

Narrative Coherence and Late Onset Psychosis

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Thesis declaration form

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

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OVERVIEW

Experiencing a psychotic episode after the age of 40 is termed ‘late onset psychosis’ (Howard, Rabins, Seeman & Jeste, 2000). This thesis aims to understand how people who experience a psychotic episode for the first time in mid to late adulthood make sense of their experiences, and how this might affect their recovery.

Part 1 comprises a systematic review of the social experience of psychosis in mid to late adulthood. Ten qualitative studies were identified and assessed using Thematic Analysis (Braun & Clarke, 2006). Results aligned with and expanded upon previous research and highlighted the centrality of the social difficulties that people with psychosis in later adulthood experience.

Part 2 comprises an empirical study of the experience of late onset psychosis in a sample of adults aged 40 years or older living in London, England. An inductive, qualitative approach, based on semi-structured interviews and Thematic Analysis (Braun & Clarke, 2006) was employed. Findings highlighted the way in which the uncertainty and disruption caused by the psychotic episode were related to difficulties associated with ‘narrative incoherence’. Some participants found the experience of engaging with mental health services gave them a new perspective on how to manage both new and long-standing difficulties following their psychotic episode.

Part 3 comprises a critical appraisal of the research process. Topics discussed include the way my assumptions may have affected the research process, difficulties with the interview process, an appraisal of the interview schedule and some methodological considerations in relation to my literature review.

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Part 1: Literature Review

The Social Experience of Psychosis in Later Adulthood

ABSTRACT

Aim: Research on people with psychosis in later adulthood has been sparse; however it is understood that despite improvement of symptoms, people with psychosis in later life are more likely to encounter difficulties relating to their social experience than younger adults. By integrating the available evidence pertaining to the perspectives of people in later adulthood, the present study aimed to develop an understanding of the way in which these individuals understand psychosis and its social impact.

Method: A systematic search process retrieved 10 relevant studies, all of which utilised qualitative techniques. Thematic Analysis was employed to analyse the data.

Results: Four major themes were identified: the perception of difference, loss, adjustment and age-related changes. Within these major themes, nine sub-themes were identified

Discussion: Results aligned with and expanded upon previous research and highlighted the centrality of the social difficulties that people with psychosis in later adulthood experience. These social difficulties were considered by the participants to be more important in later adulthood than psychosis itself. Future research is required to provide more understanding about the ways to support people with late onset psychosis to access opportunities and subjectively meaningful social activities or roles, and to enable these individuals to make sense of their experiences within the context of a life review process.

INTRODUCTION

Traditionally psychosis has been viewed as a disorder with a typical onset in adolescence or early adulthood, and is commonly considered to be a severe and chronic condition with a progressively deteriorating course (Palmer, McClure & Jeste, 2001). Cohen et al. (2001) indicate that there are significant differences in the psychopathology, neuropsychological status, social functioning, and health of older adults with psychosis that distinguish them from younger persons with the disorder. Nevertheless, the research literature on people with psychosis in later adulthood has been sparse, and there are many key areas that require further enquiry in order to prevent the implementation of inappropriate services that fail to satisfy the needs of this growing population (Howard, Rabins, Seeman & Jeste, 2000).

Long-term follow-up studies of people with psychosis in later adulthood have provided evidence that, in some cases, substantial symptomatic and functional improvements can occur with age (Belitsky & McGlashan, 1993; Jeste et al., 2003; Winokur, Pfohl & Tsuang, 1987). Yet, whilst it is understood that people with psychosis in later adulthood experience less positive symptoms, such as hallucinations and delusions, and can suffer more from negative, passive symptoms than younger adults (Ciompi, 1980), it has been found that people with psychosis in later adulthood are more likely to experience objective and subjective difficulties in relation to social functioning than younger adults (Berry & Barrowclough, 2009). Furthermore, Cohen, Talavera & Hartung (1997) found that quality of life and life satisfaction were lower among community-dwelling older persons with psychosis than their age-matched peers. Satisfaction was associated with subjective factors,

such as loneliness, having reliable social contacts and fewer perceived life difficulties, rather than objective measures such as income or physical health (Cohen et al., 1997).

The subjective social experience of people with psychosis in later adulthood is an area of particular importance. For older adults, social isolation and a lack of meaningful relationships can have a negative impact on both their quality of life and health (Lubben & Gironde, 2003); however, the majority of older adults with psychosis have few social contacts and most lack a close family caregiver (Jeste & Nasrallah, 2003). Furthermore, people with psychosis in later adulthood are only half as likely as those in the general population to be integrated into their communities, leading to isolation and poor engagement in the health care system, both of which lead to poorer health care (Cohen, Pathak, Ramirez, & Vahia, 2009). These findings highlight that, whilst much is known about the impact of social dysfunction, much remains to be learned about its causes and potential interventions that can significantly enhance social role functioning (Bellack et al., 2007).

Research on psychosis in later adulthood has traditionally focused on outcomes and used quantitative methods, which emphasise a biomedical model and measures of symptomology, social functioning and quality of life (Boydell, Stasiulis, Volpe & Gladstone, 2010). Progress in this area has been slowed by a lack of well-established, widely accepted and practical ways of assessing functioning in the community and treatment outcome measures.

Harvey et al. (2009) investigated performance-based assessments of everyday functioning, real-world disability, and achievement of milestones in people with psychosis in later adulthood in two culturally diverse populations, and found that

although there were negligible differences in the *ability* to perform everyday living skills in the assessment setting, there were marked differences in residential outcomes. This suggests that real-world outcomes may be driven by factors other than ability, and that cultural and social support systems can lead to divergent real-world outcomes among individuals who show evidence of the same levels of ability and potential.

In developing outcome goals for people with psychosis in later adulthood, in lieu of using normative measures based on symptoms and levels of functioning to construct assessments, prognosis and treatment, Cohler and Beeler (1996) contend that it might be more profitable to look at the more complex interaction between illness, aging and development. The goal of this is to build upon the subjective experiences of individuals throughout the life course in order to make their lives more meaningful and satisfying to the individual and those close to them, as opposed to focusing on normative goals and outcomes of recovery or rehabilitation. The process suggested by Cohler and Beeler (1996) involves the development of a shared understanding between the person with psychosis and those close to them about the meaning they assign to the events and struggles of their lives.

Thus, understanding the subjective experience of people in later adulthood with psychosis can provide a fuller appreciation of the human experience with the disorder and meaningfully improve services and policies affecting this vulnerable population (Strauss, 2008). Qualitative research regarding younger adults with psychosis supports the value of gaining further understanding of the subjective experiences of people with psychosis. Boydell, Stasiulis, Volpe & Gladstone (2010) undertook a review of qualitative studies on younger adults with first episode

psychosis and found that complex social processes of achieving identity, acquiring perspectives, doing activities and developing relationships were highly important experiences to the individuals and their families. These findings highlighted the contextually rich and detailed information made possible by qualitative studies, which began to account for the active engagement of individuals affected by psychosis in making sense of their experience. Furthermore, given the weaknesses of the quantitative research and the difficulties around defining what might meaningfully constitute social functioning for this group of people, it is suggested that qualitative research may provide more insight into frameworks and meaning from the perspective of the individuals themselves.

Thus, the current study undertook a literature review of qualitative research on the social experience of people with psychosis in later adulthood. By integrating the available evidence pertaining to the perspectives of people in later adulthood, this review aimed to develop an understanding of the way in which these individuals understand psychosis and its social impact.

METHOD

A systematic review and thematic synthesis was undertaken in 3 phases: (1) a systematic search of the literature, (2) critical appraisal of identified studies, and (3) thematic synthesis of search results to review over-arching and emerging themes regarding the subjective social experience of psychosis in later adulthood.

1) Search Strategy

A systematic search of electronic databases was conducted across three research databases: Web of Science, PsycINFO and Medline. In each of these databases, a search was performed to retrieve articles that examined (1) psychosis, (2) later adulthood, and (3) subjective experience. In order to retrieve as many relevant articles as possible, synonyms for each of these factors were employed in the search syntax (see Figure 1.1).

Because the search criteria specified a qualitative methodological approach, retrieved articles were subsequently examined to determine whether they focused on the experience of the individual as opposed to that of carers or healthcare professionals and also whether the papers addressed issues relating to social experience and contexts.

An article was included when it was considered that it satisfied all eligibility criteria considered within the domains of SPIDER (i.e. an acronym for sample, phenomenon of interest, design, evaluation, result type) search tool (Cooke, Smith & Booth, 2012). This acronym identifies the focus and eligibility of included studies for qualitative evidence synthesis and is used in preference to the PICOS (patients, interventions, comparator, outcome, study design) acronym for qualitative evidence synthesis.

Sample: individuals with a diagnosis of psychosis or ‘schizoaffective spectrum disorders’, who were 40 years old or older at the time of the study. For the purposes of this review ‘later adulthood’ has been defined as anyone who is aged 40 years or older because this is the minimum age requirement for somebody to be

diagnosed with late onset psychosis (Howard, Rabins, Seeman & Jeste, 2000), however individuals with both early and late onset were included.

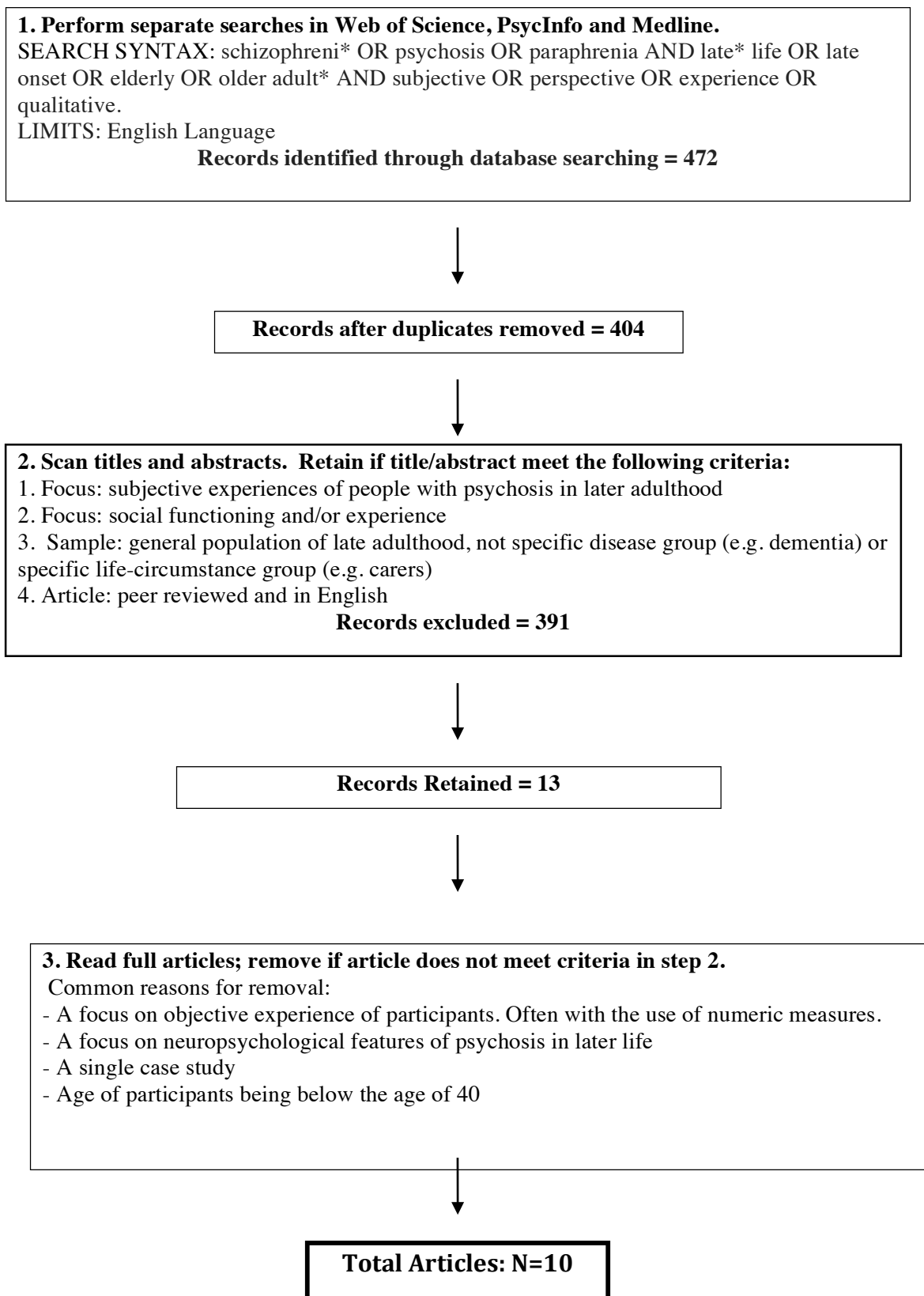
Phenomenon of interest: The focus of the article was on the subjective experiences of psychosis in later adulthood. Articles were excluded if they were not from the perspective of the individual with the diagnosis of psychosis (i.e. from the perspective of family, carers or healthcare professionals) and if they did not address issues of social experience. This was defined as any subject that considered: social environment, social support, social behaviour, social adjustment, social isolation, adaptation, psychological, interpersonal relationships, activities of daily living, quality of life, rehabilitation, vocational, social functioning, social adaptation, social performance, social competence, social dysfunction, and functional status.

Design: Qualitative design using methodologies which analysed multiple cases including phenomenology, grounded theory or thematic analysis. Case studies, quantitative research, systematic and other types of reviews, books, theses or conference proceedings were excluded.

Evaluation: Interviews documenting the experiences, views or attitudes of individuals with a diagnosis of psychosis and were published in English.

Result type: Only qualitative articles were included.

Figure 1.1: Diagram to illustrate search process.



2) Critical appraisal of the included studies

The Consolidated Criteria for Reporting Qualitative Studies (COREQ) (Tong, Sainsbury & Craig, 2007) was used to assess the quality of the included studies. The COREQ contains 32 items that identify the essential content expected in qualitative research studies. It was derived from 22 previous checklists and contains three domains: (1) research team and reflexivity (8 items centred around the interview team, their experience and the relationship between them and the participants), (2) study design (15 items considering the methodological orientation of the study, the process of how participants were identified and approached, the sample size and non-participation, the setting and interview guide, details of the data collected, the duration of interview, the saturation of the data and other aspects considering “trustworthiness” of the data collected) and (3) analysis and findings (9 items identifying the coding process, analytic procedures and the presentation of findings).

The COREQ is designed to provide clear guidelines to enable a “gold standard” approach in reporting qualitative research (Soundy et al., 2015). A summary score was calculated for each of the three COREQ domains, as well as a total score. The score is based on each question either being reported correctly (scoring a point) or not (scoring no point), with a maximum possible score of 32. All studies were retained for the current review; however, outcomes of the critical appraisal process were taken into account when reviewing findings.

3: Thematic Synthesis

The author undertook a thematic synthesis of the included studies in three stages: (1)

coding the text both by hand and using a computer software package (NVivo), (2) developing descriptive themes and (3) generating analytical themes (Braun & Clark, 2006; Thomas & Harden, 2008).

