minimum retention period has elapsed, study documentation will not be destroyed without permission from the sponsor.

END OF STUDY

The end of study is defined as the last participant’s last visit.

The Investigators or the co-sponsor(s) have the right at any time to terminate the study for clinical or administrative reasons.

The end of the study will be reported to the REC, and R+D Office(s) and co-sponsors within 90 days, or 15 days if the study is terminated prematurely. The Investigators will inform participants of the premature study closure and ensure that the appropriate follow up is arranged for all participants involved. End of study notification will be reported to the co-sponsors via email to resgov@accord.scot.

A summary report of the study will be provided to the REC within 1 year of the end of the study.

CONTINUATION OF TREATMENT FOLLOWING THE END OF STUDY

As the study is an exploratory qualitative study regarding the nature of individual’s experiences of their illness and no procedure or treatment is being given throughout the study, continuation of treatment following the end of study is not applicable.

INSURANCE AND INDEMNITY

The co-sponsors are responsible for ensuring proper provision has been made for insurance or indemnity to cover their liability and the liability of the Chief Investigator and staff.

The following arrangements are in place to fulfil the co-sponsors' responsibilities:

- The Protocol has been designed by the Chief Investigator and researchers employed by the University and collaborators. The University has insurance in place (which includes no-fault compensation) for negligent harm caused by poor protocol design by the Chief Investigator and researchers employed by the University.
- Sites participating in the study will be liable for clinical negligence and other negligent harm to individuals taking part in the study and covered by the duty of care owed to them by the sites concerned. The co-sponsors require individual sites participating in the study to arrange for their own insurance or indemnity in respect of these liabilities.
- Sites which are part of the United Kingdom's National Health Service will have the benefit of NHS Indemnity.
- Sites out with the United Kingdom will be responsible for arranging their own indemnity or insurance for their participation in the study, as well as for compliance with local law applicable to their participation in the study.

REPORTING, PUBLICATIONS AND NOTIFICATION OF RESULTS

AUTHORSHIP POLICY

Ownership of the data arising from this study resides with the study team.

REFERENCES

Birks, M. & Mills, J. (2011). Grounded theory. A practical guide. London: Sage Publications Ltd

Blumer, H. (1969). *Symbolic Interactionism: Perspectives and method.* Berkley, CA: University of California Press

Boddy, C.R. (2016). Sample size for qualitative research, *Qualitative Market Research: An International Journal, Vol. 19 Issue: 4, pp.426-432*, https://doi.org/10.1108/QMR-06-2016-0053

Braehler, C., Gumley, A., Harper, J., Wallace, S., Norrie, J., & Gilbert, P. (2013). Exploring change processes in compassion focused therapy in psychosis: Results of a feasibility randomized controlled trial. *British Journal of Clinical Psychology*, *52*(2), 199–214. https://doi.org/10.1111/bjc.12009

Braehler, C., & Schwannauer, M. (2012). Recovering an emerging self: Exploring reflective function in recovery from adolescent-onset psychosis. *Psychology and Psychotherapy: Theory, Research and Practice*, *85*(1), 48–67. https://doi.org/10.1111/j.2044-8341.2011.02018.x

British Medical Association. (2016). *Older Peoples Mental Health and Wellbeing.* London: BMA House

Brohan, E., Elgie, R., Sartorius, N., & Thornicroft, G. (2010). Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN-Europe study. *Schizophrenia Research*, *122*(1–3), 232–238. https://doi.org/10.1016/j.schres.2010.02.1065

Butler, A. C., Chapman, J. E., Forman, E. M., & Beck, A. T. (2006). The empirical status of cognitive-behavioral therapy: A review of meta-analyses. *Clinical Psychology Review*, *26*(1), 17–31. https://doi.org/10.1016/j.cpr.2005.07.003

Chand, S. (2013). How to Adapt CBT for Older Adults. *Current Psychiatry*, *12*(March 2013), 10–15.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* London: Sage Publications Ltd

Chen, R., Zhu, X., Capitão, L. P., Zhang, H., Luo, J., Wang, X., … Malhi, G. S. (2018). Psychoeducation for psychiatric inpatients following remission of a manic episode in bipolar I disorder: A randomized controlled trial. *Bipolar Disorders*, 1–10. https://doi.org/10.1111/bdi.12642

Corbin, J. & Strauss, A. (2008). *Basics of Qualiative Research: techniques and procedures for developing Grounded Theory*. London: Sage Publications

Eisen, S. V., Normand, S.-L., Belanger, A. J., Spiro, A., & Esch, D. (2004). The Revised Behavior and Symptom Identification Scale (BASIS-R). *Medical Care*, *42*(12), 1230–1241. https://doi.org/10.1097/00005650-200412000-00010

