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“What is Important in Recovery from Complex Mental Health Difficulties?”

A Research Portfolio

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March 2019

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Table of Contents

Research Portfolio Abstract.....	7
Research Portfolio Lay Summary.....	10
List of Tables.....	12
List of Figures.....	13
Journal Article 1: Systematic Review.....	14
Abstract.....	15
Introduction.....	16
The Importance of Compassion.....	16
The Three Emotional Systems.....	18
CBT for Complex Disorders.....	20
The Development of CFTs.....	21
The Impact of Stigma and Shame.....	23
Rationale for Present Review.....	24
Methodology.....	26
Inclusion Criteria.....	26
Exclusion Criteria.....	26
Results.....	29
Study Descriptives.....	29
Quality Assessment.....	38
Summary of Included Studies.....	40
Diagnosis.....	40
Quality Ratings.....	41
Control Group Studies.....	43
Summary of Studies.....	47
Repeated Measures Studies.....	50
Summary of Studies.....	56
Discussion.....	57
Interventions.....	58
Reflecting on Compassion Measures.....	59
Limitations and Future Directions.....	62

Conclusions.....	64
References.....	65
Journal Article 2: Empirical Study.....	78
Abstract.....	79
Introduction.....	81
Rationale for Current Study.....	86
Methodology.....	87
Design.....	87
Rationale for Design.....	87
Participants.....	88
Inclusion Criteria.....	88
Exclusion Criteria.....	89
Sample Size.....	89
Maintaining Confidentiality.....	90
Consent.....	90
Qualitative Data Collection.....	91
Quantitative Data Collection.....	92
CTQ.....	93
AAI.....	93
QPR.....	93
Ethical Approval.....	94
Procedure.....	94
Pilot Interviews.....	96
Sampling Schedule for GT Interviews.....	97
Memo Writing.....	97
Results.....	98
Qualitative Data.....	98
Quantitative Data.....	109
Research Questions.....	113
Internal and External Locus of Control.....	113
Discussion.....	116

Locus of Control.....	117
Lack of Choice and Self-Identity.....	119
The Importance of Stigma and Shame of Positive Contributions.....	120
Limitations and Recommendations for Future Work.....	121
Conclusions.....	123
References.....	124
List of Appendices.....	134
Appendix A.....	135
Appendix B.....	136
Appendix C.....	137
Appendix D.....	138
Appendix E.....	141
Appendix F.....	147
Appendix G.....	153
Appendix H.....	186
Appendix I.....	188
Appendix J.....	189
Appendix K.....	192
Appendix L.....	194

Research Portfolio Abstract

Introduction and Aims:

Recovery from severe and enduring mental health difficulties, such as psychosis, continues to be researched and is an area of importance regarding the development of successful interventions to help increase quality of life and wellbeing.

Systematic Review – This aimed to review the current literature base regarding studies which have investigated change in self-compassion as an outcome measure, pre to post intervention, for individuals living with severe and enduring mental health difficulties.

Empirical Study – Using a qualitative approach, this study was interested in investigating young people's experiences of early psychosis. In particular, to investigate 1) the importance of autobiographical memories in young people's recovery and 2) in what way early adverse experiences and memory formation affect future thinking and establishing an overall sense of self during this recovery process.

Methodology:

Systematic Review – Search terms were used within PsychInfo, Embase and Ovid databases in order to locate all papers which included a severe and enduring population and used compassion as an outcome pre and post an intervention. Fourteen studies were included for review. Quality was rated, using adaptations of the NICE and CASP checklists; two small meta analyses were also conducted in order to pool effect sizes.

Empirical Study – Eight young people, from 16-19 years, were interviewed using a grounded theory approach. Interviews were transcribed and coded following each individual interview and developed over time; line by line coding was initially used, followed by the development of more focused codes and salient themes. This was combined with the completion of quantitative outcome measures in order to triangulate the data.

Results:

Systematic Review – Studies were grouped into two separate categories: those which had a control group and those which had a repeated measures design. Pooled effect sizes illustrated that self-compassion was shown to increase significantly in the intervention group in comparison to controls, and for groups over two time points. Studies are discussed separately, focusing on limitations, and then drawing on similar themes.

Empirical Study – Salient categories which emerged from the interviews were: interpersonal connections, self-identity, choice and freedom, recovery and autobiographical memory. These are discussed in addition to sub-categories and with reference to quotes from young people. Locus of control was used to understand the findings, linking them to theory and models based in the literature.

Conclusions:

Systematic Review – The current review offers some support to the literature and suggests that self-compassion can be generated and increased in this population, who are susceptible to self-stigma and shame. The varied quality of studies, however, suggests a need for higher quality RCTs in order to increase our understanding and aid the development of more successful interventions for this complex population.

Empirical Study – Findings illustrate the importance of helping young people develop coherent narratives of their experiences, in turn helping to build a sense of sense following early psychosis. Locus of control was found to be a helpful concept in viewing recovery and is helpful to consider when working with this population. Results from the current study were also shown to support literature in the area of positive contributions and empowerment, which are shown to be key for young people during recovery and will be helpful areas for further research.

Research Portfolio Lay Summary

Background and Aims of Research:

Increasing our knowledge of what might help recovery for people living with severe mental health difficulties, continues to be important and take place by researchers in the area.

Study 1 – This looked to review the current work which has taken place to date regarding treatments targeting self-compassion and its importance for people with severe mental health difficulties.

Study 2 – This looked to investigate young people’s recovery from unusual and distressing experiences such as psychosis and what is important to them during this process. Questions included the importance of personal memories and difficult early experiences in how these young people see themselves.

What we did:

Study 1 – For this study, all the current research, involving individuals with severe mental health difficulties (such as schizophrenia) and where compassion had been investigated, was thoroughly searched. Fourteen studies were found to fit criteria and their quality was tested. How statistically effective each study was at increasing self-compassion, was also tested.

Study 2 – Eight young people, who had faced unusual distressing experiences, were interviewed about these. An approach was used to help investigate areas of importance and to answer the research questions. Young people were also asked to fill in questionnaires to aid our understanding of recovery from unusual experiences and how young people see themselves and their future.

What we found:

Study 1 – Study quality was shown to vary to a high degree. However, self-compassion was shown to increase overall for the groups of importance within the included studies. Increases in self-compassion were seen to correlate in some studies with a decrease in symptoms of low mood and in factors just as self-criticism. These findings suggest that it would be important for research to continue looking at treatments, involving increasing self-compassion, for this particular group of people.

Study 2 – Particular ideas were found to be important to young people from areas they talked about during interviews. Areas found to be important were: relationships (especially with friends), how young people see themselves, having choice, recovery and personal memories. Results showed that being able to build personal memories is important to young people knowing themselves more and being able to get better. This is an area which would also value further research as it is important that we know more about what is important to young people's recovery.

List of Tables

Systematic Review:

Table 1: Study descriptions for all papers included for review (p30-36).

Table 2: Quality ratings for all papers included for review (p39).

Empirical Study:

Table 3: Participant demographic information (p89).

Table 4: Stages one to four of grounded theory process, as outlined by Charmaz (2006; p92).

Table 5: Data from quantitative measures (p110).

List of Figures

Systematic Review:

Figure 1: Flow chart of searches (p28).

Figure 2: Forest plot for included studies with a control group (p42).

Figure 3: Forest plot for included studies with a repeated measures design (p49).

Empirical Study:

Figure 4: Organisation of categories (p99).

Figure 5: Internal Locus of Control and the impact on Self-identity, Autobiographical Memory and Recovery (p114).

Figure 6: External Locus of Control and the impact on Self-identity, Autobiographical Memory and Recovery (p115).

***“The Importance of Compassion for Individuals Living with Severe
and Enduring Mental Health Difficulties”***

A Systematic Review of the Literature

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Abstract

Introduction and Aims: The literature to date suggests a paucity in successful interventions for individuals living with severe and enduring mental health difficulties, such as schizophrenia and personality disorders. Due to this population often living with self-stigma and shame, there has been an increase in research investigating the role of self-compassion. Severe and enduring diagnoses include: schizophrenia or psychosis, bi polar disorder, personality disorders and recurrent depression. This review therefore aimed to review the current literature which had investigated self-compassion as an outcome, pre and post intervention, with individuals living with severe and enduring mental health difficulties.

Methodology: Search terms were used within PsychInfo, Embase and Ovid databases in order to locate all studies where severe and enduring mental health difficulties, which had included a measure of self-compassion, as an outcome, had been included. Fourteen studies in total were included for review. Quality was rated using adaptations of the NICE and CASP checklists in addition to two small meta analyses to pool effect sizes.

Results: Studies were grouped into having a control group or a repeated measures design. Pooled effect sizes illustrated overall, self-compassion increased significantly for intervention groups, compared with controls. A similar pattern was shown for studies of a repeated measures design. Study quality, however, was variable. Studies are discussed, regarding quality and limitations, drawing on similar themes.

Conclusions: This review aimed to search the current literature base investigating the effectiveness of increasing self-compassion for severe and enduring populations. Following a quality review of included studies and small meta analyses of effect sizes, the current review concluded that this is a worthy area for increased research to take place in. Increased self-compassion correlated with a decrease in symptoms, such as low mood, in some studies.

Compassion appears to be important for this population, in particular, due to high levels of self-stigma and shame that often presents. The varied quality of studies, suggesting a need for higher quality RCTs in order to strengthen more successful interventions for this complex and often treatment resistant group.

Introduction

There is a growing body of literature suggesting that severe and enduring mental health difficulties have implications on social, financial and general daily functioning (Hodgson, McCulloch & Fox, 2011). Diagnoses which fall under this description include personality disorders, bipolar disorder, recurrent depression (MDD) and psychotic disorders (e.g. schizophrenia; Department of Health, 2009). In the past decade, there has been a surge of research focusing on the impact of increasing self-compassion in this population; this attention has come from the lack of empirical evidence supporting more standard interventions for this complex group (Jones et al, 2018) and the impact that self-stigma and shame can have on recovery (Wood, Byrne, Burke, Enache & Morrison, 2017). From the literature, a lack of self-compassion appears to correlate with mental health difficulties such as anxiety and depression (MacBeth & Gumley, 2012) and for such difficulties to be maintained over a lifetime (Laithwaite et al, 2009; Capar & Kavak, 2019). It has also been proposed in recent literature that this can be a difficult population to successfully treat (Capar & Kavak, 2019). Current research therefore suggests value in reviewing work in the area which has investigated self-compassion as an outcome following interventions for severe and enduring mental health difficulties.

The Importance of Self Compassion

Compassion can be defined as holding “an orientation of mind that recognises the presence of pain, the universality of pain in human experience, and the capacity to meet this with kindness” (Feldman & Kuyken, 2011). Self-compassion is applying these concepts towards the self (Karl, Williams, Cardy, Kuyken & Crane, 2018) and doing this in an empathic manner; this is especially important during periods which could be interpreted as personal failings. Authors in the field have conceptualised compassion in different ways.

Goetz, Keltner and Simon-Thomas (2010) have described compassion through a transactional model, highlighting its importance for our survival and reproduction. Buddhists understand compassion in relation to others and alleviating others' distress. Models of attachment have been used to conceptualise self-compassion and its importance in regulating emotions (Gilbert, 2010). These models all argue the importance of self-compassion for different aspects of our lives as humans (Goetz et al, Gilbert, 2010). It is well versed in mental health and particularly mindfulness literature, that compassion is important for alleviating distress in others and self-compassion for doing similarly in the self; the importance of this for our survival and reproduction could be argued as being less documented and off less importance to the human race.

Higher levels of self-compassion have been shown to correlate with higher levels of resilience and general wellbeing (Breines & Chen, 2012); emotional intelligence is also shown to correlate with quality of life, suggesting that individuals who have not grown up with caregivers who have facilitated the regulation of emotions, are likely to have lower levels of self-compassion and an increased susceptibility to developing mental health difficulties as a result (MacBeth & Gumley, 2012; Zhang et al, 2018).

Research suggests the first few years are critical to the development of internal working models of self and others (Hermanto & Zuroff, 2016). Caregivers respond to the stress of an infant by using their 'best guess' at what is causing their child's distress; this process helps to soothe and regulate the infant's emotional state and to develop the child's own soothing system (Gerherdt, 2004). If a caregiver's response to a child's distress is frequent and consistent, the child will discover that their emotions will not overwhelm them and that they can be regulated effectively (Liotti & Gilbert, 2011; Leahy, 2005). Children who have had positive early experiences, are more likely to grow up with a affirmative self-image, view others as being trustworthy and the world as a generally safe and predictable place

(Mikulincer & Shaver, 2007). In turn, they are more likely to be able to generate self-compassion as adults and regulate their own distress.

For many people, generating self-compassion is something which has been underdeveloped and can create a barrier to help-seeking from services or from interpersonal connections (Lucre & Carten, 2013). Social mentality theory, which views self-compassion as a form of interpersonal connecting and forms the basis of compassion focused work (Hermanto & Zuroff, 2016), can aid our understanding of the development for the three emotional systems (Gilbert, 2010).

The Three Emotional Systems

These systems conceptualise self-compassion as a working model and emphasise the importance of its development (Gilbert, 2010). The first system is the threat focused emotional system, based on the fight or flight response. This is hard-wired and generated from the oldest part of our brain; it has been developed to keep us safe and can become activated in response to perceived danger (Laithwaite et al, 2009). Individuals who have not experienced caring, predictable reactions in response to stress, are likely to have an overdeveloped threat system, which can become easily activated as a result of typical human experience, such as losing a loved one (Hayes, Strosahl & Wilson, 2002). In addition to this, the threat system can become overly activated due to frequent self-criticism and negative comparisons with others. As mentioned, a heightened threat system can lead to difficulty in help-seeking, due to unhelpful cognitions regarding others being a threat and the world being unsafe (Gilbert, 2009; Longe et al, 2010) and highlights the importance of this system when considering compassion focused interventions. In addition to the threat response system, Gilbert (2010) describes two positive emotional systems.

The motivational system focuses on achieving and seeking fulfilment (Hayes et al, 2002) and is critical for attaining nourishment in the form of food, building relationships and achieving desired goals. These behaviours are essential for our survival and reproduction but can also become over activated, having a detrimental effect on mental health (Braehler et al, 2013). Bowlby (1988) hypothesised that predictable, warm and safe early connections with a primary caregiver are critical in developing secure attachments. Such secure attachment is, in turn, associated with the ability to regulate emotions more effectively (Gumley, Taylor, Schwannauer & MacBeth, 2014), leading to the development of the soothing system.

The soothing system is the third emotional system, described in CFT literature and is the part of our brain which becomes active when we are not seeking achievement nor protecting our self from perceived danger; it is our ability to activate feeling safe and content (Gilbert & Procter, 2006). It is shown to be crucial in balancing the threat and motivational systems, in generating self-compassion and building resilience to the development of complex mental health difficulties (MacBeth & Gumley, 2012). When positive experiences have been present during early life, emotional memories associated with the soothing system can be activated during times of stress (Brewin, 2006), helping to generate self-compassion. For individuals with severe and enduring mental health difficulties, these three emotional systems are often disproportional to one another, leading to difficulty in managing emotions and often negative affect (e.g. low mood).

The following section reviews some of the current literature which has investigated interventions for this complex group.

Cognitive Behaviour Therapy (CBT) for Complex Difficulties

The literature strongly indicates that CBT is effective for mild to moderate depressive symptoms (Kupfer, Frank & Phillips, 2012; Kessler et al, 2009). It has been found to be less successful, however, in treating the negative symptoms in recurrent depression and other complex mental health difficulties (Jones et al, 2018). In a meta-analysis by Cuijpers, Donker, van Straten, Li and Andersson (2010), a variety of interventions for depression were evaluated, namely CBT, Interpersonal Therapy (IPT) and Cognitive Behavioural Analysis System Psychotherapy (CBASP). Despite demonstrating some promise in symptom reduction, effect sizes were minimal for treating chronic depression (Cuijpers et al, 2010). Studies such as these have prompted further investigation into alternative treatments, such as interventions aiming to increase self-compassion (Graser, Hofling, Weblaw, Mendes & Stranglier, 2016).

Recent systematic reviews, investigating the effectiveness of CBT for individuals with schizophrenia, concluded that CBT was no more effective than standard care (i.e. treatment as usual; TAU) when reviewing 60 Randomized Control Trials (RCT) with a large sample size. This highlights a lack of evidence regarding sufficient interventions for this group (Jones et al, 2018). Such findings are supported in a review by the same authors, who compared CBT to a variety of alternative psychosocial interventions. Results from this study suggested once more that CBT was no more effective than treatments such as psychoeducation, family therapies and other talking therapies (Jones et al, 2018). These highlight important questions in how to best develop effective interventions for severe and enduring mental health.

The value in expanding our knowledge of additional therapies for this population, such as Compassion Focused Therapies (CFT), where shame and self-stigma are prevalent features, is strengthened by findings from reviews such as these.

The Development of Compassion Focused Therapies

Individuals with high self-criticism, presenting with self-stigma and shame, often have difficulty in feeling reassured from the cognitive restructuring aspects of CBT (Leahy, 2005). It has therefore been suggested that such individuals may be an optimal target presentation for CFTs (Gilbert & Procter, 2006). CFTs are a third wave therapy, based on evolutionary models of emotion regulation (Lucre & Carten, 2013) and describe the three basic emotional systems as becoming organised in a particular way early in our development. During this time, and as outlined in previous sections, the soothing system can become sufficient or diminished depending on life experiences (Gilbert, 2010) and CFT has been shown to help bolster this system as required. The process of CFT typically involves psycho education, regarding the evolutionary development of the threat system and its importance in protecting us from danger. It also describes the difficulty we face when managing our old (i.e. reptilian brain) and new (i.e. prefrontal cortex) brain. This intervention also focuses on deshaming and assisting individuals in noticing that their experiences are separate from the self (Martins et al, 2018), thus positively shifting the relationship they have with themselves (Gilbert, Clarke, Hempel, Miles & Irons, 2004). Such goals are accomplished by building warmth and kindness in a non-judgemental manner, which has shown to be helpful for individuals presenting with high levels of self-criticism, shame and self-stigma (Lucre & Carten, 2013); these are common aspects of severe and enduring presentations such as schizophrenia and personality disorders.

The importance of cultivating self-compassion, as a source of resilience to mental health difficulties, was investigated in a group of 109 participants from ethnic and racial minorities (Zhang et al, 2018). Participants completed outcome measures assessing self-compassion, lack of self-worth (i.e. shame) and depressive symptoms; results from outcome measures suggested that self-compassion mediates the link between shame and depression. Authors describe self-compassion as buffering against threats and attacks on the self in the form of stigma and shame (Zhang et al, 2018). Results from this study add to previous literature suggesting that higher levels of compassion are associated with lower levels of psychopathology (McBeth & Gumley, 2012); whether this is the result of increasing self-compassion or reducing elements such as self-judgement is unknown, but the utility of self-compassion in building resilience against mental health difficulties and therefore a better quality of life, appears an important consideration.

Gilbert and Procter (2006) developed a form of CFT described as compassionate mind training (CMT), aiming to help generate higher levels of caring and non-judging responses towards the self in times of stress and setbacks. Participants presenting with high levels of shame, self-stigma, self-criticism and who usually responded to stress in a highly attacking form, were recruited and completed quantitative measures before and after the 12-week intervention. Results suggest that CMT could have a significant impact on depression, anxiety and shame (Gilbert & Procter, 2006) in this population and adds further evidence to the literature regarding self-compassion being helpful for highly critical individuals experiencing self-stigma and shame.

Research has also looked at which parts of depression are mediated by self-compassion. In a recent study by Bakker, Cox, Hubley and Owens (2018), authors concluded that higher levels of self-compassion impacted significantly on the 'brooding rumination' aspect of depression (Bakker et al, 2018). This suggests that interventions, which aim to increase self-

compassion, could facilitate this chronic group in becoming less stuck regarding unhelpful thinking patterns. As discussed with reference to the literature, difficulties such as self-stigma and shame and have been shown to be prevalent for individuals living with mental health difficulties, often leading to poor quality of life, withdrawal from society and limited recovery (Capar & Kavak, 2019).

The Impact of Stigma and Shame

Stigma against individuals with severe and enduring mental health is something which has been a longstanding difficulty in society (Wood, Birtel, Alsawy, Pyle & Morrison, 2014; Wood et al, 2017). The literature describes two ways in which we can conceptualise stigma. It can be comprised as holding negative views towards a particular group, agreeing with those negative views and then behaving in a way which supports those negative beliefs (Corrigan & Watson, 2002). When individuals agree with the stigma they are presented with and apply this internally, it is conceptualised as self-stigma. Literature in the area has suggested the impact of self-stigma on help-seeking and recovery for individuals living with severe and enduring mental health difficulties (Morgades-Bamba, Fuster-Ruizdeapodca & Molero, 2019) and its link with depression and hopelessness (Tourinho et al, 2018). Avoidance of help-seeking for individuals with this complex presentation can occur due to the anticipation of rejection and therefore finding more maladaptive ways of coping which do not involve connecting to others or the world (Lucre & Carten, 2013). This is something which is likely to negatively influence recovery and is therefore important to learn more about and target through appropriate interventions.

Internal shame refers to thoughts and feelings about the self. It is negative and critical in content and develops with the awareness of how others perceive the self, attacking oneself

through being self-critical and de-valuing (Gilbert & Proctor, 2006). External and internal shame can often present simultaneously, leading to a person's threat system to become overwhelmed (Lucre & Carten, 2013). The importance of intervening therapeutically with populations, where shame and self-stigma are prevalent, appears to be critical and has been demonstrated in recent empirical investigations (Krieger et al, 2018; Touriño et al, 2018). Doing so requires expanding our knowledge in how alternative interventions, such as CFTs, might target self-compassion and in turn, aid the development of more effective treatment for individual's living with severe and enduring mental health difficulties.

Rationale for the Present Review

With reference to the literature described above, it is critical that the feasibility of alternative treatments continue to be investigated for individuals presenting with severe and enduring mental health difficulties.

The population investigated were selected with careful consideration. Schizophrenia, bipolar and personality disorders are considered in the literature to have similar presentations (Schretlen et al, 2007) and it is argued that schizophrenia would be more appropriately placed on a continuum rather than as a separate categorical entity (Crow, 1997). The group of disorders selected for review present similarly regarding depressive or negative symptoms, comorbidities, impact on daily functioning, employment and interpersonal connections in addition to chronicity (Schretlen et al, 2007). From the literature discussed, these disorders are linked with experiences of stigma and shame (Morgades-Bamba et al, 2019; Wood et al, 2014). Psychotic symptoms are regarded as a core feature of schizophrenia; these can also be present in personality disorders, bipolar disorders and MDD (Schretlen et al, 2007).

There has yet to be a review conducted investigating self-compassion as an outcome, pre and post various clinical interventions, for individuals with severe and enduring mental health difficulties. This study therefore aimed to review all the literature to date which has been carried out with these criteria. Details of the search strategy are presented in the following sections in addition study descriptions and quality ratings. Whether there is value in targeting self-compassion through interventions for this complex group, is discussed considering relevant limitations and possible future directions.

Methodology

In order to answer the research question being proposed, the following databases were Searched: PsychInfo, Embase and Ovid. The following terms were used: compassion* OR “compassion* focus* therapy” OR compassion* mind training” and combined with the following four searches:

1. schizo* OR psychosis OR psychotic OR psychoses OR voices OR hallucinat*
2. bipolar OR “bipolar disorder”
3. “personality disorder” or “borderline personality disorder” OR “BPD”
4. depression OR “major depressi* disorder OR “MDD” OR “recurrent depress*”

Inclusion Criteria

Studies were included if they specified:

1. Participants with a diagnosis of schizophrenia, bipolar disorder, personality disorders or major depressive disorders (MDD) in more than 50% of the sample.
2. A pre and post intervention measure of compassion.
3. That participants took part in an intervention of some form.

Exclusion Criteria

Studies were excluded if they specified:

1. More than 50% of participants having a different diagnosis to that being reviewed.
2. Using only a measure of mindfulness.
3. A qualitative research design.
4. Articles not in the English language.

Figure 1 illustrates the search process which took place on 18th October 2018.