The author adopted a data-driven approach as far as possible, in order to prioritise actual study findings over any pre-established theories. Initially, the author familiarised herself with the content by reading all articles. She then re-read the articles, before systematically applying codes to all data that bore relevance to the study question; relevance was defined as any finding that related to social experience, social environment, social roles and relationships. Data was defined by all text within the results section of the studies, which included both the 'primary data' of participants' quotes and the 'secondary data' of the authors' synthesising statements.

The coding process was iterative in as much as the author checked for the presence of any new codes in all previously coded articles. Once coding was complete, the author collated the codes into themes, and the themes were then checked against the data and refined in an iterative fashion, by moving back and forth between the themes and the data several times. This process allowed for the removal of unsupported themes and the creation of new themes, whilst homogenous themes were collapsed and heterogeneous themes were split. Finally, the author judged that the generated themes reflected the data as closely as possible. This iterative refinement process was then terminated. In a further step, the themes were organised into a smaller number of broader overarching themes.

RESULTS

The Systematic Search

472 articles were identified through the database searches, and after duplicates were removed, there were a total of 404 articles that were then screened. 391 articles were excluded following the second screening stage whereby titles and abstracts were scanned. 13 articles were read in full, resulting in the exclusion of three articles. In total 10 articles (Araten-Bergman, Avieli, Mushkin & Band-Winterstein, 2015; Avieli, Mushkin, Araten-Bergman & Band-Winterstein, 2016; Leutwyler, Chafetz, & Wallhagen, 2010; Ogden, 2014¹; Ogden, 2014²; Ogden, 2014³; Pentland, Miscio, Eastabrook & Krupa, 2003; Quin, Clare, Ryan, & Jackson, 2009; Shepherd, Depp, Harris, Halpain, Palinkas, & Jeste, 2012; Solano, & Whitbourne, 2001) were identified.

Table 1.1. displays basic details of the 10 articles retrieved by the search strategy described above. Populations examined within these studies were wide ranging in terms of size (ranging from N=5 to N=32) and nationality (including Europe, North America, and the Middle East). The ages of the participants ranged from 47-87 across the studies. Methodologies were also varied, but most studies utilized interviews and/or focus groups, and a variant of thematic analysis. Table 1.2. displays the results of the critical appraisal process.

Table 1.1. The Characteristics of Included Studies.

First Author	Code	Year	N	Country	Age Range	Sex	Analysis	Focus
Araten-Bergman	A	2015	18	Israel	60-69	M/F	Phenomenological reflective life world approach	Experience of living with schizophrenia and specific qu about what might have caused the illness.
Avieli	B	2016	18	Israel	60-69	M/F	Phenomenological content analysis	The subjective experience of suffering in aging individuals with schizophrenia.
Leutwyler	C	2010	28	USA	55-75	M/F	Grounded Theory	Perspectives of physical health
Ogden ¹	D	2014	7	USA	56-73	M/F	Thematic narrative analysis	Narratives of interpersonal relationships.
Ogden ²	E	2014	6	USA	55+	M/F	Thematic narrative analysis	Narrative insight into schizophrenia in older adults.
Ogden ³	F	2014	5	USA	50+	M/F	Thematic narrative analysis	The meaning of housing and home
Pentland	G	2003	6	Canada	47-65	F	Thematic analysis	How do women view their experiences of aging with schizophrenia?
Quin	H	2009	7	Ireland	67-87	M/F	Interpretative phenomenological analysis	Previous life experiences as well as the experience of developing and living with schizophrenia.
Shepherd	I	2012	32	USA	50+	M/F	Grounded theory	Perceived changes in the symptoms of schizophrenia and functioning over the life span.
Solano	J	2001	15	USA	50-62	M/F	No approach specified	Coping strategies in later life.

Table 1.2. The Summary of Results of the COREQ (Tong et al., 2007)

First Author/Year of Publication	Domain 1 (8) Research Team and Reflexivity	Domain 2 (15) Study Design	Domain 3 (9) Analysis and Findings	Total (32)
Araten-Bergman (2015)	7	11	5	23
Avieli (2016)	7	10	5	22
Leutwyler (2010)	5	10	6	21
Ogden ¹ (2014)	7	12	6	25
Ogden ² (2014)	7	12	6	25
Ogden ³ (2014)	7	11	6	24
Pentland (2003)	4	10	6	20
Quin (2009)	3	9	5	17
Shepherd (2012)	4	7	5	16
Solano (2001)	3	8	4	15

The Qualitative Synthesis

Four major themes were identified: the perception of difference, loss, adjustment and age related changes. Within these major themes, nine sub-themes were identified and these are presented in Table 1.3. This table identifies the individual studies that provided evidence for each theme. The studies are identified by the code ascribed to them in Table 1.1.

Study findings are reported alongside selected quotations extracted from the reviewed articles to illustrate each theme. The quotations represent both primary data

sources (i.e. quotes from the participants included in the reviewed studies) and secondary data sources (i.e. the authors' synthesizing statements). Both data sources were selected in order to provide a richer context for each theme, and to ensure that the participants' experiences remain a central focus of this review. For ease of reading, superfluous segments of quotations have been replaced with an ellipsis (...), and connecting words have been inserted (enclosed in square brackets []).

Table 1.3. Themes and sub-themes (Article identified by code in Table 1.1.)

Theme		Sub-Theme	Article Code											
			A	B	C	D	E	F	G	H	I	J		
Difference		Difference												
Loss	Relational	Existing Relationships												
		Potential relationships												
	Personal development	Employment and finance												
		Housing and independence												
Adjustment		Isolation												
		Adapting Relationships												
Age-related changes		Skills												
		Personal understanding												

Themes

1. The perception of difference - “My dad had to force me to go out to play with the kids because I was afraid they were going to laugh at me.”

This theme is concerned with the perception of difference. Four of the reviewed studies described the way in which the participants conceptualized normality and difference within the community (Avieli et al., 2016; Quin et al., 2009; Shepherd et al., 2012; Solano & Whitbourne, 2001). A shared aspect across the studies was the awareness of being different from an early stage in life.

“For most, this difference was experienced from adolescence, in relation to family and peers and often through a sense of feeling like ‘an outsider’ in their local environment.”

(Quin et al., 2009)

Three studies also considered the continuation of this sense of difference into later life and the way in which the participants felt socially isolated and excluded from ‘normative’ social communities and experiences (Avieli et al., 2016; Shepherd et al., 2012; Solano, & Whitbourne, 2001):

[One participant] “used the “garbage” metaphor to describe her perception of her position in society. For her, normative society is out of reach, and she is left “outside” (...). She describes the inability of normative people to comprehend and tolerate her behavior as part of the mental illness.” (Avieli et al., 2016).

The theme of feeling different to other people often led to difficulties with forming relationships and isolation within the community, and this continued from early

adulthood into later adulthood.

“With the move into later life, the experience of ageing contributed to participants’ experiences of self as ineffective and altered.” (Quin et al., 2009)

2. Loss

2.1. Loss of existing relationships – “I loved them so much... that is why I became sick... they left me so suddenly.”

Loss of existing relationships was a common theme across the studies reviewed (Araten-Bergman et al., 2015; Avieli et al., 2016; Leutwyler et al., 2010; Ogden, 2014¹; Pentland et al., 2003; Quin et al., 2009; Shepherd et al., 2012) and a link between the loss of relationships and the experience of psychosis was made by the participants.

Two of the reviewed studies attributed interpersonal loss to the onset of the illness (Araten-Bergman et al., 2015; Leutwyler et al., 2010). Furthermore, both studies related that the interpersonal loss was considered to be more important than the illness itself.

“Participants in this category attribute the onset of schizophrenia to a personal crisis, which became a turning point in their life course and led to the illness. The crises described by the participants are a forced break-up from spouse and children (...). Now, in old age, they construct a self-etiology in which the lived experience of traumatic

events stands at the centre of the life story, while the illness itself is pushed to the background.” (Araten-Bergman et al., 2015)

Alternatively, five of the reviewed studies indicated that the participants saw the interpersonal losses to be the consequence of psychosis (Avieli et al., 2016; Ogden, 2014; Pentland et al., 2003; Quin et al., 2009; Shepherd et al., 2012).

“Although a parent and child relationship is typically lifelong, all but one of the participants experienced a relational loss of his or her parents, children or both, and believed that those losses were connected to symptoms of schizophrenia-spectrum diagnoses or to the consequences of their diagnosis that they had identified.” (Ogden¹, 2014).

The studies indicated that the loss of relationships remained a central aspect of the difficulty of living with psychosis in later adulthood. In many cases, the lost relationships were not re-established and this continued to cause the participants distress and sadness. This emphasised the centrality of the social experience of people with psychosis in later adulthood and the impact that interpersonal losses can have across the life course.

“For these women, the effect [of psychosis] on family life seemed most devastating. All but one of the women are now single. Some gave their children up for adoption and others lost custody to their ex-spouse. (...) There was consensus that ‘being

schizophrenic' had caused them tremendous suffering and losses that continue to have profound effects as they age.” (Pentland et al., 2003)

2.1.2. Loss of potential relationships – “I would have liked to have had a family... And I would have liked, in lieu of a family, to have some sort of decent sex life”.

The studies highlighted the experience of being unable to develop new relationships, both of an intimate and platonic nature (Avieli et al., 2016; Leutwyler et al., 2010; Ogden, 2014¹; Pentland et al., 2003; Quin et al., 2009).

“The most significant aspect of suffering described by the participants is unfulfilled intimate relationships (...). [One participant’s] lifelong experience has taught him that he, as a person with schizophrenia, is destined to live without love. This painful understanding is acknowledged by him as his greatest tragedy (...) and the notion that the illness deprived him of living fully and experiencing love for a spouse or children leaves him feeling alone.” (Avieli et al., 2016)

The studies indicated that the absence of these relationships was keenly felt due to the age and life stage of the participants, when the relationships that would normally be present for them were absent. Participants identified the void of not having a family and the loneliness that this entailed across a number of studies.

“All but one participant experience relational voids, the non-occurrence of relationships that older adults in the general population typically engage in at some point in their lives, including relationships with spouses, offspring, co-workers or colleagues and/or friendships.” (Ogden¹, 2014).

2.2. Loss of personal development – “I feel I have never lived enough.”

Many of the studies highlighted the way in which the experience of psychosis earlier in the interviewees’ lives had disrupted their ability to pursue important social opportunities throughout the life course, such as relationships, employment, education and living independently. The growing sense of loss was associated with the process of ageing, and conveyed a sense of disappointment about an unfulfilled past and projects hopelessness about an unfulfilled future.

“I feel that I have never lived enough... as I keep going on this just keep getting worse because I feel like I’m not living up to my expectations of what I thought my life was going to be. And I just, it keeps getting worse as I get older. I just keep losing.” – (50-year-old man; Shepherd et al., 2012)

The next sections will highlight the ways in which this sense of loss was felt throughout different aspects of social experience.

2.2.1. Loss of employment and financial opportunities - “My mother was a dentist and my father ran a hospital. I could have had all this...”

Many of the reviewed studies discussed the impact of a disrupted education and the inability to work due to illness on the participants. (Araten-Bergman et al., 2015; Avieli et al., 2016; Pentland et al., 2003; Shepherd et al., 2012).

“Living with schizophrenia for years has prevented the participants from acquiring an education and being employed, thereby causing decline in their financial position, social status and self-esteem. (...) [one participant] describes and mourns the loss of a promising career and future that could have brought financial and social benefits, and thus an opportunity for a different life course. Due to the onset of schizophrenia, at this stage of his life, he reflects upon these losses, which cause him pain and suffering. This gap provides exceptional suffering as a potential opportunity for gaining a respectable profession, which appeared to be “in the palm of his hand” and “faded away as the result of illness”. (Avieli et al., 2016)

The disruption of a career due to psychosis was a theme that came up in a number of the reviewed studies. Although some participants had managed to return to work following the initial onset of psychosis, the chronic nature of the illness also appeared to have impacted upon the loss of employment opportunities for the participants in a number of studies. The participants related the inability to maintain stable employment and income to psychosis:

“Some individuals had been able to manage their illness well enough to pursue a higher education (...). Some individuals worked intermittently; a few were able to hold down

jobs for months and even years but were forced to quit when their symptoms became unmanageable.” (Shepherd et al., 2012)

2.2.2. Loss of independence – “I wish I was free in my own home”

Loss of independence and housing were connected themes in a number of studies (Avieli et al., 2016; Leutwyler et al., 2010; Ogden, 2014³; Pentland et al., 2003). A common theme across the studies was the desire to live independently; however, many of the participants were unable to do so because of their requirement of treatment, care and support. Although the studies did not indicate that the participants’ lived in supported accommodation under compulsory terms, it was evident that the participants felt they had little choice in where they lived due to a lack of alternative options, financial resources and difficulties with self care.

“I wish I was free in my own home. Not in a sheltered house... it’s not really free... I would like to have my own room; to go wherever I want, whenever I want, so that no-one tells me what to do... I have no other choice.” (Jacob, 65 years old; Avieli et al., 2016)

The participants described difficulties in managing tasks of daily living, which were a shared theme across the studies, and having support was viewed as ‘essential’.

“All participants’ viewed their lodging home as an essential support system for living “independently” in the community. Their meals were prepared, clothes washed, and a clean bed is ready to sleep in.” (Pentland et al., 2003)

The studies highlighted the anxiety that the participants’ felt about what would happen to them in the future. Lack of social networks, family and support systems meant that the participants were aware of the need to rely on healthcare systems.

“Fears about who will care for them were common among participants. Most had lost contact with their families when they became ill and were hospitalized, and were unable to build strong relationships with their children and other family members. Consequently they did not perceive the availability of family as potential support and expected to have to rely on formal care. In particular, these participants worry about being put in a nursing home.” (Pentland et al., 2003)

3. Adjustment

Patterns of adjustment were evident throughout the reviewed studies and these adaptations were typically made in response to both the sense of being ‘different’ to other people and the various losses that have been discussed in the previous section. Two sub-themes of (1) isolating and (2) adapting relationships were identified within the reviewed studies.

3.1. Isolate – “I just isolate myself, because I don’t feel most people can understand or relate to what I have to say.”

A theme throughout the studies referred to the participants’ description of isolating themselves (Araten-Bergman et al., 2015; Avieli et al., 2016; Ogden, 2014²; Quin et al., 2009; Shepherd et al., 2012). In some cases, this was a response to the discrimination and stigmatization that they had experienced as the result of their mental illness (Avieli et al., 2016, Shepherd et al., 2012):

“With limited opportunities for socialization and the fear of being rejected or discriminated against, they were leery of interacting with people outside familiar environments. The interviewees often worried about displaying symptoms in public.”

(Shepherd et al., 2012)

In other studies, isolation was explained as being a response to feeling that other people were unable to understand them and that they therefore needed to rely on themselves rather than depend on others for support and understanding: (Araten-Bergman et al., 2015; Avieli et al., 2016; Quin et al., 2009).

“As a result of this experience, they can feel that they have become ‘lone wolves’ – seeking alone for understanding not provided by anyone else.” (Araten-Bergman, et al.,

2015)

Overall, these studies described a tendency of people with psychosis in later adulthood to cope alone.