Fourie, R. (2009). Qualitative study of the therapeutic relationship in speech and language therapy: perspectives of adults with acquired communication and swallowing disorders. *International Journal of Language & Communication Disorders*, *44*(6), 979–999. https://doi.org/10.3109/13682820802535285

Giblin, S., Clare, L., Livingston, G., & Howard, R. (2004). Psychosocial correlates of late-onset psychosis: Life experiences, cognitive schemas, and attitudes to ageing. *International Journal of*

Geriatric Psychiatry, *19*(7), 611–623. https://doi.org/10.1002/gps.1129

Green, J., & Thorogood, N. (2018). Qualitative methods for Health Research (4th Ed.). London: Sage Publications

Gumley, A., & Macbeth, A. (2014). A pilot study exploring compassion in narratives of individuals with psychosis: implications for an attachment-based understanding of recovery. *Mental Health, Religion and Culture*, *17*(8), 794–811. https://doi.org/10.1080/13674676.2014.922739

Harper, D., & Thompson, A.R. (2011). *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for students and Practitioners*. Chichister: Wiley & Sons Lt

Jeste, D. V., & Maglione, J. E. (2013). Treating older adults with schizophrenia: Challenges and opportunities. *Schizophrenia Bulletin*, *39*(5), 966–968. https://doi.org/10.1093/schbul/sbt043

Jeste, D. V., Wolkowitz, O. M., & Palmer, B. W. (2011). Divergent trajectories of physical, cognitive, and psychosocial aging in schizophrenia. *Schizophrenia Bulletin*, *37*(3), 451–455. https://doi.org/10.1093/schbul/sbr026

Johnstone, L. & Boyle, M. with Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D. & Read, J. (2018). *The Power Threat Meaning Framework: Overview*. Leicester: British Psychological Society

Jones, P. B. (2013). Adult mental health disorders and their age at onset. *British Journal of Psychiatry*, *202*(SUPPL. 54), 5–10. https://doi.org/10.1192/bjp.bp.112.119164

Kartalova-O'Doherty, Y., Stevenson, C., & Higgins, A. (2012). Reconnecting with life: A grounded theory study of mental health recovery in Ireland. *Journal of Mental Health*, *21*(2), 136–144. https://doi.org/10.3109/09638237.2011.621467

Klapheck, K., Nordmeyer, S., Cronjäger, H., Naber, D., & Bock, T. (2012). Subjective experience and meaning of psychoses: The German subjective sense in psychosis questionnaire (SUSE). *Psychological Medicine*, *42*(1), 61–71. https://doi.org/10.1017/S0033291711001103

Knight, B.G., & Poon, C.Y.M. (2008). The Socio-cultural context in understanding older adults: contextual adult lifespan theory for adapting psychotherapy. In Woods, R., & Clare, L. (Eds). *Handbook of the Clinical Psychology of Ageing* (439-456). Chichester: Wiley & Sons

Langdon, R., Still, M., Connors, M. H., Ward, P. B., & Catts, S. V. (2013). Attributional biases, paranoia, and depression in early psychosis. *British Journal of Clinical Psychology*, *52*(4), 408–423. https://doi.org/10.1111/bjc.12026

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science and Medicine*, *71*(12), 2150–2161. https://doi.org/10.1016/j.socscimed.2010.09.030

Lobban, F., & Barrowclough, C. (2005). Common Sense Representations of Schizophrenia in Patients and their Relatives. *Clinical Psychology & Psychotherapy*, *12*(2), 134–141. https://doi.org/http://dx.doi.org/10.1002/cpp.443

Martins, M. J. R. V., Castilho, P., Carvalho, C. B., Pereira, A. T., Santos, V., Gumley, A., & De Macedo, A. F. (2017). Contextual Cognitive-Behavioral Therapies across the psychosis continuum a review of evidence for schizophrenia, schizoaffective and bipolar disorders. *European Psychologist*, *22*(2), 83–100. https://doi.org/10.1027/1016-9040/a000283

McCulloch, Y., Clare, L., Howard, R., & Peters, E. (2006). Psychological processes underlying delusional thinking in late-onset psychosis: A preliminary investigation. *International Journal of Geriatric Psychiatry*, *21*(8), 768–777. https://doi.org/10.1002/gps.1561

Möhler, R., Köpke, S., & Meyer, G. (2015). Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare: Revised guideline (CReDECI 2). *Trials*, *16*(1), 1–9. https://doi.org/10.1186/s13063-015-0709-y

Overall, J.E., & Gorham, D.R. (1962). The Brief Psychiatric Rating Scale, *Psychological Reports, 10,* 799- 812