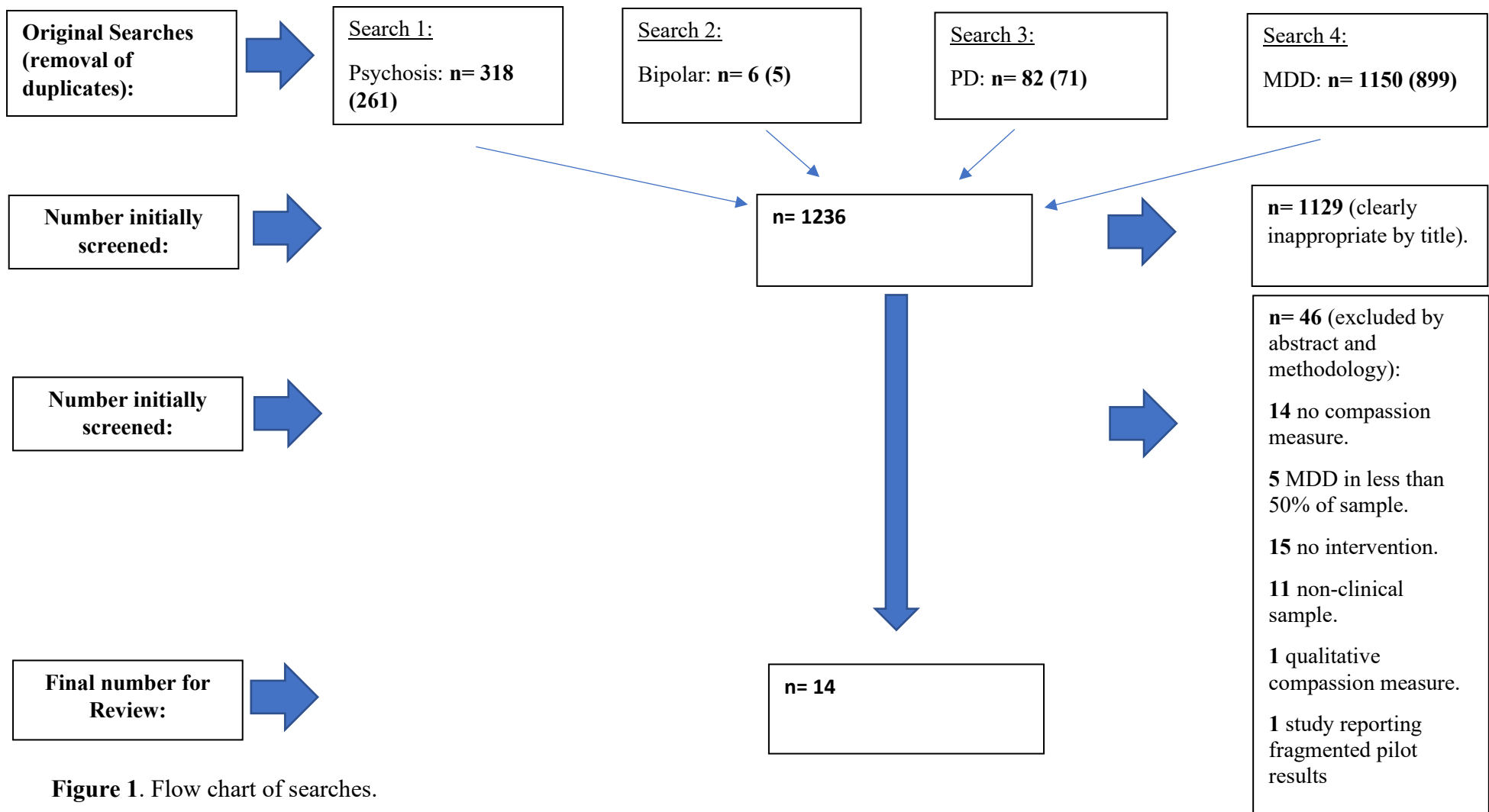


Figure 1. Flow chart of searches.

Results

Study Descriptions

Table 1 details each of the included studies for review. Participant demographics are presented, in addition to the study aims, the included compassion measure in addition to any other outcome measures. These will be analysed and discussed in in the subsequent sections.

Table 1. Study descriptions for all papers included for review.

Study.	No. of participants, gender and age.	Diagnoses.	Aims of study.	Study design.	Measure of compassion.	Additional measures.	Study outcome.
1. Asano et al (2017).	n= 13 (3f/10m); mean age= 40.5.	Primary diagnosis of MDD.	This study aimed to evaluate the feasibility and acceptability of group-based CBT with compassion training on outcomes of depression, self-criticism and self-compassion.	Repeated measures design. Ptps observed pre and post intervention.	SCS-J.	BDI-II, evaluation of feasibility and acceptability was measured by interviews, intervention completion and adherence to sessions. Ptps were also asked questions regarding group satisfaction.	Results from this intervention demonstrated an increase in compassion but this did not reach significance level. Compassion dropped from post intervention to follow-up. Qualitative information demonstrated that ptps were satisfied with the group format.
2. Ascone, Sundag, Schlier amd Lincoln (2017).	CF (9m/17m); mean age= 40.2. NC (6f/19m); mean age= 36.2.	Current psychotic disorder and present or past episodes of paranoid delusions.	To investigate changes in self-reassurance, self-compassion and happiness prior to and following CFI; this was compared with a control group.	This was a repeated measures RCT. CFI intervention v control imagery condition.	SCS.	FSCRS, Negative and Positive affect (Stemmler, Heldmann, Pauls & Scherer (2001), skin conductance levels	There was a significant effect of the emotion induction found on skin conductance. There were non-significant changes to self-compassion following the mood induction and between the groups. CFI did show significant effects on self-reassurance and happiness.

						(affectivia®, 2012, Paranoia Checklist (Freeman et al, 2005), Appraisal and perceived subjective benefit of imagery intervention, affective Valence and arousal (Bradley & Lang, 1994).	
3. Berggraf et al (2014).	STDP (14f/21m); mean age= 33.4. CT (11f/14m); mean age= 34.6.	Cluster c personality disorders.	To investigate whether AA and IA influenced changes in compassion in SoS and SoO scales.	RCT. STDP was investigated against CT.	The SoS subscale of the ATOS, measuring compassionate self-description.	AA subscale, IA subscale, SoO subscale.	Results showed that AA can help facilitate change in self-compassion regarding sense of self and sense of others. Changes were shown to reach significance level. Discussion suggests whether increasing AA or reducing IA is most relevant in clinical practice.
4. Cladder-Miscus et al (2017).	n=106 (66f/40m); mean age= 47.1.	Recurrent depression.	To investigate the effectiveness of MBCT + TAU against TAU only on self-compassion	RCT. Participants assigned to MBCT (+TAU) or TAU only. TAU= mental	SCS.	IDS-SR, MINI, RRS-EXT, WHOQOL, FFMQ.	Completers of MBCT showed a significant decrease in depressive symptoms. A significant increase in self-compassion scores was shown

			and additional measures.	health care for depression.			for the MBCT group only, with small to medium effect sizes
5. Falconer et al (2016).	n= 15 (10f/5m); mean age= 32 years.	Recurrent depression.	To investigate whether the effects of self-identification with virtual bodies within immersive virtual reality could facilitate an increase in self-compassion.	Case series design.	SCCS, Fears of Compassion Scales (Gilbert, McEwan, Matos & Ravis (2016).	PHQ-9, Virtual Reality Experience Questionnaire (Sanchez-Vives & Slater, 2005).	Results showed that two repetitions of this scenario led to significant reductions in depression and self-criticism. Self-compassion did not significantly increase post intervention, but was shown to at follow up.
6. Feliu-Soler et al (2017).	LKM (16f/0m); mean age= 35.1 MCT (14f/2m); mean age= 32.5.	BPD.	To investigate the effects of a 3-week intervention of LKM v CM on symptom severity, mindfulness skills, self-evaluation and compassion.	RCT. LKM was investigated against CM.	SCS.	DIB-R, BSL-23, FSCRS, PHLMS.	Three weeks of LKM and CM led to significant changes in the self-kindness scale of the SCS. This showed a large effect size. Changes in the SCS were not significant for the MCT group. Mindfulness ability was also shown to significantly increase only for the LKM/CM group with a large effect size. This suggests that increasing present moment experience can increase self-compassion.
7. Kramer, Pascual-Leone, Rohde and Sachse (2018).	n= 17 (7f/10m); mean age= 39.4.	Narcissistic personality Disorder.	To investigate changes in shame and compassion throughout	Repeated measures design.	Self-compassion category	SCL-90-R, BDI-II, CAMS, Processing-Content-	Results showed an increase in self-compassion across time points, but this did not reach significance. This study

			intervention and how this impacts patient-therapist interaction at different phases of treatment.		of the CAMS.	relationship Scale (Kramer et al, 2018)	suggests the possible central role of shame in the therapeutic process of ptps with NPD. It tentatively suggests that one way to resolve shame is for pts to access underlying self-compassion.
8. Laithwaite et al (2009).	n= 19 (19m/0f); mean age= 36.9.	Schizophrenia (paranoid, or bipolar affective disorder). Eight had co-morbidity of personality disorders.	To investigate the effectiveness of a 'Recovery after Psychosis' programme on measures of depression, self-esteem, self-compassion and shame.	This was a repeated measures design. Outcomes were taken pre, mid and post intervention. Measures were also taken at 6-week follow up.	SCS.	SCS, OAS, BDI II, RSE, SIP-AD, PANSS.	Significant changes and small to medium effect sizes were shown for social comparison, other as a shamer, depression, self-esteem and self-image profile. Changes were not significant for self-compassion.
9. Mayhew & Gilbert (2008).	<u>Participant 1</u> : 64 years, male. <u>Participant 2</u> : 26 years, male. <u>Participant 3</u> : 44 years, male.	Schizophrenia and have experienced hostile auditory hallucinations.	To investigate the degree to which this population can access positive emotions such as warmth and contentment in order to increase self-compassion and reduce symptoms. This was done pre and	Case series design.	SCS.	BAVQ, FSCRS, FSCS, SCL-90, Voice Rank Scale (Birchwood, Meaden, Trower, Gilbert, & Plaistow, 2000), Weekly Diary of Voice Activity, Self-Critical and Self-	Slight increases in self-compassion were shown across ptps. Due to no statistical analysis being performed, it is not clear whether significance level was reached. This study's main finding was that CMT appeared to have an impact on auditory hallucinations.

			post CMT intervention.			Compassionate Thoughts (Gilbert et al, 2004; Gilbert & Proctor, 2006).	
10. Naismith, Mwale and Feigenbaum (2017).	<p><u>Study 1</u>: n= 53 (44f/9m); mean age= 32.</p> <p><u>Study 2</u>: n= 17 (15f/2m); mean age= 34.</p>	Personality disorders.	<p><u>Study 1</u>: To investigate ptps' ability to generate compassionate imagery pre and post CFI intervention.</p> <p><u>Study 2</u>: To investigate self-compassion, self-criticism, depression and anxiety pre and post CFI intervention.</p>	<p>Study 1: Repeated measures. Measures taken pre and post a mood manipulation task.</p> <p>Study 2: Repeated measures, evaluating changes in self-criticism and self-compassion following intervention.</p>	SCS-SF.	<p><u>Study 1</u>: SCID-II, PANAS, FSCRS, ESS, ECRS.</p> <p><u>Study 2</u>: SCS-SF.</p>	<p><u>Study 1</u>: Negative affect and an inability to use mental imagery, led to poorer ability to generate compassionate imagery and mood.</p> <p><u>Study 2</u>: Practicing CFI regularly for 7 days significantly improved self-compassion with a large effect size. Improvement was associated with more practice; practice was associated with higher baseline imagery ability and self-compassion.</p>
11. Schanche, Stiles, McCullough, Svartberg and Hostmark Nielsen (2011).	n=50 (50f/50m); mean age= 34.	Cluster c personality disorders.	To investigate whether self-compassion increases from early to later intervention sessions.	RCT, comparing STDP with CT.	SoS (subscale of the ATOS).	SCL-90-R II, MCMI.	Results showed that when self-compassion increased from session 6 to 36, psychiatric symptoms, interpersonal problems and personality pathology were shown to also decrease. Significant changes were shown in self-

							compassion from early to late in treatment; a large effect size was demonstrated.
12. Schoenberg & Speckens (2015).	MBCT (20f, 6n); mean age= 47.8. WL (12f, 13m); mean age= 51.2.	MDD.	To examine the potential modulating effects of an 8-week MBCT programme on event-related EEG variables, depression severity and self-compassion.	RCT. MBCT was investigated against a WL control group.	SCS.	IDS, RRS, FFMQ, STAI, CDS, Electrophysiological recordings.	Self-compassion was shown to significantly increase following intervention compared with WL controls. Ameliorated depressive severity and increased self-compassionate experience pre to post MBCT and correlated with a-ERD change.
13. Schuling et al (2018).	<u>Group 1</u> : n= 14 (13f/1m); mean age= 56. <u>Group 2</u> : n= 13 (11f/2m); mean age= 58.	Recurrent depression.	To investigate the feasibility and acceptability of a MBCL programme as a follow-up intervention to MBCT. Effects on self-compassion and other measures were investigated.	RCT. Ptps completed a MBCL programme; 10 then went on to complete MBCT. These groups were looked at against one another.	Dutch translation of SCS.	FFMQ-NK, PSWQ, BDI-II.	Results from this pilot study on the feasibility of compassion training for recurrent depression was found to be promising. Changes in the BDI-II did not reach significance. MBCL was shown to be no more effective than MBCT.
14. Wadsworth et al (2018).	n= 582 (285m/294f); mean age= 33.3.	MDD, bipolar or psychotic disorder.	To look at correlations between self-compassion, RNT, depression and anxiety in a group-based clinical	This was a repeated measures design. The same group of ptps completed measures before	SCS-SF.	MINI, CESD-10, GAD-7, PTQ, CBT-SQ, DBT-WCCL.	Significant decreases in negative compassion and significant increases in positive compassion were demonstrated from time point 1 to time point 2 with medium effect sizes.

			setting using CBT and DBT. Self-compassion was measured pre and post intervention.	and after intervention.			Changes in RNT and NA-SC could explain changes in depression. Changes in RNT could explain changes in anxiety. Rumination shown to mediate the relationship between self-compassion and depression as well as self-compassion and anxiety.
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Study references are provided below for measures which have an abbreviation. For non-abbreviated studies, these are written in full in Table 1 above and referenced accordingly.

* IDS-SR The Inventory of depressive symptomatology (Rush, Gullion, Basco, Jarrett & Trivedi, 1996), MINI Mini International Neuropsychiatric Interview (Sjuehan et al, 1998), WHOQOL World Health Organization Quality of Life Scale (Skevington, Lotfy & O’Connell, 2004), RRS-EXT Rumanitive Response Scale (Schoofs, Hermans & Raes, 2010), FFMQ Five Facet Mindfulness Questionnaire (Baer et al, 2008), SCS Self Compassion Scale (Neff, 2003), ATOS Achievement of Therapeutic Objectives Scale (McCullough et al, 2003), SCL-90-R II Symptom Check List-Revised (Derogatis, 1983), IIP Inventory of Personal Problems (Harowitz, Rosenberg, Baer, Ureno & Villasenor, 1988) MCMII Millon Clinical Multiaxial Inventory (Millon, 1984) , SCID-II Structured Clinical Interview for DSM-IV-TR (First, Gibbon, Spitzer, Williams & Benjamin, 1997), PANAS Positive and Negative Affect schedule (Watson, Clark & Tellegen, 1988), SCS-SF Self-Compassion Short Form (Raes, Pommier, Neff & Van Gucht, 2011), FSCRS Forms of Self-Criticism/Attacking and Self-Reassuring Scale (Gilbert et al, 2004), FSCS Functions of Self Critisizing/Attacking Scale (Gilbert et al, 2004) ESS Experiences of Shame Scale (Andrews, Qian & Valentine, 2002), ECRS-S Experiences in Close Relationship Scale-Short Form (Wei, Russell, Mallinckrodt & Vogel, 2007), SCS Social comparison Scale (Allan & Gilbert, 1995), OAS the Other as a Shamer Scale (Goss, Gilbert & Allan, 1994), BDI II Beck Depression Inventory II (Beck, Steer, Ball & Ranieri, 1996), RSE Rosenberg Self-Esteem measure (Rosenberg, Schooler, Schoenbach & Rosenberg, 1995), SIP-AD The self-image profile for adults (Butler & Gasson, 2004), CESD-10 Center for the Epidemiological Studies of Depression-10 (Anderson, Vestergaard & Lauritzen, 1994), GAD-7 The 7-item Generalized Anxiety Disorder Scale (Spitzer, Kroenke, Williams & Löwe, 2006), PTQ Perseverative Thinking Questionnaire (Ehring et al, 2011), CBT-SQ Cognitive Behavioral Therapy Skills Questionnaire (Jacob, Christopher & Neuhaus, 2011), DBT-WCCL Dialectical Behavior Therapy Ways of Coping Checklist (Neacsiu, Rizvi, Vitaliano, Lynch & Linehan, 2010), IDS Inventory of Depressive Symptomatology (Rush, Gullion, Basco, Jarrett & Trivedi, 1996), RRS Ruminative Response Scale (Nolen-Hoeksema

& Morrow, 1993), STAI State-Trait Anxiety Inventory (Spielberger & Gorsuch, 1983), CDS Cambridge Depersonalisation Scale (Sierra & Berrios, 2000), DIB-R Diagnostic Interview for Borderlines Revised (Barrachina et al, 2004), BSL Borderline Symptom list-23 (Bohus et al, 2009), PHLMS Philadelphia Mindfulness Scale (Cardaciotto et al, 2008), , 2005), PSWQ Penn State Worry Questionnaire (Meyer, Miller, Metzger & Borkovec, 1990), PHQ-9 Patient Health Questionnaire (Krownke, Spitzer & Williams, 2001), CAMS Classification of Affective-Meaning States (Pascual-Leone & Greenberg, 2005), BAVQ Belief about Voices Questionnaire (Chadwick & Birchwood, 1995), SCL-90 Multi-dimensional symptom self-report inventory.

* MBCT Mindfulness Based Cognitive Therapy, TAU Treatment as Usual, CFI Compassion Focused Imagery, STDP Short Term Dynamic Psychotherapy. CT Cognitive Therapy, RNT Repetitive Negative Thinking, WL Wait List, LKM Loving Kindness Meditation, CM Compassion Mediation, MBCL Mindfulness Based Compassionate Living, GCBT Group Cognitive Behavioural Therapy, COP Classification Orientated Psychotherapy, CMT Compassionate Mind Training.

Quality Assessment

A quality assessment tool adapted from the Critical Appraisal Skills Programme (CASP) for Case Control Studies and the National Institute for Health and Care Excellence (NICE) for intervention studies was used to help score the studies met for inclusion in this review.

Details of both can be seen in Appendices A and B respectively. Quality scores were checked for inter-rater reliability (IRR), using Cohen's kappa to demonstrate consistency of ratings for two coders (McHugh, 2012; Hallgran, 2012). A kappa of 0.80 was initially computed, illustrating a disagreement on two quality rating scores and is described in the literature as being an almost perfect score of agreement (McHugh, 2012). Following discussion, however, a kappa rating of 1.0 was agreed, although some ratings were argued as being subjective. Final agreed scores are outlined in Table 2; weightings for each quality criteria are detailed in Appendix C.

Table 2. Quality rating scores for all papers under review.

Study.	Study Aims.	Design.	Recruitment.	Participants.	Blinding.	Intervention.	Attrition.	Validity of Measures.	Follow-up.	Analysis.	Power.	Internal Validity.	External Validity.	Totals (/26)
1.	1	1	2	2	0	2	2	1	2	2	0	1	1	17
2.	2	2	1	2	1	2	2	1	0	2	0	1	2	18
3.	2	2	2	2	1	2	2	2	0	2	2	1	2	22
4.	2	2	2	2	0	1	2	1	2	2	2	2	2	22
5.	1	1	1	2	0	1	1	2	1	2	0	1	1	14
6.	2	2	1	2	0	2	1	2	0	2	0	1	2	17
7.	2	1	1	2	0	2	1	2	0	2	0	1	1	15
8.	2	1	2	2	0	2	2	1	1	2	0	1	1	17
9.	2	1	2	2	0	1	2	2	2	0	0	1	1	16
10.	2	1	1	2	0	1	0	2	0	2	2	1	1	15
11.	2	2	2	2	0	2	2	2	2	2	2	1	2	23
12.	2	1	2	2	0	2	1	1	0	2	2	1	2	18
13.	2	1	1	2	0	1	2	2	0	1	0	0	1	13
14.	2	1	1	2	0	1	1	2	0	2	0	0	1	13
Totals	26	19	21	28	2	22	21	23	10	25	10	13	20	

Summary of Included Studies

Fourteen papers were included for review. Six of the 14 included studies were RCTs, six were repeated measures and two were a case series design. The mean age of participants included in studies was 39.5 years; most were female, and all included an intervention with pre and post measures of compassion. Quality ratings are illustrated in Figure 2 showing a variation between studies.

Diagnosis

Papers evaluating depression were Cladder-Miscus et al (2017), Schoenberg & Speckens (2015), Schuling et al (2018), Falconer et al (2016) and Asano et al (2017). Five studies included participants with a range of personality disorders which were Schanche et al (2011), Naismith et al (2017), Feliu-Soler et al (2017), Berggraf et al (2014) and Kramer et al (2017). Papers by Ascone et al (2017) and Meyhew & Gilbert (2008) included participants diagnosed with schizophrenia or psychosis. Two studies included a mixture of schizophrenia, MDD and bipolar in their recruitment; these were Laithwaite et al (2009) and Wadsworth et al (2018). Three studies which had a sample of MDD were found to have significant results; three studies including PD were also shown to have significant results. There did not appear to be any notable pattern regarding studies which yielded significant changes in compassion and the diagnosis they included.

Despite its inclusion in these two papers, the current review highlighted a paucity of literature surrounding compassion as an outcome for individuals living with bipolar disorder.

Quality Ratings

Cladder-Miscus et al (2017), Schanche et al (2011) and Berggraf et al (2014) were shown to most accurately meet quality guidelines presented by NICE and CASP. Studies mainly fell short, however, on blinding. Overall, only two studies used blinding and eight studies did not include follow up.

Studies which scored as average on quality were Laithwaite et al (2009), Feliu-Soler et al (2017), Asano et al (2017), Schoenberg and Speckens (2015) and Ascone et al (2017). Once more, the prominent area where these studies lost points, was on blinding researchers and participants during allocation to treatment groups; these studies also fell short on carrying out or reporting follow up procedures in addition to power calculations. Naismith et al (2017), Schuling et al (2018), Falconer et al (2016), Kramer et al (2017), Wadsworth et al (2018) and Meyhew and Gilbert (2008) all scored low quality ratings. Studies dropped points on most of the detailed criteria and this affected internal and external validity. Recruitment and participant demographics were consistently reported by most studies as were details of appropriate analysis in addition to validity and reliability of included outcome measures.

In addition to quality ratings, pooled effect sizes were calculated separately for studies with a control group and studies which had a repeated measures design; two studies (Meyhew & Gilbert, 2008; Laithwaite et al, 2009) were not included due to the required data being unavailable for extraction. Results of this small meta-analysis are outlined in Figures 2 and 3.

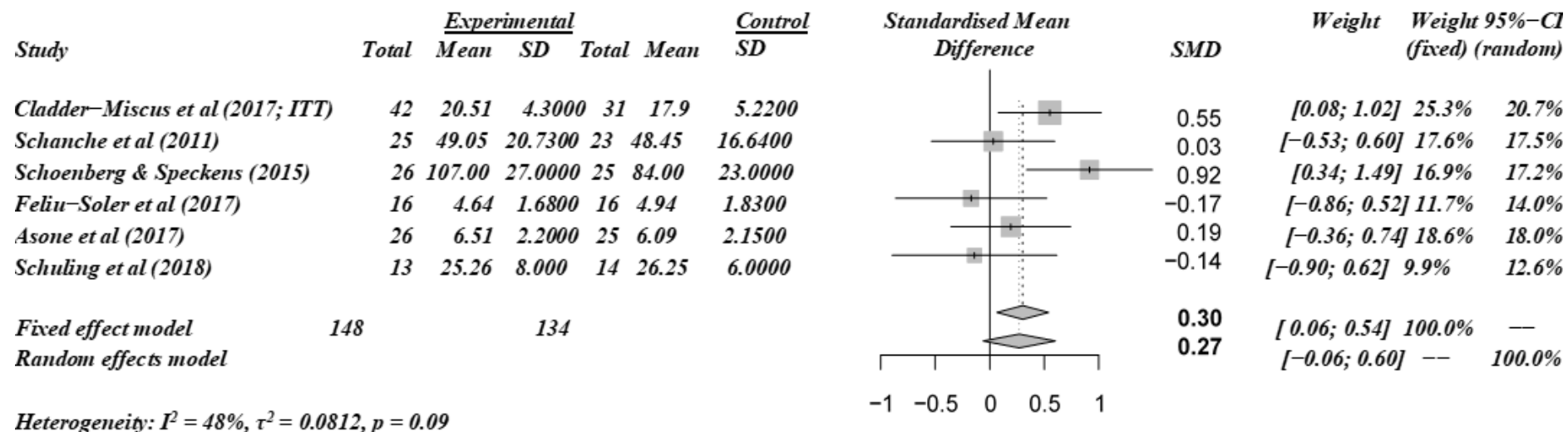


Figure 2. Forest plot for included studies with a control group.

Control Group Studies

Figure 2 illustrates a forest plot of included studies which had a control group. Due to heterogeneity being below 50% ($I^2 = 48\%$), a fixed effects model was used, which assumes little variation between studies and runs the analysis accordingly. Pooled results are shown to be significant ($p < 0.05$), suggesting that overall, interventions used in the studies were significantly more effective in increasing compassion in participants in comparison to those of the control group.

Studies yielding the significant results, as illustrated in the forest plot, were, Cladder-Miscus et al (2017), Schoenberg and Speckens (2015) and Feliu-Soler et al (2017). The remaining were shown to be no more effective than the control group. Study quality is described below in further detail including more information regarding the interventions used, in addition to limitations worth consideration.

Cladder-Miscus et al (2017)

Participants in this study had a diagnosis of depression with an average of 2.69 previous episodes, suggesting treatment resistance. Following MBCT, significant increases in self-compassion and large effect sizes were shown for the intervention group when compared to controls ($p < 0.01$). This study also yielded a high-quality rating score. Results highlighted that participants in the MBCT group reported lower levels of rumination, better quality of life and an increase in mindfulness. A per protocol analysis highlighted a significant reduction in depressive symptoms for participants who completed the intervention, suggesting the importance of engagement and individuals being ready and accepting of treatment for change to take place.

Results suggest self-compassion can be targeted effectively by this intervention for individuals who have been resistant to previous first-hand treatments (i.e. CBT and IPT). One limitation of potential significance is, however, that some participants altered their medication levels throughout the duration of the study; we therefore cannot be certain that changes in compassion were due to the psychological intervention and not medication.

Schoenberg and Speckens (2015)

The impact of an eight-week group MBCT programme on electroencephalogram (EEG) variables, depression severity and self-compassion in participants with MDD was this study's main aim. A significant increase in self-compassion was found in comparison to controls, but the study was found to have an average quality rating score, suggesting some limitations. A reduction in depressive symptoms was shown to reach significance.

Some participants continued to engage in individual therapy outwith the study, all participants were tasked with doing mindfulness home practice and true randomisation did not occur. Participants who applied for MBCT, when there was less than eight weeks until its initiation, were automatically allocated to the experimental group. It is worth considering whether less motivated individuals were more likely to be included in this particular group, and the limitations that the other factors may have had.