“For various reasons, many preferred to avoid discussing the psychotic phenomena.

Some felt that others ‘wouldn’t understand’.” (Quin et al., 2009)

3.2. Adjusted relationships – “My social worker sees me every Friday... [...] If anything happens, I call her.”

As discussed above, the theme of interpersonal loss and rejection was predominant throughout the reviewed papers. A coping strategy that was described in a number of the studies was of adapting relationships to fit within the parameters of the participants’ experience of mental illness (Ogden, 2014¹; Pentland et al., 2003; Solano & Whitbourne, 2001). There were a number of descriptions throughout the studies reviewed of individuals building relationships with peers and mental health professionals, to replace those that were absent in the form of family and friends.

“All seven participants made relational adaptations by establishing relationships that substituted for those absent because of relational losses and voids. The new relationships were with either treatment providers or peers with mental illness: persons whom the participant would likely know only in a different capacity without the presence of a psychiatric diagnosis. (...) Participants agreed that these relationships had taken on special importance because of the absence or distance of family and friends,

promoting a sense of wellbeing that might have otherwise been absent.” (Ogden¹, 2014).

In connection to the participants’ descriptions that people without psychosis were less likely to understand them, it was described that people with psychosis found that people with similar experiences of mental health were able to understand them better and that they felt more comfortable with these relationships:

“Participants find it especially helpful to live with persons who also have schizophrenia because they feel such persons are more understanding to take to since “they know what you’re going through.” As one participant explained, “they have their bad days too and I have my bad days too, they helps me that way.” (Pentland, et al., 2003)

4. Developing new knowledge, skills and understanding in relation to age

This theme contains two sub-themes; (1) developing better knowledge and skills in managing symptoms of psychosis and (2) the importance of the participants’ understanding and how they make sense of their social experience and lives (Araten-Bergman et al., 2015; Ogden, 2014²; Ogden, 2014³; Shepherd et al., 2012; Solano & Whitbourne, 2001).

4.1. Knowledge and skills – “You’re wiser... you’ve been through it before.”

There was a shared theme across the studies that described way in which people in later adulthood felt that they had learnt over time to manage the symptoms of their illness better (Pentland et al., 2003; Shepherd et al., 2012; Solano & Whitbourne, 2001).

“Life seems better because they report looking at life differently and understanding themselves and their illness better, all improving their ability to deal with problems now.

(...) Participants report they have learned coping strategies for living with schizophrenia and feel some control over the illness.” Pentland et al., 2003)

Although the participants tended to describe difficulties in other areas of their lives, such as relationships and living situations, their management of their illness had improved with age and factors such as feeling ‘wiser’, experience and maturity contributed to this positive development.

4.2. Importance of personal understanding - “At this point in my life, it’s really irrelevant what label you would put on me”

A number of studies identified the way in which people with psychosis in later adulthood position their social experiences as being more central and more important to

them than the illness of psychosis itself (Araten-Bergman et al., 2015; Ogden, 2014²; Ogden, 2014³).

‘Clinical descriptions of the illness symptoms were less relevant than their own unique experiences of the symptoms, and perhaps more importantly, the symptoms were less relevant than what they considered to be the consequences of those symptoms. They absorbed and accepted the clinical description of schizophrenia only so far as it described their experience.’ (Ogden², 2014).

DISCUSSION

Qualitative research into the experience of psychosis is growing in importance and the current study aimed to review literature describing the subjective social experiences of people with psychosis in mid and later adulthood (aged 40 years and over). Thematic Analysis (Braun & Clark, 2006) was used to review 10 studies. Data was organized into nine themes that were then grouped into four overarching categories. Most of the papers reviewed described the participants’ experience of symptom improvement over time; however the difficulties associated with the social experience of people with psychosis in later adulthood was perceived by the participants to become more important with age than the illness itself.

The findings of this review described this populations’ experience of long standing social difficulties, which included stigmatization, rejection, misunderstood

behavior, and instability and resulted in them expressing various feelings of sadness, frustration and regret about lost relationships and unfulfilled social hopes and desires. Furthermore, feelings of isolation and loneliness seemed to increase with age and raised questions such as who would take on the responsibility of care-giving in old age.

The participants engaged in a number of processes in order to adjust to these experiences, such as isolating themselves in order to avoid rejection or stigmatization, and relying on peers and professionals involved in their care and treatment in lieu of social networks consisting of family and friends. The ability to find people who are able to offer support is a central tenet to the recovery process, because ‘recovery is a deeply human experience, facilitated by the deeply human responses of others. Recovery can be facilitated by any one person’ (Anthony, 1993).

Lack of Opportunity

Difficulties in attaining functional milestones such as employment, relationships and independent living were consistent themes throughout the reviewed papers. It was evident that the prospect of an education and career was considered by the participants to not only provide a source of income, but also a sense of meaning, structure and a position within society that they perceived to be important and meaningful. The loss of the ability to achieve this in their lives was therefore keenly felt by the participants in the reviewed studies and can be viewed as a barrier to recovery (Anthony, 1993).

Harvey et al. (2009) suggested that social and cultural factors play an influential role in the outcomes of individuals with psychosis in later adulthood. This was

reflected in the findings of the present review whereby the participants acknowledged their lack of independence in terms of their living situation and also an awareness that the future was likely to entail more dependence on the systems in which they were already integrated. Also some of the participants described difficulties with holding down jobs due to challenges with managing at times when symptoms became unmanageable. This further reinforces the suggestion that individuals with psychosis have the ability to function in various social capacities, but that social and cultural factors can impact upon maintaining employment and education.

Cohler and Beeler (1996) emphasise the importance of holding 'normative' expectations for people who are recovering from episodes of a psychiatric illness, in order to provide them with a sense of purpose, identity connection and self-worth. Furthermore, they relate that 'reduced normative expectations' may only create further distress and exacerbation of illness (Cohler & Beeler, 1996). The findings of this review support this view, and can be seen in participants' descriptions of feeling that they have 'never lived enough' and their desire to pursue career and education opportunities.

Finally, the divergent nature of wanting to be independent whilst simultaneously depending on healthcare systems and professionals was evident in results of the present review and experienced by the participants themselves with a sense of passivity and hopelessness. This also draws attention to the 'double stigma' of ageing with a severe mental illness in a Western society (Meesters et. al., 2010) and emphasises the need of a greater focus to be placed on enabling people with psychosis in later adulthood to access opportunities that are important and meaningful to them.

Life Review Process

The results of the current review highlighted that the participants engaged in a process of review of their lives from the perspective of later adulthood in a way that was meaningful for them. For example, the papers demonstrated an awareness of the participants' feelings of loss and regret whilst also acknowledging the participants' sense of change over time. The participants described feeling 'wiser' and more in control of their mental health, was contributed to the general sense of life being 'better' than it was in their earlier adulthood. This process was considered to be related to ageing and demonstrates the relevance of the 'life review process' (Haber, 2006) for people with psychosis in later adulthood.

A life review process involves the examination of how memories contribute to the meaning of one's life and also the attempt to come to terms with more difficult memories (Haber 2006). This supports the suggestions of Cohler & Beeler (1996), which describe the importance of focusing on the interaction between illness, aging and development in order to build upon the subjective experiences of individuals throughout the life course and to support them to make their lives more meaningful and satisfying to both themselves and those close to them.

Limitations

The current study was subject to a number of limitations. Of note, the systematic search retrieved only 10 articles that met the criteria for the current review; therefore the findings are limited by the somewhat restricted information contained within the retrieved studies. Additionally, it was felt that the review process did not reach

“saturation”, defined as the point to which additional data does not lead to the generation of new ideas of themes when undertaking qualitative analysis (Charmaz, 2006).

Although the studies shared many themes, there were also smaller and alternative themes in most of the papers, which suggests that additional conclusions could have emerged if more studies had been available to review.

The process of critically appraising the studies revealed that the studies were of varying quality, ranging from relatively high to relatively low. The COREQ (Tong, Sainsbury & Craig, 2007) was used in order to address difficulties relating to accounts of methodological procedures and contextualised findings, and in an attempt to make the quality of the evidence as transparent as possible. Although it was hoped that this approach would allow the reader to judge the credibility of the themes for themselves, it remains possible that the findings of this study were biased by the inclusion of studies with a low quality rating. However, the absence of a weighting process during the quality appraisal process is likely to have diminished the importance of well-conducted studies and enhanced the importance of poorly conducted studies in this review. Whilst the approach taken in this review allowed for plurality of results across all of the papers, it is likely that weighting the results in such a way that would have allowed higher quality papers to have more emphasis in the analysis and themes of the included papers would have prioritised those papers with higher methodological procedures, and allowed them to shape the results accordingly.

The present review included papers that were concerned with the social experience of people in later adulthood with psychosis, and this included both individuals with early onset psychosis and late onset psychosis. A limitation of the

present paper therefore relates to the way in which some of the themes that were identified may not apply equally to people with early onset and late onset psychosis. Such themes included Theme 2.2. (Loss of Personal Development), in which the results discussed the way in which the studies described how living with psychosis from an early age had prevented participants from accessing opportunities relating to employment and the development of independent living skills. Furthermore, Theme 4. (Age-related Changes) described various skills and perspectives that some of the studies denoted participants as having developed in older adulthood. Both of these examples demonstrate perspectives that relate more to people with psychosis in later adulthood with an early onset, rather than individuals with late onset psychosis.

Finally, only four studies reported the duration since the initial onset of the psychotic episode (Araten-Bergman, Avieli, Mushkin & Band-Winterstein, 2015; Avieli, Mushkin, Araten-Bergman & Band-Winterstein, 2016; Quin, Clare, Ryan, & Jackson, 2009; Shepherd, Depp, Harris, Halpain, Palinkas, & Jeste, 2012). This therefore undermines the ability to draw conclusions about the impact of age-related changes or the duration of time that the participants had lived with the illness.

Implications for future research

Research focusing on first episode psychosis has prioritized improvement in areas of social functioning as a key clinical target area and psychosocial interventions are considered to be more effective than interventions that target symptom management alone (Harvey & Bellack, 2009); however, based on the results of the present study, it is

recommended that more research is carried out with the aim of understanding and improving the social experiences of people with psychosis in later adulthood.

Existing research on recovery from psychosis in younger adults indicates that the development of a cohesive personal narrative is an integral part of the recovery process, rather than being an indication of outcome or change (Roe & Davidson, 2005). The role of age in the development of narratives is supported by research on older adults without a mental illness, which found that resilient outcomes depended on constructing narratives that interpreted past adversity in light of recent events (Hildon, Smith, Netuveli & Blane 2008). It is therefore recommended that future research explores the role of age in the development of subjective and personal narratives across the life course, and the extent to which this is a meaningful process for the individual and those close to them.

It is also recommended that research is extended to exploring the beliefs and attitudes of those surrounding people in order to understand the potential assumptions and expectations of change that people involved in supporting people with psychosis in later adulthood may have. The present study indicated that people with psychosis in later adulthood felt that they had missed important opportunities in life due to being unwell; however, in later adulthood they also felt more in control of their symptoms. Furthermore, research by Harvey et al. (2009) has indicated that outcomes of older adults with psychosis are likely to be influenced by social and cultural factors, rather than the abilities of the individuals themselves. It would therefore be interesting to understand whether with more support and encouragement from those around them, people with psychosis in later adulthood were better able to pursue meaningful

opportunities in order to enable them to feel more connected with their values and goals, and integrated in society.

In line with this, it is of note that whilst the studies included participants from a range of backgrounds, their findings did not provide particular insights into any cultural variations in the social experience of psychosis in later adulthood and the findings are likely to be biased towards westernised cultures and social systems. Considering the emphasis that such cultures place on individualism and the higher rates of disparity within families and between generations, it would be interesting to carry out research in cultures with different values and social variations.

Finally, only one paper (Quin et al., (2009) was identified which focused on the experiences of people with late onset psychosis. It is therefore likely that the findings of this review are biased towards people with psychosis in later adulthood with an early onset, and who had a significantly longer duration of illness since diagnosis. Given the dearth of qualitative research exploring the experiences of people with late onset psychosis, it is recommended that future research seeks to gain insight into this under-researched population.

Conclusion

Overall, the current results indicate the challenges experienced by people with psychosis both in later adulthood and throughout their life course. Although the studies indicated that psychotic symptoms had less impact upon the individuals in later life, the participants continued to experience difficulties related to the social impact of their illness over time. The importance of understanding people's own sense of well-being

and life satisfaction is central to these findings and emphasises the importance of measuring outcomes and recovery in an idiosyncratic and meaningful way, defined subjectively by each individual.

Finally the current findings delineated several areas of inquiry that future research in the people with psychosis in later adulthood might prioritise, such as the effectiveness of developing personal narratives across the life course, exploring the opinions and expectations of caregivers about people with psychosis's ability and process of recovery, understanding the experiences of recovery for people with late onset psychosis and the impact of cultural and social variations on the subjective experience of people in later adulthood with psychosis.

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Part 2: Empirical Paper

Narrative Coherence and Late Onset Psychosis

ABSTRACT

Introduction: It is estimated that between 20-25% of people diagnosed with psychosis will have an initial onset after the age of 40 years (Harris & Jeste, 1988; Salzman & Tune, 2001); however, little is known about the experience of late onset psychosis and the recovery from this illness. This study therefore sought to explore the experience of late onset psychosis in a sample of adults aged 40 years or older living in London, England. **Method:** An inductive, qualitative approach, based on semi-structured interviews and Thematic Analysis (Braun & Clarke, 2006) was employed. **Results:** Participants described a long-standing sense of being ‘different’ to other people and a solitary coping style was utilised both before and during the onset of the psychotic episode. They described experiencing the psychotic episode as a confusing and disruptive experience which impacted upon their concept of self-identity, themselves in relation to other people and their ability to make sense of their experiences and to communicate these to others. They described recovery as a process with which they were still engaging, and many of the participants remained uncertain about their future. **Discussion:** It was concluded that the experience of late onset psychosis has a severe impact upon an individual’s life and the impact of the psychotic episode left them uncertain about their experiences, self and ability to think about the future. Whilst the uncertainty and disruption caused by the psychotic episode was experienced as an ‘impasse’ to the process of recovery, some participants found their experiences of engaging with mental health services gave them a new perspective on how to manage difficulties.

INTRODUCTION

Defining Psychosis and Recovery

Psychosis

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013), psychosis can be defined by the presence of delusions, hallucinations, disorganized thinking, grossly disorganized or abnormal motor behavior or negative symptoms. Historically, psychosis was considered by psychiatry to be an inherently chronic and deteriorating condition (Kraepelin, 1919, p.3); however, empirical data has challenged this chronic disease model and the assumption that psychosis has a life-long deteriorating course (DeSisto et al., 1995; Harrison et al., 2001; Lieberman, 1999). As a result, psychological treatments for psychosis are becoming an integral aspect of the approach to this condition (Morrison, Renton, Dunn, Williams & Bentall, 2004; p5).