Parker, S., French, P., Kilcommons, A., & Shiers, D. (2007). Report on early detection and intervention for young people at risk of psychosis. CSIP North West and CSIP West Midlands. Available: http://www.iris-initiative.org.uk/silo/files/early-detection-report.pdf

Pyle, M., & Morrison, A. P. (2014). “It’s just a very taboo and secretive kind of thing”: Making sense of living with stigma and discrimination from accounts of people with psychosis. *Psychosis*, *6*(3), 195–205. https://doi.org/10.1080/17522439.2013.834458

Ross, E.M.H. (2010). *"Negotiating the dance of disclosure": A grounded theory study of psychologists's experiences of childhood sexual abuse disclosures from clients in Adult Mental Health.* Unpublished doctoral thesis, Edinburgh University.

Scottish Government. (2017). Inpatient Census , 2017 Hospital Based Complex Clinical Care & Long Stay An Official Statistics Publication For Scotland Executive summary Key Points, (March), 1–20.

Theodore, K., Johnson, S., Chalmers-Brown, A., Doherty, R., Harrop, C., & Ellett, L. (2012). Quality of life and illness beliefs in individuals with early psychosis. *Social Psychiatry and Psychiatric Epidemiology*, *47*(4), 545–551. https://doi.org/10.1007/s00127-011-0360-1

Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M., & Study, I. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia : a cross-sectional survey. *The Lancet*, *373*(9661), 408–415. https://doi.org/10.1016/S0140-6736(08)61817-6

Turkington, D., Kingdon, D., & Weiden, P. J. (2006). Cognitive behavior therapy for schizophrenia. *American Journal of Psychiatry*, *163*(3), 365–373. https://doi.org/10.1176/appi.ajp.163.3.365

Turner, D. T., Van Der Gaag, M., Karyotaki, E., & Cuijpers, P. (2014). Psychological interventions for psychosis: A meta-analysis of comparative outcome studies. *American Journal of Psychiatry*, *171*(5), 523–538. https://doi.org/10.1176/appi.ajp.2013.13081159

Tzouvara, V., Papadopoulos, C., & Randhawa, G. (2018). Self-Stigma Experiences Among Older Adults with Mental Health Problems Residing in Long-Term Care Facilities: A Qualitative Study. *Issues in Mental Health Nursing*, *39*(5), 403–410. https://doi.org/10.1080/01612840.2017.1383540

Vass, V., Morrison, A. P., Law, H., Dudley, J., Taylor, P., Bennett, K. M., & Bentall, R. P. (2015). How stigma impacts on people with psychosis: The mediating effect of self-esteem and hopelessness on subjective recovery and psychotic experiences. *Psychiatry Research*, *230*(2), 487–495. https://doi.org/10.1016/j.psychres.2015.09.042

Wang, K., Link, B. G., Corrigan, P. W., Davidson, L., & Flanagan, E. (2018). Perceived provider stigma as a predictor of mental health service users’ internalized stigma and disempowerment.