Feliu-Soler et al (2017)

Changes in self-compassion were significant only for the intervention group (i.e. LKM) in comparison to controls (i.e. MBT) and large effect sizes were noted; individuals in the LKM were also shown to have a reduction in symptom severity and self-criticism. The main

difference between these interventions was the element of visualisation in LKM, which is thought to be the key component in aiding generation of compassion and acceptance of difficulties. An average quality rating score was attained for this study.

A small number of only three sessions were offered and only an average of 1.94 sessions were attended out of these three. Authors describe extremely low sample size and drop-out rate; it is therefore unclear whether the LKM components for changes seen in outcome measures. It is also unclear whether all participants attended all training sessions, as participation would likely have an impact on study findings

Results illustrated that LKM was superior to continuing mindfulness practice and authors suggest that sessions on LKM may compliment mindfulness practice for individuals who are able to generate compassionate images.

Schuling et al (2018)

Fourteen participants, with a diagnosis of MDD, took part in an initial group working on MBCT; ten participants from this group then went on to take part in a MBCL group where an additional three participants joined. This study demonstrated that although an increase in self-compassion was shown, the intervention of MBCL was no more effective than the control group (i.e. MBCT). There was also poor quality observed for this study.

The second group was constructed following a feedback session. This appears to be a helpful inclusion but it is unclear whether feedback came from all participants who completed the first group or from only a few who were perhaps most confident. This raises questions as to how the second group was shaped and delivered. There was also home study as part of the intervention and, as mentioned in previous studies, it is difficult to measure to what extent this practice varied between participants. The recruitment process also appeared to have a

significant flaw; the study reports that only participants who were motivated to take part were selected. This is likely to be unethical, in addition to impacting the results of the study to the extent that they are not able to be generalised to a wider population.

Ascone et al (2017)

In this recent study, participants with psychosis and paranoia were the target population. The study was observed as having average quality and although changes in self-compassion were shown to be present for the intervention group, these did not reach significance. Changes in self-compassion correlated with increases in self-reassurance and happiness although these were also found to be non-significant.

Participants were randomised and received a negative mood induction by facilitators from reading through a script; participants were then asked to generate a compassionate image in their minds. The control group were read a similar script but asked to visualise a neutral object. These interventions are described well but it is difficult to comprehend to what extent each participant was engaging with the task and in what detail. The intervention appeared to be successful in increasing self-compassion immediately, but if practiced, could help maintain self-compassion more consistently; due to the study reporting no follow up, it is unclear as to whether results can be sustained over time.

One consideration is that imagining a neutral object in the control intervention, could have impacted on emotions in the form of distraction from difficult internal feelings. This could account for non-significant decreases shown in negative symptoms.

Schanche et al (2011)

In this study, looking at treatment resistant individuals diagnosed with Cluster c PD, data from a previously conducted RCT was used which looked at STDP against a CT control group. Although increases in self-compassion were detailed for the intervention group in comparison to controls, this was not significant. There was, however, found to be a significant change when the sample was looked at as a whole. Change in compassion from early to later in therapy, predicted a significant reduction in symptoms for individuals presenting with cluster c PD. A high-quality rating score was obtained.

Sixty-five student rated video tapes of sessions and scored these using the ATOS. They are reported to have had 16 hours of training, but it is still likely that scores were subjective and these could have varied significantly. Self-compassion was only measured at two time points throughout therapy, we therefore cannot be certain that confounding factors did not account for such changes, such as what was being discussed in those particular sessions.

Summary of Studies

On analysing these six studies, there were some themes and comparisons to draw on. Two of the studies (Cladder-Miscus et al, 2017; Schoenberg & Speckens, 2015), which obtained significant changes in the intervention group compared with controls, used an intervention of MBCT with a population presenting with MDD. This intervention was well described and both studies involved eight 2.5-hour group sessions. Sessions worked on training attention for individuals to notice and make changes to repetitive negative cycles, generating higher levels of empathy for the self and learning to live with uncertainty. For both studies, individuals in the intervention group also took part in daily practice, which has been noted as being subjective to results. For both of these studies, which has been noted as a limitation in

others, facilitators were shown to be highly trained in mindfulness and general clinical practice for several years. These factors suggest that further investigation into MBCT for treatment resistant MDD could be helpful rather than typical treatments such as CBT or IPT and experienced facilitators are important. As with all groups, it's unclear whether it was the group (i.e. social) aspect which was of most importance.

Findings from the other significant study in this cluster of studies (Feliu-Soler et al, 2017) suggest that LKM could be a beneficial addition to MBCT. Including participants with BPD, LKM was shown to have a significant impact on symptom presentation in addition to self-compassion levels in a short number of sessions. It is worth noting that there was no follow up group, so LKM would most likely be of benefit in conjunction with other treatments in order to maintain results.

There did not appear to be any patterns between study quality and those which yielded significant results, suggesting that these findings should be treated with caution.

Figure 3 illustrates a forest plot for all studies which had a repeated measures design.

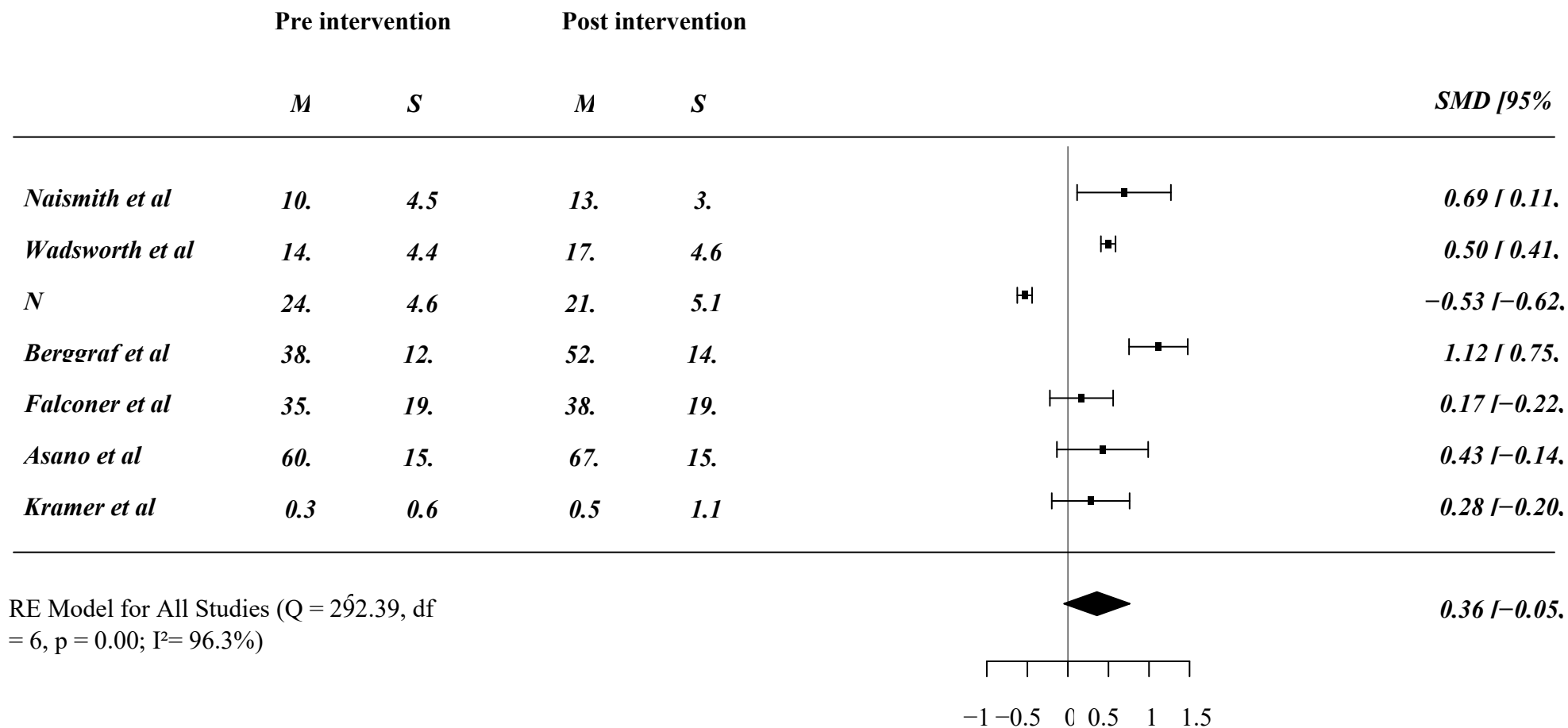


Figure 3. Forest plot of included studies with a repeated measures design.

Repeated Measures Studies

Figure 3 shows the magnitude of the effect for each study and the pooled effect for all studies with a repeated measures design demonstrating that self-compassion increased from pre to post intervention. Random effects modelling was used due to high heterogeneity ($I^2= 96.3\%$) and demonstrated overall significance for pooled studies with a repeated measures design ($p<0.05$). Studies which yielded significant results were Naismith et al (2017), Wadsworth et al (2018) and Berggraf et al (2014). Further detail regarding intervention is described below in addition to study limitations.

Berggraf et al (2014)

This study, as with Cladder-Miscus et al (2017), demonstrated significant changes in self-compassion throughout intervention and high-quality ratings. The aim of this study was to investigate the change in AA and IA throughout therapy, once more from rating videotapes, and how these changes impacted changes in the SoS and SoO scales. This was done taking information from an early therapy session and a later one.

Results showed the higher the AA demonstrated in sessions, the more they saw others in a compassionate light (i.e. increase in SoO). Overall, it was suggested that reductions in IA may be impact more on self-compassion that increases in AA. Patients with higher levels of IA at the beginning of therapy did not show a significantly different rate of change compared to those who began therapy with lower IA; this suggests that change can still occur for these individuals but a longer intervention may be required.

The SoS and SoO are described as being similar regarding question content and this may have caused some confusion for already distressed individuals with complex needs.

Individuals rating these videotapes are likely to have subjective opinions on their classification and levels of compassion witnessed.

Naismith et al (2017)

This paper reported on two separate studies which used a repeated measures design and included participants with PD. A significant increase in self-compassion was shown from pre to post intervention but a low-quality rating was obtained. The main focus, regarding change in self-compassion was study two, where participants practiced soothing rhythm breathing and CFI for 5 minutes every day for two weeks. Results illustrated that regular practice of soothing rhythm breathing led to a significant increase in self-compassion, suggesting that CFI can be helpful for individuals diagnosed with PD. This study also suggests, however that the ability to use imagery appears to be key and is similar to the findings by Ascone et al (2017).

Attrition for study two was high; the ability for results to be generalised to wider context is therefore unclear. Authors also mention the SCS (Neff, 2003) and that the definition of compassion by Neff may be out of date; there is a more recent scale by Gilbert et al (2017) which is referred to, based on the definitions more accurately surrounding CFT. Authors wonder whether this may have been more accurate to the current study's intervention and there have produced different results. This is discussed further in the following section.

Asano et al (2017)

This study investigated group-based CBT for one hour per week for 10 weeks, focusing on CBT skills in addition to compassion for individuals with MDD. There was found to be no

significant impact on self-compassion, but depression did reduce pre and post intervention. Authors compared results to a previous study which was done using 12 weeks of a 90-minute group session. The current group was a success in that it utilised fewer group sessions and only one hour per week with individuals with a similar presentation.

Limitations include that group facilitators did not have any training in compassionate interventions and raises questions as to how this component of the group was delivered. This could also be a reason for there being no notable changes in measures of self-compassion.

Other limitations to consider are that it appears participants continued to engage in individual psychotherapy throughout the group CBT programme. It is not clear whether all participants were receiving this and what form therapy took, but due to there being no control group, it is unclear whether individual therapy or group CBT resulted in changes in depression. Authors also detail that medication was not controlled for, limiting the ability for these findings to be generalised.

Falconer et al (2016)

This study was an uncontrolled case series, utilising an unusual compassion intervention of a virtual nature and included participants with MDD. Despite significant increases shown in self-compassion, this was from pre intervention to follow up and not immediately post intervention which the current review was investigating. Changes in self-compassion were found to correlate with significant reductions in depression and self-criticism. This study was observed as having poor quality.

The intervention was not well described and would therefore be difficult to replicate on the details provided and generalise to clinical practice. Due to the small sample and no control, it is not clear whether results are due to the CFI intervention specifically; it was also eluded to

that participants received a form of compassionate psychoeducation, but this, again, is unclear. Authors note that the compassion scale was taken on three occasions and that this may have affected its validity (Falconer et al, 2016). Equipment was also described as being expensive, highlighting possible implications for clinical practice.

Kramer et al (2017)

This study demonstrated an increase in self-compassion over time for individuals with narcissistic personality disorder, but this did not reach significance. Authors discuss the importance of shame and that this can mediate low self-compassion.

Therapeutic sessions were video recorded and two sessions (early and mid-intervention) were observed and evaluated for perceived levels of self-compassion. Once more, the different individual raters suggest high subjectivity. The recruitment was not clearly described but did elude to being self-referral, suggesting a possible bias towards motivated individuals.

One important factor was said to be timing, specifically when considering the measure of self-compassion. From review of the video tapes, it was highlighted by raters that the evidence of self-compassion would increase and decrease throughout the session, which can make it difficult to capture in an outcome measure. This is worth considering when attempting to measure compassion in a severe and enduring population and in this manner.

Wadsworth et al (2018)

This study aimed to investigate the impact of increasing self-compassion on repetitive negative thinking. Authors used the SCS-SF (Raes et al, 2011), which can be split into positive and negative aspects of compassion; results showed significant increases for positive

aspects of self-compassion and significant decreases in negative aspects. Effect sizes were medium. This suggest that both changes in negative aspects of compassion (i.e. self-judgement, over-identification) and changes in repetitive negative thinking had an impact on depression. This, in turn, suggests that targeting negative thinking and negative aspects of self-compassion could be helpful areas to develop interventions. Despite significant findings, a low-quality rating was found.

A major limitation in this study was the clarity in its description of whether there was a control group used or not. Authors detail participants being allocated deliberately to a variety of groups depending on their need; this suggests that participants attended a different number of groups in addition to groups with varying content. It is therefore difficult to draw clear conclusions from results other than there being helpful changes in self-compassion and negative repetitive thinking which impacted depression; changes in self-compassion were not shown to influence anxiety. The intervention was also vague in its description. The authors make a foot notes, stating that most participants attended a 45-minute session introducing Neff's (2003) model of self-compassion; the number of participants who attended this is not noted and its impact on results remains unclear.

Due to not having the appropriate data for extraction of the forest plots, studies by Mayhew and Gilbert (2008) and Laithwaite et al (2009) were not included in the meta-analysis

Mayhew and Gilbert (2008)

This study utilised a case series design and obtained a poor overall quality rating. It investigated the impact of CMT on individuals presenting with malevolent auditory hallucinations. The intervention consisted of 12-one-hour individual sessions with three male participants, where the ability to generate self-compassion was practised. Each participant

also completed a weekly diary noting down qualitative self-critical and self-compassionate thoughts.

Results are described in terms of change in measure scores between two time points and should be considered with caution due to there being no statistical analysis conducted. One important finding reported by authors was that CMT appeared to influence participants' auditory hallucinations. Individuals reported that their voices altered from being malevolent to being more reassuring but when this was followed up over a year later, participants provided very different updates on their difficulties. This makes the intervention almost impossible to assess. One interesting finding was that participants were shown to rate self-compassion as relatively high on the included measure, but this was recorded as being poor in their diaries. This raises debate as to whether measures of self-compassion are valid within this population without a qualitative aspect.

Laithwaite et al (2009)

The main aims were to attempt to reduce depression, develop and increase self-compassion and reduce self-criticism to help aid recovery and is the first study to conduct a programme for building compassion in a forensic setting for psychotic patients. This study achieved average quality and found changes in self-compassion to be non-significant. Despite this, results are described as having a large magnitude of change for depression and self-esteem, a moderate magnitude of change for social comparison and general mental health symptoms with a small magnitude of change noted for shame.

Authors made an interesting point about anger and how this can often be a result of feeling shame. This is especially true for males of this age group and this has been discussed in previous research (Gilbert & Miles, 2000). Focusing on reducing shame, as mentioned by

Kramer et al (2017) could therefore be helpful in improving anger and therefore relationships with others (Laithwaite et al, 2009) and could lead to an improvement in compassion over a longer time period.

Summary of Studies

On analysing these six studies and in particular, the three which yielded significant results, it was difficult to draw any pattern. Two of the significant studies included a sample of PD but varying interventions, suggesting that this population can be targeted and change can occur in self-compassion. In Naismith et al's (2017) study, attrition was noted as being a barrier to home practice and therefore to change; this would suggest that interventions would be more appropriate if they were led by experienced facilitators to encourage engagement with this particular complex group. Studies by Wadsworth et al (2018) and Berggraf et al (2014) demonstrated the largest effect sizes but one with high and one with low reported quality ratings.

This suggests variability of findings and implies it be worthwhile to treat findings with caution once more. All of the studies with non-significant findings were shown to have mid or low quality; none of these yielded high-quality ratings which suggests flaws in recruitment and designs. Interventions for this group varied, as did recruitment. It is therefore difficult to draw any clear patterns from findings in this cluster of studies.

Discussion

The aim of this review was to search the literature and critically evaluate studies which have looked at compassion as an outcome, pre and post intervention, for individuals with severe and enduring mental health difficulties, such as schizophrenia, personality disorder, bipolar and MDD. Fourteen studies met inclusion criteria when using key words to search relevant databases; these were then quality reviewed using adaptations from NICE and CASP checklists. In addition to evaluating study quality, pooled effect sizes were presented as two separate forest plots, grouping studies which included a control group and those with a repeated measures design. Studies were then discussed considering limitations and drawing on common themes.

Findings from this review add to the literature which tells us that practicing compassion towards others and the self can have psychological benefits (Kannan & Levitt, 2013); in contrast, a lack of compassion and high shame, has been shown to correlate with mental health difficulties such as anxiety and depression (Brown et al, 2010; Crocker, Canevello, Breines & Flynn, 2010). Extensive research suggests that the quality of caring we receive early in our lives, helps us begin practising self-compassion and therefore resilience to distress (Gilbert et al, 2017); not having these early experiences, can lead to difficulty in regulating emotions and increase susceptibility in developing mental health difficulties. Results from the current review suggest that compassion could be a helpful aspect to target in this population, demonstrated by significant findings for the intervention group in both the control group studies and studies with repeated measures design. A lack in RCTs and the variation in study quality, however, suggests that high quality research is required to evaluate the effectiveness of self-compassion further.

Interventions

Interventions adopted in the studies which showed significant increases in compassion over time or compared with control groups, were shown to be MBCT (Schoenberg & Speckens, 2015; Cladder-Miscus et al, 2017), CFI (Naismith et al, 2017), CBT, DBT (Wadsworth et al, 2018) and STDT (Berggraf et al, 2016). In Falconer et al (2016), their intervention of CFI was shown to have a significant impact on self-compassion at a 4 week follow up, but not immediately post treatment; this suggests the possible long-term benefits of this intervention although further investigation using an RCT design would be warranted. Authors describe this sample as having well-rehearsed internal negative monologues which can be extremely difficult and time consuming to shift (Falconer et al, 2016) and wondered whether the compassionate exercise being indirect, helped shift and maintain self-compassion. Further research into the effectiveness of interventions for increasing self-compassion in this population, would be of benefit and is something which can be taken from this review.

In CMT (Meyhew & Gilbert, 2008), participants were found to be able to generate neutral images, but found it difficult to create an image of compassion. One participant reported that the thought of human warmth felt 'frightening' and untrustworthy, which could be a barrier to this form of intervention and may restrict any shifts in self-compassion being made. From these findings, it is likely that this population would benefit from more intensive and long-term intervention, with therapeutic alliance being key to maintain engagement.

In the study by Wadsworth et al (2018) utilising an intervention of CBT and DBT, it was hypothesised that an increase in self-compassion could interrupt maladaptive, unhelpful thinking styles which can trigger and maintain depression (Beck, 2011). Significant findings in this study suggest that targeting the negative aspects of self-compassion can help target

negative thinking cycles and therefore influence positive changes in depression (Wadsworth et al, 2018).

McCullough et al (2003) developed the ATOS, which is a coding system design to give therapists an idea of a patient's behaviour and aids our understanding of how near or far such patients are in reaching therapeutic goals. For example, how much compassion are individuals demonstrating during sessions (Schanche et al, 2011). Affect phobia is a theoretical understanding and a model of treatment for the complexity of symptoms often presenting for individuals living with Cluster c PD. Adaptive AA are described as positive emotions such as closeness, healthy fear, grief with IA describing more negative emotions such as shame, guilt, pain and anxiety.

These studies by Schanche et al (2011) and Berggraf et al (2014) adopted a similar method of rating sessions. This form of assessing self-compassion was thought to be highly subjective, with individuals likely to vary in how they rate sessions and participants likely to shift presentation frequently throughout sessions; the addition of a more concrete measure of self-compassion may be helpful in establishing change throughout intervention.

Reflecting on Compassion Measures

Five aspects of compassion have been described by Strauss et al (2016), regarding how one responds to the suffering of the self. First is to be aware of this suffering, understanding this as being a normal experience within humanity. Feeling kindness towards others who are suffering is another aspect of compassion, in addition to being able to accept pain and suffering but showing commitment in changing this. Considering this definition, it felt important to consider which measure of self-compassion the included papers used, whether

this was appropriate and whether its inclusion was likely to have any impact on study results.

The main measure used by studies was the SCS (Neff, 2003).

Mayhew and Gilbert (2008) reported an interesting finding in their case series study, when using the SCS (Neff, 2003) with individuals presenting with malevolent auditory voices. Scores on the SCS suggested that participants believed that they were being compassionate towards themselves; qualitative information from completed weekly diaries, however, suggested this was inaccurate. This implies that individuals who have severe and enduring difficulties may be unsure what it is to feel self-compassion, perhaps due to early life experiences; in turn, they may be unaware that this is not present for them (Meyhew & Gilbert, 2008). This adds value to the inclusion of psychoeducation for this population before undergoing self-compassion interventions and is something which only five of the included studies detailed; three of these yielded significant findings regarding changes in self-compassion.

Neff's (2003) description of self-compassion focuses mainly on how one acts towards themselves (i.e. using kindness, humanity and mindfulness) and this measure does not therefore cover all aspects of compassion described above by Strauss et al (2016). Instead, attributes linked with the coping process are the focus and is perhaps more relevant to the intervention studies described in this review. Authors have argued that positive and negative aspects of self-compassion should be studied separately as they have a varying impact on individuals developing and recovering from mental health difficulties (Gilbert et al, 2017). Papers using this measure failed to discuss why it was chosen and to make note of this possible limitation.

Another measure which was included in one study, was the State Self-Compassion measure (Falconer, King & Brewin, 2015). This scale uses scenarios to capture levels of compassion

and assumes that both self-compassion and self-criticism go hand in hand. Scenarios are included to elicit self-compassion; this part of the scale has been tested with healthy and patient samples with good internal reliability, suggesting its appropriateness and raises questions regarding its use in only one of the fourteen included studies for review. This study also included a fears of compassion scale (Gilbert et al, 2016), which adds an additional layer to our understanding of difficulty in generating self-compassion.

The SoO subscale measures individuals' descriptions of compassion towards others, such as being able to hold both positive and negative attitudes in mind. The SoS subscale looks at the quality of these descriptions and the ability for individuals to be kind to themselves, avoiding self-criticism. These subscales from Berggraf et al (2014) are described as being very similar constructs which could be confusing for participants as a result. Timing was concluded as being an important factor when considering the measure of self-compassion; as mentioned, from the reviewing of video tapes, raters highlighted that evidence of self-compassion increased and decreased throughout the session, which is likely to be difficult to capture in an outcome measure. This is worth considering when attempting to measure self-compassion in a complex population and in this manner.

Due to limitations with the measures discussed above, an alternative Self-compassion Scale was introduced by Gilbert et al (2017). Authors describe their rationale for the development of this measure, mainly being due to critique surrounding the SCS (Neff, 2003); as mentioned, this has been criticised for including both positive and negative items within the same measure. High scores on both positively and negatively slanted questions could therefore lead to a similar outcome to low scores on both positively and negatively slanted questions. Gilbert et al's (2017) measure considers three aspects of compassion: compassion towards the self, compassion from others and towards other people (Gilbert et al, 2017).

We know from the literature that these can have psychological benefits (Lucre & Corten, 2013; Gilbert & Procter, 2006). Authors were keen to capture the ‘flow’ of compassion (i.e. how this varies between the three aspects) and how this compassion ‘flow’ presents will vary based on individuals’ early childhood experiences. Further comparisons of included compassion measures for complex mental health would be valid and helpful in unpicking important aspects of compassion change targeted by interventions.

Limitations and Future Directions

Compassion was often a secondary outcome measure for studies and was therefore not the primary target for change. This offers one explanation regarding a lack of significant change in self-compassion for many of the included studies. Further research would benefit from including self-compassion as a primary outcome in order to directly assess impact of interventions.

The studies included for review recruited participants with varying diagnoses, with some studies reporting that these individuals experienced varying levels of stigma and shame (Wood et al, 2014). Several studies have reported that schizophrenia has the highest level of stigma and is viewed most negatively by the public (Wood et al, 2014; Holzinger, Beck, Munk, Weithaas & Angermeyer, 2003); this population have also been found to experience the highest level of rejection in a study by Corrigan and Watson (2002) when compared with other complex presentations. It is therefore worth considering whether it is helpful to group different diagnoses together, when their experiences of stigma, and therefore the effect of compassion, could vary. Having a measure of stigma or shame, as part of inclusion criteria, could also be a more helpful addition or alternative.

In one study, participants reported that it was ‘terrifying’ to create and rely on a compassionate image to generate self-compassion, as other people feel untrustworthy; this appears to be a significant barrier to this form of intervention for this population, suggesting that interventions should be facilitated by trained professionals and given time for therapeutic alliance to be fostered and maintained.