Recently, the British Psychological Society's (BPS) Division of Clinical Psychology have called for 'a paradigm shift' in approaches to understanding and treating psychosis and recommend the use of 'collaborative' formulations that explore the personal meaning of the events, relationships and social circumstances of someone's life, and of their current experiences or distress (Cooke, 2014). This emphasises the importance of supporting people in their recovery from psychosis, in a way that is meaningful, empowering and individualised.

Recovery

The definition and measurement of recovery in mental health can be roughly organised into two types (Silverstein & Bellack, 2008): those that outline recovery as outcome based and focusing on singular factors such as symptoms, relapse rates and functioning (Addington, Penn, Woods, Addington, Perkins 2008) and those that have considered it to be a long-term process of identity change, incorporating hope for the future, rebuilding self and rebuilding life (Pitt, Kilbride, Nothard, Welford & Morrison, 2007). As Bellack (2006) noted, the latter type of definition is very important to individuals when considering their subjective experiences of recovery from psychosis. Recovery should therefore be primarily conceptualised by the person making the recovery journey and treatment outcome measures should reflect this individuality (Wood, Price, Morrison & Haddock, 2010).

Late Onset Psychosis

In 2000, the International Late-Onset Schizophrenia Group clarified late onset psychosis as psychosis with an onset between 40 and 60 years of age and very-late-onset schizophrenia-like psychosis (VLOSP), which has an onset after 60 years of age (Howard, Rabins, Seeman & Jeste, 2000). Harris and Jeste (1988) approximated that initial onset occurs after the age of 40 in about 20% of people diagnosed with psychosis, while Salzman and Tune (2001) cited initial onset after the age of 40 in 25%.

It is understood that people with late-onset psychosis tend to experience more

positive and fewer negative symptoms than first episode psychosis (Pearman & Batra, 2012). For example, persecutory and paranoid delusions and visual, tactile, and auditory hallucinations tend to be more prominent in people with late onset psychosis than in earlier onsets (Chase & Cohen, 1989; Mason, Stott & Sweeting, 2013; Pearman & Batra, 2012); however, it remains unclear whether these differences relate to the age at which the onset of psychosis occurs or are the result of factors that trigger or delay the onset itself (Chase & Cohen, 1989). Also, given the cognitive changes that happen as people age, cognitive symptoms may appear more pronounced in middle-age and older patients with a diagnosis of late onset psychosis than those in adolescence or younger adulthood (Pearman & Batra, 2012).

Late-onset psychosis has a higher proportion of women than early-onset illness (Howard et al., 2000), and this is a robust finding that cannot be explained in terms of gender differences in care-seeking and social role expectations (Hambrecht, Maurer, Häfner, & Sartorius, 1992) or in delay between symptom onset and accessing help (Riecher, Maurer, Löffler, Fätkenheuer, an der Heiden & Häfner, 1989). Furthermore, in comparison to first episode psychosis, people with late onset psychosis tend to be more likely to be married or to have been married and tend to have better work histories (Kohler et al., 2007); however, social isolation and interrupted employment does appear to be higher in people with late onset psychosis than their age-matched peers (Howard et al., 2000; Woodside & Krupa, 2010).

Psychosis, Recovery and Narrative Coherence

Williams (2000) highlighted the way in which narratives that refer to the illness experience result in a better understanding of the relationship between identity and illness. In particular he demonstrated how illness could become part of one's personal biography, with life-events interpreted as factors that may have caused the illness. Although these theoretical developments have predominantly focused on chronic physical illness, growing attention has been given to chronic psychiatric illnesses such as psychosis and the role of narratives and biographical disruption (Lysaker and Buck, 2007).

Current research that focuses on recovery from psychosis is as interested in the subjective changes in how people appraise their lives and the way in which they experience themselves as meaningful agents in the world, as it is in symptom remission and the achievement of psychosocial milestones (Lysaker, Glynn, Wilkniss & Silverstein, 2010). It is considered that one of the key features of psychosis is the impaired ability to create coherent narratives about one's experiences and self (Roe & Davidson, 2005) and, subsequently, research focusing on people who experience psychosis in early adulthood has indicated that 'narrative coherence' is an integral element of recovery (Bourdeau, Lecomte & Lysaker, 2015). The majority of research in this area has focused on younger adults (Lysaker, et al., 2002; Lysaker & Lysaker, 2002; Roe & Davidson, 2005) and little research has been carried out with the aim of understanding how people who experience a psychotic episode for the first time in mid or later adulthood make sense of their experiences.

Recovery from Late Onset Psychosis

Williams (2000) suggests that as adults reach an older age, they may be better equipped with skills that enable them to deal with crises and successfully adapt to new situations such as chronic illness, or alternatively, that they have lower expectations of health in older age and meet it with a greater sense of acceptance (Pound et al., 1998). Williams therefore argues that age could be a key factor that mediates between the experience of chronic illness and the way in which an individual both responds to, and manages, chronic illness.

Using thematic narrative analysis informed by the developmental life course perspective, Ogden (2014) found that older adults who had developed and lived with chronic psychosis since they were younger adults were able to ‘profit from the later life accumulation of biographical material, using it to make sense of their illness in a way that did not diminish their sense of self-worth’. The older adults in this study demonstrated coherent narratives because they integrated their illness into their narratives ‘in such a way that the damage from the label could be minimized in their constructions of self’ (Ogden. 2014). This meant that all of the participants had developed personal stories about their lives with psychosis, which was suggested by Ogden (2014) to have addressed the internal developmental task of creating an integrated identity in later life that decreased self-stigma and celebrated personal resilience. This indicates that these older adults demonstrated an enhanced and coherent narrative style as a result of being later in life, and being able to draw on more life experiences when coping with adversity and the duration of their illness.

To date, there is little existing research on the experience of, and recovery from,

late onset psychosis. Quin, Clare, Ryan & Jackson (2009) used interpretative phenomenological analysis to explore participants' previous life experiences as well as the experience of developing and living with late onset psychosis. Whilst this study indicated that the experience of late onset psychosis emerged in the context of psychosocial vulnerabilities combined with adversities associated with the experience of ageing, the sample consisted of people over the age of 60, and so these findings cannot be generalized to all people who experience psychosis in later adulthood (from the age of 40).

Study Aims

The aim of the present study is to build upon the research carried out with younger adults (Lysaker, et al., 2002; Lysaker & Lysaker, 2002; Roe & Davidson, 2005) that seeks to understand how people with psychosis make sense of their experiences of psychosis, and their ability to create coherent narratives about their self and experiences (Roe & Davidson, 2005). It is hoped that this approach will increase our knowledge and understanding of recovery from late onset psychosis and explore the impact that the psychotic episode has had on the person and their understanding of themselves, others and their recovery.

METHOD

Ethical Approval and Declaration of Joint Working

Ethical approval was obtained from the East Midlands - Leicester Central Research Committee on 4th August 2016 (See Appendix A). A joint ethics application was submitted with another trainee clinical psychologist from UCL. Only the ethics application and recruitment process were conducted jointly by both trainees. The task of completing the ethics application form was completed together and the task of recruitment from seven boroughs in North East London Foundation Trust was divided evenly (See Appendix B for a declaration of the joint work that was carried out).

Participant Selection

Participants were identified through consultation with members of staff at NHS community mental health centres for adults and older adults in North East London.

Inclusion Criteria:

- Participants were aged 40 years or older. This is in line with definitions of ‘late onset schizophrenia’ (Howard et al., 2000)
- The participants must have experienced a psychotic episode within the past 2 years. A psychotic episode is defined as the experience of positive symptoms of psychosis, such as hallucinations or delusions.

Participants with a formal diagnosis of dementia were excluded from this study because it is possible that this disorder could represent a different kind of biographical disruption to that caused by the experience of a psychotic episode. Also, participants who were not able to understand and communicate in conversational English were excluded from this study as it is likely that this would impact upon the person's narration of their experience and their ability to engage in the interview process.

Procedure

The potential participants were initially contacted about the study by their care coordinators or the lead professional working with them, at which point they were provided with a recruitment leaflet (see Appendix C). The present study represents the first component of the research explained on the leaflet, i.e. the research interview. If the potential participant expressed interest in the research and consented to being approached by the researcher about the study, they were then contacted by their preferred method of communication (telephone, letter or face-to-face). The potential participant was also able to specify whether they were interested in taking part in one or both of the research options at this stage of the recruitment process. Participants who were interested in just the interview component were then approached by myself and if they were interested in participating in both components of the research, myself or my fellow researcher would both arrange to meet with the participant on two separate occasions.

A time, date and location to meet was then agreed with the participant. Three meetings were carried out at the participants' homes, and eight were carried out at the

service that the participant usually accessed. During this meeting, participants were provided with an information sheet (See Appendix D) which the researcher read with them and allowed time for any questions. Participants were informed at the time of being presented with the information sheet that participation was voluntary, that their decision to take part would not affect their care in any way and they could withdraw at any stage. It was stressed that any information they shared would be anonymous and that data protection procedures would be followed. The researcher then re-checked that the participant was willing to take part in the study before asking them to complete the consent form (see Appendix E) and beginning the interview.

Demographic information was collected before proceeding to the interview. Interviews were audio-recorded and lasted between 25 and 80 minutes. Open-ended semi-structured interview questions were employed flexibly and worded conversationally, sometimes being omitted or adapted according to the demands of the particular interview. One participant had a friend present during the interview, otherwise all other interviews were carried out with no one else in the room.

Participants were provided with a £10 gift voucher to compensate them for their time; two participants declined payment. Following the interview, participants were sent a written summary of the interview by the researcher. An example summary letter can be seen in Appendix F. This was then followed up with a phone call in order to provide an opportunity for the participants to provide feedback about whether they felt the researcher had accurately reflected their experiences, or to provide any other comments or feedback that they felt necessary. Two participants stated that they did not wish to receive a written summary of their interviews.

Materials

A semi-structured interview schedule (See Appendix G) was developed for the study. The Indiana Psychiatric Illness Inventory (IPII; Lysaker, et al., 2002) was used as a framework from which to base the interview schedule. The IPII was developed as way of eliciting an individual's ability to create a narrative about their experience of psychosis (Lysaker et al., 2002). The interview consisted of open-ended questions worded in a 'conversational style'. It began with broad information regarding how participants would define themselves, before exploring the way in which they considered the experience of psychosis to have impacted upon different areas of their lives. It also explored the concept of recovery and what their hopes and expectations were for the future.

The interview schedule was reviewed and amended after the first, initial interview in order to include a question about how the participants saw themselves. This was done in order to provide more information about this aspect of their experience, and so that some more rapport was developed with the participants before moving on to focus on their illness experiences.

The style of the interview was one of "directed conversation" (Pidgeon & Henwood, 1996) and was intended to be as flexible and open-ended as possible, so as to allow participants to tell their own story and share their perceptions in their own words. Further prompts and questions were included as needed, to further guide the discussion and to offer more structure to those participants who found it difficult to talk at length and in detail.

Qualitative Data Analysis

The interviews were transcribed in full and any identifying information removed. The data was analysed according to Braun and Clarke's (2006) approach to thematic analysis. This was considered to be an appropriate analytic approach because it is a theoretically-flexible method for exploring patterns in data, allowing for a detailed account of the lived experiences of individuals with particular clinical conditions. Other qualitative methodologies were considered during the design of this study, and may have been more appropriate to the aims of the present study, but due to practical reasons, were unable to be undertaken. These alternative, qualitative methodologies included Narrative Analysis, which would have provided more detailed focus around issues of identity construction and self-exploration, whereas Interpretative Phenomenological Analysis would also have provided more insight into subjectivity and the experience of the self and the body (p. 441-448, Griffin & May, 2012).

Thematic analysis is composed of six stages of coding and theme development (Braun & Clarke, 2006). The primary researcher familiarised herself with the data set by transcribing each interview. She then read and re-read the whole data set, noting any initial observations (phase one). She then methodologically coded the data both by hand and using NVivo Software, identifying key features (phase two), which were then studied for wider patterns of meaning and themes (phase three). The patterns of meaning and themes were then subjected to a process of review (phase four), themes were refined, described and named (phase five), resulting in three overarching themes. Producing this paper constituted the last phase of analysis. Exemplar and compelling extracts were selected to illustrate themes and the fit between the data and the

researcher's understanding of them (Elliott, Fischer, & Rennie, 1999). See Appendix H for an excerpt from a transcribed and coded interview.

The analysis was conducted within an essentialist/realist paradigm (Braun and Clark, 2006). This enabled the researcher to theorise motivations, experience and meaning in a straightforward way because a largely unidirectional relationship was assumed between meaning and experience, and language was understood to reflect and allow individuals to articulate meaning and experience (Braun & Clarke, 2006). As far as possible, the data were analysed in an inductive, data-driven way, in which the themes identified were strongly related to the data. Analysis incorporated both descriptive and interpretative components, with an attempt to theorise the significance of themes and their broader meanings and implications (Braun & Clarke, 2006).

Trustworthiness

Multiple steps were taken to ensure the trustworthiness of results (Elliott et al., 1999).

The research process was transparently presented, efforts were made to contextualise the study and its participants, and quotes were employed to vividly illustrate themes to enable readers to critically judge the value and transferability of findings. The author wrote a subjectivity statement (see below) to describe her personal biases (Preissle, 2008). A qualified clinical psychologist experienced in qualitative research separately coded three transcripts, followed by a process of comparison of interpretations, consensus building and elaboration of themes with the primary researcher. Two

supervisors were involved in discussing evolving themes and refining theme labels to best capture the interview data. Respondent validity was sought by inviting the participants to provide feedback on a summary of their interview.

Subjectivity statement

I am a female, white British, middle-class trainee clinical psychologist in my late twenties. My interest in the experiences of people with psychosis in later adulthood stems from my clinical experience of working in recovery-oriented services and with people with psychosis across a range of ages. Nobody in my immediate or extended family has experienced a psychotic episode to my knowledge.

My prior assumptions included the idea that people who were diagnosed with a psychotic episode in later adulthood would cope ‘better’ with the illness than a younger adult or adolescent and that they would be more likely to have coping strategies and support systems available to them. I also assumed that people who had more positive life experiences would be those who were more able to engage with the process of recovery. Given my experience of training as a clinical psychologist, I was aware of the need to refrain from viewing peoples’ experiences from a ‘professional’ perspective. I attempted to ‘bracket’ these personal assumptions while conducting the research (Barker, Pistrang, & Elliott, 2002).

RESULTS

Participants

Eleven individuals (6 female, 5 male) living in North East London and Essex participated in this study. Table 2.1 shows participant demographics. To ensure anonymity, all names have been removed and the participants are identified by a code which was assigned in the order of their interviews. The sample ranged in age from 40 to 76 years (mean = 57, SD = 13). Six of the participants were white British. One participant had never worked and four were retired. At the time of interview, three participants were on sick leave from work, two were in employment and one was unemployed but actively looking for a job. At the time of interview, all participants were accessing community mental health services.