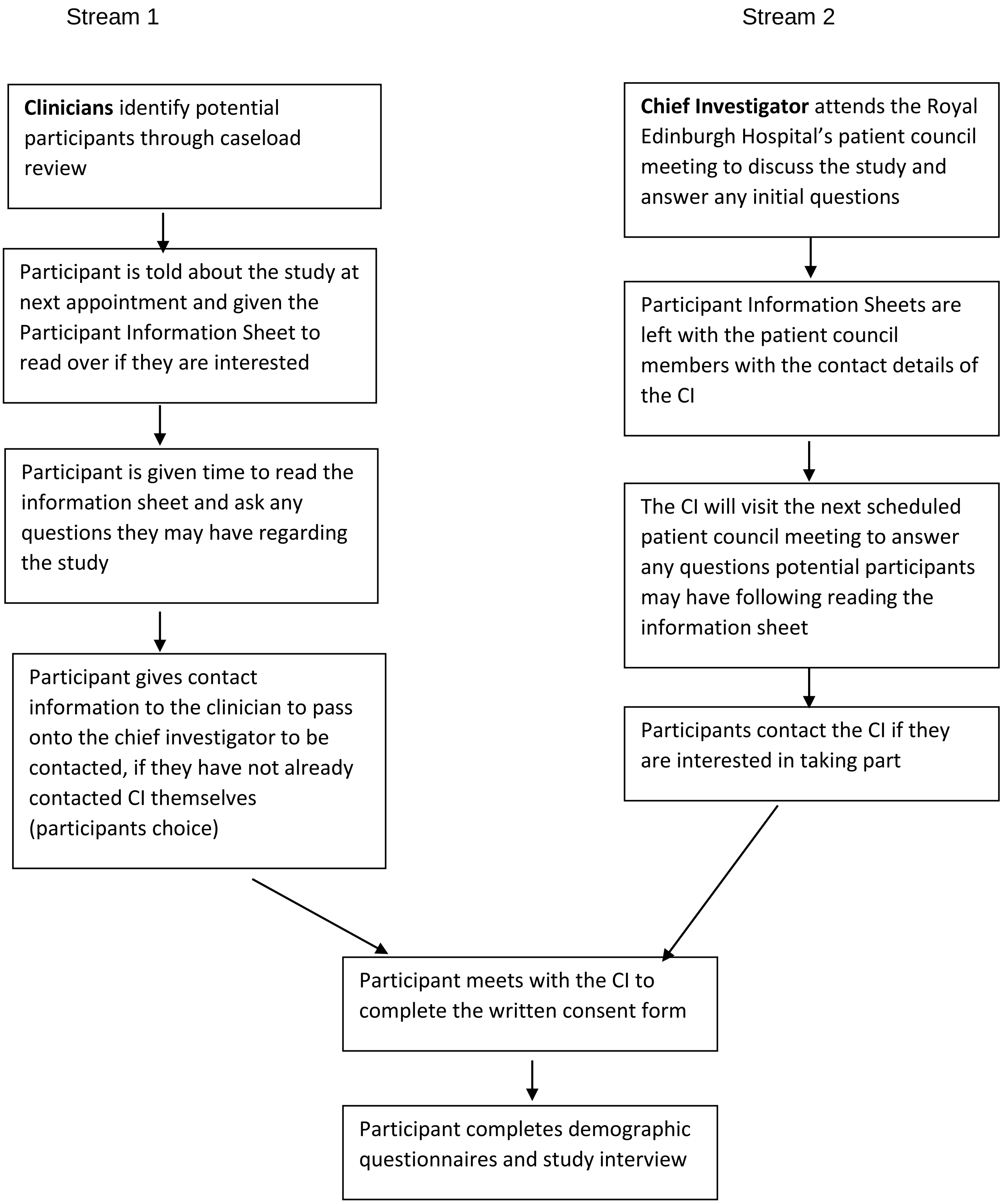
Psychiatry Research, *259*(October 2017), 526–531. https://doi.org/10.1016/j.psychres.2017.11.036

Whitbourne, S. K., Sneed, J. R., Skultety, K. M., Krauss, S., Sneed, J. R., Identity, K. M. S., … Skultety, K. M. (2009). Identity Processes in Adulthood : Theoretical and Methodological Challenges Identity Processes in Adulthood : Theoretical and Methodological Challenges, *3488*. https://doi.org/10.1207/S1532706XID0201

Wilson, L.E. (2011) *"It is tough being a boy": A Grounded Theory study of help-seeking pressures and promoters encountered by 12 and 13 year old boys.* Unpublished doctoral thesis, Edinburgh University.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

PROTOCOL APPENDIX 1: FLOW CHART OF RECRUITMENT STREAMS



Stream 1

Clinicians identify potential participants through caseload review

Participant is told about the study at next appointment and given the Participant Information Sheet to read over if they are interested

Participant is given time to read the information sheet and ask any questions they may have regarding the study

Participant gives contact information to the clinician to pass onto the chief investigator to be contacted, if they have not already contacted CI themselves (participants choice)

Stream 2

Chief Investigator attends the Royal Edinburgh Hospital’s patient council meeting to discuss the study and answer any initial questions

Participant Information Sheets are left with the patient council members with the contact details of the CI

The CI will visit the next scheduled patient council meeting to answer any questions potential participants may have following reading the information sheet

Participants contact the CI if they are interested in taking part

Participant meets with the CI to complete the written consent form

Participant completes demographic questionnaires and study interview

PROTOCOL APPENDIX 2: EMERGENCY CONTACT NUMBERS

Samaritans: 116 123 (free 24 hour helpline)