Finally, studies were not included for the current review if they used a measure of mindfulness. Mindfulness and compassion are similar concepts, which overlap in several ways and both consider awareness of the self and other (Karl, Williams, Cardy, Kuyken & Crane, 2018). Neff (2003) describes common humanity and moving towards alleviating suffering as being key concepts for self-compassion; in the current review, these appeared to overlap with questions in mindfulness outcome measures and, on reflection, it may have been useful to include both compassion and mindfulness measures in order to review a larger number of studies and is something which would be helpful for future reviews to undertake.

Conclusions

Overall, this review aimed to gather all studies which have looked at the use of a self-compassion measure before and after a psychological intervention for individuals presenting with a severe and enduring mental health difficulty. Results from this review illustrate significant changes in compassion when effect sizes were pooled for studies with control groups and repeated measures designs. It is detailed, however, that due to the large amount of variability in study design and quality, further high quality RCT studies are required to add clarity to this area.

In summary, compassion does appear a useful construct to target during interventions with this particular population presenting with often high levels of shame. Further research is, however, warranted looking at grouping specific interventions, diagnoses and self-compassion outcome measures.

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* Studies included for review.

“Knowing the Story of our Lives”

Young Peoples’ Experiences of Recovery from Early Psychosis and the Role Autobiographical Memory and Self Identity Play

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Abstract

Introduction and Aims: Adolescence is a critical period where change is occurring mentally, physically and socially. Experiencing psychosis during this time has been shown to be extremely disruptive to many of these processes and can have a severe impact on the development of self-identity. Due to paucity of research within early psychosis in an adolescent population, this study aimed to investigate 1) the importance of autobiographical memories to young people's recovery from early psychosis and 2) In what way early adverse experiences and memory formation affect future thinking and establishing an overall sense of self during this recovery process.

Methodology: A qualitative design was followed, combining a grounded theory approach with the completion of quantitative outcome measures in order to strengthen findings. Eight young people, varying in age from 16-19 years, were interviewed. Five young people were outpatients attending local mental health services for support with early psychosis; four were recruited from an inpatient setting. Outcome measures used were the CTQ, QPR and AAI. Using Charmaz's grounded theory guidelines, interviews were conducted and developed over time; line by line coding was initially used, followed by the development of salient themes and categories.

Results: Themes were grouped into categories which linked together to give an understanding of the data in line with the current study's research questions. Final categories were the items most salient to come from young peoples' experiencing of early psychosis. These were identified as: interpersonal connections, self-identity, choice and freedom, recovery and autobiographical memory. Sub-categories linked with these are discussed with reference to quotes from young people.

Conclusion: The author felt it appropriate and helpful to look at the results from this study through the lens of locus of control. Approximately half of participants were found to approach recovery through an internal locus of control while the remaining young people had a more external sense of control. The impact that this has on memory formation, recovery and future thinking is discussed in line with early experiences. Findings are also discussed in line with quantitative measures. This study's findings add to the current literature base and suggest that working therapeutically, considering the impact of locus of control and personal contributions on recovery, may aid our understanding of early psychosis. Study limitations and thoughts regarding future research are discussed.

Introduction

Adolescence is a critical time when individuals begin to develop a more concrete sense of self and greater autonomy in the world (1). This period is also important for developing and strengthening interpersonal connections, increasing one's understanding of their own identity and their identity in respect to others (2). Experiencing psychosis during this period can lead to these typical processes becoming disrupted and for recovery to take place, research suggests that finding meaning in the experience and rebuilding a sense of self is key (3,4).

When young people move through adolescence and experience psychosis during this period, they are at risk of over identifying with their illness and defining themselves as part of this (1). Over identifying with the illness can lead to depersonalisation and a loss of future thinking with regards to goals and aspirations in line with the self (5, 6). Research focusing on the role that autobiographical memory plays in the establishment of self-identity, is an emerging literature base, key to our understanding of recovery within this complex population.

There is a growing body of literature suggesting that early adverse experiences impact on the development of psychosis (7, 8). Prolonged exposure to such adverse events is now known to increase the likelihood of the development of psychosis during adolescence, and there is a dose-response effect (9). Early adverse events refer to a range of negative life experiences including physical, sexual and emotional abuse as well as physical and emotional neglect (10). Cognitive models of psychosis describe early trauma as facilitating the development of self-critical internal working models (11, 12) and that these experiences have increased the likelihood in developing negative schematic models, highlighting others as untrustworthy and the world as unsafe (11, 13). Research in the area has also looked retrospectively on the lives of adults with psychosis and found significant levels of trauma in their past (13, 14); this

supports studies investigating childhood trauma, which have highlighted a 50% reduction in autobiographical memories compared to those without trauma histories (15). The importance of early adverse experiences on the formation of particular attachment styles, is another key area of research, in relation to the impact these styles have on the formation of autobiographical memory and recovery (16).

Young people who develop psychosis have been found to have mainly avoidant and disorganised attachment styles (16); a disorganised attachment style as a child is known as a dismissing attachment style in adulthood and such attachment styles have been shown to increase the likelihood of a 'sealing over' or avoidant approach to recovery (17, 1). Adopting an avoidant approach can lead to a reduction in reflective function regarding experiences which can lead to recovery being less successful (18, 19). Alternatively, if young people can be more integrative in their approach, this suggests they can create meaning in a coherent narrative of autobiographical events, which is less fragmented, helping to rediscover what is important to them when looking to the future and setting goals towards recovery (5).

Systematic reviews in the area (16, 20) have agreed that studying attachment style is relevant to improve our understanding of the development of psychosis (21) and to facilitate the most helpful interventions to aid recovery and promote quality of life for this population. For individuals who have experienced early adverse events, which have increased the likelihood of developing disorganised or dismissing attachment styles, the formation and recall of autobiographical memories has been shown to be depleted, impacting on how they see themselves and look towards the future (4, 18).

Declarative memory is conceptualised in the literature as semantic and episodic memory (22). Semantic memory refers to general knowledge or facts (2) which are accumulated over time but with no clear recollection of where and when such memories were formed. Episodic

memories are personal events which are directly linked to the self and are paired with knowledge of when such memories were formed in time and the emotions associated with such events (23). Research in the area of autobiographical memory refers mainly to those episodic experiences which give us a sense of who we are as a person and who we aspire to be in the future, in line with our values and goals (22, 5).

During typical development, non-mentally ill individuals are able to form and consciously recollect autobiographical memories (2, 23), with increased levels of encoding taking place during the latter years of adolescence (i.e. the final stages of self-identity formation; 2). The literature suggests that consciously recollected memories, such as autobiographical memory, influence past and future goals (24, 25); we are more likely to recall memories when they support goals and aspirations which are important to us and such goals are influenced by how someone sees themselves (26). The recollection of autobiographical memories and therefore the establishment of a consistent sense of self, has been shown to be depleted in individuals with a diagnosis of schizophrenia, having experienced early psychosis (4). Young people who have fragmented memories about significant events in their life, tend to find it difficult to establish a sense of what their values are which can be a barrier to future thinking (2). Such changes to memory and future thinking in atypical development are outlined in recent studies.

Holm and colleagues (2) aimed to clarify how self-defining memories are distributed before and following diagnosis of schizophrenia, how these differ from matched controls and how they may impact on recovery. Twenty-five participants, with a diagnosis of schizophrenia and a mean age of 26 years were recruited; twenty-five controls were also recruited and matched for gender and age. Participants were asked to recall three memories which were at least 12 months old and evoked strong emotions; selected memories were to be detailed, important to each person and events which would help describe them as a person. Results

demonstrated that autobiographical memories for the clinical sample increased in the period prior to diagnosis and abruptly decreased following this; authors suggest that this is due to the challenges faced by these individuals in developing existing views of themselves or building a new self-identity (2). One could argue that this could be predicted due to the likely significant changes which were occurring to individuals prior to diagnosis of a severe and enduring mental health difficulty. The clinical sample was also shown to recall memories in less detail and at a younger age, which authors suggests is an impairment in the final part of identity formation, impacting on the formulation of a sense of self (2). Literature in the area of memory formation tells us that children are more likely to be able to create a coherent story about their lives when they have grown up with caregivers who were elaborate in their narratives (15); stress has also been shown to affect hippocampal development and the potential for young people to learn (27).

Andresen and colleagues (18), identified four key processes to recovery following early psychosis: building hope, finding meaning in life, culminating responsibility and re-establishing self-identity. Such goals appear reasonable; these are likely to be challenging, however, for individuals who struggle to see others as trustworthy and the world as safe (11, 13). Research is therefore suggesting that autobiographical memories are depleted in individuals who have experienced early psychosis and that this impacts on how they see themselves currently and in the future. Findings such as these support the literature suggesting value in establishing a sense of self through the development of goals and aspirations important to each person (4, 2). This is a concept investigated further by Goodby and MacLeod (5).

The Future Thinking task has been used to establish whether future thinking is a feature of impairment in individuals who have experienced psychosis and within 12 months of their first episode (5). Using a matched control design once more, authors found that the clinical

sample were more hopeless in their ability to think into the future when compared with matched controls of a similar age. Authors also found that there was a lack of negative appraisals of future thinking, suggesting that, in addition to evidence of hopelessness when looking ahead, there is a general disengagement and avoidance in doing this (5). Taylor and colleagues (28) hypothesised that possessing fragmented and non-specific memories of one's past, may be an adaptive coping mechanism from suicidality for individuals living with psychosis. In this study, 60 participants with a diagnosis of schizophrenia were recruited; forty of these individuals had also made previous suicide attempts which was assessed by completion of the Revised Suicidal Behaviours Questionnaire (SBQ-R; 29). To assess the ability for participants to recall memories, The Autobiographical Memory Test (AMT; 30), which has been shown to be a robust outcome measure, was also used. Responses to this test were audio recorded and memories were coded at varying levels of specificity regarding how much detail was given and whether these were linked to autobiographical memory retrieval or vague in description.

Results illustrated that participants who had previous suicide attempts, recalled more specific memories when compared with those who had less precise memory recall (28). Findings suggest that when memory is specific in this population, it is possible that early adverse experiences are accessed in more detail, therefore increasing hopelessness and risk of suicide. This is a concept which has been researched for alternative complex mental health difficulties, such as personality disorders and individuals with a history of abuse (32) in which similar findings were drawn. This aids our understanding regarding fragmented memory and its use as an adaptive coping mechanism.

The current literature presents the argument that autobiographical memories are crucial to the development of self-identity throughout adolescence (26, 23) and that these are both key processes in the recovery from early psychosis (2). The concept of early adverse experience,

which impact on attachment style (16), are woven throughout recovery, regarding which path this will take following the, often disruptive experience of psychosis (1).

Rationale for Current Study

The literature described, outlines our current understanding of early psychosis, its impact on self-identity and the importance of autobiographical memory and early experiences (i.e. attachment and trauma) in recovery from this. To the researcher's knowledge, there is yet to be a study investigating the impact of these elements within an adolescent sample using a qualitative approach. The paucity of literature focusing on the adolescent population, highlights the importance in broadening our knowledge and understanding regarding the impact of early psychosis within this critical period of development, in order to improve appropriate interventions for recovery.

The current study will aim to answer the following research questions:

1. How are autobiographical memories important to young people's recovery from early psychosis?
2. In what way do early adverse experiences and memory formation affect future thinking and establishing an overall sense of self during this recovery process?

Methodology

The following section will describe the methodological process which the study took prior to and during recruitment in addition to the analysis stage.

Design

The current study used a qualitative design; quantitative measures were used, with an emphasis on the former design, using grounded theory. Due to the relatively scarce literature around the experiences of psychosis within an adolescent population, this project was exploratory in nature, building hypotheses for future, larger studies.

Rationale for Design

Focusing on a qualitative approach facilitated the process of discovery of similar, shared experiences which occurred in a common context. Hypotheses were developed as interviews took place, grounding them in the research and allowing the generation of theory from the collective experiences of the young people being interviewed (33). Unlike pure qualitative research, the current design allows for the measurement of key quantitative variables which are rooted in the literature, aiming for a richer understanding of experiences. There has been debate over whether quantitative and qualitative approaches should be combined in any way, with a purist perspective arguing that these are two exclusive assumptions (34); in contrast, a pragmatist perspective argues that the design which is more likely to yield optimum outcomes, should be the one selected (35). The latter is the stance the researcher took in the current study.

Methodological triangulation uses different techniques to come to a more fixed position (34). From triangulation of the data, similar themes can be ‘tapped’ into from different perspectives, adding strength to the design, the data and the reliability of the outcomes (33). In the current study, significant events were discussed during the grounded theory interviews but were also accessed through the trauma and loss subscale of the AAI and quantitatively from the CTQ. The content of memories was accessed through grounded theory interviews and through the process of the AAI. Regarding young peoples’ insight into their recovery, the QPR was the quantitative measure used; young peoples’ experiences of this were also accessed through grounded theory interviews. Quantitative measures were used to group participants and these are looked at in further details in the following section.

The researcher chose to follow guidelines from grounded theory (33). This approach was selected over other qualitative methodologies due to its approach being open and allowing the discovery and development of themes to come from shared experiences of the young people being interviewed.

Participants

Participants were eight young people, aged 16 -19 years who were in contact, at the time of interviewing, with mental health services in NHS Lothian for treatment following early psychosis or ‘at risk’ symptoms. Inclusion and exclusion criteria are outlined below.

Inclusion Criteria:

- Young people between the age of 13 and 25 years who are currently attending NHS Lothian Mental Health Services in the context of early psychosis.

Exclusion Criteria:

- Individuals unable to provide consent to take part in the research project.
- Individuals unable to understand English sufficiently to take part in the study. This due to measures only being available in English.

Additional participant demographics are detailed in the Table 3.

Table 3. Participant demographic information.

Young Person	Age (years)	Referred to EPSS/IPU	Recruited from:
S001	18	August 2017	EPSS
E002	19	March 2016	EPSS
R003	18	June 2017	EPSS
R004	18	October 2016	EPSS
B005	16	July 2018	IPU
L006	16	January 2018	EPSS
R007	17	December 2018	IPU
D008	17	February 2019	IPU

Participant Sample Size

Sample size within qualitative research is usually purpose driven rather than probability focused; diverse data, which is rich in quality is the aim, as opposed to seeking high numbers of participants (36). Data saturation occurs when the ability to obtain new information has been reached and when there is enough new material to replicate the research (37); when saturation occurs, interviews should end. For the current study, as mentioned, it was not possible to follow a pure grounded theory approach, therefore pragmatic sampling was followed; participants were not selected from a pool of particular characteristics, but the sensitivity of participants and size of sample was pragmatic and can be described as a ‘stage

one' grounded theory stance (33). Proximate saturation was followed as it was beyond the scope of the current study to use a theoretical saturation approach (i.e. the point when no further insights emerge from the data; 36).

Maintaining Participant Confidentiality

Participant identifiable information was anonymised and done so at the earliest possibility. Audio recordings were taken during interviews on encrypted devices covered by Caldicott, adhering to NHS Lothian approved data transfer procedures. Following interviews with young people, audio recordings were immediately stored on NHS computers within a private folder available only to the chief investigator and project supervisors. All interviews were transcribed within the following few days and subsequently removed from all devices; all identifiable information was eliminated during the transcription process using pseudonyms and codes to protect participants' identity. Keys for identifying information within the transcripts were available only to the chief investigator.

Other participant identifiable information, such as consent forms, were stored securely in locked cabinets within secure NHS Lothian premises.

Participant Consent

Clinicians working within NHS Lothian mental health services were asked to approach appropriate young people for inclusion in the study; such clinicians were asked to use their clinical skills in deciding whether each young person had capacity to provide informed consent to participate. It was made clear that all young people were free to withdraw this consent at any point and that this would not affect their treatment as usual (TAU). The

researcher was to have no contact with young people or have any details regarding potential participants until they had given consent to be contacted. A participant information sheet was developed, outlining all aspects of the study, answering key questions and the steps involved in giving informed consent (See Appendix D for an example of the consent form and Appendix E for the patient information sheet issued).

Due to most young people in contact with NHS Lothian services for early psychosis and available for recruitment being over the age of 16 years, it was not possible for the current study to collect the experiences of those 13-15 years, which could have added a different perspective to the overall finding.

Qualitative Data Collection

Qualitative analysis took the form of a grounded theory approach which, throughout the interviews, aims to construct theories ‘grounded’ in the data. Data was interpreted early on, helping gaps to be identified and filled by guiding subsequent interviews in particular directions. During analysis, data was separated, arranged and synthesised through initial ‘line by line’ coding, which helps construct the ‘bones’ of the analysis (33). Themes are based on these codes, which are labels attached to the data; through coding, common themes were extracted which helped to clarify what is happening in the data as the participants’ lives and experiences are formulated. Subsequent interviews were then guided in the direction of themes which had been initially drawn, to help build a theory and answer principle research aims. Such qualitative methods allow data, which is of key interest, to be followed up and investigated further. All grounded theory interviews followed guidelines (33) to facilitate this procedure.

The researcher moved through three stages. Following each interview, the researcher reflected on the audio content whilst transcribing, constructing memos to facilitate subsequent interviews (see Appendix F for a codebook example of memo writing).

The stages of processes are outlined in Table 4.

Table 4. Stages one to four of grounded theory process, as outlined by Charmaz (33).

Stage of Grounded Theory Process	What Happened at each Stage
Stage 1: ‘Line by line’ Coding	This involved using the participants own words to start conceptualising the raw data. An example of this is outlined in Appendix J.
Stage 2: ‘Focused’ Coding	Initial codes were grouped and synthesised into broader categories. Themes helped to identify common patterns emerging from the data and aid shaping of subsequent interviews.
Stage 3: Selective Coding	At this point, the researcher went back through the grounded theory interviews and recoded larger sections of transcript which fitted with the focused codes. This was important in order for all dialogue to be coded appropriately and in line with focused codes.
Stage 4: Theoretical Analysis	This stage involved finding relationships between focused codes and generating a theory grounded in the research.

Quantitative Data Collection

In addition to qualitative interviews, quantitative measures were gathered.

The Childhood Trauma Questionnaire (CTQ; 38)

This is a 28-item measure which looks at five different domains of adverse early experiences – emotional, physical and sexual abuse, and emotional and physical neglect. Responses range from never true to very often true and are recorded on a 5-point Likert scale. Test-retest coefficient has been shown to be close to 0.8. According to the copyright holders, Pearson Clinical, it takes participants five minutes to complete on average (www.pearsonclinical.co.uk).

Adult Attachment Interview (AAI; 39)

This measure is used to classify attachment style by asking participants to reflect on early experiences with primary caregivers regarding trauma, loss, rejection and separation. It consists of 18 questions and has been used to reliability classify attachment styles. This measure touches on early adverse experiences such as trauma and also on the process of memory formation.

The Questionnaire about the Process of Recovery (QPR; 40)

This is a 22-item measure developed by service users. With attempts to move away from symptoms, this measure looks at recovery more in terms of increased quality of life and empowerment. The QPR has reasonable reliability, construct validity and internal consistency (40). It can assist clients with goal setting, evaluation of these goals and promoting recovery from psychosis. Questions are answered in relation to the past seven

days and answers are given on a 5-point Likert scale (disagree strongly, disagree, neither agree or disagree, agree, agree strongly).

See Appendix G (within the study protocol) for details of these outcome measures.

Ethical Approval

Using the standard Integrated Research Application System (IRAS), ethical approval for the current study was granted by the East of Scotland Research Ethics Service (REC reference: 17/ES/0158). Approval was given following minor amendments of documentation.

Following this, Lothian NHS Research and Development Office reviewed the study and it was approved to proceed (see Appendix H for relevant details).

Procedure

Following ethical approval, the chief investigator attended a multidisciplinary team meeting within the appropriate mental health services and outlined the current research project, its aims and methodology. Inclusion criteria were discussed with clinicians who were asked to identify appropriate young people to take part. Participants were approached by clinicians during planned appointment times. Potential participants were informed regarding what the research entailed and if interested, they were given a participant information sheet to read and consider. Young people could also contact their clinician or the chief investigator directly through details displayed on the relevant posters within their NHS mental health services (see Appendix I details or recruitment poster). Potential participants were given a minimum of 24 hours to consider all information in the participant information sheet before being asked to

give verbal and written consent; they were given time to ask the researcher any questions before consent was taken.

For young people who wished to take part in the study, interviews took place with two young people initially in clinic rooms within NHS Lothian premises. The two initial interviews were transcribed and coded using Nvivo 11 software, drawing out common themes in line with answering the proposed research questions. An interview schedule was developed to guide dialogue directions, taking care to be open, reflective and pulling as rich a data source as possible.

Remaining interviews built on initial themes which were extracted from the first set of interviews, allowing them to be in-depth and evolving, following guidelines for grounded theory (33). After the first four interviews, the researcher paused to identify themes which recurred throughout all interviews; themes which were idiosyncratic and themes which were surprising to the researcher during interviews were of interest. Identification of these allowed interview questions to be shaped in order to extract further detail from recurring themes and adapt the focus as required. The adaption of questions also allowed idiosyncratic and surprising themes to be investigated further in subsequent interviews. From the initiation of interviews until the final one took place, questions which did not appear to connect with participants experience were removed, and additional questions developed to tap into those themes which were emerging (see Appendix I for an example of a revised interview schedule - highlighted sections, are those which were added to build on salient themes). The three measures detailed above were also taken from participants, focusing on early adverse experiences (CTQ), recovery (QPR) and attachment style (AAI).

The CTQ and QPR were administered following the grounded theory interview (i.e. to avoid the completion of these to influence the interview in any way); each young person worked

through the questions and ticked the answer they felt most relevant. The AAI was carried out by the researcher, usually in a separate meeting or following a break. AAI's were recorded with permission from the young person and transcribed by the researcher with reference to the official transcription guidelines. These interviews were then coded by the researcher's supervisors, who are both trained in this process. The outcome codes were discussed with the researcher prior to the write up of the research. As mentioned, see Appendix G for further details of the AAI.

The grounded theory interviews allowed one hour in length for each participant and the quantitative measures also allowed a similar duration. Most interviews took place over one single session. Data from measures and grounded theory interviews were then considered for analysis, aiming to answer key research questions.

Pilot Interviews

The researcher had not been involved in qualitative interviews prior to this study. She therefore arranged two practice sessions with peers within her cohort. These individuals had both experienced a significant change in their life which altered their sense of self and feelings about the future. These practice interviews were audio recorded, reflected on by the researcher's clinical supervisor with feedback given. The researcher was then able to modify questions appropriately.

The researcher acknowledged that these interviews were artificial did not reflect exactly how interviews would be like with the young people recruited. However, conducting an interview with a young person from the clinical sample and being unable to use this data towards results, did not feel ethical.

Sampling Schedule for Grounded Theory Interviews

As mentioned, two grounded theory interviews were conducted initially. These were then transcribed (pulling out any anonymous information) and coded before the next two interviews took place. 'Line by line' coding was followed by gradually creating themes of common codes and arranging these. After the first four interviews had been coded, themes were thoroughly analysed by the researcher; these were also considered by her academic supervisor. The researcher considered themes which came up throughout interviews, themes which came up once or twice and those themes which were surprising. These themes could then help to shape ongoing interviews in order to move towards a more in-depth level of understanding. (See Appendix K for an example of 'line by line' coding).

Memo writing

Memos were also used to help detail the interviewer's thoughts throughout the process and were frequently documented by the interviewer. These allowed the interviewer's thoughts from interviews to be recorded and reflected upon independently and during supervision. Memos also allowed for emotions in the room to be captured in addition to body language and the interviewers' own feelings, which were not necessarily detailed through transcriptions.

Personal reflections regarding the process of grounded theory are detailed in Appendix L.

Results

Qualitative Data

Figure 1 illustrates the main categories and subcategories which emerged from the qualitative interviews with young people regarding their experiences of psychosis. Young people talked about interpersonal connections, self-identity, having a lack of choice and freedom and recovery. Throughout the interviews, how young people accessed autobiographical memories was observed in order to answer the proposed research questions.

In this section, main categories and subcategories will be discussed with reference to direct quotes from young people. Findings from quantitative measures will then be described before these are analysed together to answer the research questions. How these main categories draw on theory and link with the current literature base, will be discussed in the final section.

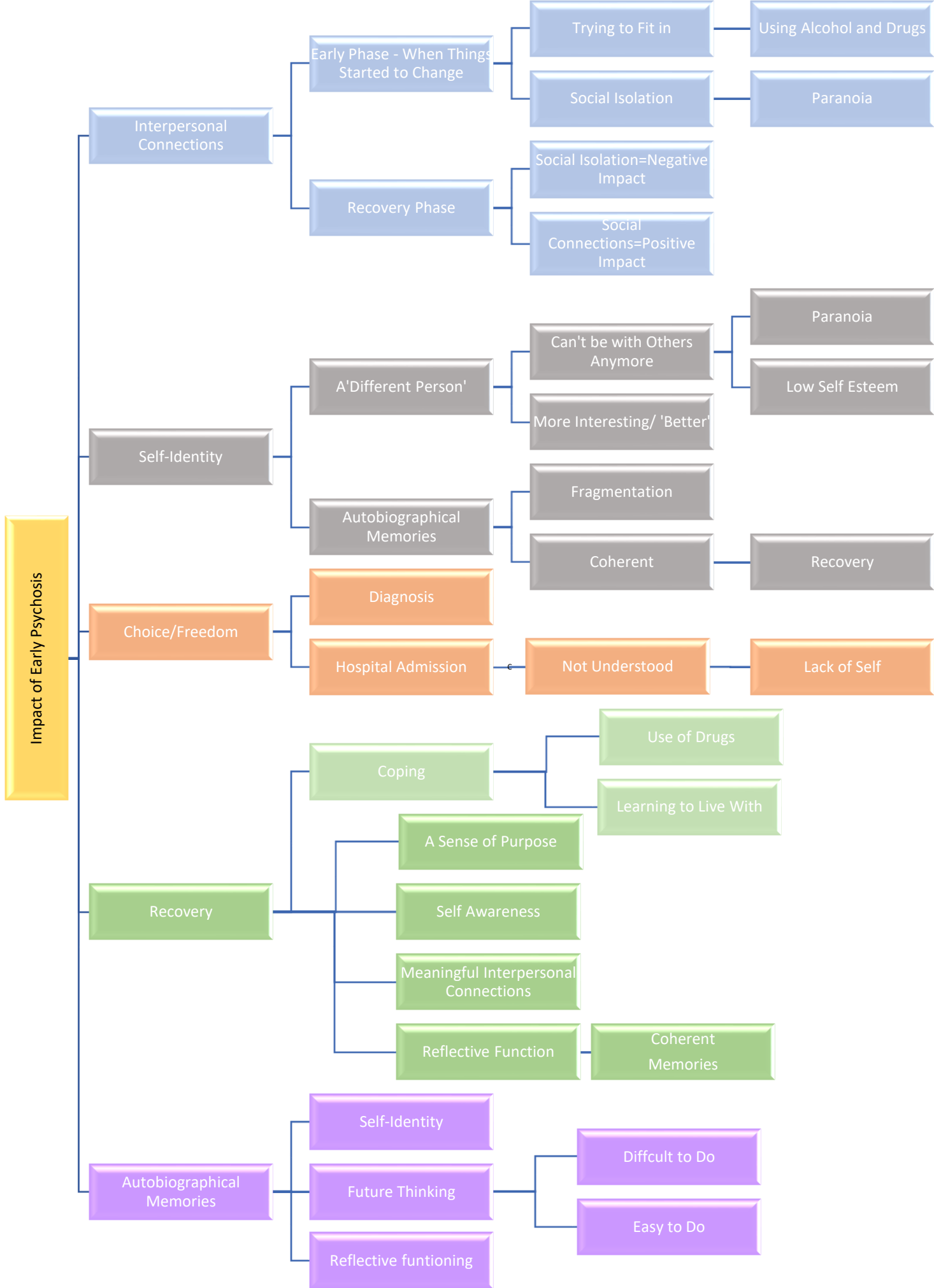


Figure 4. Organisation of final categories and sub-categories.