Table 2.1: Participant Demographics

Participant Code	Age	Date of Diagnosis	Profession	Ethnicity	Gender
PPS1	76	2016	NA	White - British	Female
PPS2	72	2016	Retired	Black - Caribbean	Female
PPS3	55	2016	Civil servant*	White British	Female
PPS4	41	2016	Teacher*	White British	Female
PPS5	60	2016	Retired	Black British	Female
PPS6	40	2016	Gardener	White - Israeli	Male
PPS7	49	2016	Shop attendant*	White - British	Male
PPS8	56	2016	Cashier	Asian - Indian	Female
PPS9	64	2016	Retired	White - British	Male
PPS10	69	2008	Retired	White - British	Male
PPS11	44	2015	Unemployed	Black - African	Male

*Currently on sick leave from work

Themes

Analysis led to the generation of three themes and ten subthemes (see Table 2.2). An example of a coded excerpt is presented in the Appendix. In what follows, themes are described with illustrative quotes. Participants are identified by codes corresponding to Table 2.1. and ‘Int’ denotes the interviewer. For ease of reading, repeated words and non-words have been deleted, superfluous segments have been replaced with an ellipsis [...] and connection words have been inserted (enclosed in square brackets []).

Table 2.2: Themes and Subthemes

Theme	Subtheme
1. Difficulty coping	1.1: You're used to being on your own
	1.2: Not being able to cope at work
	1.3: Too much trauma along the way
2. Spiraling	2.1: I don't know where I was in my mind
	2.2: I become a different person
	2.3: Self in relation to others
	2.3.1: I'm isolated in this
	2.3.2: People don't really understand
3. Still Recovering	3.1: I feel a little bit down and sometimes lost
	3.2: Not being at work is a big one for me
	3.3: I want to be a better person

Theme 1: Difficulty coping - “My brain couldn’t cope with all the stress and that and it all, shut down, sort of thing.” (PPS7)

This theme described the participants’ experiences of coping before their psychotic episode.

1.1: “You get that way because you’re used to being on your own.” (PPS5)

Six participants described coping strategies that were of a solitary nature and that involved them relying on their own personal resources. These coping strategies were described as being long-standing in nature and related to difficulties in social relationships from an early stage in life.

PPS2: “I didn’t have any relatives or someone to depend on or, to, you know, discuss anything with. I sort of to do things by trial and error.”

One participant related this solitary coping style to her cultural background and her experience of not talking about difficulties with other people.

PPS8: “I’m a very shy person. And I always felt like I had problem connecting with people. It’s hard to connect with people, like some people connect easily and for me it’s always been, I don’t know something, that skill I haven’t learnt. [...] I always take time to connect with people. And always, in our culture, like, when we grow up, we not always talk about the problem, we’re not allowed to ask question. So, some of the unanswered question always build up, yeah, and I remember I felt more vulnerable in young age, yeah.”

Another participant reflected that he would have coped better with becoming unwell if it had have happened to him when he was younger, and he related this to having more social support.

PPS9: “Probably if I had it earlier in life, I’m not sure, I might have coped with it more quickly.”

INT: “I wonder what might’ve made the difference?”

PPS9: “Well, I had my friend Sarah then who was a very close friend and she passed away 6 years ago, [...] so I would have had her to support me.”

1.2: “This started with not being able to cope with work” (PPS4)

Five participants attributed the etiology of their illness to work-related stress and pressure. These participants all described working in jobs that took up a lot of their time, leaving little space for recreational activities and creating a poor work-life balance.

PPS3: “It was quite a responsible job and, um, the last three years was getting really quite stressful for me, the work, and um, I didn’t realize really, I didn’t realize at the time but looking back now, um, all I’ve been doing is working and not really living. [...] I was getting more and more anxious about paperwork that was toing and froing from work.”

The participants also described being overwhelmed by work and feeling that they were under-performing and inadequate at their jobs.

PPS4: “It started off very much as an obsession with my work [...], like not being able to cope with work, things getting on top of me at work, then taking time off and then while I was off just completely turning it over again and again to the point where, um, I

felt, that, I still do feel, that I'm really inadequate, that I haven't done a good job, that I've messed up a lot of things at work."

In contrast to the above, two participants who were retired indicated that work had been protective factor for them.

PPS10: "I was alright when I was in work. As soon as I packed in work, I took redundancy and I went straight in the mental hospital. I just went mad".

Although this participant seemed unclear about the specific reasons for becoming unwell, he made a link between the cessation of employment and mental illness. Similarly the following quote indicates the way in which being employed served a social function for this participant, and without this, they were felt more alone.

PPS5: "When I was working it wasn't so bad, you know, because you're always with other people. But it's like, when you're on your own, you sort of get that way because you're used to being on your own, so you get quiet and it stay that way."

1.3: "I think I had too much trauma along the way" (PPS2)

Five participants described numerous adverse life events that they considered led to them feeling that they were unable to cope any longer. These included difficulties with work, relationships, financial pressure, homelessness, social isolation and traumatic loss.

PPS11: "The one that most affected me was the family. That one affected me. Then after family, I went homeless. I was on the street for quite some time. I was working at

the time but I could not cope with the work because I'm sleeping on the buses and then I was doing construction. So I have to give up because nowhere to have shower or going to work, heavy job, hard job, then again nowhere to sleep. But I give up. 2014. I give up. I could not make it because I was exhausted."

Theme 2: "It spiral me down" – (PPS2)

This theme conveyed the way in which the participants' experienced the psychotic episode as a deeply confusing and disruptive event (2.1), which affected their sense of identity (2.2) and their ability to relate to other people (2.3.1 & 2.3.2).

PPS2: "And it spiral me down. Yeah. I go into a spiral and they not... um I stop be communicative. I'm not aware of what goin' on around me."

2.1: "I don't know where I was in my mind." (PPS2)

Eight participants described feeling a sense of confusion about their experiences whilst unwell.

PPS1: "I didn't know if [...] physically I'm ill and it's making me like this or am I mentally ill and its make me physically unwell? It was like a complete... I don't know, a complete muddle if you like, something I couldn't get away from. And I wanted to die."

Attempting to make sense of their experiences and understanding how much of their experiences were real or not was a process that the participants described engaging

in.

PPS4: “That’s the part of the psychosis that I’m not sure how much was real and how much was imagined. Those, that meeting that I went to and the, the time I went back to the school, and that’s what remained like a bit of an impasse for me through all this. I can’t get my head around it.”

This sense of uncertainty and confusion was an upsetting and worrying experience for the participants, and they described their continued efforts to make sense of their experiences whilst they were unwell.

PPS2: “So how come I get to this point where I’m absolutely stupid and don’t know what I’m doing? And thinking about that even make me get upset. I couldn’t sleep. I toss and turn and everything else. And up until now I’m still trying to go over what happened. And I really cant see the sense of it [...]!”

2.2: “I felt like I become a different person. That wasn’t me. It was like I was another person, I was taken over.” (PPS3)

This subtheme referred to the way in which participants described how they understood their sense of self and identity both during and following the psychotic episode. Four participants referred to the experience of thinking that they were a ‘different person’ whilst unwell, but indicated that they now think differently:

PPS10: “It [the psychosis] made me think... I don’t know... I thought I was Jesus Christ.”

INT: “What do you think about it now?”

PPS10: “Now I think its ridiculous.”

INT: “And, how did you know you were unwell at the time?”

PPS10: “Cause I was making silly statements. I know I was making silly comments. Particularly when I went and stole that knife and stabbed myself and then I rang up the hospital to get an ambulance, and the hospital said to me ‘Who stabbed you?’ and I said ‘No, I stabbed myself’.”

The impact of the psychotic episode was described by six participants as having affected their sense of identity at the time of interview.

PPS4: “To be honest, nothing feels very stable at the moment. I feel very differently about myself to how I felt a year ago. Um, I suppose I’m a mother.”

INT: [...] “If someone was to describe you what would they say?”

PPS4: “Well my friends would say that I was quite lively and, and enthusiastic about things and, uh, quite gregarious and all that sort of stuff. But that’s changed quite a lot recently (*laughs*). So, um, I wouldn’t say they’re stable over time. Um, yeah, that’s a difficult question.”

In contrast to this, three participants described more stable personality traits that had remained important to them from before the onset of psychosis.

PPS2: “In a way I’m a strong person. Yeah. I may have problems because I lost my money and the council can’t believe how I lost my money and I took it as if I lost a penny. But because I’m a strong person, because I think, ‘well then I came from Jamaica’, I think whatever happens I have to survive somehow, with someone’s help or whatever I can do, and, um, and so I just carry on as it was.”

2.3: Self in relation to others

These subthemes described how the psychotic episode impacted upon the participants’ ability to relate to other people because they felt isolated in their experiences (2.3.1) and struggled to both understand and explain to others what was happening to them at the time (2.3.2).

2.3.1: Isolation: “I’m isolated in this’ (PPS2)

Seven participants commented on other people not spending as much time with them as they used to before the psychotic episode.

PPS3: “I used to go out with my mum and sister. Um, but they haven’t really, I don’t know whether its because of the way I am or have been, that I haven’t, that they haven’t been asking me out. [...] We used to go to the cinema and go out to eat. But we don’t do that so much now.”

Two participants related that they had intentionally ‘cut off’ from friends and family.

PPS9: “I actually did cut away from my friends. I wanted to be away from them because it seemed to me that they were having an enjoyable time and I was having a horrible time. So there was too much contrast going on.”

In contrast, four participants described positive and supportive relationships during the time that they were unwell and the way in which this has led to improved relationships with family members.

PPS10: “My wife stuck by me through all of this, [...] and I think my family have been more considerate”.

2.3.2: Understanding and explaining: “I feel that people don’t really understand.” (PPS3)

Seven participants related that they felt other people didn’t understand them and what they had been through. This was also connected to a difficulty in explaining their experiences to other people. The below participant demonstrated this when she said that she did not think her boyfriend understood what she had been through and that she felt unable to ‘make’ him ‘see things the way I do’.

PPS 3: “My boyfriend, he really doesn’t understand. Doesn’t understand because all he can think about is himself and what he’s suffering. [...] So it’s very hard for him to see.

And I can’t, I can’t make him, I can’t make him see things the way I do. So it’s quite difficult really.”

INT: “What would you want him to, or, how would you know that he understood you?”

PPS 3: (pause: 6.0 secs) “I suppose by coming in and seeing what I’m doing here.”

INT: “So becoming a bit more involved in your treatment I suppose, that would be helpful for you?”

PPS 3: “Yeah. Yeah.”

INT: “And what about other people, it sounds like you’re feeling like they don’t get it like you want them to. How could that be improved or what could they do to make you feel like you were more understood?”

PPS 3: “I don’t know, maybe they could come along as well. Because I can’t quite, I can’t quite know how to go about it.”

Five participants described the difficulties they experienced in explaining to other people what was happening when they were unwell and the changes that they were continuing to experience.

PP9: “Oh, its hard because if its for the first time you haven’t had that experience, then you don’t know how to cope with it. And its hard to explain it to your friends because its not like you’ve had a history. Because my brother who has the prostate cancer also is bipolar, and he’s had a history of that. So you know, he’s had a terrible history of being

unwell. So, there is a difference, you know? You know when he's becoming unwell but
with me it was just like a sudden thing."

The participants described awareness of other peoples' confusion about the changes they had noticed, and the desire to explain that they were still the 'same' person as before the psychotic episode.

PPS4: "I've got a 6 year old as well and my 6 year old just talks about having another mummy. And when will the other mummy come back? He occasionally talks about old
mummy."

INT: "What do you say or how do you manage that?"

PPS 4: (pause: 5.0 secs) "I've tried to explain to him more recently that this is mummy (*laughs*), this is it, that old mummy and new mummy are the same mummy (pause: 6.0 secs). It was when I was going through psychosis, it was, I was much more cut off emotionally from, from them than I am now, even now, so I think he feels like he's got a little bit of old mummy back now (pause: 11 secs). But it's been confusing for them."

3: Still Recovering

This theme described the way in which the participants experienced recovery from the psychotic episode to be a process with which they were still engaging.

3.1: Feeling lost: “I’m still recovering actually because I’m sometimes, still, I feel a little bit down and sometimes lost.” (PPS3)

Five participants referred to the on-going experience of depression and feeling ‘lost’.

PPS 4: “And I’m supposed to recover! This is *me* trying to recover! But, it feels very empty, I feel very empty. I think that’s the difference with the emotions from before psychosis and now, it’s just this emptiness I’m feeling, I don’t, and the hopelessness. There’s a real feeling of hopelessness around it. And I do want to get better but I need someone to point out a route, and no one can. There’s no one there with a little diagram for me.”

The difficulty that the participants experienced in overcoming this sense of being lost and putting their lives back together made them feel uncertain about the future.

PPS6: “Its difficult because, you know, its like, yes I wanna do things in the future but I don’t believe its possible or I don’t believe its worth the trouble.”

3.2: Employment: “This thing about being at work and not being at work is a big one for me.” (PPS4)

Four participants described uncertainty about returning to work.

PPS4: “The problem I think that has persisted and has then brought back quite a lot of depression for me is the fact that I’m still not back at work. And I’m pretty sure I’m not gonna go back to that job which is really frightening for me.”

The participants linked returning to work with the need to redevelop confidence, and saw this as part of the recovery process that they hoped to achieve in the future.

PPS11: “I see confidence. And I’ll be back as I was before. I was happy life. I was good. Working. No stress, nothing. Stress free. But for the time being, I’m coping.”

Three of the participants who were retired said that they missed aspects of having a job, such as having other people to talk to and worrying less about finances.

INT: “How did you find retiring?”

PPS 9: “Strange. Strange. I found I’d prefer to be back at work.”

INT: “You’d rather be back at work?”

PPS 9: “I think I would yeah. Overall, yeah. But it will make life a lot more easier for me, once I get my state pension, I won’t have to worry about financial things.”

INT: “So, is the kind of interest into going back to work for financial reasons or to kind of keep you occupied?”

PPS 9: “If it wasn’t for financial reasons then if I do some work now it will be like charity work, maybe go and work for Age Concern or something.”

3.3: A new me: “I want to be a better person” (PPS8)

Four participants described the way in which the experience of psychosis and seeking professional help had enabled them to gain a new perspective on life and had changed their expectations and hopes for the future in a positive way.

PPS8: “I didn’t know how to do it before. But now I know what I’m doing and I have to do what’s right for me and what makes me feel good about myself. I want to be a better person. First I have to get better and to be a better person I have to help other people like me. That is my goal.”

For these participants, their experiences had provided them with an opportunity to review their lifestyle and they had considered making changes to this.

PPS3: “I’d like to start living more. Living a life I wanna live. I felt like I haven’t been really living that.”

DISCUSSION

This qualitative study used an interview-based method to understand the experiences of people with late onset psychosis and their recovery. Using thematic analysis, three themes and ten sub-themes were identified from interviews with people who had experienced a psychotic episode within the past two years. The participants viewed late

onset psychosis as a confusing and disruptive experience, which impacted upon their understanding of themselves and of themselves in relation to other people. They discussed their understanding of some of the difficulties they experienced before they became unwell and the way in which they experienced recovery to be a process with which they were still engaging. In what follows, the findings of the present study will be discussed within the context of existing research, limitations of the study will be considered and recommendations for future research and clinical approaches will be suggested.