www.samaritans.org.uk

Mind: 0300 123 3393 or text 86463

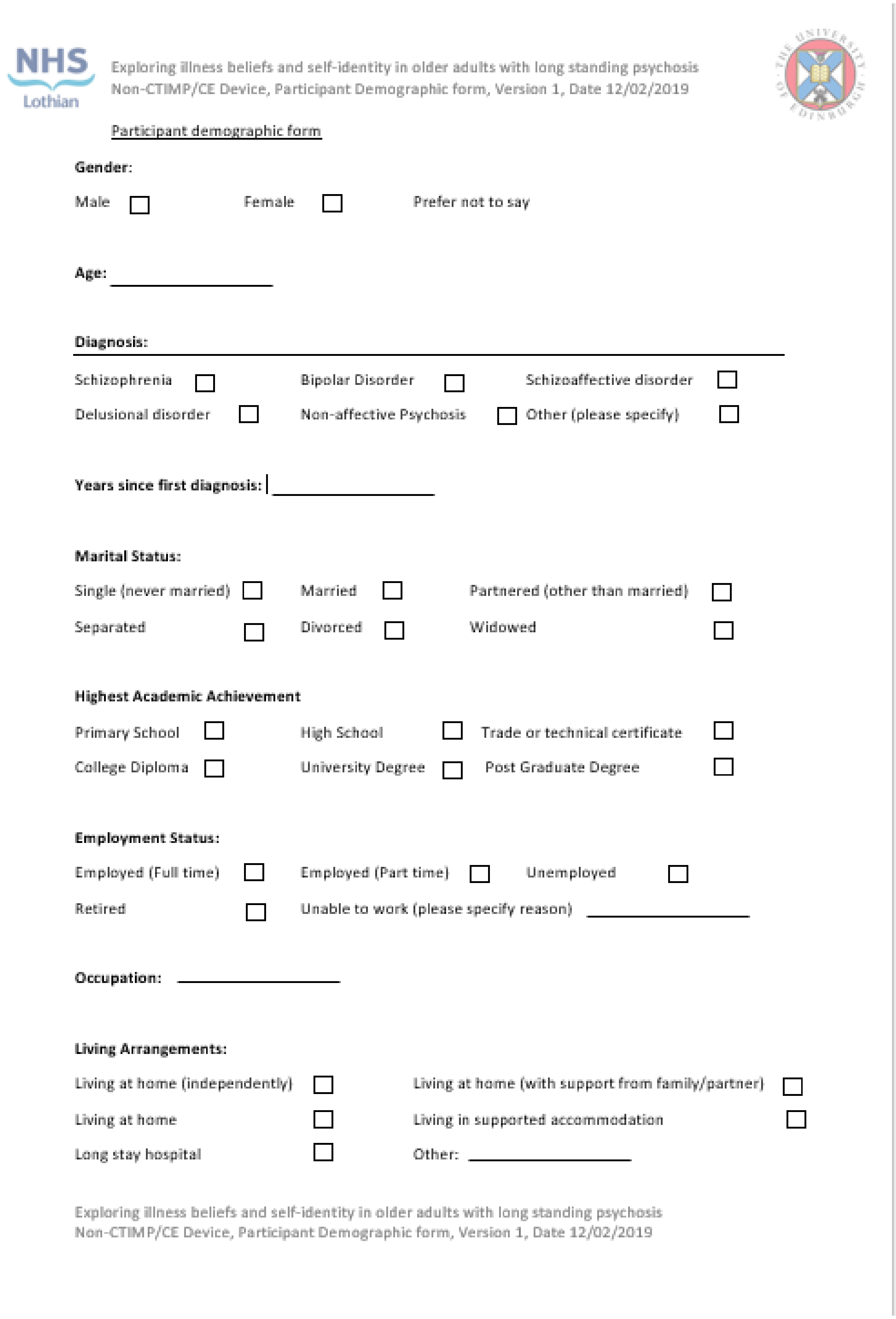
www.mind.org.uk

Breathing Space: 0800 83 85 87 (Monday- Thursday 6pm – 2am/ Friday 6pm- Monday 6am)

www.breathingspace.scot

NHS 24: 111

APPENDIX 8: Demographics Questionnaire



NHS
Lothian

Exploring illness beliefs and self-identity in older adults with long standing psychosis
Non-CTIMP/CE Device, Participant Demographic form, Version 1, Date 12/02/2019

Participant demographic form

Gender:

Male ☐ Female ☐ Prefer not to say

Age: ____________________

Diagnosis:

Schizophrenia ☐ Bipolar Disorder ☐ Schizoaffective disorder ☐
Delusional disorder ☐ Non-affective Psychosis ☐ Other (please specify) ☐

Years since first diagnosis: | ____________________

Marital Status:

Single (never married) ☐ Married ☐ Partnered (other than married) ☐
Separated ☐ Divorced ☐ Widowed ☐

Highest Academic Achievement

Primary School ☐ High School ☐ Trade or technical certificate ☐
College Diploma ☐ University Degree ☐ Post Graduate Degree ☐

Employment Status:

Employed (Full time) ☐ Employed (Part time) ☐ Unemployed ☐
Retired ☐ Unable to work (please specify reason) ____________________

Occupation: ____________________

Living Arrangements:

Living at home (independently) ☐ Living at home (with support from family/partner) ☐
Living at home ☐ Living in supported accommodation ☐
Long stay hospital ☐ Other: ____________________