Interpersonal Connections

Trying to Fit in

This first category was consistently raised by young people as being important to every stage of their journey during and following early psychosis. Young people initially spoke about interpersonal connections when things began to change for them; some young people described that they were trying to fit in during this time, taking drugs and alcohol, and at times, getting involved with the ‘wrong’ peer group.

R004 described:

“And I was trying to do the cliché things, get a girlfriend and speak to people and go to stupid parties in the woods called ‘seshes’ and ye - and half way through S3 I kind of hanged around with the wrong crowd and I got into smoking weed. I never smoked a cigarette before and I never drank”

R007 also spoke about trying to fit in and doing things which she didn’t particularly enjoy:

“I would go out drinking all the time and ye - was just going out a lot and doing all the same things that I was doing but then after I started smoking cannabis – the thing is, I hate the feeling of being drunk - I guess I was doing it to try and fit in..”

L006 spoke about trying to fit in leading to things beginning to change for him and the impact this had:

“I’d kind of started smoking cannabis and stuff. And then I’d been taking MDMA and stuff. That’s like right before I had the seizure – Em, I just felt really low in my life and felt like I couldn’t trust anyone”

Social Isolation

Other young people described withdrawing socially when things began to change, illustrating two distinct sets of behaviours that young people were engaging in. In line with this, E002 spoke about avoiding friends:

“Em. Ye I know I just didn’t go to school for a few days. Ye. I just like couldn’t bear to see them”

Similarly, L006 described:

“Ye. I mean eventually I just stopped doing stuff and lost most of my friends - and was just in my room most of the time. And like not doing anything really”

The reasons as to why some young people were trying to fit in and others withdrew socially, are not clear and would warrant further investigation regarding whether stigma from others, resulting in self-stigma, impacted on the path of recovery.

Self-Identity

A Different Person

Most young people spoke about a change in, or lack of self-identity during the recovery phase of their experience. Most young people described feeling ‘someone else’ to the person they had been previously; some described having a different personality and not behaving the same with their peers (i.e. not being ‘good’ socially) in particular.

R007 shared a perceived change in personality:

“I think I’m more apathetic than I was before. Just generally more dulled down than I used to be. I suppose.. just.. I’m less passionate about some things than I used to be”

“People probably think I’m a little bit more... I think people would describe me as a little bit dead inside compared to what I was like then. I think I’ve lost quite a lot of my personality - I don’t do anything with other people anymore”

Similarly, E002 shared that:

“Probably pretty much everything is different... so there is not – I mean I don’t know where to start really”

One young person stood out, in that they saw their experiences as being positive, interesting and changing them for the better. R004 had the following response in answer to a question about setbacks and reflecting on experiences:

“Apart from getting ill again, which isn’t even a setback really, it’s more of a step forward because it really made me realise that what I was doing really wasn’t great. Like over drinking, well drinking at all... I honestly think it’s helped me. I think it’s made me a better person because it’s given me more experience in life. Before I was just boring and I hadn’t experienced anything and nothing that interesting had happened in my life before. So my entire life was based on school but now I am focused on music and other things”

B005 thought that his experiences had made him a better person, although found it difficult to say more about this:

“No. Well I think they have made me better ye. But I don’t think they’ve changed me”

The researcher was aware that this young person had experienced an extremely difficult early life; this was not reflected in his account of experiences or in the quantitative measures.

Choice/Freedom

Diagnosis and Hospital Admission

Young people consistently spoke about a lack of choice and freedom particularly at the point of help seeking and diagnosis; they also spoke about this during hospital admissions. During

her initial contact with mental health services, R007 spoke about being unaware of what was going on:

“I just remember them speaking to my dad for a very long time... but I don’t remember them ever saying to me what was wrong. I just know because I’ve been told what was on my notes. It’s been kind of stressful. Especially feeling like they are trying to medicate you for something you don’t believe you have. It’s really horrible”

S001 also described:

“Well I didn’t have much choice about it. At that point”

Most young people had poor experiences of being an inpatient and reported consistent lack of choice and freedom. R003 reported that:

“Well when you’re at home, you can do stuff, but when you’re in hospital, you’ve got a bed and nothing else. So you have to sleep or stay awake and do nothing. You’re just kind of forced into it. I didn’t want to be there and I felt that people were holding me in”

R007 also described a lack of choice during hospital admission:

“They can give you advocacy workers and all this stuff, but at the end of the day. It does just feel like you’ve been thrown in somewhere and there’s nothing you can do about it. And that is kind of the truth”

Recovery

Coping

Recovery meant coping with symptoms and interpersonal difficulties for many of the young people. Drugs and alcohol were one way of coping with these and others had accepted that they will have to learn to live with their difficulties rather than hope that they will ever be rid of them. In reference to this, E002 described:

“It’s more like you have to learn to live with things. I guess it’s more like not about getting rid of things but more like just learning to deal with things and to find a way”

L006 also described:

“I need to still smoke to relax and get on with things.. well I’m not really getting on with stuff, but I mean just to cope I guess”

Meaningful Interpersonal Connections

As mentioned, interpersonal connections have been shown to be significant throughout all aspects of young peoples’ experience of early psychosis; they have been observed as salient when things started to change (i.e. often described as being disrupted, with young people reporting that they often withdrew socially often due to feeling stigmatised) and these connections were found to be particularly significant during the recovery phase. Young people spoke about the difficulty in making friendships, but the importance of these. Stigma and shame appeared to be an important thread throughout young peoples’ recovery and may

be influencing interpersonal connections and how accepting they are of their difficulties and moving forward.

Interpersonal challenges are described below by R007 and R004; a difficulty in developing these in addition to craving for them, can be sensed. This quote from R007 was in response to being asked whether she now does things differently, following her experiences:

“I basically don’t do anything with other people anymore – I’d like to have friends though and just be able to function as a normal human being”

R004 describes trying to fit in when things started to change, but on reflection can see that he can have more meaningful connections with more like-minded individuals. This links in with rebuilding the self:

“Ye. And I’ve been let down by so many people that I’ve put my time into as well, so I just stick to my guns now and try to trust people who are similar to me... I don’t try and fit in with people for the sake of it anymore”

Reflective Functioning

This was shown to be important for young people in making sense of their difficulties and to reflect on positive and negative memories and supports the current literature; this can aid development of a coherent story, build self-identity and facilitate recovery. Some young people were able to make sense of their experiences, holding a degree of understanding and control over them:

“I just kind of wish I’d done a lot of stuff differently and didn’t do quite a lot of stuff

basically.. ye because I don't think.. I think if I'd done things differently, I don't think I'd be in the crap situation I'm in now. Especially with drugs and alcohol"

Other young people found it more difficult to reflect and make sense of their experiences, which is something observed by the researcher qualitatively through memo writing. Such young people provided an unclear and often confusing narrative of their experiences and these did not feel integrated into their recovery, but more a coping strategy. In line with this observation, some young people appeared to feel more in control of their difficulties and recovery whilst others had a more outward perspective, often blaming others and the world for their negative experience of psychosis.

Autobiographical Memories

Overall, memories were observed by the researcher and described through memo writing as being largely fragmented and difficult to recall for most young people.

R003 gives an example of this:

"So I think the whole time I was having incoherent thoughts, so when you look back at something which is incoherent, when you're thinking incoherently. It becomes really really disjointed and doesn't make any sense"

He was able to be reflective enough to see that his thinking was incoherent during the psychotic episode, leading to confusion. More detail regarding how memories impacted on sense of self, future thinking and recovery, are tied together in the following sections.

Future Thinking

Thinking ahead was shown to be difficult for most young people interviewed and this, again, supports the current literature base. Some young people could look ahead to the short term, but not beyond that.

R003 reflected that:

“In 6 months time. I think I know where I will be. But 2 years time.. It’s quite hard to conceptualise that”

Others found the prospect of looking ahead in any time frame, challenging:

“I don’t know. It’s one of these things that you couldn’t really imagine. Because it just feels quite far down the line”

“That’s really difficult for me. It’s difficult for me to see time. I don’t even know what time of day it is. I dunno, I have a really odd perception of time”

In contrast, R004 had no difficulties looking positively into the future:

“No. I’ve got ambitions; I don’t have dreams because dreams make it sound like it’s impossible to achieve it. I want to go to uni and do a masters in it and then I want to

establish myself here and then I want to move to LA and then I want to be like a music mogul and I want to release my own music projects as well”

It is worth considering whether young people were unable to look to the future due to a lack of self-identity and therefore clarity regarding aspirations linking with their values, or whether they were simply being realistic with where they felt they were in their recovery. It is also worth considering whether the young people who could look ahead, were less aware of how their experiences had impacted them and therefore unrealistic regarding future achievements.

Quantitative Data

In addition to qualitative interviews, quantitative data was also gathered in order to offer triangulation of the data. Table 3 illustrates the quantitative data collected from young people following grounded theory interviews. These scores are from the QPR, CTQ and AAI. As detailed in previous sections, the higher the score on the QPR, the better the young person perceived their recovery. Higher scores on the CTQ subscales indicate presence of some form of abuse; whether these scores met cut off for being moderate or severe, are detailed in Table 5.

Table 5. Data from quantitative measures.

Young Person	QPR	AAI Classification	Emotional Abuse	physical Abuse	Sexual Abuse	Emotional Neglect	Physical Neglect	Denial
S001	22	Ds	5	5	6	14	13 (severe)	0
E002	17	Ds	18 (severe)	5	5	13	10 (moderate)	0
R003	41	Ds	9	7	5	19 (severe)	5	0
R004	49	F	15 (moderate)	5	5	17 (moderate)	13 (severe)	0
B005	41	Ds	5	5	6	14	13 (severe)	0
L006	37	Ds	6	6	5	7	5	2
R007	32	Ds	9	5	5	8	6	0
D008	45	Ds	5	6	5	10	5	0 (2 scores of 4)

*Ds= Dismissing attachment style; F= Secure attachment style.

Table 5 illustrates that young people varied in how they perceived their own recovery from psychosis. AAI classifications are shown to be mainly dismissing, illustrating potential early adverse experiences and suggesting possible difficulties in relationships with family and friendships. This is something which was salient from grounded theory interviews one of the main categories discussed. Most of the young people interviewed were shown to have a dismissing attachment style, suggesting a tendency to keep their distance from close relationships (41); this likely difficulty in interpersonal connections could mean a barrier to recovery.

Research Questions

In order to answer the initial research question, the interaction between self-identity and autobiographical memory can be analysed in further detail from themes which emerged from grounded theory interviews and triangulation with quantitative measures.

Question one: *“How are autobiographical memories important to young peoples’ recovery from early psychosis?”*

Interviews from the current study support the literature which suggests that autobiographical memories help build a sense of who we are (1); young people encode and recall memories more easily when they reinforce who we are as a person and link with our interests, goals and future aspirations (26, 2). As each interview was carried out, the importance of autobiographical memories became clearer; young people who were able to access memories and describe a more coherent story, were observed by the researcher and described through memo writing as being more reflective and accepting of difficulties compared with those who struggled to engage in a narrative of their journey.

Looking further at the link between early adverse experiences and memory formation on development of the self and future thinking, aids in answering the second research question.

Question two: *“In what way do early adverse experiences and memory formation affect future thinking and establishing an overall sense of self during this recovery process?”*

We know that early adverse experiences are strongly associated with the development of psychosis (9, 17) and the literature suggests that this population have a more fragmented sense of self identity as a result (2). Early adverse experiences can lead to a heightened stress response activation which can disrupt memory encoding, leading to a fragmented sense of self-identity (17). Stress affects hippocampal (i.e. the centre of memory formation) development and potentially the capacity for young people to learn (14). This literature is supported by findings from the current study, where young people described heightened stress (resulting in attempts to ‘fit in’ with others or ‘social isolation’) around the time when things began to change, resulting in the inability to learn and process.

In addition to having mainly incoherent narratives, most young people were shown to have difficulty in looking ahead, implying that memory formation does impact a sense of self and future thinking for most individuals from the current study.

Through the function of memo writing, the researcher was able to notice that four out of the eight young people reflected on recovery with a level of acceptance and understanding regarding what had happened to them. They were able to see the possible part in which they played in its development and felt that they possessed some level of control in recovery from this. For the remaining young people, they spoke about the world having control over their difficulties, suggesting that they themselves were not empowered to make changes regarding

their recovery. Through organisation of the final categories, the concept of locus of control therefore felt useful in understanding the themes important to young peoples' recovery. In particular, how they coped and how self-identity and memory formation impacted on this. The researcher felt that this could be an important concept to consider when working with young people recovery from early psychosis.

Internal and External Locus of Control

The concept of locus of control and its impact on making sense of experiences through formation of memories, emerged from the data following interviews; how this concept influences overall self-identity during recovery was also apparent.

With reference to the research questions discussed, locus of control can help in linking some of the key categories that young people spoke about (i.e. autobiographical memory, self-identity and recovery). Figure 5 illustrates the interaction between autobiographical memories and self-identity for individuals with internal locus of control and how this may impact recovery. Figure 6 illustrates this interaction for individuals with a more external locus of control.

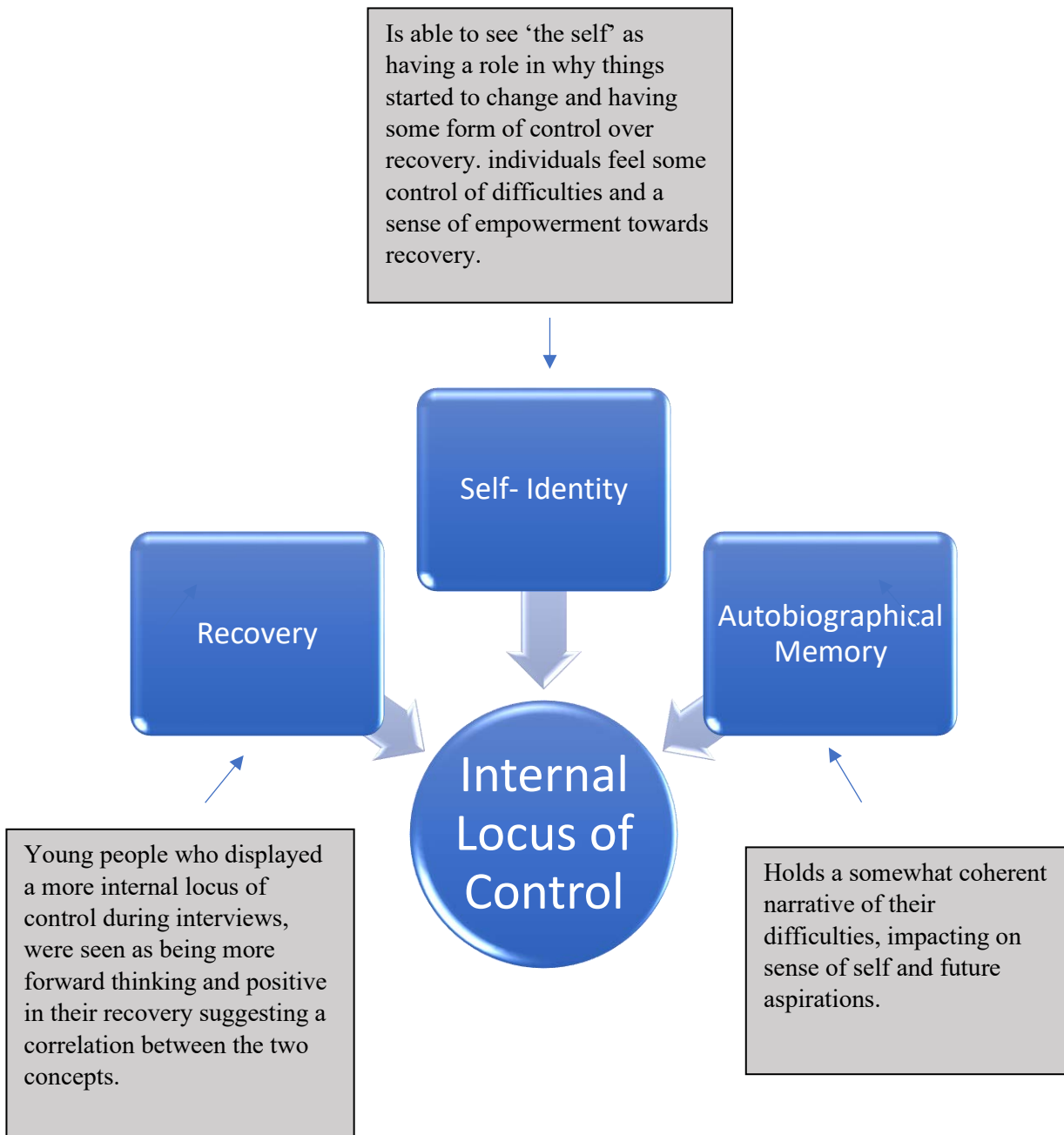


Figure 5. Internal locus of control and the impact on self-identity, autobiographical memory and recovery.

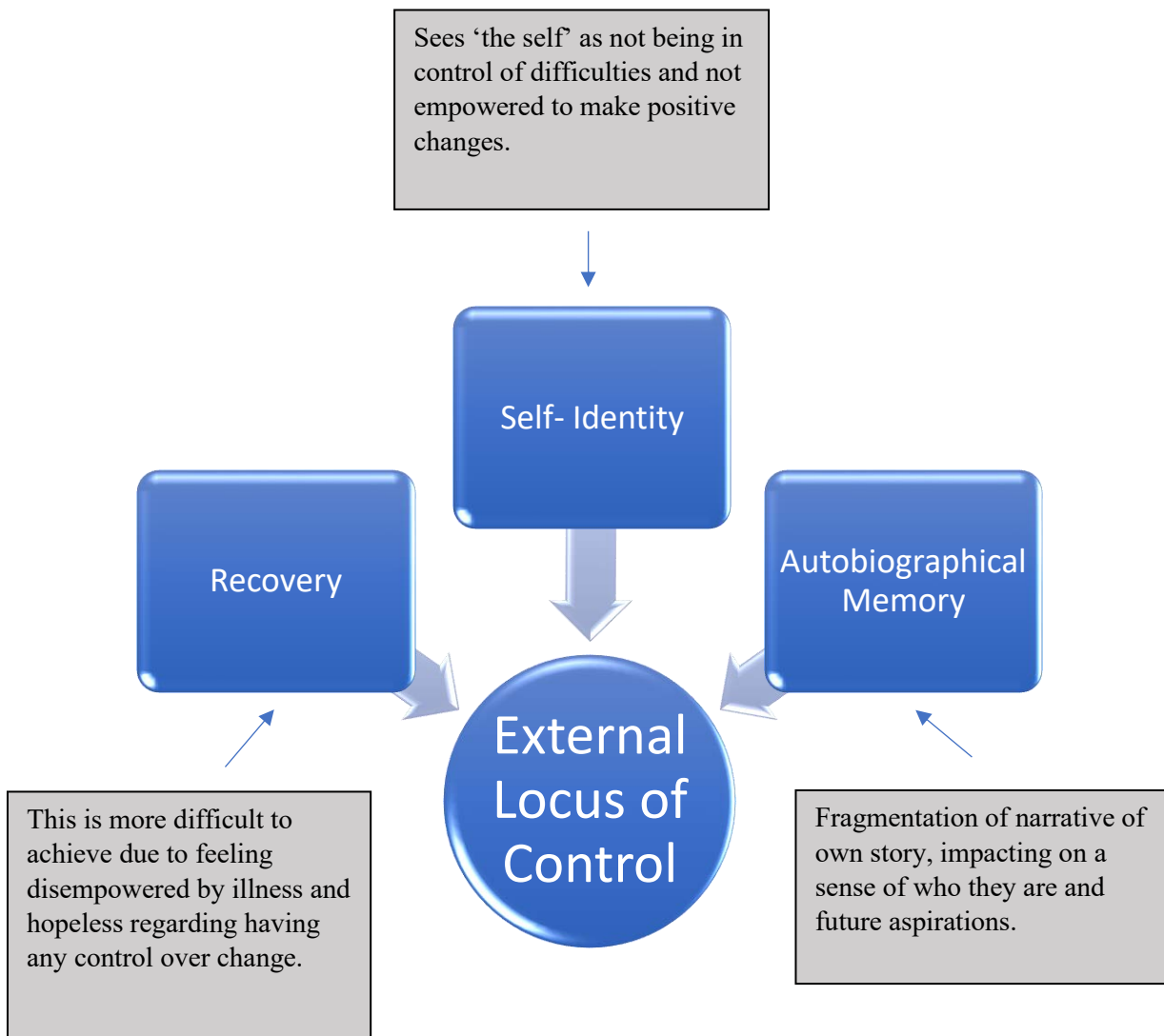


Figure 6. External locus of control and the impact on self-identity, autobiographical memory and recovery.

The concepts detailed are discussed in the following section with reference to the current study’s research questions and in line with theory rooted in the literature base.

Discussion

The aim of the current study was to explore young peoples' experiences of early psychosis; in particular, the role that autobiographical memory plays in the recovery process. The importance of early adverse experiences and attachment style on the development of self-identity was also a key question in addition to their influence on future thinking in overall recovery.

Results from a qualitative design, incorporating quantitative measures, revealed that young people relayed their experiences under five key areas of importance: interpersonal connections, self-identity, choice and freedom, recovery journey and autobiographical memory, with sub categories adding further depth to these experiences. Linking back to the original research questions, Young people who were able to tell their story more coherently and access autobiographical memory more appropriately, were shown to be more on a road to recovery than others who were not able to do this. Those who were able to be more accepting of difficulties and reflect on these were also shown to be more content with their recovery journey. Therefore, autobiographical memory is shown to be of importance.

Adverse early experience was not shown to impact on recovery or future thinking from the current study; having a sense of self was, however shown to impact on future thinking and overall acceptance difficulties

When organising the final categories, young peoples' views appeared to fall into two categories; some young people tended to blame others or external sources for their difficulties whilst others appeared to be more accepting of their difficulties and in their role in recovery. Through organisation of the final categories and with these observations in mind, the concept of locus of control was felt a helpful lens in making sense of these key areas and to facilitate answering the research questions.

Locus of Control in Recovery

Locus of control is a construct generated through social learning theory (42). It relates to how someone perceives the world and how strongly they believe the things that happen to them are within their own control (43). Social theory tells us that the expected outcome of a behaviour impacts on the level of motivation to engage in that behaviour. This is a concept which the researcher felt was consistent with the current study, where some young people felt empowered to change and others were observed as having more outward blame towards family, friends and the world. Millan and colleagues (44) suggested that early trauma can lead to an external locus of control; this is something which was not supported by the current study's findings, where patterns in early trauma and later psychosis were not observed.

From qualitative interviews, those who were shown to be more reflective in their account of experiences and who were felt to have a more internal locus of control towards recovery, were shown to have higher overall scores on the QPR as a group. Young people who were observed by the researcher as having a more external locus of control, are shown to have slightly poorer overall perceived recovery.

Studies by Harrow and colleagues (43), Tooth and colleagues (45) and Hoffman and Kupper (46) all drew similar conclusions, that possessing a more internal locus of control results in an increased acceptance over difficulties and more effort towards recovery; acceptance and internal locus of control has been found to be associated with better recovery (43). This is something which was shown to be present for some of the young people in the current study and which emerged through memo writing and general reflection by the researcher. Such individuals were able to reflect on the possible part they played in the development of their illness and had made some sense of their overall experience. This is tentatively supported by quantitative findings from the current study, which suggested that more reflective and

accepting young people, tended to have a higher score on recovery measures. This reflection, in turn, is in line with previous work regarding the importance of reflective functioning, suggesting that if young people can have an integrative approach when looking at their experiences, this proposes that they are more likely to be able to create a coherent narrative of events and in turn, rebuild self-identity more easily, aiding recovery (1). The current findings also give some support to literature regarding post traumatic growth, an area increasing in interest, which suggests that how we view experiences, can impact positively or negatively on the self (47); one young person was able to see his experiences as changing him for the better, which increased his ability to look forward and imagine his future in constructively.