Coping Alone

This study indicated that many of the participants were able to identify various difficulties that they found hard to cope with before the onset of their psychotic episode. The participants also described the way in which many of them had a long-standing tendency to cope alone. This finding is consistent with that of Quin et al., (2009), who identified that individuals with very late onset psychosis also used solitary coping mechanisms throughout life and during the episode of psychosis.

The tendency to cope alone was also evident in how the participants described feeling at the time of the interview. The participants spoke about feeling 'isolated' and some of them also acknowledged that they had actively 'cut off' from friends and family when becoming unwell, which reinforced the way in which individuals with late onset psychosis used solitary coping mechanisms both throughout life and during the psychotic episode. Participant 3 suggested that it would be helpful for her boyfriend

and family to learn more about the work she had done in therapy, by ‘seeing what I’m doing here’. This has implications for the targets of future interventions with this population because it draws attention to the need to support people to communicate their experiences more effectively with those around them to improve support systems, and to involve friends and family in treatment and care plans if the participant expresses that this would be helpful.

Disruption

The results of this study highlighted that late onset psychosis severely impacted upon an individual’s sense of self and their social experience. The theme ‘Spiralling’ within the results section was indicative of the way in which the psychotic episode could be seen as a confusing and disruptive event that affected the participants’ understanding of both their experiences and themselves in relation to their own self and that of other people. In terms of making sense of their own sense of self, the participants described feelings of instability in relation to their self-identity.

Research on chronic illness discusses the experience of illness as a ‘biographical disruption’, which is derived from a fundamental re-thinking of the person’s self-concept (Bury, 1982; Charmaz, 2002). The results of this study support this notion because of the way in which the participants described feeling fundamentally different to their self-concept. This was highlighted when Participant 3 said: “I felt like I become a different person. That wasn’t me.”

Bury (1982) has argued that the experience of illness can be viewed primarily as a ‘disruption’ whereby taken-for-granted structures, routines and knowledge are

disrupted, along with relationships. This interpersonal disruption can lead to change within the normal rules of reciprocity and mutual support within relationships, leading to the feelings of uncertainty that the participants described in relation to their relationships and social roles. Participant 4 said: “I feel very differently about myself to how I felt a year ago. Um, I suppose I’m a mother.” The use of the word ‘suppose’ introduced an aspect of uncertainty into this participant’s identity as a mother, and suggested that there had been aspects of this relationship and role which she had struggled with since experiencing the psychotic episode.

Relevance of Duration of Illness

The findings of the present study indicated that people with late onset psychosis struggled to make sense of their experiences, both in relation to their own self and to communicate their experiences to other people. This is in contrast to existing research on older adults who had developed and lived with chronic psychosis since they were younger adults (Ogden, 2014). Ogden (2014) found that these older adults demonstrated coherent narratives, which integrated their illness into their understanding of their experiences over the life course. This draws attention to the relevance of the duration since illness onset.

It is therefore possible that the participants in the present study experienced difficulty making sense of their experiences due to the relatively short duration of their illness. Unlike the older adults in Ogden’s (2014) study, the participants in the present study were not found to have addressed the internal developmental task of creating an integrated identity and described feelings of being ‘lost’ in the process of recovery and

still unsure about their identities and social roles. Thus, despite the known differences between the presentations of people with late onset and first episode psychosis (Hambrecht et al., 1992; Howard et al., 2000; Pearman & Batra, 2012), the findings of the present study suggest that the duration of illness was more relevant than the age of onset when thinking about narrative coherence. This may indicate that people with late onset psychosis may have needs that are in line with people with first episode psychosis with a relatively recent onset (regardless of their age).

Recovery as a Process

The participants of the present study described their attempts to distinguish between the experience of ‘confusion’ during the psychotic episode and their understanding of ‘reality’. For example, Participant 4 said: “I’m not sure how much was real and how much was imagined. Those, that meeting that I went to and the, the time I went back to the school, and that’s what remained like a bit of an impasse for me through all this. I can’t get my head around it.” This example reflected uncertainty about the reality of the participants’ experiences during the psychotic episode and the way in which this remains to be an ‘impasse’ for these individuals - a source of concern which prevents them from moving forward in some aspects of their recovery. For some participants, the uncertainty about their experiences during the psychotic episode had prevented them from attempting to become involved in a number of activities which included returning to work, talking to people and thinking about the future.

Traditional views and ideas about recovery have focused on the need to meet certain outcome indicators of symptom reduction and ‘improvement’ (Silverstein &

Bellack, 2008); however there has recently been more emphasis placed upon considering recovery from psychosis as a process which cannot be simply conceptualised as having clear cut differences between being recovered and not recovered (Wood et al., 2010). This can be seen in the results of the present study because the participants described experiencing a range of on-going difficulties following their psychotic episode, including feeling lost, a sense of hopelessness about the future, low self-esteem, depression and anxiety.

In contrast to the difficulties described above, the participants of the present study were also able to identify areas of change that were meaningful to them, and indicative of change and progress to improve upon how they were living their lives before the psychotic episode. For these participants, they were able to reflect upon and review their previous experiences and identify areas in which they wanted to live their lives differently. This is in line with research that focuses on the development of wisdom across the life course, which relates that ‘wisdom is acquired incrementally over the life course through some level of confrontation, direct or indirect, with the fundamental themes and questions of human existence’ (p76, Gluck & Bluck, 2013). Gluck & Bluck (p. 79, 2013) argue that wisdom is predicted by the way in which individuals deal with and integrate experiences, rather than merely the age of that individual or that amount of experience they have encountered across their lives, and that it involves a process of ‘review’ which occurs over time.

Limitations

From a methodological perspective, the nature of semi-structured interviews allows for

the possibility that aspects of participants' experiences were omitted or emphasised during data collection. In this study, weight was given to participants' subjective accounts in as much as verification of their accounts was not sought through, for example, checking medical records. This approach was based on the postulation that these accounts reflected participants' subjective realities, irrespective of alternative perspectives; however, it remains important to recognise that the results were inevitably shaped by the context of the study and were therefore necessarily incomplete. Furthermore, although the aim of this study was to stay as close to participants' experiences as possible, the nature of qualitative research means that the researcher has an inevitable shaping influence.

The study was based on a small sample of participants from one urban setting and thus the findings may not be generalizable to other contexts and populations. Furthermore, it is probable that the current results are somewhat biased as a result of the sample that was recruited to this study for a number of reasons. Firstly, all participants who were recruited had received a psychological intervention and were accessing a community mental health service at the time of participation. This meant that these particular participants had experienced a psychotic episode relatively recently and were all at an early stage in their recovery. The fact that many of the participants had been referred to psychological services suggests these individuals were likely to be 'well' enough to engage with such work and teams, and that they had been exposed to ideas of recovery and mental health. These limitations highlight the need for research that directly examines barriers to research in late onset psychosis in order to facilitate future progress in this field. It also highlights the need to extend research on people with late

onset psychosis to those with a longer duration of illness, who may not be currently accessing mental health services and therefore have different experiences of the process of recovery.

Clinical and Research Implications

Relevance of Duration of Illness

The findings of the present study suggest that people with late onset psychosis may have needs which are more in line with people with first episode psychosis, regardless of their age; however, future research is required to further establish the similarities and differences between these two onsets and also the similarities and differences between age-matched older adults with both early and late onset psychosis. The implication of this suggestion is that, considering that first episode psychosis services typically have a cut-off age of 35 years, it is recommended that this is extended to encompass people who experience psychosis for the first time after the age of 40 years, in order to improve upon current approaches for this population.

Biographical Disruption and Narrative Approaches

The results of the present study suggested that people with late onset psychosis found it difficult to make sense of their experiences, and to explain these to other people. This is in line with existing research on psychosis, which indicated that when people first experienced psychosis, they were not aware initially that what they were experiencing was a mental illness and they do not know how to account for them, leading to a sense of

confusion and ‘narrative incoherence’ (Roe & Davidson, 2005).

Regaining a sense of self as a social agent and a restored life narrative not only indicates a marked recovery from psychosis, but also plays a crucial role in the process of recovery itself (Roe & Davidson, 2005). As a result, narrative approaches that aim to help people regain an understanding of themselves and their experiences via the reconstruction of narrative coherence are growing in popularity (Lysaker & Lysaker, 2002; Roe & Davidson, 2005). Narrative approaches propose that people organize their life experiences in the form of a narrative in order to make sense of it to themselves and others, and much research to date has focused on making sense of the experience of illness (Murray, 2008, p114). Narrative accounts strive for a sense of order to disruption in one’s life, by encouraging individuals to expand their repertoire and to construct new and alternative stories which are able to encompass disruptions and areas of incoherence (Murray, 2008, p111).

Thus, based on the findings of the present study, it is suggested that research looking at interventions that enable people to develop cohesive personal narratives could be an important direction for individuals who experience late onset psychosis. The aim of a narrative approach would be to support these individual to develop a narrative understanding of the role that psychosis has played in their life and to encourage them to absorb the experience into an integrated narrative identity, which made sense to both them selves and other people. McAdams’ (1996) research on the narrative life review process draws attention to the sociocultural nature of narratives and narrative identity, and that narrative identities build slowly over time as people tell stories about their experiences to and with others (McAdams & McLean, 2013). It is understood that

‘through repeated interactions with others, stories about personal experiences are processed, edited, reinterpreted, retold, and subjected to a range of social and discursive influences, as the story-teller gradually develops a broader and more integrative narrative identity’ (McAdams & McLean (2013)). Consequently, the role of psychological interventions in enabling people recovering from psychosis to rebuild a narrative identity within a psychosocial framework seems to be an important element in the process of recovery. Adler (2012) identified that increases in personal agency were both preceded and predicted by improvement in therapy, because ‘as patients told stories that increasingly emphasized their ability to control their world and make self-determined decisions, they showed corresponding decreases in symptoms and increases in mental health.’

Social Isolation and Psychosocial Interventions

The results of the present study would meet the eligibility criteria for the literature review about the social experiences of people with psychosis in later adulthood, which was reported in the first section of this thesis. The results of the literature review indicated that there was a predominance of social isolation in later adulthood and long-standing difficulties with social relationships, which included experiences of stigmatization, rejection and instability, and that interpersonal difficulties tended to remain unresolved for people with psychosis in later adulthood despite better management of symptoms. The findings of the present study would support these findings, and contribute information about the way in which people with late onset psychosis are vulnerable to stress and pressure in later adulthood, from sources such as

work and social isolation. However, unlike people in later adulthood with first episode psychosis who are likely to have experienced greater chronicity of their illness, people with late onset psychosis may not be demonstrate the ability to make sense of their experiences as successfully, and to integrate their illness into a narrative of their experiences over the life course.

Conclusion

The findings of this study highlight the impact of late onset psychosis and some of the challenges of the recovery process. Taken together, the present results suggest that late onset psychosis has a significant impact upon an individual's ability to make sense of their experiences and affects their understanding of their self –identity and themselves in relation to others. It is therefore suggested that a focus on enabling people with late onset psychosis to address these areas of understanding and are possibly an integral part of the recovery process itself, rather than an outcome of recovery. Furthermore, the present study suggests that people with late onset psychosis present with varied life experiences and these were viewed as being very relevant to the participants when thinking about their illness and how they have coped in the past. The present study highlights that people with late onset psychosis have needs that would be best managed with an approach that takes into consideration their age of onset and duration of illness, and it is suggested that future research and interventions seek to determine the similarities and differences with first episode psychosis across the life course.

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Part 3: The Critical Appraisal

INTRODUCTION

This appraisal focuses on the main issues that arose during the process of this research project. Firstly, I will focus on the empirical paper, and describe the way in which my assumptions may have affected the research process, difficulties with the interview process and an appraisal of the interview schedule. I will then describe some personal reflections on the interview process. Finally, I will discuss some methodological considerations in relation to my literature review.

THE EMPIRICAL PAPER

Initial Personal Assumptions

It is acknowledged that researchers have assumptions that reflect their personal values, beliefs and experiences, and that these will inevitably influence their work (Preissle, 2008). I recognize that I arrived at this project with a number of assumptions that may have may have influenced the research project throughout the research process. My personal background and experiences are likely to have attracted me to this research topic to begin with, informed the choice of methodology and shaped how the interviews were conducted. I attempted to maintain a level of awareness and transparency about these assumptions throughout, by acknowledging them in the Subjectivity Statement (Preissle, 2008) in the empirical paper, and by ‘bracketing’ these assumptions (Barker,

Pistrang, & Elliott, 2002).

Literature on qualitative methodology emphasises the importance of “bracketing” and it is understood that bracketing involves identifying and attempting to suspend one’s preconceptions in order to limit their ability to influence on the research unduly (Fischer, 2009). The extent to which bracketing is truly possible is debated, as is the definition of what should be bracketed and at what stages of the research process (Fischer, 2009). Whilst bracketing does not involve detaching from one’s ideas in order to maintain objectivity, it can facilitate thoughtful and reflective engagement with the data (Tufford & Newman, 2010). An integral element of the bracketing lies in ensuring that it is a transparent process, in which the possibility of alternative perspectives of both researchers and readers are allowed (Fischer, 2009).

I found that ‘bracketing’ included the inclination to shape the interview process due to clinical training and that I was both helped and hindered by my efforts to bracket the ideas and preconceptions that I had accumulated throughout my clinical training and experience. My experience of working with a systemic and narrative model facilitated my ability to practice a ‘curious’ approach, in order to prioritise the lived experience of the participants as the central to the interaction (White and Epston, 1990). Furthermore my experience Solution Focused Therapy helped me to encourage the participants to engage with future-oriented questions (Iveson, 2002).

On the other hand, I sometimes questioned my success in bracketing, and found that training and clinical experience influenced me in my interactions with participants more than I expected it to. On a number of occasions during the interview processes, I

felt inclined to engage in techniques that I would normally use within a therapeutic context. For example, during interviews I was on occasion aware that I had suggested links or rephrased content that the participants had not themselves said. I also felt a great inclination to provide reassurance and support to participants during particularly upsetting or distressing moments of the interaction. Given the sensitive topic matter, I think it was important to create an environment where participants felt comfortable to talk, especially because we had little previous knowledge and experience of working together and the interview schedule touched on personal and sensitive areas of their experiences. While I believe that my therapeutic skills helped me in this, I was aware of the importance of maintaining a balance between responding with genuine warmth and empathy whilst maintaining a neutral, non-directive stance, in order to prevent an artificial shaping of the interview.

Difficulties with the Interview Process

Interviewing individuals with psychosis sometimes presented some challenges. These included working with delusional thoughts and interviewing participants with less reflective ability. I will also discuss the limitations of the interview schedule in this section.

Narrative Incoherence and Delusional Thoughts

Some of the participants I interviewed continued to experience positive symptoms of

psychosis, particularly in the form of delusional thoughts and paranoia. In some interviews, participants struggled to answer the questions of the interview and would provide answers that contained information unrelated to the question I had posed and that I had difficulty following. At these times I noticed that I felt quite overwhelmed when the information provided didn't seem to make sense, because it made me question whether I was understanding them properly. On reflection, it is likely that at such times, the participants were demonstrating 'narrative incoherence' (Roe and Davidson, 2005) which impacted upon their ability to provide a clear and coherent account of their experiences. I noticed that participants who demonstrated more delusional thoughts and beliefs also expressed higher levels of narrative incoherence. The following excerpt from a transcript taken from Interview 5 is an example of this:

INT: And how have these, kind of, experiences affected how you think and how you feel?