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Non-CTIMP/CE Device, Participant Demographic form, Version 1, Date 12/02/2019

Length of stay in your current accommodation: ____________________

Ethnicity

White:

British ☐ Any other white background (Please specify) ____________________

Black:

British ☐ Caribbean ☐ African ☐

Any other black background (Please specify) ____________________

Asian:

British ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐

Any other Asian background (please specify) ____________________

Chinese:

British ☐ Chinese ☐ Any other Chinese background (please specify) ________________

Mixed:

White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐

White and Chinese ☐ Any other mixed background (please specify) ____________________

Current weekly alcohol intake in units (guideline- 25ml spirit= 1 unit; 1 small glass of wine= 1.8; 1 pint of beer= 2.3 units):

Currently weekly prescribed medication use (type of medication and dosage):

Currently weekly non-prescribed medication use (type of drug and usage):

Previous treatment received for psychosis?

Psychological therapy ☐ Medication ☐ Social supports ☐

Additional information about this:

Number of psychotic episodes experienced in the last 5 years (if known): ____________________

Duration of untreated psychosis (time between diagnosis and first reported symptoms) (if known): ____________________

APPENDIX 9- Sample interview schedule (for initial interviews, prior to development of questions in line with GT methodology)

Semi-structured interview plan

1) **Broad introduction/contextual questions:** Can you tell me about when you first started experiencing [*insert symptoms acknowledge/endorsed in the BPRS*]?
    a. What was this like for you?
2) How long did you experience [insert terminology used by participant re symptoms] before you saw someone for this, or started medication?
    a. What was the time like for you between experiencing [insert terminology used by participant re symptoms] and getting treatment?
3) Can you tell me a little bit about what was happening in your life at that point?
4) Who did you see first about what you were experiencing?
    a. What "diagnosis" were you given at this time?
    b. How did you feel about this at the time?
    c. How do you feel about this now?
5) What was your understanding of what [insert "diagnosis"/terminology endorsed by participant re diagnosis] meant?
    a. How (if at all) has this understanding changed over time?
6) What information were you given by your health care provider at the time about [insert terminology used by participant re symptoms], and what this meant for you going forward?
    a. What do you wish you had been told at the time?
7) **Illness perception questions:** How did you understand what you were experiencing and how this came about? *The cause of the experiences.*
    a. Is this still the same way you understand how things started or has this changed at all?
8) How long did you think what you were experiencing might last for?
    a. Was there anything you felt you could or couldn't do to make a difference to what you were experiencing?
    b. How did this make you feel?
    c. Are there things now that you feel you can do to change/manage what you are experiencing?
9) What were the biggest changes to your life following being told you had [insert "diagnosis"/terminology endorsed by participant re diagnosis]?
    a. How did you manage with these changes? *Positive/negative connotations associated with these changes?*
10) **Perceived stigma/social support:** Who around you did you share your experiences with? What influenced who you did/did not share this with?
    a. How did they respond to you?
    b. How did that make you feel? Was it helpful or unhelpful to you?
    c. What made it so?
11) *If they had chosen not to share with others:* What was it like not telling anyone about what you were experiencing/how you were feeling?
    a. How did eventually talking with someone come about?
12) How did you feel talking about what you were experiencing?
    a. Do you still feel this way or has it changed?
    b. How did this change come about?
13) Do you feel like the way you have been treated has changed in any way over the years? *What was it like? What is it like now?*

    a. By health professionals
    b. In your social support networks (family/friends/other social supports)
14) **Self-identity:** What impact (if any) do you feel your [insert "diagnosis"/terminology endorsed by participant re diagnosis] had on how you thought about yourself?
    a. What contributed to you feeling this way?
    b. Has this changed over time?
    c. What happened to contribute to this change?
15) How did you cope with your mental health?
    a. Has this changed over the years?
16) How do you feel now about your experiences of your mental health journey?
    a. Is there anything you would have changed or liked to have received?
    b. Is there anything that would have helped you to feel better supported/understood?