Locus of control has been found to have an impact on the development of affective mood states (e.g. depression and anxiety) and reduces individuals' ability to cope with such difficulties (46). The literature suggests that possessing a more external locus of control, can lead to more withdrawal from society, a sense of hopelessness about the future and negative mood states (45, 46). This is something which is touched on in the findings from the current study, the presentation of low mood and social anxiety appeared common; this can help our understanding of the development of negative affect and how overall recovery for young people following early psychosis is impacted.

One theme which the researcher felt came from interviews with young people, the description of feeling 'trapped' or having 'no choice' following their experience of psychosis and during the recovery phase. This was found to be important to recovery from psychosis and supports previous literature in the area.

Lack of Choice and Self-Identity

Self-perceptions of failure are said to be at the heart of thoughts regarding entrapment and defeat and such thoughts can cause a barrier in looking to the future (28). Statements such as these are supported by work in the field by Zoellner and Maercher (48) who highlighted that if young people feel that they have a sense of control during their crisis or in the aftermath of this, recovery can be significantly and positively impacted upon. This suggests that encouraging personal agency during this time is vital (48) and should be an important part of interventions. Such findings link with research which has highlighted that perceived defeat or entrapment from psychosis, can increase suicidality (49). The Schematic Appraisals Model of Suicide (SAMS; 50) tells us that young people who perceive themselves as hopeless in the eyes of psychosis and who feel they have no control over this, is a key mechanism underlying the risk of attempting suicide (28). This supports findings from the current study which emphasised the importance of having a positive sense of self separate to the psychotic experience. The idea that young people perceive themselves as hopeless in the eyes of psychosis, also suggests that being aware of individual contributions, which young people offer to their own lives and to others', is important in combatting stigma and shame. As discussed in previous sections, stigma and shame are often experienced by individuals living with complex mental health difficulties such as early psychosis and have been shown to influence recovery. Throughout interviews, the researcher was made aware of the presence of stigma and shame and reflected on how this impacted on the themes drawn through memo writing.

Work in the area of positive contributions, stigma and shame, has been investigated qualitatively in recent work by Allman and colleagues (51) and is in line with themes drawn from the current study's grounded theory interviews.

The Importance of Stigma and Shame on Positive Contributions

In this study by Allman et al (51), authors were interested in how young people and their relatives perceived psychosis and were interviewed regarding positive contributions which had come from these experiences (51). Similarly, to the present study, authors found that most young people reported that their experience of psychosis had changed how they viewed themselves (i.e. their self-identity) mostly in a negative way. Another significant theme which emerged from this study was 'acting normal', which again links with the current study's findings where young people were observed as 'trying to fit in' when they began to feel unwell and when things began to change for them. Allman and colleagues (51) found that for most of the sample interviewed, there was a significant interaction between shame and stigma and how young people identified with themselves. This was found to overshadow their contribution and empowerment towards recovery and authors reported that this also affected the way relatives supported the young people.

Overall, these findings highlight once more, the importance of interpersonal support in the form of family and friendships and suggest interventions should focus positively on contributions young people can bring (48, 51),

Such conclusions are consistent with work by Markowitz and colleagues (52), who found that stigmatised self-appraisals in young people, following early psychosis may lead to poorer long-term outcomes and recovery. Other authors have described this in their work, reporting that the experience of psychosis, plus self-stigmatised appraisals, can lead to the overshadowing of any positive contributions and the self and psychosis becoming enmeshed as one (53, 54). Moreover, any helpful changes made by the young person can often become overlooked and seen as something someone else has done, such as medication or mental

health support (51, 55). This is likely to impact on the young person feeling empowered to make changes towards recovery.

The significance of stigma and shame has been also been reported in previous research by Holzinger and colleagues (56) and Link and colleagues (57) who noted that individuals with severe mental health difficulties, such as schizophrenia, will often conceal their diagnosis from employers and family members. Authors found that higher levels of perceived self-stigma correlated with higher levels of maladaptive coping strategies, namely withdrawal socially and concealing their illness (58); they reported that this was due to fear of social rejection and judgement (56). Findings suggest that this may be a barrier to interpersonal connections and employment, which previous research and the current study found to be important to recovery.

Research such as this and findings from the current study emphasise the importance of empowering young people to have a voice throughout their recovery. The lack of choice and freedom has been shown to impact on self-identity, creating a narrative of their journey and encouraging social withdrawal ultimately affecting interpersonal connections. It is key that young people feel empowered, developing an internal locus of control towards their recovery.

Limitations and Recommendations for Future Work

We know the importance of possessing a coherent narrative of one's life and how this links with having a sense of who we are and what our desires are for the future. From the current study, it is worth considering that three of the young people were regular attendees in service research and are likely to have had told their story and reflected on this on several occasions.

This suggests that the analysis undertaken regarding autobiographical memory and its

importance in self-identity and recovery, should be looked at with caution due to possible 'practice' effects.

The present study utilised proximate saturation throughout the recruitment phase rather than the optimal theoretical sampling used in pure grounded theory research (33). It was beyond the scope of the current study to alter recruitment of young people based on specific characteristics as the interviews progressed, which would have added to the strength of the findings. This is therefore described as a preliminary grounded theory model, created from a modest sample size and requiring further investigation applying theoretical sampling within this population.

The present study looked at a number of variables which could impact on self-identity, future thinking and recovery from early psychosis. It may be of interest to look at these individually and in more depth through grounded theory interviews and alternative measures. The researcher used locus of control as a lens in understanding how young people recover from early psychosis; previous research has been conducted in this area but there is an overall paucity within the adolescent literature which may be helpful to build on.

Support is provided to previous literature, focusing on the importance of interpersonal connections to recovery in this population. There have been small but promising trials investigating the effectiveness of peer support groups (59) and body oriented psychosocial therapy (60) which would be an area warranting further investigation.

Conclusions

This study aimed to add to the literature regarding what is important to young people in their recovery of early psychosis. Key questions, referring to the concepts of autobiographical memory, early adverse experiences and future thinking, were focused on. Themes such as ‘interpersonal connections’ and ‘choice and freedom’ were shown to be salient to young peoples’ recovery. In addition to this, giving young people as much choice as possible was also something which emerged from grounded theory interviews.

This study adds to previous research suggesting that helping young people build a sense of identity following psychosis is key. Locus of control and its impact on recovery is also something which emerged from the current study and adds to previous research in the area of psychosis and recovery; this is something worth considering and could be tackled in therapeutic work during the recovery phase.

The literature tells us that early intervention is crucial for successful recovery from early psychosis (Boonstra et al, 2012); it is therefore crucial that research continues in this emerging area and young peoples’ experiences and voiced and heard following early psychosis within an adolescent population.

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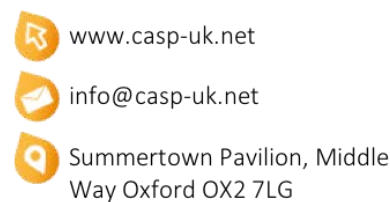
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List of Appendices




Appendix	
A	CASP Quality Checklist.
B	NICE Quality Checklist.
C	Quality Rating Weights.
D	Participant Consent Form.
E	Participant Information Sheet.
F	Codebook Example.
G	Study Protocol (including outcome measures).
H	Ethic Approval.
I	Recruitment Poster.
J	Revised Interview Schedule.
K	Example of 'line by line' Coding.
L	Personal Reflections of Grounded Theory Experience.

Appendix A: CASP Quality Checklist



CASP Checklist: 11 questions to help you make sense of a [Case Control Study](#)

How to use this appraisal tool: Three broad issues need to be considered when appraising a case control study:

- Will  Are the results of the study valid? (Section A)
-  What are the results? (Section B)
-  the results help locally? (Section C)

The 11 questions on the following pages are designed to help you think about these issues systematically. The first three questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Case Control Study) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

For full checklist see: <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Case-Control-Study-Checklist-2018.pdf>

Appendix B: NICE Quality Checklist

Methods for the Development of NICE public health guidance (third edition)

Process and methods

Published: 26 September 2012

nice.org.uk/process/pmg4

For full checklist see: <file:///C:/Users/user/Desktop/NIC.pdf>

Appendix C: Quality Rating Weights

	2	1	0
Design	Design of the study is appropriate and an explanation for its choice is given.	Design appears to be appropriate but no explanation for its choice.	Design does not appear to be appropriate and no explanation for choice given.
Recruitment	The recruitment of participants clearly defined and representative of the population.	Some detail of recruitment but not clearly defined.	Described in limited detail and appears to be biased.
Participants	Participant characteristics are described in detail.	Some participant details given, but not fully.	Participants are not described.
Blinding	Double blind: both participants and researchers blind to randomization.	Single blind: only participants were blind to randomization.	Not blinded or not clear.
Intervention	Was this clearly described so as to be replicated.	Described, but not clearly enough to be fully replicated.	Not clear what the intervention was.
Attrition	Was loss of participants throughout the study clearly described: numbers and reasons why.	Attrition mentioned but not clear regarding numbers or reasons.	This is not detailed.
Validity of Outcome Measures	Measures are detailed with references, reliability and validity scores.	Measures are detailed, but no validity/reliability scores detailed.	No details of measures. No consideration of their reliability.
Follow-up	Was follow-up >3 months.	Was follow-up <3 months.	There was no follow-up.
Analysis	The analysis appropriate to test the hypotheses. Was this detailed sufficiently (p values, effect sizes).	The analysis appeared appropriate but was not detailed in full (missing p values or effect sizes).	Statistical details not given.
Power	Power calculation was detailed, with optimum sample size needed.	This was mentioned but not in detail.	No mention of power, so unclear as to whether sample size would be large enough to find an effect.
Internal Validity	The study considered and minimised any sources of bias. Confident that the effects found in the results are due to the intervention itself.	No significant confounders but some study flaws which could account for bias.	Significant flaws in the study design. Cannot be sure that findings are due to the intervention described.
External Validity	Sufficient details given about the study to determine if the findings are generalisable to the population.	Not enough details given to be sure of this.	Study flaws are significant enough to determine that findings cannot be generalisable.

Appendix D - Study Consent Form



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CONSENT FORM

Exploring self-identity in the recovery of early psychosis within an adolescent population

Participant ID:

Linsay Dunnett (Chief Investigator)

Email:

Dr Helen Griffiths (NHS Supervisor)

Email:

Tel: 0131 537 5948

Professor Matthias Schwannauer (Academic Supervisor)

Email:

Tel: 0131 651 3954

Please initial box

1. I confirm that I have read and understood the information sheet (Version 2, 24/1/18) for the study and have had the opportunity to consider the information and ask any additional questions.

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

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by the researcher, individuals from the regulatory authorities and from the Sponsor (NHS Lothian and University of Edinburgh). I give permission for those individuals to have access to my records.

4. I agree that audio recordings may be made of the interview sections of the study to allow for responses to be scored and analysed. I understand that care will be taken with regards to recording (adhering to NHS Lothian audio and recording policy). Recordings will be stored on a password protected database, on a password protected computer within NHS Lothian premises.

5. I give my consent for anonymised quotes from audio recordings to be included in the written report for this study for the purposes of submission to the University of Edinburgh, Doctorate in Clinical Psychology training course and for anonymised quotes to be included in any publications or conference presentations.

6. I agree to my General Practitioner being informed of my participation in the study.

7. I understand that all the information I provide in the study will be anonymous and confidential. I understand however that if I chose to share any information about possible harm to myself, or others, that information will be passed on to a member of my current care team. This will most likely be my keyworker/ care-coordinator.

8. I agree to give permission for non-identifiable data to be used in future research.

9. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Original (x1) to be retained in site file. Copy (x1) to be included I patient notes. Copy (x1) to be retained by the participant.

Appendix E – Participant Information Sheet



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Participant Information Sheet:

“Self-Identity and recovery following early psychosis”

My name is Linsay Dunnett, and I’m a Trainee Clinical Psychologist at the University of Edinburgh. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish and contact us if there is anything that is not clear or if you would like more information.

Why are we doing this study?

We want to do this study to help us understand young people’s experiences of recovery from an episode of psychosis. We want to know more about how young people think about themselves and how this affects the process of recovery. We are interested in experiences which happened early on in your life and how these may have impacted on how you see yourself today.

Why have I been invited to take part?

You have been asked to take part because you have experienced early psychosis and are currently in contact with NHS Lothian Mental Health Services.

Do I have to take part?

No, it is completely up to you whether you decide to take part. If you do decide to take part in the study, you will be asked to sign a consent form (which confirms that you want to take part). Even if you do this, you will still be free to withdraw at any time and without giving a reason for this. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive now or in the future.

How do I take part?

There are two ways in which to express your interest in taking part in the study.

The **first way** is to contact the researcher directly through the email address given on the posters advertising the study, which is displayed in your mental health clinic and on this information sheet. The researcher will then contact you via telephone to discuss the study in more detail. During this telephone call, the researcher will give you more information about the study, answer any questions you may have, and will ask you some questions to find out whether it will be appropriate for you to take part in the study. The researcher will also ask you whether it is ok for us to contact your keyworker/ care-coordinator to find out if they think it would be appropriate for you to take part in the study. The researcher will then send you a copy of this form.

You can decide whether you would like the researcher to get back in touch with you to remind you about the study after receiving this form. If you would like to be reminded about the study, you will always have at least 24 hours to look over this form before the researcher contacts you again to find out if you are still interested in taking part.

The **second way** in which you can take part is if a member of your mental health care team approaches you about the current study and ask you if you would be interested in taking part. This team member will give you this patient information sheet to look over. Again, you will always have at least 24 hours to look over it before the researcher contacts you to find out if you are still interested in taking part.

If it is not appropriate for you to take part in this study, the researcher will explain why.

What will happen if I decide to take part?

You will have at least 24 hours to look over this information sheet. You will then be contacted by the researcher to discuss any questions you have about taking part. If you decide to take part, you will be asked to read and sign a consent form before we meet again to begin the study.

The study will involve two interviews. The first interview will be approximately one hour in length where you will have the opportunity to talk about your experience of early psychosis and what has felt important to you in your recovery from this.

The second interview will be take more of a structure and will aim to look at experiences from early on in your life and important relationships you had growing up. This will also be approximately one hour in length and breaks can be taken whenever you need one. During this second part, we will ask you to complete two short measures. The first measure will ask you to answer more questions about your experiences of childhood in more detail and the second measure will ask you to answer questions about your recovery from early psychosis in more detail.

Some people might prefer to bring someone that they know along with them while they participate in the study. If you would like to do this, you can discuss with your keyworker/ care coordinator if they would be available to accompany you.

The interviews will be recorded using an audio device. This should not be off putting to the interviews. See the section below called 'How will my data be managed?' which goes through this in more detail.

What are the possible benefits of taking part?

It is unlikely that taking part will benefit you directly. You can, however, ask for information gathered during the study to be shared with your mental health care team to help support the care that you receive from them.

Your participation and feedback will help us understand more about young peoples' experiences of their recovery from early psychosis. It will also help us to better understand how young people think about themselves following these experiences. Knowing more about this can help lead to better mental health care being developed and can also help the treatment for people experiencing similar difficulties in the future.

What are the possible disadvantages and risks of taking part?

It is possible that the researcher might ask you about things that you find upsetting (e.g. experiences during childhood; relationships with parents) which could result in short term distress. There is no evidence, however, to suggest that asking people about difficult events during childhood, results in any serious or long-lasting harm. The researcher will check in with you about how you are feeling throughout the interviews and will make sure there is time available to discuss how you are feeling at the end.

It is also possible that you may find the interview and questionnaires tiring. You can have as many short breaks as you need and are free to stop the interview at any point.

Will my taking part in the study be kept private?

Once we have your permission, we will inform your GP that you are taking part in the study. More detailed information collected during the study will **NOT** be fed back unless you ask us to do so. Only the researcher and clinical supervisors will have access to private information, collected through the interviews and questionnaires for the duration of the project; we are all employed by NHS Lothian and follow to appropriate policies and guidelines.

The only reason that the researcher may need to share more private and detailed information would be if you were to talk about anything that made the researcher concerned about your safety or the safety of someone else. This is in line with routine confidentiality guidelines. If this was to happen, the researcher would follow standard NHS procedures and share this information with your keyworker/ care-coordinator or a member of your mental health team to keep you and others safe. At this point, the researcher would discuss why information must be shared and who this will be shared with. If you have any questions about this, please ask the researcher.

What will happen to my data?

Your name, contact details, consent form and completed questionnaires, will be stored securely by the researcher in a locked filing cabinet on NHS Lothian premises. It will be destroyed once the study is finished. NHS Lothian audio policies will be followed. Audio devices will be held on NHS Lothian premises, only transported when necessary and returned as soon as possible. During transportation, recorders will be kept as secure as possible with every care taken by the researcher. Interviews will be transcribed (typed-up) and stored as soon as possible within a password protected database on a password protected NHS Lothian computer. Participants' contact details (names, locations etc) will be pseudonymised (given an artificial identifier) and removed from audio devices as soon as possible.

You can ask for your data to be removed from the study until the results are analysed. After this time, it will not be possible to remove your data from the study. If consent is withdrawn before the point that the results are analysed, no data will be kept for further use.

What will happen to the results of the study?

This study forms part of the researcher's Doctorate in Clinical Psychology training and results will be written up as part of a thesis. Anonymised data, including anonymised quotes from audio recordings of interviews may be written up for publication or presented at a conference. You would not be able to be identified from this.

A summary of the findings from the study will be put together for participants if they would like this.

Who is doing this study?

As I mentioned above, my name is Lindsay Dunnett and I am a Trainee Clinical Psychologist based in NHS Lothian and a student with the University of Edinburgh. This study is part of my training for the Doctorate in Clinical Psychology Programme and I work within mental health services in NHS Lothian.

What if there is a problem?

In the unlikely event that something goes wrong and you are harmed during the research (due to someone's mistake) then you may have grounds for legal action against NHS Lothian. Please note that these may not be paid for you. The normal NHS complaints mechanisms will still be available to you (see below).

Who is organising the research?

The research has been designed and is being carried out by a Trainee Clinical Psychologist undertaking a Doctorate in Clinical Psychology at the University of Edinburgh. The study is being supervised by Professor Matthias Schwannauer (Head of Clinical and Health Psychology, University of Edinburgh) and Dr Helen Griffiths (Consultant Clinical Psychologist within the Early Psychosis Support Service, Child and Adolescent Mental Health Services, NHS Lothian). The study is co-sponsored by the University of Edinburgh and NHS Lothian.

Who has reviewed the research?

The East of Scotland Research Ethics Committee (REC), which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available by NHS Lothian Mental Health board. It is their role to make sure that the research is being carried out appropriately.

Who can I contact if I have a complaint?

You are free to discuss any concerns about the study with the researcher (contact details at the end of this leaflet) who will do her best to address your concerns. If you remain unhappy and wish to complain formally, you can do this by contacting the team below, who are not part of the current research team:

NHS Lothian Complaints Team

2nd Floor, Waverley Gate, 2-4 Waterloo Place

Edinburgh

EH1 3EG

Tel: 0131 536 3370

Email: feedback@nhslothian.scot.nhs.uk

Who can I contact about further information regarding this study?

If you would like any further information about the study or think you might like to take part, please contact the researcher:

Linsay Dunnett, Trainee Clinical Psychologist, NHS Lothian.

You can also contact someone who is part of the university but who is not involved in this project:

Dr Angus MacBeth

Lecturer in Clinical Psychology

Department of Clinical Health

School of Health in Social Science

The University of Edinburgh

Doorway 6

Teviot Place

EH8 9AG

If you would prefer, you can ask a member of your care team to contact the researcher on your behalf.

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

Appendix F – Codebook Example

Nodes\\Themes

Name	Description	Sources	References
Acceptance of Difficulties	Being aware of what has happened to them, what they find difficult and need support with? Having insight? This ties with increased awareness of self and able to reflect on experience. Having a clear narrative. Can these yp look ahead more easily?	6	21
Anger	Mainly from D008 but also S001. Links with blaming others.	1	5
Behaviour Changes	Risky behaviours? Acting weird? Doing things differently that others mainly noticed before the yp. About half the yp were doing risky things - mainly drugs just before a breakdown. Paranoia was a big part of things changing for most yp.	8	120
Behaviours that Help	Some of the things that yp found helpful to be doing when they were unwell or recovering. Some were doing this more than others - E002, R004. L006 kept doing drugs after seizure, others locked themselves away from others (R007, D008, R003) due to anxiety/paranoia.	7	63
Blaming other for Difficulties	Internal v external locus of control? R007, L006, R004 were able to see their behaviours as influencing their difficulties. D008, S001, E002 appeared to blame others. 'things just happen to us'; 'I blamed my parents', 'when the eczema goes, I'll be fine'.	1	8
Bullying	Links with fall outs with friends and interpersonal difficulties. This was talked about mostly by D008. Wasn't common for others.	1	8
Changes to self	The self, changing in personality, usually becoming more withdrawn when things started to change and acting odd. Social awkwardness was common for yp and trying to fit in. Some yp felt they were a different person now to before.	8	68
Doing Things Differently	What are yp doing differently now to before? Most yp are different with other people - socially anxious, don't do things with other people. Used to be confident and popular but not now (R007,	8	41

Name	Description	Sources	References
	R003. L006). Other are more similar to how they were before (E002, S001, D008). D008 and B005 were more unaware of things.. felt they were still good with other people and there were no real mental health difficulties.		
Fall outs with Friends	Links with interpersonal changes/difficulties. And not fitting in.	1	2
Family System	Are these supportive or not? Who is in them. Most had difficulties with family members not understanding them or feeling heard by them. R007, L006, D008 did have a parent to go to. Do AAI classifications link with what story they were telling?	8	66
Feeling confused and 'weird'	This was often the feeling talked about when things started to change. Not feeling themselves and often still not having a sense of this now.	2	10
Feeling terrified	This was a common feeling when things started to change. Directly talked about by D008 and links with police involvement.	1	5
Having a break down	A couple of yp talked about this - R007 and L006. Quite sudden changes. Others did not talk about it being so sudden. It was others noticing more gradual changes.	1	2
Having a Sense of Purpose	This appeared to help yp. R003 was the only one working? E002 was at uni. Others talked about not having one.	3	21
Hospital Admission	Positive v negative experiences, loss of choice? Social aspects and interpersonal links were sometimes positives. Not sure anyone apart from R004 saw hospital as positive in any way.	8	60
Impact of experiences	This was mainly significant and changed each yp. R004 saw his experience as a positive one and changed him for the better. It made him interesting. Most others wished it hadn't happened and are now struggling,	2	6
Increased Stress	A few yp talked about stress of school bringing on changes (R007, D008, R003). R007 talked about separation of parents. All had some sense of stress leading to changes.	2	11

Name	Description	Sources	References
Interpersonal Changes	Not trusting others, difficulties with friends and social groups in particular were the interpersonal changing talked about by more yp. There was also some bullying and trying to fit in but being isolated from groups. Yp often reported that they now find it difficult to socialise and fit in.	8	76
Lack of Awareness	Do they have insight into what has happened to them? B005 and D008 stood out as not really seeing any problems and not reflecting on a true reality. Check these QPR scores (are these high because they think they're fine?) and AAI classification? (would expect dismissing?).	8	66
Loss of Choice and Freedom	Whilst being in hospital, but just when things began to change in general. "things happen to us and you just get on with it" - E002. R007 absolutely agrees with having no choice or control.	7	55
Medication	Has this helped? How do they feel about this. Most dont want to be on anything. Links with recovery.	4	12
Memory Difficulties	Not being able to access memories. Use my own reflections and AAI for this also. R003 did this well. B005 and D008 particularly bad. Also, S001 and L006 were noticeable in session.	7	77
Mood Changes	Anxiety, depression when things began to change? Was this present before? Some yp described being quiet before anything happened (E002) but others described having anxiety and depression that was not there before and generally felt a different person (R007, L006).	8	62
Others and Trust	Trying to fit in. Makes it difficult to make the necessary interpersonal connections that yp seek. Links with paranoia and family systems. Also stop yp looking ahead?	6	19
Others Noticing Changes	The yp often did not notice things changing - it was the others around them. This links with behaviour changes.	6	13
Paranoia	Most yp became paranoid and this linked with social anxiety and difficulties with interpersonal relationships. Thinking others are out to get them.	6	29
Physical difficulties impact on mental health	This was prominent for D008. He didn't think mental health was an issue.	1	9

Name	Description	Sources	References
Police Involvement	This was mainly for D008. Didn't appear to accept he had done wrong. 'I was frustrated with the eczema'.	1	7
Professional Support	When was this sought and what did it look like. Feelings towards it. Some yp recalled their admission to hospital or the crisis point where they spoke to drs and were asked lots of qus. Recalled not knowing what was going on etc. Others making decisions.	7	62
Recovery	This is one of my research questions and one of the quantitative measures. Yp conceptualised recovery differently. Some were reflective and others not so much - D008 did not see himself as mentally ill for example. R007, reflective that she felt a different person and drugs and stress impacted on things changing for her.	8	59
Reflecting	Making sense of the experience helps recovery? Reflecting on school, feelings, significant events, psychosis. Did some yp do this better than others? B006 and D008 seemed as if they weren't reflecting on their experience accurately. Everything was 'fine'.	7	135
Regret	L006 and R007 had a strong sense of regretting drug taking. D008 appeared to have some regret in how he acted towards parents. R004 regretted trying to fit in with the wrong people. But this made him a better person now.	1	2
Risky behaviour	Links with drug taking. L006 and R007. D008 behaving very strangely and violently towards mum before and during admission.	2	14
School and University	Positive or negative experience? Bullying? (D008). All had difficulties with friendships at school - either all through or only when things started to change (L006, R007).	7	62
Self Awareness and Knowing the Self Better	Is there insight? Has yp's experiences made them more reflective. B005 and D008 found it difficult to integrate their experiences. L006 seemed fully immersed by his experience.	7	78
Self Harm and Self Blaming	Most yp had/have self critical thoughts. R007 said she had a completely different personality. L006	4	21

Name	Description	Sources	References
	didn't appear to like himself. D008 had that message from others (eg. dad).		
Self Identity	Some yp felt that their experience of psychosis had changed them quite a lot and others did not. Some felt more aware now of themselves and two in particular did not seem more aware (B006 and D008). Most looked on the experience as negative. One looked at it very positively - R004. One didn't believe they had psychosis - D008 and it was all physical.	7	47
Sleep	This is something which seemed to go wrong when things started to change. We know that a lack of sleep can bring on psychosis (Helen's refs from aps). All had difficulties with sleep.	3	10
Social Support Leading to Recovery	In the interviews, there was a lot of talk around social connections helping and withdrawing from these when things changed and psychosis took hold. Yp talked about wanting more social connection in some form although this felt difficult.	6	24
Thinking Ahead	Most yp found this quite difficulty to do but some found it easier - R004 was able to do this and B005 but in a less aware way. Does difficulty thinking ahead link with lower scores on the QPR? What about different AAI classifications? or moderate scores on CTQ subscales?	8	25
Transitions	Many yp had difficulties transitioning to high school. This links with interpersonal difficulties. D008 talked about a transition to scotland.. new friend group. Family and friend difficulties to fit in. The move didn't help! R007 and L006 appeared to be popular and alcohol/drugs led to changes. R004 struggled to fit in.	1	5
Trying to Fit in	Not trusting, difficulties with friends and social groups in particular coming out. L006 and D008 were trying to fit in. Also R007. Drugs etc.	6	19
Understanding of Difficulties	Links with self awareness and acceptance	1	1
Unhelpful Behaviours	Using drugs, withdrawing from people, becoming aggressive, not engaging with services, locking self away, not using family system - all things which did not help mood and recovery but all were doing some of these. Some more aware than others.	3	9

Name	Description	Sources	References
Use of Drugs and Alcohol	This was sometimes something which was done before and still used (L006) to cope. yp talked about drug induced psychosis (L006 and R007, B005?). L006 still uses to cope. Often using this to fit in before psychosis.	5	44
When Things Started to Change	What was going on when things began to change - when psychosis began? How did things change and how did yp feel about this? Most yp talked about others noticing changes before they did. They reflected on socially withdrawing or trying to fit in too much (taking drugs, going out a lot).	8	57
Withdrawing Socially and things Getting Worse	This is consistent throughout interviews. Psychosis led to difficulties maintaining friendships, due to social anxiety and paranoia often being present. There wasn't one person who described no difficulties with friendships. B005 was probably less bothered about this and D008 was inconsistent.	8	93

Appendix G – Study Protocol



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Study Protocol: Self-identity and recovery following an episode of psychosis within an adolescent population: A mixed method approach.