PPS 5: Ahh, I suppose I've been there for one or two and I've never had this other problem before. Now with the people and because of my epilepsy I've got it with a disabled one as they pass away and what not. It never used to happen when they was still there. I suppose they pass away and people want to buy property and what not and let them, uh. And even they wanted me to buy, to buy my place and I said 'it's not mine to buy, it's the council'. So I can't let them go.

INT: Okay... What do other people in your life think about the things that have been happening?

PPS 5: None of them believe me. Uh, none of them believe me. I don't, I think, was it my daughter at some stage because it keep going on so long she, she sort of, at first she come and she hear noise and she wonder where on earth is it coming from. And somebody else because she don't come in the car, she come via foot and somebody else that came by foot as well, um, so it's more than once she heard it. And they, when they give me massage she tells me I do the massage because of this, um, she was again, she hear the noise going on as well and wonder what it is. Why they making so much noise? And, um, so the other people that hear as well besides me. I don't know. I'm not making it up but it's sad to think that somebody's making up. So all and all I would like somebody to find out what is going on.

My feeling of being overwhelmed during such accounts is likely to have compromised my ability to remain receptive and reflective. Upon reflection, it would have been more helpful to check with the participants that they understood what I was asking them in order to facilitate a better collaboration between them and I, and to perhaps spend more time on building up a shared understanding between what I was asking them and what they were trying to communicate. This would have been more in line with a collaborative approach when working with people with psychosis, which centralizes the individual's own framework of meaning and experiences.

It is possible that the difficulties I experienced during these interviews impacted upon the results of this study and biased my interpretation of the results towards interviews that were made more sense to me, therefore under-representing the accounts of people who presented with more delusional thoughts and 'narrative incoherence'.

Reflective Ability of the Participants

Some of the participants communicated less than others during the interviews, and tended to provide more factual information as opposed to reflections on their experiences. It possible that for these participants, they found it difficult talking to someone who they had vey little previous experience of working with, and that they were aware that the interview was a one-off occasion, resulting in them feeling less inclined to discuss information of a personal and sensitive nature. Another suggestion is that people who experience late onset psychosis are more likely to have a long-standing solitary coping style, meaning that they may have had few opportunities in their life to speak to someone about their difficulties and experiences (Quin, Clare, Ryan & Jackson, 2009). This apparent difficultly in reflecting on and communicating experiences can be seen in the following excerpt:

INT: How old were you then?

PPS 7: 23 (pause: 4.0 secs). And we had our first child in 91 as well. I've got four children.

INT: And how old are they?

PPS 7: Uhh, 25, 23, 22 and 18. And (pause: 8.0 secs). I'm not a good talker really.

INT: You're not a good talker, you think?

PPS 7: No.

INT: No? OK. Would you like me to ask you some more questions to help?

PPS 7: Yes please.

INT: Okay, so I guess you've mentioned being at school to getting married. So what did you do between that time? Between leaving school and getting married?

PPS 7: Like work-wise and stuff?

INT: Yeah, I suppose so.

PPS 7: I started work, I went to college and done mechanics and then I started a part-time job at a [fast food] bar and then I wanted to go full-time so I went full-time for and I stayed there for about two years and then I went to [Fast food restaurant] and I was there until another two years. Then I spent five years unemployed and then I done an engineering job for 7 years. Then I was made redundant (**pause: 5.0 secs**)

INT: Mhmm.

PPS 7: And then I spent six months unemployed and then I get a job refilling engine cartridges, printer cartridges. And then, I got a job as a casual stock taker. I done that for another 6 years and then I started working for [supermarket]. I'm still there now.

INT: Okay so how long have you been at [supermarket] for?

PPS 7: Two years.

INT: Two years. And how do you find work? What's it like for you?

PPS 7: At the moment?

INT: Or, kind of, generally throughout your life, how's it felt?

PPS 7: Well I've struggled really.

INT: Mhmm, in what way do you mean?

PPS 7: In keeping up with other people (**pause: 7.0 secs**). I can't do things if I was like some people.

INT: Okay. Um, do you find that kind of work has been a stress?

PPS 7: Yes. Especially recently.

INT: Can you tell me a bit more about why it's been stressful recently?

PPS 7: Because I've been suffering from depression. And anxiety. It's been really hard
the last few months.

INT: Mhmm, in what way do you notice it's been difficult?

PPS 7: Well when I get to work I wanna go home again. My knees go funny. They gave
me tablets for it.

I became aware during transcribing such interviews that I tended to ask more questions and make more links that were not made by the participant, than in interviews where participants provided longer responses to my questions. For example, in the above excerpt, I introduced the concept of 'stress' which had not been explicitly expressed by the participant. On reflection, I think I did this to 'help' the participants with their expression and to encourage engagement by attempting to demonstrate an understanding with what they were telling me by forming links between their experiences using my clinical knowledge. Although this served to keep the interview broadly on-topic and moving, the information obtained possibly reflects my interests and assumptions more than it reflects the participants' own views of their lives. As a consequence, the views of less reflective individuals were possibly underrepresented following analysis.

Appraisal of the Interview schedule

The semi-structured interview schedule was designed to facilitate discussion about how participants defined themselves, before exploring the way in which they considered the experience of psychosis to have impacted upon different areas of their lives. It also explored the concept of recovery and what their hopes and expectations were for the future. As discussed in the results section, most participants struggled with question that asked them to describe themselves as people. As I progressed with data collection I was aware that difficulty answering this questions and providing a description of how they saw themselves was common throughout all of the interviews; however I decided not to adapt the interview schedule in response this.

This decision was made because I felt that the difficulty answering the question was an important finding and that the participants attempts to define themselves in terms of their social roles was very relevant to the impact of the psychosis episode. I think that I became better skilled as I progressed with interviews to elicit information around this question and to encourage participants to think about a concept which they were struggling with. I found that it was helpful to enquire about whether this was something that was difficult for them to answer, and to provide reassurance that this question might not have been something that they usually think about.

Future-oriented questions also seemed challenging for participants. Upon reflection, this can perhaps be attributed the stage at which they were at in the recovery process. Many of the participants continued to engage in the process of making sense of what had happened to them during their psychotic episode and this appeared to be a barrier to thinking about what they were hoping and planning for the future. It would be

interesting to explore these questions with people who had a longer duration of time since their onset of psychosis.

Personal Reflections on the Interview Process

This was my first experience of conducting qualitative interviews. I found that I enjoyed the interviewing process at times, particularly with participants who engaged well with the questions and achieved a level of reflection over their experiences, which they told was really helpful for them. At other times, I experienced the content and process of conducting interviews with people who had experienced severe mental illness to result in me feeling anxious and frustrated.

At the commencement of this research study, I had a number of assumptions. In particular I assumed that people who experienced psychosis in later adulthood would be better able to cope with their illness due to accumulated life experience and coping skills. This assumption was perhaps based upon my own personal experiences of members of my family and wider social network, who I have observed to have coped with adversity and crises better with age. Furthermore, I found the concept of ‘wisdom-accumulated knowledge and skills’ (Baltes & Staudinger, 1993) to be have been particularly helpful in my clinical work with older adults. Holding this assumption did not prepare me for the extent of psychological distress that some of the participants expressed, and I found that their sense of hopelessness and difficulty around finding a way to cope following the psychotic episode had an emotional impact upon me. I was aware that the need to ‘bracket’ my clinical experience and therapeutic skills during

these interactions left me feeling inadequate in the face of distress, and with a desire to help and support.

In contrast to this, I was really pleased to hear some of the participants talk about the positive experience they had had accessing mental health services, and the role that psychology had played in helping them. I was particularly interested to notice that two of these participants were from a different cultural background, having been born in India and an African country. These participants both expressed the important role that psychological intervention had played in, not only their recovery, but also enabling them to better understand themselves and resolve long-standing difficulties around self-expression, thinking and managing thoughts and feelings associated with traumatic memories and experiences. The excerpt is an example of this:

PPS11: “At the moment, before, things were not very good but after I had a session with a psychologist and then from that time I’ve changed. Everything keeps changing. In a good way. ‘Cause before I as not even sleeping. I was sleeping during the day and after I see [psychologist], she was my psychologist, after we been meeting for a year and everything she explained to me! I learn a lot and since then I’ve changed everything. And then we had another group... something group? You see I thought I was all on my own but there are people who experience difficulties, but since then... I’m fine.

INT: Oh, it’s really nice to hear that you have noticed change! What sorts of things do you think are different now?

PPS 11: I think because one of the things is that I used to not sleep at night. I had so many dreams. Recall things happening before. But after sessions now I change everything. Every time I remember this word – if you go to sleep, say you are sleeping.

Don't think of anything else. And it change me!

INT: Great! What word do you say?

INT11: We would talk about if it happens say 'No!'. Just make sure say 'No!'. And its working! Because like, uh, two weeks ago, I had a lot of dreams and I'm dreaming when I'm walking. I'm seeing funny things, strange things, bad things, but I say 'No!', according to my psychologist, I say 'No, its not real!'. Before I used to think its real. I could even feel someone pulling me. But now I say 'Its not real'. 'Its not!' I say.

While I found these interactions easier and more enjoyable than working with some of challenges I discussed above, I realised the importance of maintaining reflexivity about this and being aware of the possibility the my own feelings and attitudes towards these interviews and participants may have led to their accounts being overrepresented within the analysis.

THE LITERATURE REVIEW

A principal challenge of qualitative research is related to the difficulties in determining a unified approach to the critical appraisal (Barbour & Barbour, 2003; Barbour, 2001;

Cohen & Crabtree, 2008; Dixon-Woods, 2004; Long & Godfrey, 2004; Walsh & Downe, 2006). This is associated with the way in which qualitative research is not a unified entity because it encompasses a broad range of epistemological stances and reflects a plurality of approaches. These varied approaches entail different indicators of quality, and consequently, tools for the critical appraisal of qualitative studies need to reflect these differences. Furthermore, assessing the quality of interpretations of data is problematic due to the inherently idiosyncratic, intangible and creative nature of the interpretive process (Dixon-Woods, 2004). Therefore, the critical appraisal of interpretive procedures is likely to be dependent and reliant upon subjective judgments (Dixon-Woods et al., (2007).

Although measures were taken to encourage transparency of the range of outcome ratings of the critical appraisal process in order to reduce ‘researcher bias’ (Hannes, 2011; p. 2), the methodological quality of the included papers was varied. On reflection, the findings of the present literature review would be improved upon by evaluating the themes identified in papers with a high methodological quality rating against those with lower ratings.

Additionally, it was felt that the review process did not reach “saturation”, defined as the point to which additional data does not lead to the generation of new ideas of themes when undertaking qualitative analysis (Charmaz, 2006). Although the studies shared many themes, there were also smaller and alternative themes in the papers which suggests that additional conclusions could have emerged if more studies had been available to review and the methodological quality of the included papers was of a more consistent nature. However, based on the findings of the current review, examples of

smaller or alternative themes include 'substance misuse', 'religious beliefs and experiences' and 'institutionalisation'.

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Appendices

Appendix B: Trainees' contribution to the joint research project

Only the ethics application and recruitment process were conducted jointly by both trainees – Elaine Ching and Lucy Viney (nee Smyth). The task of completing the ethics application form was completed together. The task of recruitment from seven boroughs in North East London Foundation Trust was divided evenly. Both trainees contacted an equal number of teams and clinicians at the beginning of the recruitment process. Both trainees screened an equal number of referred participants.

My Story for Recovery

Talking about life since psychosis

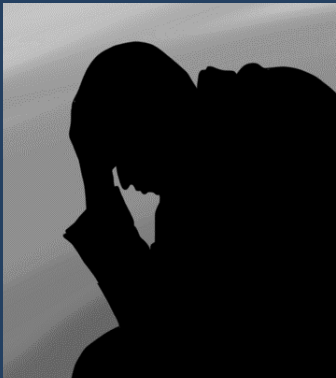


A research project

What is Psychosis?

Psychosis describes a collection of experiences such as seeing things, or hearing voices, that other people don't. Or losing control of your thoughts. Or believing yourself to have gained new and unusual status or powers.

Psychosis is generally experienced for the first time in a person's teens or twenties. If a person has such experiences for the first time aged 40 or older, it is called 'late-onset psychosis'.



More questions? Feel free to contact us on:

Elaine Ching

Telephone: 0300 555 1200 x67942

Email Address: yee.ching.14@ucl.ac.uk

OR

Lucy Smyth

Telephone: 0300 555 1200 x67942

Email Address: lucy.smyth.14@ucl.ac.uk



We **value** your views.

Your involvement can help improve and direct the future of our services.

Talking about life since psychosis

Experiencing psychosis can have a big impact on a person's life. Everyone's experience is unique, but there may be common themes.

We would like to hear from people who experienced psychosis for the first time when they were aged 40 or more. We would like to understand what impact this has had. This knowledge will help guide future services for people on the journey to recovery after psychosis.

What would taking part in this study involve?

There are 2 parts of the study (Date: TBC, Location: TBC). You can take part in either, or both.

1: An informal interview/chat about your experiences of psychosis

2: Letting us know your views on, and experience of, an 10-week long therapy group. The therapy involves:

- bringing together your life story with the story of your life since psychosis

- sharing your experience with others

A full information sheet is available for you to read and consider before deciding whether to take part.

If you have experienced psychosis for the first time aged 40 or older, and are interested in hearing more about the research, please complete and return this form to your keyworker.

Full Name:

Contact Tel:

One of the researchers (Lucy or Elaine) will contact you using these details.

Your contact details will only be used to get in touch about this study. They will not be given to anyone else.

Appendix D: Information Sheet



Participant Information Sheet: Version 3, Date: 18/05/16

Recovery From Late Life Psychosis: A Narrative Approach

You are being invited to take part in a research study. This information sheet explains the purpose of the research study and what participating will involve. Please take time to read the following information and discuss it with others if you wish. If there is anything that is unclear, or if you would like more information, please ask.

What is the reason for the study and why is it important?

We would like to explore the experiences of people who have psychosis for the first time in mid or later life, and we are interested in understanding the process of recovery. The information will help us to find ways to support people better.

Why have I been invited to take part?

You have been invited to participate in this study because you have experienced a psychotic episode in the past 2 years.

Do I have to take part?

No, participation is completely voluntary. You are free to withdraw at any point without giving a reason. Your decision will not affect your patient rights or your care.

What will happen if I take part?

There are 2 different parts to this research. You can take part in either, or both. If you take part, we will let your GP know, and your Care-Coordinator, if you have one.

1. Understanding your experiences and recovery: An informal interview

This part of the research is a single, informal interview lasting no longer than an hour and a half. We will ask questions about your experiences related to your mental health and other relevant experiences, such as employment and family life.

The interview will be arranged at a time convenient for you. With your consent, we will audio-record the interviews so that we do not miss anything important that you tell us, and then type up the recording. We will then destroy the recording.

If you take part in this interview, you can keep a copy of this information sheet. You will be asked to sign a 'consent' form to show that you understand the purpose of the study and agree to participate. As a thank you for taking part we are offering £10 shopping vouchers.