APPENDIX 10- Sample interview transcription and preliminary coding

Transcript example	Initial Code/Ideas	Latter Theoretical Code
I: and in terms of when you were first brought in, how much information were you given about …you know, you said there that trying to make sense of that yourself was very hard. How much information did you get? What were you told about Bipolar or Psychosis? P: nothing. Absolutely nothing. There was eh… Dr xxxx (psychiatrist) was lovely, ermm… but really, I was shocked! I have to say, at the lack of information. Erm… I wouldn't say that the staff weren't very supportive, they were very supportive, and they… they… they did say encouraging things about my eh… my stay in hospital. Eh… but there was no… structure to your day. You were just left to eh… wander about the corridor and look out the window. And that was another thing that happened, talking about them opening the window. Erm… (pause)… talking about the psychotics… I am… watched a flock of pigeons… walking backwards… and I couldn't look. I had to come away from the window (laughs)… but the first diagnosis wasn't Bipolar. The first diagnosis was a "severe psychotic depression". That was the first one. And that wasn't… I don't think I was diagnosed as Bipolar until… I had two admissions here (psychiatric hospital), then my husbands company… erm… they had a… private wing at eh… it was a hospital in xxx (a Scottish city), and it was xxxx (name of hospital). And that first erm… the consultant had said, he said to my husband, "it looks like she could have Bipolar". Eh… but erm… I eh… when I was… eh… the second time… when I went to xxxx (name of hospital), I had been seeing Dr xxxx (psychiatrist) in the alcohol problems. They said, I didn't think I had alcohol problems, but the reason they did that was because I knew too many people, too many staff, in the hospital and it was making me feel uncomfortable. So I saw him, he was in xxxx (road name). so I didn't have to come into the grounds. Making it more private, more of a erm…. So eh they eh… (pause/stutter)… the consultant at the xxxx (hospital in other city)… he got in touch with xxxx (name of psychiatrist here)... this was the second time I had been at xxx (hospital in other city)… two here and two at xxxx (hospital in other city), and he said "I told you the last time", he really gave him a right roasting, and said eh "I told	Lack of information for making sense of what's happening/lack of communication. Staff trying to support; but lack of communication/info or to take ownership and make sense of own experiences. Lack of clarity around diagnosis. Insight into coping mechanism? ?indicative of receiving treatment not through choice, if not thinking they had alcohol problems Stigma ? and shame from knowing people at the hospital on a social level- not wanting mh problems to be known	Powerlessness Power Stigma Power

you she was Bipolar and you've done nothing about it". You know, so… I really feel erm… I, I… I don't know, I don't know about these things, so you just have to… you just have to eh… put up with it. You just have to take it, you know?	"done nothing about it": caught between two services? Resignation that nothing more can be done- locus of control/self-efficacy low	
I: yeah. And again, that sounds like you were being told one thing, and then being told another thing and the communication there was…		
P: there was not… there was not good communication at all. But then… you know it… it… it could be there that the xxxx (psychiatric hospital here), they had the first two of my admissions and then I kind of reneged on that from them and went through to xxxx (other city) to xxx (other hospital), because of this need to be private. I didn't want… you know, there are people who are friends, who I've worked with, and I thought "no, I can't do this". If this is what… if this is what my life… is this is what my life is, I can't go in. I just can't… I just can't do it. I can't do it. Or go in. I didn't want to go in!	Lack of communication Stigma and ?shame; needing to keep MH from being known by others. ? Fear Repetition= emphasis	Stigma
I: yeah, it sounds like it would have felt very exposing?		
P: yeah! Yeah, I felt too exposed, I felt … no, this can't happen. Erm… that's, I meant that's… you're going back to the 80's when this happened. We've come a long way, as far as the eh… stigma, and being more open with dialogue about it, you know? Erm… eh, and I think that its fantastic because erm… you don't get that opportunity when you come in here. There really isn't a… I mean that xxx (other hospital), that was great because it was 1:1, you know, and you could chat to people and you know, it was much nicer facilities and was all just nicer, it was a much nicer place. Erm… but… but I didn't feel relaxed enough here, I was strung up the whole time.	Stigma – being different in the 80's Lack of opportunity for communication with professionals/others; feeling alone Environmental factors: ? feeling of safety	Stigma Choice- power
I: and you were saying there that was about knowing other people and not wanting to feel as exposed as you were whilst you were here. So you said a really important point there about how, we have maybe shifted a little bit now in terms of this stigma and how we talk about mental health, but at the time, how do you feel that impacted on how you thought about yourself?		
P:… (pause)… oh well, erm… I was ermm… I don't know, I just didn't feel … I just felt depressed, I felt … I don't know just… uch (sigh)… I can't even really described it, you feel		Stigma

worthless. You just feel like "what is this all about?". Erm… and … to give my husband his due, he did try and get me some help, you know, at home and stuff like that. But my life wasn't worth living at home, because the girls wouldn't talk to me. And it was really upsetting me quite a bit. You know, and they would just go out whenever they felt like it and did their own thing and … it was hell. Absolute hell. Erm	Impact of MH experiences and stigma on self-image? Social networks and the impact of rejection/stigma within these	Family/Community

Appendix 11- Additional Supportive Quotes for Illustrating Themes

Additional quotes from participants interviews and data to support the emerging categories.