Protocol Author: Linsay Dunnett, Trainee Clinical Psychologist

List of Abbreviations

AAI	Adult Attachment Interview
QPR	Questionnaire about the Process of Recovery
EPSS	Early Psychosis Support Service
CTQ	The Childhood Trauma Questionnaire
NHS	National Health Service
REC	Research Ethics Committee
TAU	Treatment as Usual

Background

Adolescence is a critical time when individuals begin to develop a more concrete sense of self and greater autonomy in the world (Braehler & Schwannauer, 2012). Experiencing

psychosis during this period can lead to such developments becoming disrupted, which can lead to an increase in negative symptoms for some people (Gumley, O'Grady, Power & Schwannauer, 2004). Young people responding to early psychosis have been shown to go through similar stages as to individuals who are grieving a loss; some young people will adopt a 'sealing over' approach to recovery with others being more integrative in their approach and this can determine which path recovery will take (Braehler & Schwannauer, 2012; Andresen, Oades & Caputi, 2003).

There is an accumulation of literature suggesting links between adverse early experiences and the development of psychosis (Varese, 2012), with evidence suggesting that prolonged exposure to such adverse events increases the likelihood of the development of psychosis during adolescence (Schenkel, Spaulding, DiLillo & Silverstein, 2005). Early adverse events refer to a range of negative life experiences including physical, sexual and emotional abuse as well as physical and emotional neglect (Larkin & Reid, 2008). In addition to this, there is an accumulation of literature suggesting that attachment style is key when studying recovery from adolescent onset psychosis.

Young people who develop psychosis have been shown to have mainly disorganised and avoidant attachment styles (Gumley & Schwannauer, 2006). Possessing such attachment styles has been shown to increase the likelihood of a 'sealing over' approach to take place when recovering from the experiences of psychosis (Tait et al, 2004). Adopting this approach can result in reflective function being generally poorer for this population and recovery less successful as result (Andresen et al, 2003; Spaniol, Wierowski, Gagne & Anthony, 2002). Recent systematic reviews in the area (Gumley, Taylor, Schwannauer & Macbeth, 2014; Korver-Nieberg, Berry, Meijer, & Haan, 2014) have agreed that studying attachment style is relevant to improve our understanding of the development of psychosis (Russo et al, 2017) and to facilitate the most helpful interventions to aid recovery and promote quality of life for this population. For individuals who have experienced early adverse events, which has in turn increased the likelihood of such young people developing disorganised or avoidant attachment styles, the formation of memories in this population becomes an interesting concept to consider.

During 'normal' development, encoding of autobiographical memories happens more so during the years of adolescence compared with other developmental time periods (Conway, 2007); this is said to be due to adolescence being a crucial period for developing a sense of self. Control groups can recall more detailed memories around this time compared with a clinical group of young people who have experienced early psychosis (Holm, Pillemer, Bliksted & Thomsen, 2017). In comparison, this group are shown to recall memories in less detail and at a younger age, suggesting impairment in late adolescence (i.e. the final part of identity formation and formulating a sense of self; Holm et al, 2017). The literature base regarding how this impacts on recovery is currently in its infancy.

Research suggests that consciously recollected memories link with past and future goals; such goals, in turn, link with a sense of self (Raffard, D'Argembeau, Lardi, Bayard & Boulenger, 2009; Davidson, & Strauss, 1992) as we are more likely to recall memories more easily when they support goals and aspirations which are important to us (Conway, 2007).

Rationale for Current Study

Adopting a mixed method design, relevant quantitative measures (tapping into trauma, attachment and recovery) in addition to a qualitative grounded theory approach will be used to answer key research questions.; mainly, the current study is interested in young peoples' recovery from first episode psychosis and identity development, exploring how the formation of autobiographical memories are affected and may influence recovery. Recent research has touched on the idea that there is a general disengagement with the future during early psychosis (Goodby & MacLeod, 2016) and further research would be beneficial in how this links with a disruption in the development of self-identity. The concepts of and the interaction between autobiographical memories, self-development and attachment would benefit from additional exploration as psychosis continues to be viewed as a disrupting life event which interacts negatively with these processes.

Due to the relatively scarce literature around the experiences of psychosis within an adolescent population, this project will be exploratory in nature, building hypotheses for future, larger studies. No previous work has been conducted to date within this particular area and the current study therefore aims to add to the literature base.

Study Aims

The current study will aim to expand our understanding of the factors which are important to young people and their recovery from psychosis, considering:

- 1) How are autobiographical memories important to young peoples' recovery from early psychosis?

- 2) In what way do early adverse experiences and memory formation affect future thinking and establishing an overall sense of self during this recovery process?

Methodology

Design

The current study will use a mixed methodology; both quantitative and qualitative approaches will be used, with an emphasis on the latter design in the form of a grounded theory approach. Focusing on a grounded theory approach will facilitate the process of discovery of similar, shared experiences which have occurred in a common context. Hypotheses are developed as interviews take place, grounding them in the research and allowing the generation of theory from the collective experiences of these young people (Charmaz, 2006). Unlike pure qualitative research, a mixed methods approach allows for the measurement of key variables which are rooted in the literature, aiming for a richer understanding of young individuals' experiences. From triangulation of the data, similar themes can be 'tapped' into from different perspectives adding strength to the design, the data and the reliability of the outcomes.

Participants

Participants will be eight to 10 young people between the ages of 13 and 25 who are currently involved with mental health services in NHS Lothian for treatment following early psychosis. Inclusion criteria includes young people within the ages noted above who have experienced an episode of psychosis and are currently attending NHS Lothian mental health services for treatment. Potential participants must have capacity to consent (which will be assessed individually by experienced clinicians) and be able to understand the English language sufficiently. This is due to the measures which are being used in the study, only being available in English. A participant information sheet has been developed, outlining all aspects of the study, answering key questions for participants who decide to take part in the study and the steps involved in giving informed consent. Clinicians working within these mental health services will approach appropriate young people for inclusion in the study; such clinicians will use their clinical skills in deciding whether each young person has the capacity to provide informed consent to participate. It will be made clear that all young people will be free to withdraw this consent at any point and that this will not affect their treatment as usual (TAU). Young people can also approach their clinician or the chief investigator directly through details provided on posters, which will be available to view in the waiting rooms of appropriate mental health services in NHS Lothian. The researcher will have not contact young people or have any detail regarding potential participants until they have given consent to be contacted. The researcher can then be involved in taking consent for young people to take part in the study.

Participants under the age of 16 will be sought for participation in line with the research aims of the study. It is important that the experiences of individuals throughout adolescence are captured effectively to add to the scarce literature in the area and aid the understanding of appropriate interventions and overall recovery. The principle of direct consent will be followed; that is, young people (who are deemed to have the capacity to consent by experienced clinicians) will be asked whether they want to participate in the study directly. Parents and guardians can be provided with information about the study if required.

Whenever possible, participant identifiable information will always be anonymised and done so at the earliest possibility. Audio recordings will be taken during interviews and such recording devices will be encrypted and covered by Caldicott, adhering to NHS Lothian approved data transfer procedures always. Audio recordings will be immediately stored on NHS computers within a private folder available only to the chief investigator and project supervisors. All interviews will be transcribed as soon as possible and then removed from all devices; all identifiable information will be removed during transcription using pseudonyms and codes to protect participants being identified. Keys for identifying information within the transcripts will be stored securely on an NHS Lothian computer within a private folder available only to the chief investigator and project supervisors.

Other participant identifiable information which must be kept (e.g. consent forms with names and potentially other identifiable information) will be protected by being stored securely in locked cabinets within secure NHS Lothian premises.

Participant sample size:

Sample sizes within qualitative research is usually purpose driven rather than probability focused; diverse data, which is rich in quality rather is the aim as opposed to seeking high numbers of participants (Hennink, Kaiser & Marconi, 2017). As the design of the study is mainly qualitative, a non-probabilistic sample size will be used. Data saturation is reached when the ability to obtain new information has been reached and when there is enough information to replicate the research (Fusch & Ness, 2015); when saturation occurs, interviews will end. The sample size for this study will be based on previous published research in the area and an estimated number of eight to 10 young people have been proposed. For previous research in the area, this number of participants has been appropriate in order to reach theoretical saturation (i.e. the point when no further insights emerge from the data; Hennink et al, 2017).

Procedure

Following ethical approval, the chief investigator will attend a multidisciplinary team meeting within the appropriate mental health services and will outline the current research project, its aims and methodology. Inclusion criteria will be discussed at this team meeting with clinicians who will identify appropriate young people to take part in the project. Participants will be approached by experienced clinicians within NHS Lothian mental health services and it is likely that this will be during planned appointment times. Potential participants will be informed regarding what the research entails and if they are interested, they will be given a participant information sheet to read over and consider. As mentioned, young people can also contact their clinician or the chief investigator directly through details displayed on the relevant posters within their NHS mental health services.

Potential participants will be given a minimum of 24 hours to consider all information in the participant information sheet before being asked to give verbal and written consent. They will also have time to ask the researcher any questions before being asked to give consent to take part. Experienced clinicians will decide whether young people, who wish to take part in the study, can provide informed consent (i.e. whether they have the capacity to consent). Adhering to the principle of direct consent, participants under the age of 16 will be able to give consent if clinicians feel they have capacity to do so. Parents of potential participants under the age of 16 can be informed regarding the detail of the study but will not be required to provide consent for these young people. Consent will be verbal and written and written consent forms will be kept secure within locked filing cabinets on NHS Lothian premises.

For young people who wish to take part in the study, two interviews will take place with two young people initially. Interviews will take place in clinic rooms within NHS Lothian premises or in participants' homes if appropriate. Home visits are routinely conducted within NHS mental health teams working with vulnerable individuals and are only carried out following risk assessments and in line with lone working policies. These will be followed by the researcher and home visits will only take place with individuals deemed suitable to be seen at home.

These two interviews will then be transcribed and coded, drawing out common themes in line with answering the proposed research questions. An interview schedule has been developed to guide dialogue directions, taking care to be open, reflective and pulling as rich a data source as possible. Remaining interviews will build on initial themes which have been extracted from the first two interviews, allowing them to be in-depth and evolving, following guidelines for grounded theory by Charmaz (2006). Three measures will also be taken from participants, focusing on early adverse experiences, recovery and attachment style. The grounded theory interviews should be one hour in length for each participant and the quantitative measures should also take approximately one hour to complete. These will be done over two separate sessions. Data from measures and grounded theory interviews will then be analysed, aiming to answer key research questions.

Analysis

As mentioned, quantitative measures will be taken in addition to conducting qualitative interviews. Qualitative analysis will take the form of a grounded theory approach which, throughout the interviews, aims to construct theories ‘grounded’ in the data. Data is interpreted early on, helping gaps to be identified and filled by guiding subsequent interviews in particular directions. During analysis, data is separated, arranged and synthesised through coding, which helps construct the ‘bones’ of the analysis. Themes are based on these codes, which are labels attached to the data; by coding, common themes can be extracted, and it can become clearer as to what is happening in the data as the participants’ lives and experiences are formulated. Subsequent interviews can then be guided in the direction of themes which have been initially drawn, to help build a theory and answer principle research aims. Such qualitative methods allow data, which is of key interest, to be followed up and investigated further. All grounded theory interviews follow guidelines (Charmaz, 2006) to facilitate this procedure.

In addition to grounded theory interviews, three measures will be taken from participants, focusing on early adverse experiences, attachment style and recovery. Data from measures and grounded theory interviews will be analysed together, aiming to answer research questions.

Study Measures:

I propose to use quantitative measures with participants (focusing on adverse early events, attachment and recovery) which will be completed in addition to the main grounded theory interviews. Measures will include the Childhood Trauma Questionnaire (CTQ), the Adult Attachment Interview (AAI) and the Questionnaire about the process of recovery (QPR):

The Childhood Trauma Questionnaire (CTQ; Pearson, 1998): This is a 28-item measure which looks at five different domains of adverse early experiences – emotional, physical and sexual abuse, and emotional and physical neglect. Responses range from never true to very often true and are recorded on a 5-point Likert scale. Test-retest coefficient has been shown to be close to 0.8. According to the copyright holders, Pearson Clinical, it takes participants five minutes to complete on average (www.pearsonclinical.co.uk). See appendix one for the content of this questionnaire.

Adult Attachment Interview (AAI; George, Kaplan & Main, 1996): This measure is used to classify attachment style by asking participants to reflect on early experiences with primary caregivers regarding trauma, loss, rejection and separation. It consists of 18 questions and has been used to reliably classify attachment styles. This measure touches on early adverse experiences such as trauma and also regarding the process of memory formation. See appendix two for sample questions from this questionnaire.

The Questionnaire about the Process of Recovery (QPR; Neil et al, 2009): This is a 22-item measure developed by service users. With attempts to move away from symptoms, this measure looks at recovery more in terms of increased quality of life and empowerment. The QPR has reasonable reliability, construct validity and internal consistency (Neil et al, 2009). It looks to be helpful in assisting clients to set goals, evaluation of these goals and promoting recovery from psychosis. Questions are to be answered in relation to the past 7 days and answers are given on a 5-point Likert scale (disagree strongly, disagree, neither agree or disagree, agree, agree strongly). See appendix three for the content of this questionnaire.

Project Management Timetable

Thesis Proposal Submitted	May 2017
Feedback on Proposal Received	June 2017
Refine study following feedback	July-August 2017
Prepare ethics application	August - November 2017
Submit ethics application	November 2017
REC meeting and response	Dec 2017/Jan 2018
Recruitment in NHS Lothian	Feb -November 2018
Systematic Review	June 2018 - November 2018
Final Draft to Supervisor	January 2019
Final Corrections	February 2019
Thesis Submission	March 2019
Viva	April 2019
Corrections and Preparation for Publication	April 2019

Management of Risks to the Project

Potential Risks to Participants:

Although recruitment will be done using a potentially vulnerable population, participants will continue to engage in treatment as usual (TAU) with experienced clinicians who can provide

support for any difficulties young people experience. Clinicians will manage risk as appropriate to TAU.

Literature suggests that encouraging individuals to think about or report any past trauma memories is unlikely to lead to psychological harm in the long term (Read, Hammersley & Rudegeair, 2007). It has also been stated in the literature, that individuals who are not asked about abuse during their assessment appointment are likely to express dissatisfaction (Lothian & Read, 2002). If participants were to show signs of distress, the chief investigator's own experience as a Trainee Clinical Psychologist will be used (e.g. using empathy, active listening and grounding techniques where appropriate). Regular breaks will also be offered to participants whenever necessary. Guidelines to manage risk will be followed and interviews are likely to take place within NHS premises where there will be experienced staff present. Participants will be reminded that withdrawal from the study is always an option and at any point throughout the duration of the study.

Failure to Recruit Required Sample Size:

The study will aim to recruit eight to 10 participants from NHS Lothian mental health services. The academic and clinical supervisors for this project hold a clinical caseload within NHS Lothian and together it is felt that this number of participants for recruitment will be achievable. Considering previous published research in the area (who have recruited from within NHS Lothian) eight to 10 participants has been achieved without any notable difficulties.

Challenges which are worth considering, however, would be the possibility that participants may not want to continue with the project for a variety of reasons. Another challenge could be if there are not sufficient numbers of young people who fit the inclusion criteria for the study currently receiving treatment within NHS Lothian mental health services.

As a qualitative approach will be the main design, a non-probabilistic sample size will be used and when saturation occurs, interviews will end. Data saturation occurs when the ability to obtain new data has been reached and when there is enough information to replicate the research (Hennink et al, 2017; Fusch & Ness, 2015). The Early Psychosis Support Service (EPSS) will be the initial service used for recruitment; if it is not possible to recruit a minimum of eight participants from EPSS, other services within NHS Lothian will be approached if they are seeing individuals who meet inclusion criteria for the current study.

Reliance on members of staff within NHS Lothian mental health services:

For this project, members of staff within EPSS and possibly Adult Mental Health Services within NHS Lothian will be relied upon to facilitate recruitment of participants. Such reliance can be unpredictable. To facilitate this process, the chief investigator's final

placement is due to be arranged within EPSS, so links with key clinicians and positive working relationships can be made. This project will be carried out in conjunction with a research team who have a longstanding relationship with EPSS. As mentioned, the projects academic and clinical supervisors both hold clinical caseloads within NHS Lothian mental health services which is likely to aid recruitment and engagement with both staff and young people.

Data Protection Concerns:

Prior to giving consent, potential participants will be given an information sheet regarding how data will be collected and used. Identifiable information will be removed prior to data being used and all research data will be stored on password secured computers within NHS Lothian and/or University of Edinburgh. Caldicott guidance for the approved data transfer procedures will be adhered to at all times.

Consent for Participants under 16 years:

Taking consent will follow the principle of direct consent guidelines. This means that experienced clinicians will judge whether potential participants for the current study have the capacity to provide consent to take part in the study. If they are deemed to have capacity to consent, all young people recruited will give consent themselves as to whether they wish to take part in the current study. For individuals under the age of 16, information regarding the study can be provided for parents or guardians. Participants will be reminded that they can withdraw consent at any point.

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Appendix 1: Questions from Childhood Trauma Questionnaire (CTQ; Pearson, 1998)

When I was growing up ...

1. I didn't have enough to eat.
2. I knew that there was someone to take care of me and protect me.
3. People in my family called me things like "stupid", "lazy", or "ugly".
4. My parents were too drunk or high to take care of the family.
5. There was someone in my family who helped me feel that I was important or special.
6. I had to wear dirty clothes.
7. I felt loved.
8. I thought that my parents wished I had never been born.
9. I got hit so hard by someone in my family that I had to see a doctor or go to the hospital.
10. There was nothing I wanted to change about my family.
11. People in my family hit me so hard that it left me with bruises or marks.
12. I was punished with a belt, a board, a cord, or some other hard object.
13. People in my family looked out for each other.
14. People in my family said hurtful or insulting things to me.
15. I believe that I was physically abused.
16. I had the perfect childhood.
17. I got hit or beaten so badly that it was noticed by someone like a teacher, neighbour or doctor.
18. I felt that someone in my family hated me.
19. People in my family felt close to each other.
20. Someone tried to touch me in a sexual way, or tried to make me touch them.
21. Someone threatened to hurt me or tell lies about me unless I did something sexual with them.
22. I had the best family in the world.
23. Someone tried to make me do sexual things or watch sexual things.
24. Someone molested me.

25. I believe that I was emotionally abused.
26. There was someone to take me to the doctor if I needed it.
27. I believe that I was sexually abused.
28. My family was a source of strength and support.

Appendix 2: Protocol - Adult Attachment Interview (AAI)

ADULT ATTACHMENT INTERVIEW PROTOCOL

I'm going to be interviewing you about your childhood experiences, and how those experiences may have affected your adult personality. So, I'd like to ask you about your early relationship with your family, and what you think about the way it might have affected you. We'll focus mainly on your childhood, but later we'll get on to your adolescence and then to what's going on right now. This interview often takes about an hour, but it could be anywhere between 45 minutes and an hour and a half.

1. Could you start by helping me get oriented to your early family situation, and where you lived and so on? If you could tell me where you were born, whether you moved around much, what your family did at various times for a living?

This question is used for orientation to the family constellation, and for warm-up purposes. The research participant must not be allowed to begin discussing the quality of relationships here, so the "atmosphere" set by the interviewer is that a brief list of "who, when" is being sought, and *no more than two or three minutes* at most should be used for this question. The atmosphere is one of briefly collecting demographics. In the case of participants raised by several persons, and not necessarily raised by the biological or adoptive parents (frequent in high-risk samples), the opening question above may be *"Who would you say raised you?":*

The interviewer will use this to help determine who should be considered the primary attachment figure (s) on whom the interview will focus.

Did you see much of your grandparents when you were little? If participant indicates that grandparents

died during his or her own lifetime, ask the participant's age at the time of each loss. If there were

grandparents whom she or he never met, ask *whether this (these) grandparents) had died before she*

was born. If yes, continue as follows: Your mother's father died before you were born? How old was

she at the time, do you know? In a casual and *spontaneous* way, inviting only a very brief reply, the

interviewer then asks, *Did she tell you much about this grandfather?*

Did you have brothers and sisters living in the house, or anybody besides your parents? Are they living nearby now or do they live elsewhere? -

2. I'd like you to try to describe your relationship with your parents as a young child if you could start from as far back as you can remember?

Encourage participants to try to begin by remembering very early. Many say they cannot remember early childhood, but you should shape the questions such that they focus at first around age five or earlier, and gently remind the research participant from time to time that if possible, you would like her to think back to this age period. Admittedly, this is leaping right into it, and the participant may stumble. If necessary, indicate in some way that experiencing some difficulty in initially attempting to respond to this question is natural, but indicate by some silence that you would nonetheless like the participant to attempt a general description.

3. Now I'd like to ask you to choose five adjectives or words that reflect your relationship with your mother starting from as far back as you can remember in early childhood--as early as you can go, but say, age 5 to 12 is fine. I know this may take a bit of time, so go ahead and think for a minute...then I'd like to ask you why you chose them. I'll write each one down as you give them to me.

Not all participants will be able to think of five adjectives right away. Be sure to make the word *relationship* clear enough to be heard in this sentence. Some participants do use "relationship" adjectives to describe the parent, but some just describe the parent herself -- e.g., "pretty"... "efficient manager"--as though they had only been asked to "pick adjectives to describe your mother".

These individual differences are of interest only if the participant has heard the phrase, "that reflect your childhood *relationship*" with your mother. The word should be spoken clearly, but with only slight stress or emphasis. Some participants will not know what you mean by the term *adjectives*, which is why we phrase the question as "adjectives or words". If the

participant has further questions, you can explain, "just words or phrases that would describe or tell me about your relationship with your (mother) during childhood". The probes provided below are intended to follow the entire set of adjectives, and *the interviewer must not begin to probe until the full set of adjectives has been given*. Be patient in waiting for the participant to arrive at five adjectives, and be encouraging.

This task has proven very helpful both in starting an interview, and in later interview analysis. It helps some participants to continue to focus upon the relationship when otherwise they would not be able to come up with spontaneous comments. If for some reason a subject does not understand what a memory is, you might suggest they think of it like an image they have in their mind similar to a videotape of something which happened when they were young.

Make certain that the subject really does not understand the question first, however. The great majority who may seem not to understand it are simply unable to provide a memory or incident.

The participant's ability (or inability) to provide both an overview of the relationship and specific memories supporting that overview forms one of the most critical bases of interview analysis. For this reason it is important for the interviewer to press enough in the effort to obtain the five "overview" adjectives that if a full set is not provided, she or he is reasonably certain that they truly cannot be given.

The interviewer's manner should indicate that waiting as long as a minute is not unusual, and that trying to come up with these words can be difficult. Often, participants indicate by their non-verbal behaviour that they are actively thinking through or refining their choices. In this case an interested silence is warranted. Don't, however, repeatedly leave the participant in embarrassing silences for very long periods. Some research participants may tell you that this is a hard job, and you can readily acknowledge this. If the participant has extreme difficulty coming up with more than one or two words or adjectives, after a period of two to three minutes of supported attempts ("Mm... I know it can be hard ...this is a pretty tough question... Just take a little more time").

Then say something like "Well, that's fine. Thank you, we'll just go with the ones you've already given me." The interviewer's tone here should make it clear that the participant's response is perfectly acceptable and not uncommon.

Okay, now let me go through some more questions about your description of your childhood relationship with your mother. You say your relationships with her was (you used the phrase) Are there any memories or incidents that come to mind with respect to (word)

The same questions will be asked *separately* for *each* adjective in series. Having gone through the probes which follow upon this question (below), the interviewer moves on to seek illustration for each of the succeeding

adjectives in turn:

You described your childhood relationship with your mother as (or, `your second adjective was", or "the second word you used was"). Can you think of a memory or an incident that would illustrate why you chose to describe the relationship?