2. Sharing your experiences of the 'My Story for Recovery' group

This part of the research is only for people who are due to take part in the 'My Story for Recovery' group that is being offered as part of NELFT's psychosis pathway. The research involves filling in some questionnaires about your well-being and views of psychosis. We are also inviting you to take part in an interview to let us know your views on the 'My Story for Recovery' group.

The 'My Story for Recovery' group uses an approach called 'Narrative Enhancement and Cognitive Therapy' in eight x 90minute group sessions led by NELFT psychologists. Five or six other people will be in the group. All group members will have had a psychotic episode for the first time in recent years. The aim of the therapy is to help each person make sense of their experiences. Being able to tell one's own story can help recovery from illness. So can the support of others.

If you take part in the research study, you will be asked to fill in some questionnaires about your well-being and views of psychosis before you start attending the 'My Story for Recovery' group. After each group session you will be asked to fill in some short questionnaires. Then, after the eight sessions are complete, we will invite you to repeat the questionnaires that we used at the start. This helps us to find out whether there have been any changes to your wellbeing, or views of psychosis. All research questionnaires will be anonymous and use an ID (identification) number rather than your name.

After the 'My Story for Recovery' group sessions have finished, you will be invited to take part in one more meeting. This will either be a focus group or individual interview. The purpose of this meeting will be to tell us your views of the therapy - what did you find useful? Do you have any suggestions to make the group more helpful? If you have discussed your views of the group with a family member or close friend, or if they have opinions on how the group affected you, then they can also take part in the focus group or interview. The focus group/interview will be audio-recorded to ensure we do not miss anything. We will offer you £10 cash for your time should you or your supporter want to participate in this meeting.

What will happen to the information I provide?

All audio-recordings will be typed up so that the researchers can read the interviews. The audio-recordings will then be destroyed. Names or any details which could identify you will be changed or deleted. The researchers will identify ideas, such as those that are talked about by more than one person. These ideas will be written up into a report.

If you complete any questionnaires, the researchers will study these to see whether your well-being or views of psychosis had changed over time. The information will be analysed and written up into a report.

All information will be stored securely according to the trust and university's data protection policies. No identifiable information will be passed from NELFT to the University.

If you would like a copy of the final research report you can contact the research team. If you decide to leave or withdraw from the study, all information you have provided will remain in the study unless you request that it be deleted.

What are the risks and possible benefits of taking part?

Some people find it upsetting to talk about things that have happened when they are unwell. If this happens, you can ask the researcher to take a break at any time. You do not have to answer any questions that make you feel uncomfortable. If you feel upset during the group, let one of the group leaders know, and they can offer you support.

You may find that talking about, reflecting and sharing your experiences is interesting and helpful. We also hope that our findings from this study will benefit other people who go through similar experiences.

Confidentiality and anonymity

All data will be collected and stored in accordance with the Data Protection Act 1998. Audio recordings from the interviews will be stored on a password-protected computer and will be deleted once we have the content of the interviews written down. Names and other personally identifiable information will be removed from these written content of the interview to ensure privacy. We may include direct quotations from interviews in published reports but will not include names of participants and we will make sure that any quotations we use cannot be linked to individuals. We will store written records of the interviews in a secure location for three years after publication of the results. If you tell the researcher something that leads them to think that you or somebody else is at risk of significant harm, they may have to discuss this with your GP or those involved in your care.

What if there is a problem?

If you are unhappy about the way you have been approached or treated during the research, you can complain. NELFT and UCL have complaints procedures. If you wish to complain, contact the chief investigator using the details given below.

In the unlikely event that taking part in this study harms you, compensation may be available. If you suspect that the harm is the result of the Sponsor's (University College London) or the psychology service's negligence then you may be able to claim compensation. After discussing with the student researcher, please make the claim in writing to Dr Georgina Charlesworth who is the Chief Investigator for the research and is based at UCL. The Chief Investigator will then pass the claim to the sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Funding and review of the research study

This research has been reviewed and funded by the Department of Clinical, Educational and Health Psychology at University College London, and is being conducted by researchers at the Department of Clinical, Educational and Health Psychology at University College London. It has been reviewed by a NHS national research ethics committee

Contact for further information

If you would like further information please contact the study chief investigator Dr Georgina Charlesworth, Senior Lecturer in Clinical Psychology, University College London, g.charlesworth@ucl.ac.uk (Tel: [REDACTED])
Research Department of Clinical, Educational and Health Psychology
University College London
Gower Street
London WC1E 6BT

Thank you for considering taking part.

Appendix E: Consent Form



**Recovery From Late Life Psychosis: A Narrative Approach
Version 1, 23/01/2016**

I confirm that my participation in the above project has been explained to me. I have read and understood the information sheet and have had the opportunity to ask questions.

I am aware that (please initial in the boxes):

- I confirm that I have read and understood the information sheet dated 30/30/2016 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily
- I am free to withdraw from the project at any time and to withdraw any data that I have supplied without giving any reason.
- The interview will be audio-recorded and all data or information used for research or publication purposes will be anonymous.

In addition

- I give consent for quotes from the interview I take part in to be included in reports of the research findings.

I agree to participate in the following parts of the study:

- Service user: Part 1. Understanding your experiences and recovery (An informal interview)
-



Please turn page.

Participant's Name:

Signature:
Date:

Researcher's Name:

Signature:
Date:

If you would like any further information please contact Dr Georgina Charlesworth,
Research Department of Clinical, Educational and Health Psychology, University
College London, Gower Street, London WC1E 6BT g.charlesworth@ucl.ac.uk (Tel: 
)

Appendix F: Summary Letter



ADDRESS OF PARTICIPANT

Research and development (R&D)
1st Floor Maggie Lille Suite
Goodmayes Hospital Site
157 Barley Lane
Goodmayes
IG3 8XJ
Tel: 0300 555 1200

<<DATE>>

Dear {Interviewee 7}

Thank you for taking the time to meet with me on {DATE} and for agreeing to participate in the research project. As we discussed, I am writing to you with a summary of our meeting. I hope that this summary will provide you with an opportunity to review the conversation we had and I would be very grateful for any feedback that you may have about this summary.

Summary

At the beginning of our meeting, you told about some of the important events that have happened in your life. These related to your family; you said that you got married in 1991 and have four children who are aged 18, 22, 23 and 25 years. Only your youngest child lives at home and he has been diagnosed with Asperger's syndrome. You said that your family and your children are very important to you, and that you value being able to give them things that you didn't have growing up, such as a stable home environment and having the "right toys". You also told me that you have found your wife to be supportive of your difficulties and that you have been getting on well recently.

You told me about the different jobs you have had since leaving school. You studied mechanics at college. You said that you have been working in your current job for the past two years, however you have been finding it stressful and you have been struggling to keep up with the work load. When we met you told me that you were having a "break" from work. We talked about some of the changes that have happened at your workplace, such as the new 92% performance rule, which made it harder for you to cope and keep up.

You said that you have been feeling stressed and overwhelmed, and that certain events keep going through your mind "over and over again". These stressful events include paying the bills, travelling, sleep and finding a parking space. You told me that you have been feeling depressed and that the last few months have been "really hard"; however you also said that you have always been someone who has 'worries' about things and you remember feeling this way since the age of 12, when your parents got divorced and you lost your brother.

In terms of your recovery, we discussed that you were about to start having therapy sessions to help you manage your mood, and specifically to help you cope with your anxiety. You also said that you were finding your medication was starting to be helpful. You said that you feel that you have lost confidence since feeling unwell and that you have stopped doing things that you enjoy, such as washing the car and listening to records. However you also said that you have not heard the voices for a while and that you are beginning to feel more in control.

What next?

Thank you once again for taking part in this research project. I have enclosed a voucher to thank you for taking the time to share your experiences with me.

I will be in touch over the next week to speak to you about this summary and to give you an opportunity to feedback any thoughts that you may have, particularly with regards to how accurately you feel I have (or haven't) understood the experiences you talked to me about.

Please do not hesitate to contact me if you have any questions about any of the above in the meantime.

Yours sincerely,

Lucy Smyth
Primary Researcher
Trainee Clinical Psychologist
University College London

Supervised by Dr Georgina Charlesworth
Chief Investigator
Consultant Clinical Psychologist
University College London

Appendix G: Interview Schedule

Narrative Eliciting questions:

- What kind of person do you see yourself as?
- Is there a story about your life?
- Are there other sides to you?

Section 1: General understanding of experience

- Can you tell me your understanding of how you've come to be here today?
- Do you think you have a mental illness and if so what do you think it is?
- Can you say more about your experience of mental illness in the past, about what caused these problems, how you feel about having this mental illness and what is going to happen in the future?

Section 2: Impact of psychotic episode on life:

- Since the experiences you have described, what do you think has changed and what do you think has stayed the same?
- If the participant does not describe aspects of the following areas, prompt them by asking: 'have you noticed anything has changed or stayed the same in...'
 - Employment ('your job/work life')
 - Your Social life/relationships with friends and family
 - The lives of other people around you
 - How you think and feel (or, 'your emotions')
 - Your personality

Section 3: Degree of influence of illness

- To what extent and in what ways does your "mental illness" control your life?
- To what extent and how well are you able to control your "mental illness"?
- How have others been affected by your "mental illness"?

Section 4: Insight and recovery

- What did "unwell" look like?
- How did you know you were "unwell"?
- Do you think you have recovered?

Section 5: The future

- What do you see ahead of yourself in the future?
- What do you expect to be different and what do you expect to be the same?

Appendix H: Excerpt of Transcribed and Coded Interview

Transcript	Codes
INT: So can you say a little more about feeling alone, what is it that makes you feel that way?	Feeling alone
PPS 3: It's just the, the way I feel that people don't really understand. What I've, what I've been going through and what I am going through now. They just don't understand. Like my mum, even when I was experiencing this before when I come back, when I first stayed with my mum, she was like kind of dismissive as though to say oh you know, you're not really, you're not really, there's nothing wrong with you, you know? This is before I took the pills or whatever, you know.	Not feeling understood Family - parent Experience of dismissiveness /invalidation Suicide/self harm
INT: And so do you think they feel the same now that you've kind of come out of hospital that they're not really understanding that you're, that there might be something wrong?	
PPS 3: I think they know that, that definitely there was something wrong. Now it's a little bit more different. But I still don't think that they understand.	Experience of illness Not feeling understood
INT: Is there something particular that sticks out as lack of understanding? Areas that people just don't understand for you?	
PPS 3: Matt doesn't understand. My boyfriend, he really doesn't understand. Doesn't understand because all he can think about is himself and what he's suffering. So he's suffering depression so he can't quite understand me. He should be because he's, I think he's in denial that he's in this kind of depression himself. So it's very hard for him to see. And I can't, I can't make him, I can't make him see things the way I do. So it's quite difficult really.	Relationships – intimate Not feeling understood Difficulties of other people – psychological Feeling unable to explain
INT: Mhmm, it sounds really difficult. Especially if you live together, being on those different levels.	
PPS 3: Yeah, yeah	

INT: What would you want him to, how would you know that he understood you? If he had some change and he could understand.

Accessing mental health services

PPS 3: (pause: 6.0 secs) I suppose by coming in and seeing what I'm doing here.

Involving others in treatment and recovery

INT: So becoming a bit more involved in your treatment I suppose, that would be helpful for you?

Recovery

PPS 3: Yeah. Yeah.

INT: And what about other people, it sounds like you're feeling like they don't get it like you want them to. How could that be improved or what could they do to make you feel like you were more understood?

Support system

PPS 3: I don't know, maybe they could come along as well. Because I can't quite, I can't quite know how to go about it.

Involving others in treatment and recovery

Difficulty knowing what to do
Difficulty explaining

INT: And so do you feel that you're understood here?

PPS 3: Oh yes, definitely.

Accessing mental health services

INT: So there is somewhere that's helped you feel understood?

PPS 3: Oh yeah, I'm definitely supported here. I've had a lot of support from here, especially from the psychiatric nurse that I've been seeing. Although he'd backed away at the moment because I'm now seeing [psychologist].

Feeling understood

Support

Mental health professionals



Health Research Authority

East Midlands - Leicester Central Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

04 August 2016

Dr Georgina Charlesworth
Senior Lecturer
University College London
Room 442, Research Department of Clinical, Educational and Health Psychology
1-19 Torrington Place, London
WC1E 7HB

Dear Dr Charlesworth

Study title:	Recovery From Late Onset Psychosis: A Narrative Approach
REC reference:	16/EM/0275
IRAS project ID:	194877

Thank you for your letter of 15th July 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

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

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Recruitment flyer]	2	20 May 2016
Copies of advertisement materials for research participants [Recruitment leaflet]	2	20 May 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter]	1	18 May 2016
GP/consultant information sheets or letters [GP letter]	1	03 May 2016
Interview schedules or topic guides for participants [Topic guide - narrative interview]	1	03 May 2016
Interview schedules or topic guides for participants [Topic guide - post intervention]	1	20 May 2016
IRAS Application Form [IRAS_Form_16062016]		16 June 2016
IRAS Checklist XML [Checklist_22072016]		22 July 2016
Letter from funder [UCL approval letter and funding]	1	03 May 2016
Letter from sponsor [Sponsor UCL confirmation]	1	18 May 2016
Other [Risk assessment page 1]	1	03 May 2016
Other [Risk assessment page 2]	1	03 May 2016
Other [Response to validation query]		18 May 2016
Other [UCL lone worker policy]	1	18 July 2016
Other [NELFT lone worker policy]	1	19 July 2016
Other [Cover letter response to REC provisional comments]	1	15 July 2016
Participant consent form [Consent form - part 1 interviews]	2	15 July 2016
Participant consent form [Consent form - part 2 intervention measures]	2	15 July 2016
Participant information sheet (PIS) [PIS carer provider]	4	15 July 2016
Participant information sheet (PIS) [PIS - service user]	4	15 July 2016
Research protocol or project proposal [study protocol]	2	15 July 2016
Summary CV for Chief Investigator (CI) [CV CI]	1	03 May 2016
Summary CV for student [Student CV - Elaine Ching]	1	03 May 2016
Summary CV for student [Student CV - Lucy Smyth]		18 May 2016
Summary CV for supervisor (student research) [CV supervisor 2 Vyv Huddy]	1	03 May 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol flowchart]	1	03 May 2016
Validated questionnaire [Measures list]	1	03 May 2016

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.

After ethical review

Reporting requirements

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 Training

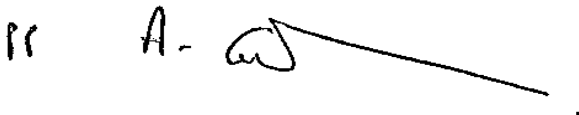
We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/EM/0275

Please quote this number on all correspondence

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

Yours sincerely

A handwritten signature in black ink, appearing to read 'John Baker', with a long horizontal line extending to the right.

John Baker
Vice Chair

Email: nrescommittee.eastmidlands-leicestercentral@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Emily Ikelle
Dr Sandeep Toot, Research and Development Directorate - North
East London NHS Foundation Trust