Core category- Powerless to Empowered

Powerless

> "*ehh I can't remember, but … I don't remember all of what happened, except that…ermm… (long pause) the psychiatrist gave me drugs which… the results was I forgot. But I do remember being taken into hospital because I got handcuffed, which was absolutely, totally unreasonable! … the doctors give you a… drug that knocks you out and spoils your memory" (Margaret)*

> *"See eh… (pause)… what am I to them? An object, an experiment, a guinea pig, a laboratory rat? I do not like the way they consider me, they do not take me seriously" (Tommy).*

> *"And it's to do with not feeling safe, and it's to do with eh… not feeling in control, it's to do with a fear of what's coming up, you know." (John)*

Lack of communication and understanding during initial experiences; feeling different

> *"I wasn't told for a number of years that it was schizophrenia"; "It was shocking" (Joyce)*

“*What’s wrong with me*?!” (Carol).

> *“But the problem is, I don’t like very much the frame of mind of the medical professions because they look down… they look down onto patients. They think they are better.” (Tommy)*

> *“I’m the only one caught in this psychiatric realm” (Joyce)*

Empowered

> *“empowering. It’s empowering. Yes, yeah. Yeah. Yes it is. That’s really why I took it up, the patient’s council” (Carol)*

> *“Getting older. Getting older. Getting calmer. Ehhh… just getting… being able to step back from things a little bit and you know… just kind of ehh… just calmer and older, and… and ehh… a bit wiser” (John)*

The role of aging and experience

> *“I’ve grown to see that I can have a say. Whereas initially I didn’t”… “more empowered now”… “yes, I think I would be [able to ask questions]. Much much better than I did initially.” (Edward)*

P: And I've had it two or three times when… by the patients complaining about it, but it falls on deaf ears. They [management] don't listen. "Well there's nothing we can do about it". Yes there is, get off your backsides and challenge it! (Laughs).

I: yes absolutely. And I guess that's something we've not touched on there, but the idea that you are very involved in the patient council and in advocacy and the volunteering work that you referenced as well. Erm… so is that in a way… now trying to think of a word to describe this…

P: empowering. It's empowering. Yes, yeah. Yeah. Yes it is. That's really why I took it up, the patient's council" (Carol's interview)

"I think in some ways it's easier… (pause)… I think… as you're getting older… (long pause)… I think having had the CBT over this last year has helped tremendously. (long pause)… cause, yeah… I'm more aware. I've always been aware of… of myself. But when you get too ill obviously you can't. And when I start to feel myself getting ill, I've got all these techniques now as well as having support here" (Joyce)

"Recovery is all over the place" (John)

"well it's nice to think that eh… there was a period at a time when you could recover … but I don't really think… I don't believe… I don't really think that there is. I think it's an ongoing, day by day, step by step erm… ongoing process. Where eh… you have to… really be quite…inward looking. And think about yourself. And stop… thinking about other people." (Carol)

Stigma

"That's when stigma started to come in [when friends would not visit participant]" (Carol)

"I don't think he [boss] knew what to say. Because he knew… for some, I don't know how…but, but he knew, that I had these problems. And he marked me down and all sorts of stuff. And it was like… pfff… (gestures hands in the air/shrug)". (Joyce)

"[I was at a] party or something like that, and she said "but xxx (participant's name), there's nothing wrong with you. Your hands aren't even shaking". So this was… this is what I was faced with on a daily basis" (Carol)

"It [psychosis] has impacted a lot. It's impacted a lot. Ehh… I think still, how I perceive the world and myself in it, and everyone around me, is ehh… through a filter of those past experiences" (John)

"That just because you've been told that you've got mental health problems doesn't actually mean you're stupid. You know?"… "I think it's quite easy to do that, isn't it? That thought… you're vulnerable. You're vulnerable. You know…" (Joyce)

"See, I didn't want to go and… associate with people… you know, they were smelly and… do you know what I mean? Badly dressed and… (pause)… I… I mean I… that was just me. A wee bit snobby"… (Carol)

Family/community

> *"I didn't… I didn't really share that much with them"… "… in my family, you know you didn't really talk about feelings, and you had to present yourself. You always had to be nice to people. You had to be nice to people, put other people's interests in front of your own"… "middle class in Scotland, they're all about doing things and working and making money, you know? But they're not good with feelings, it's putting on a show a little bit, you know, you want to present yourself, it's really important. And the really kind of profound and meaningful things are shoved into the background. Which is exactly what I did, I hid everything, I shoved it into my background" (*John)

> *"I want to get back home, this [hospital and day centre] really isn't for me"; "people were so unwell. Because you really don't understand what's going through their minds, you know" (Joyce)*