The interviewer continues, as naturally as possible, through each phrase or adjective chosen by the participant, until all five adjectives or phrases are covered. A specific supportive memory or expansion and illustration is requested for each of the adjectives, separately. In terms of time to answer, this is usually the longest question.

Obviously, some adjectives chosen may be almost identical, e.g., "loving ... caring". Nonetheless, if they have

been given to you as separate descriptors, you must treat each separately, and ask for memories for each. While participants sometimes readily provide a well-elaborated incident for a particular word they have chosen, at other times they may fall silent; or "illustrate" one adjective with another ("loving ...um, because she was generous"); or describe what usually happened--i.e., offer a "scripted" memory--rather than describing specific incidents. There are a set series of responses available for these contingencies, and it is vital to memorize them.

If the participant is silent, the interviewer waits an appropriate length of time. If the participant indicates nonverbally that she or he is actively thinking, remembering or simply attempting to come up with a particularly telling illustration, the interviewer maintains an interested silence. If the silence continues and seems to indicate that the participant is feeling stumped, the interviewer says something like, "well, just take another minute and see if anything comes to mind". If following another waiting period the participant still cannot respond to the question, treat this in a casual, matter of fact manner and say "well, that's fine, let's take the next one, then".

Most participants do come up with a response eventually, however, and the nature of the response then determines which of the follow-up probes are utilized. If the participant redefines an affective with a second adjective as, "Loving ---she was generous", the interviewer probes by repeating the original adjective (loving) rather than permitting the participant to lead them to use the second one (generous). In other words, the interviewer in this case will say, "Well, can you think of a specific memory that would illustrate how your relationship was loving?" The interviewer should be careful,

however, not to be too explicit in their intention to lead the participant back to their original word usage. If the speaker continues to discuss "generous" after having been probed about loving once more, this violation of the discourse task is meaningful and must be allowed. As above, the nature of the participant's response determines which follow-up probes are utilized.

If a specific and well-elaborated incident is given, the participant has responded satisfactorily to the task, and the interviewer should indicate that she or he understands that. However, the interviewer should briefly show continuing interest by asking whether the participant can think of a second incident.

If one specific but poorly elaborated incident is given, the interviewer probes for a second. Again, the interviewer does this in a manner emphasizing his or her own interest.

If as a first response the participant gives a "scripted" or "general" memo[y, as "Loving. She always

took us to the park and on picnics. She was really good on holidays" or "Loving. He taught me to ride

a bike"--the interviewer says, "Well, that's a good general description, but I'm wondering if there

was a particular time that happened, that made you think about it as loving?"

If the participant does now offer a specific memory, briefly seek a second memory, as above. If another scripted memory is offered instead, or if the participant responds "I just think that was a loving

thing to do", the interviewer should be accepting, and go on to the next adjective. Here as elsewhere

the interviewer's behaviour indicates that the participant's response is satisfactory.

4. Now I'd like to ask you to choose five adjectives or words that reflect your childhood relationship with your father, again starting from as far back as you can remember in early childhood--as early as you can go, but again say, age 5 to 12 is fine. I know this may take a bit of time, so go ahead and think again for a minute...then I'd like to ask you why you chose them. I'll write each one down as you give them to me. (Interviewer repeats with probes as above).

5. Now I wonder if you could tell me, to which parent did you feel the closest, and why? Why isn't there this feeling with the other parent?

By the time you are through with the above set of questions, the answer to this one may be obvious, and you may want to remark on that ("*You've already discussed this* a bit, but I'd like to ask about it briefly anyway..."). Furthermore, while the answer to this question may indeed be obvious for many participants, some--particularly those who describe both parents as loving--may be able to use it to reflect further on the difference in these two relationships.

6. When you were upset as a child, what would you do?

This is a critical question in the interview, and variations in the interpretation of this question are important. Consequently, the participant is first encouraged to think up her own interpretations of "upset", with the interviewer pausing quietly to indicate that the question is completed, and that an answer is requested. Once the participant has completed her own interpretation of the question, giving a first answer, begin on the following probes. Be sure to get expansions of every answer. If the participant states, for example, "I withdrew", probe to understand what this research participant means by "withdrew". For example, you might say, "And what would you do when you withdrew?"

The interviewer now goes on to ask the specific follow-up questions below. These questions may appear similar, but they vary in critical ways, so the interviewer must make sure that the participant thinks through each question separately. This is done by placing vocal stress on the changing contexts (as we have indicated by underlining).

-----***When you were Upset emotionally when you were little, what would you do?*** (Wait for participant's reply).

Can you think of a specific time that happened?

-----***Can you remember what would happen when you were hurt. physically?*** (Wait for participant's

reply). ***Again, do any specific incidents (or, do any other incidents) come to mind?***

-----***Were you ever M when you were little?*** (Wait for participant's reply). ***Do you remember what would happen?***

When the participant describes going to a parent, see first what details they can give you spontaneously. Try to get a sense of how the parent or parents responded, and then when and if it seems appropriate you can briefly ask one or two clarifying questions. Be sure to get expansions of every answer. Again, if the participant says "I withdrew", for example, probe to see what the participant means by this, i.e., what exactly she or he did, or how exactly they felt, and if they can elaborate on the topic.

If the participant has not spontaneously mentioned being held by the parent in response to any of the above questions, the interviewer can ask casually at the conclusion to the series, ***"I was just wondering, do you remember being held by either of your parents at any of these times--I mean, when you were upset, or hurt, or ill?"***

In earlier editions of these guidelines, we suggested that if the participant answers primarily in terms of responses by one of the parents, the interviewer should go through the above queries again with respect to the remaining parent. This can take a long time and distract from the recommended pacing of the interview. Consequently, it is no longer required.

What is the first time you remember being separated from your parents?

--How did you respond? Do you remember how your parents responded?

--Are there any other separations that stand out in your mind?

Here research participants often describe first going off to nursery school, or to primary school, or going camping. In this context, participants sometimes spontaneously compare their own responses to those of other children. This provides important information regarding the participant's own overall attitude towards attachment, so be careful not to cut any such descriptions or comparisons short.

8. Did you ever feel rejected as a young child? Of course, looking back on it now, you may realize it wasn't really rejection, but what I'm trying to ask about here is whether you remember ever having rejected in childhood

----How old were you when you first felt this way, and what did you do?

----Why do you think your parent did those things--do you think he/she realized he/she was rejecting

you?

Interviewer may want to add a probe by reframing the question here, especially if no examples are

forthcoming. The probe we suggest here is, *Did you ever feel pushed away or ignored?"*

Many participants tend to avoid this in terms of a positive answer.

So, were you ever frightened or worried as a child?

Let the research participant respond "freely" to this question, defining the meaning for themselves. They may ask you what the question means, and if so, simply respond by saying "It's just a more general question". Do not probe heavily here. If the research participant has had traumatic experiences which they elect not to describe, or which they have difficulty remembering or thinking about, you should not insist upon hearing about them. They will have a second, brief opportunity to discuss such topics later.

9. Were your parents ever threatening with you in any way - maybe for discipline, or even jokingly?

-----Some people have told us for example that their parents would threaten to leave them or send

them away from home.

-----(Note to researchers). In particular communities, some specific kind of punishment not generally

considered fully abusive is common, such as "the silent treatment", or "shaming", etc. One question

regarding this one selected specific form of punishment can be inserted here, as for example, *'Some*

people have told us that their parents would use the silent treatment---did this ever happen with your

parents?': The question should then be treated exactly as threatening to send away from home, i.e.,

the participant is free to answer and expand on the topic if she or he wishes, but there are no specific

probes. The researcher should not ask about more than one such specific (community) form of punishment, since queries regarding more than one common type will lead the topic away from its more general intent (below).

Some people have memories of threats or of some kind of behaviour that was abusive.

-----Did anything like this ever happen to you, or in your family?

-----How old were you at the time? Did it happen frequently?

-----Do you feel this experience affects you now as an adult?

-----Does it influence your approach to your own child?

-----Did you have any such experiences involving people outside your family?

If the participant indicates that something like this did happen outside the family, take the participant through the same probes (*age? frequency? affects you now as an adult? Influences your approach to your own child?*).

Be careful with this question, however, as it is clinically sensitive, and by now you may have been asking the participant difficult questions for an extended period of time. Many participants simply answer "no" to these questions. Some, however, describe abuse and may some suffer

distress in the memory. When the participant is willing to discuss experiences of this kind, the interviewer must be ready to maintain a respectful silence, or to offer active sympathy, or to do whatever may be required to recognize and insofar as possible to help alleviate the distress arising with such memories. If the interviewer suspects that abuse or other traumatic experiences occurred, it is important to attempt to ascertain the specific details of these events insofar as possible. In the coding and classification system which accompanies this interview, *distressing experiences cannot be scored for Unresolved /disorganized responses unless the researcher is able to establish that abuse (as opposed to just heavy spanking, or light hitting with a spoon that was not frightening) occurred.*

Where the nature of a potentially physically abusive (belting, whipping, or hitting) experience is ambiguous, then, the interviewer should try to establish the nature of the experience in a light, matter-of-fact manner, without excessive prodding. If, for example, the participant says "I got the belt" and stops, the interviewer asks, "And what did getting the belt mean?". After encouraging as much spontaneous expansion as possible, the interviewer may still need to ask, again in a matter-of-fact tone, how the participant responded or felt at the time. "Getting the belt" *in itself will* not qualify as abuse within the adult attachment scoring and classification systems, since in some households and communities this is a common,

systematically but not harshly imposed experience. Being belted heavily enough to overwhelmingly frighten the child for her physical welfare at the time, being belted heavily enough to cause lingering pain, and/or being belted heavily enough to leave welts or bruises will qualify.

In the case of sexual abuse as opposed to battering, the interviewer will seldom need to press for details, and should be very careful to follow the participant's lead. Whereas on most occasions in which a participant describes themselves as sexually abused the interviewer and transcript judge will have little need to probe further, occasionally a remark is ambiguous enough to require at least mild elaboration. If, for example, the participant states 'and I just thought he could be pretty sexually abusive', the interviewer will ideally follow-up with a query such as, 'well, could you tell me a little about what was happening to make you see him as sexually abusive?'

Should the participant reply that the parent repeatedly told off-colour jokes in her company, or made untoward remarks about her attractiveness, the parent's behaviour, though insensitive, will not qualify as sexually abusive within the accompanying coding system. Before seeking elaboration of any kind, however, the interviewer should endeavour to determine whether the participant seems comfortable in discussing the incident or incidents.

All querying regarding abuse incidents must be conducted in a matter-of-fact, professional manner. The interviewer must use good judgment in deciding whether to bring querying to a close if the participant is becoming uncomfortable. At the same time, the interviewer *must not avoid the topic or give the participant the impression that discussion of such experiences is unusual*. Interviewers sometimes involuntarily close the topic of abuse experiences and their effects, in part as a well-intentioned and protective response towards participants who in point of fact would have found the discussion welcome. *Participants who seem to be either thinking about or revealing abuse experiences for the first time-- "No, nothing ...no... well, I, I haven't thought, remembered this for, oh, years, but ...maybe they used to... tie me..."-- must be handled with special care*, and should *not* be probed unless they clearly and actively seem to want to discuss the topic. If you sense that the participant has told you things they have not previously discussed or remembered, special care must be taken at the end of the interview to ensure that the participant does not still suffer distress, and feels able to contact the interviewer or project director should feelings of distress arise in the future.

In such cases the participant's welfare must be placed above that of the researcher. While matter-of-fact, professional and tactful handling of abuse-related questions usually makes it possible to obtain sufficient information for scoring, the interviewer must be alert to indications of marked distress, and ready to tactfully abandon this line of questioning where necessary. Where the complete sequence of probes must be abandoned, the interviewer should move gracefully and smoothly to the next question, as though the participant had in fact answered fully.

10. In general, how do you think your overall experiences with your parents have affected your adult personality?

The interviewer should pause to indicate she or he expects the participant to be thoughtful regarding

this question, and is aware that answering may require some time. ***Are there any aspects to your early experiences that you feel were a set-back in your development?*** In some cases, the participant will already have discussed this question. Indicate, as usual, that you would just like some verbal response again anyway, "for the record".

It is quite important to know whether or not a participant sees their experiences as having had a negative effect on them, so the interviewer will follow-up with one of the two probes provided directly below. The interviewer must stay alert to the participant's exact response to the question, since the phrasing of the probe differs according to the participant's original response.

If the participant has named one or two setbacks, the follow-up probe used is:

---Are there any other aspects of your early experiences, that you think might have held your development back, or had a negative effect on the way you turned out? If the participant has understood the question, but has not considered anything about early experiences

a setback, the follow-up probe used is:

---Is there any thin about your early experiences that you think might have held your development back, or had a negative effect on the way you turned out?

Although the word ***anything*** receives some vocal stress, the interviewer must be careful not to seem to be expressing impatience with the participant's previous answer. The stress simply implies that the participant is being given another chance to think of something else she or he might have forgotten a moment ago.

RE: PARTICIPANTS WHO DON'T SEEM TO UNDERSTAND THE TERM, SETBACK.

A few participants aren't familiar with the term, **set-back**. If after a considerable wait for the participant to reflect, the participant seems simply puzzled by the question, the interviewer says, *"Well, not everybody uses terms like set-back for what I mean here. I mean, was there anything about*

your early experiences, or any parts of your early experiences, that you think might have held your

development back, or had a negative effect on the way you turned out?"

In this case, this becomes the main question, and the probe becomes

-Is there anything else about your early experiences that you think might have held your development

back, or had a negative effect on the way you turned out?

11. Why do you think your parents behaved as they did during your childhood?

This question is relevant even if the participant feels childhood experiences were entirely positive. For

participants reporting negative experiences, this question is particularly important.

12. Were there any other adults with whom you were close, like parents, as a child?

--- Or any other adults who were especially important to you, even though not parental?

Give the participant time to reflect on this question. This is the point at which some participants will mention housekeepers, au pairs, or nannies, and some will mention other family members, teachers, or neighbours. Be sure to find out ages at which these persons were close with the participant, whether they had lived with the family, and whether they had had any care giving responsibilities. In general, attempt to determine the significance and nature of the relationship.

13. Did you experience the loss of a parent or other close loved one while you were a young child--for example, a sibling, or a close family member?

(A few participants understand the term "loss" to cover brief or long-term separations from living

persons, as, "I lost my mom when she moved South to stay with her mother". If necessary, clarify that you are referring to death only, i.e. specifically to loved ones who had died).

-----*Could you tell me about the circumstances, and how old you were at the time?*

-----*How did you respond at the time?*

-----*Was this death sudden or was it expected?*

-----*Can you recall your feelings at that time?*

-----*Have your feelings regarding this death changed much over time?*

If not volunteered earlier. *Did you attend the funeral, and what was this like for you?*

If loss of a parent or *sibling*. *What would you say was the effect on your (other parent) and on your*

household, and how did this change over the years?

-----*Would you say this loss has had an effect on your adult personality?*

-----*Were relevant How does it affect your approach to your own child?*

13a. Did you lose any other important persons during your childhood?

(Same queries--again, this refers to people who have died rather than separation experiences).

13b. Have you lost other close persons, in adult years? (Same queries).

Be sure that the response to these questions covers loss of any siblings, whether older or younger, loss of grandparents, and loss of any person who seemed a "substitute parent" or who lived with the family for a time. Some individuals will have been deeply affected by. Probe any loss which seems important to the participant, including loss of friends, distant relatives, and neighbours or neighbour's children. Rarely, the research participant will seem distressed by the death of someone who they did not personally know (often, a person in the family, but sometimes someone as removed as the friend of a friend).

If a participant brings up the suicide of a friend of a friend and seems distressed by it, the loss **should be fully** probed. The interviewer should be aware, then, that speakers may be assigned to the unresolved/disorganized adult attachment classification as readily for lapses in

monitoring occurring during the discussion of the death of a neighbour's child *experienced during the adult years* as for loss of a parent in childhood.

Interviewing research participants regarding loss obviously requires good clinical judgment. At maximum, only four to five losses are usually fully probed. In the case of older research participants or those with traumatic histories, there may be many losses, and the interviewer will have to decide on the spot which losses to probe. No hard and fast rules can be laid out for determining which losses to skip, and the interviewer must to the best of his or her ability determine which losses--if there are many--are in fact of personal significance to the participant. Roughly, in the case of a participant who has lost both parents, spouse, and many other friends and relatives by the time of the interview, the interviewer might elect to probe the loss of the parents, the spouse, and "any other loss which you feel may have been especially important to you". If, however, these queries seem to be becoming wearying or distressing for the participant, the interviewer should acknowledge the excessive length of the querying, and offer to cut it short.

14. Other than any difficult experiences you've already described, have you had any other experiences which you should regard as potentially traumatic?

Let the participant free-associate to this question, then clarify if necessary with a phrase such as, *I mean, any experience which was overwhelmingly and immediately terrifying.*

This question is a recent addition to the interview. It permits participants to bring up experiences which may otherwise be missed, such as scenes of violence which they have observed, war experiences, violent separation, or rape. Some researchers may elect not to use this question, since it is new to the 1996 protocol. If you do elect to use it, it must of course be used with all subjects in a given study.

The advantage of adding this question is that it may reveal lapses in reasoning or discourse specific to traumatic experiences other than loss or abuse.

Be very careful, however, not to permit this question to open up the interview to all stressful, sad, lonely or upsetting experiences which may have occurred in the subject's lifetime, or the purpose of the interview and of the question may be diverted. It will help if your tone indicates that these are rare experiences.

Follow up on such experiences with probes only where the participant seems at relative ease in discussing the event, and/or seems clearly to have discussed and thought about it before.

Answers to this question will be varied. Consequently, exact follow-up probes cannot be given in advance, although the probes succeeding the abuse and loss questions may serve as a partial guide. In general, the same cautions should be taken with respect to this question as with respect to queries regarding frightening or worrisome incidents in childhood, and experiences of physical or sexual abuse. Many researchers may elect to treat this question lightly, since the interview is coming to a close and it is not desirable to leave the participant reviewing too many difficult experiences just prior to leave taking.

15. Now I'd like to ask you a few more questions about your relationship with your parents. Were there many changes in your relationship with your parents (or remaining parent) after childhood? We'll get to the present in a moment, but right now I mean changes occurring roughly between your childhood and your adulthood?

Here we are in part trying to find out, *indirectly* (1) whether there has been a period of rebellion from the parents, and (2) also indirectly, whether the participant may have rethought early unfortunate relationships and "forgiven" the parents. Do not ask anything about forgiveness directly, however--this will need to come up spontaneously. This question also gives the participant the chance to describe any changes in the parents' behaviour, favourable or unfavourable, which occurred at that time.

16. Now I'd like to ask you, what is your relationship with your parents (or remaining parent) like for you now as an adult? Here I am asking about your current relationship.

---Do you have much contact with your parents at present?

---What would you say the relationship with your parents is like currently?

---Could you tell me about any (or any other) sources of dissatisfaction in your current relationship

with your parents? any special (or any other) sources of special satisfaction?

This has become a critical question within the Adult Attachment Interview, since a few participants who had taken a positive stance towards their parents earlier suddenly take a negative stance when asked to describe current relationships. As always, the interviewer should express a genuine interest in the participant's response to this question, with sufficient pause to indicate that a reflective response is welcome.

17. I'd like to move now to a different sort of question--it's not about your relationship with your parents, instead it's about an aspect of your current relationship with (specific child of special interest to the researcher, or all the participant's children considered together). How do you respond now, in terms of feelings, when you separate from your child / children? (For adolescents or individuals without children, see below).

Ask this question exactly as it is, without elaboration, and be sure to give the participant enough time to respond.

Participants may respond in terms of leaving child at school, leaving child for vacations, etc., and this

is encouraged. What we want here are the participant's feelings about the separation. This question has been very helpful in interview analysis, for two reasons. In some cases it highlights a kind of role-reversal between parents and child, i.e., the participant may in fact respond as though it were the child who was leaving the parent alone, as though the parent was the child. In other cases, the research participant may speak of a fear of loss of the child, or a fear of death in general. When you are certain you have given enough time (or repeated or clarified the question enough) for the participant's naturally occurring response, then (and only then) add the following probe:

-----*Do you ever feel worried about (child)?*

For individuals without children, you will pose this question as a hypothetical one, and continue through the remaining questions in the same manner. For example, you can say, *now I'd like you to imagine that you have a one-year-old child, and I wonder how you think you might respond, in terms of feelings, if you had to separate from this child?" Do you think you would ever feel worried about this child?"*

18. If you had three wishes for your child twenty years from now, what would they be? I'm thinking partly of the kind of future you would like to see for your child I'll give you a minute or two to think about this one.

This question is primarily intended to help the participant begin to look to the future, and to lift any negative mood which previous questions may have imposed. For individuals without children, you again pose this question in hypothetical terms.

For example, you can say,

"Now I'd like you to continue to imagine that you have a one-year-old child for just another minute. This time, I'd like to ask, if you had three wishes for your child twenty years from

now, what would they be? I'm thinking partly of the kind of future you would like to see for your imagined child I'll give you a minute or two to think about this one':

19. Is there any particular thing which you feel you learned above all from your own childhood experiences? I'm thinking here of something you feel you might have gained from the kind of childhood you had.

Give the participant plenty of time to respond to this question. Like the previous and succeeding questions, it is intended to help integrate whatever untoward events or feelings he or she has experienced or remembered within this interview, and to bring the interview down to a light close.

20. We've been focusing a lot on the past in this interview, but I'd like to end up looking quite a way into the future. We've just talked about what you think you may have learned from your own childhood experiences. I'd like to end by asking you what would you hope your child (or, your imagined child) might have learned from his/her experiences of being parented by you?

The interviewer now begins helping the participant to turn his or her attention to other topics and tasks. Participants are given a contact number for the interviewer and/or project director and encouraged to feel free to call if they have any questions.

Appendix 3: Questions from the Questionnaire about the Process of Recovery (QPR)

- 1. I feel better about myself*
- 2. I feel able to take chances in life*
- 3. I am able to develop positive relationships with other people*
- 4. I feel part of society rather than isolated*
- 5. I am able to assert myself*
- 6. I feel that my life has a purpose*
- 7. My experiences have changed me for the better*
- 8. I have been able to come to terms with things that have happened to me in the past and move on with my life*
- 9. I am basically strongly motivated to get better*
- 10. I can recognise the positive things I have done*

11. *I am able to understand myself better*
12. *I can take charge of my life*
13. *I can actively engage with life*
14. *I can take control of aspects of my life*
15. *I can find the time to do the things I enjoy*

Questions are to be answered in relation to the past 7 days and answers are given on a 5-point Likert scale (disagree strongly, disagree, neither agree or disagree, agree, agree strongly).

Appendix 4: Semi- structured Interview Schedule for Grounded Theory Interviews



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Semi-structured Interview Schedule

Introduction:

- Introduce self and explain the limits of confidentiality as noted in patient information sheet
- Allow the participant to introduce themselves and clarify what they like to be called
- Give an outline of the interview and what it will entail – a description of this is also outlined in the patient information sheet
- Remind participants that they can take breaks throughout the duration of the interview

Opening questions:

- Could you describe your experiences of psychosis?
- What is/has been important to you in the recovery from early psychosis?
 - Could you say a bit more about what has been important and why?

Appendix H – R&D Approval for NHS Lothian Recruitment

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ
FM/LM/approval

Lothian

19 February 2018

Research & Development
Room El .16.
Tel: 0131 242 3330

Miss Lindsay Dunnett

Email:
accord@nhslothian.scot.nhs.uk

NHS Lothian

Department of Clinical Psychology
School of Health in Social Science
Doorway 6, Old Medical School
Edinburgh

Director: Professor Tim Walsh

EH8 9AG

Dear Miss Dunnett

Lothian R&D Project No: 2018/0042REC No: 17/ES/0158

Title of Research: Exploring self-identity in the recovery of early psychosis within an adolescent population: a mixed methods approach

Participant Information Sheet:
Version 2.0 dated 24 January 2018

Consent Form:
Version 1.0 dated 10 November 2017

Protocol: Version 2.0 dated 24 January 2018

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

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

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

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

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

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

I wish you every success with your study.

Yours sincerely

Ms Fiona McArdle
Deputy R&D Director

CC: Mr Tim Montgomery, Director of Operations, REH



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Appendix I – Poster for Recruitment



Self-Identity and Recovery following Early Psychosis



Are you currently receiving care from an NHS
Mental Health Team?

Are you a young person (13 – 25 years)
recovering from an episode of psychosis?

We are interested in what is important to young people
in their recovery journey and learning more about self-
identity during this time.

We would like to invite you to take part in a research
study exploring experiences during childhood,
experiences of recovery from early psychosis and the
psychological factors that might explain this relationship.
This will be through the means of interviews (which will
take approximately 2 hours, over two meetings) and also
from the completion of two short questionnaires.

If you would like further information about this study,
please speak to a member of your NHS Mental Health
Team or contact:

Linsay Dunnett, Trainee Clinical Psychologist

Email: s0967495@sms.ed.ac.uk



Appendix J – Revised Interview Schedule

Interview Schedule

Did you get in ok today - a bus, walk?

Introduction - Trainee Psychologist, doing some research within EPSS as part of my doctorate.

Check they read the PIS - any questions? Do they still want to take part?
Sign consent sheets

Appreciation - thanks for agreeing to talk with me today. Will be approximately 1 hour altogether. I hope to understand more about your experience of psychosis and recovery and how this has impacted on how you see yourself. We will start by having talk about these experiences and then I will ask you to complete a couple of short measures.

Would you feel ok to let me know if you want a break at any point of if you want to stop? I will also check in.

Confidentiality - things will be kept private within the team working with you. Only exception is if you tell me something which makes me concerned about your safety or the safety of someone else. Then I will contact the relevant professionals at this point to keep you safe. I will be recording this session today so it can be analysed, but it will be stored safely.

Do you have any questions?

Start recorder.

1. I wonder if you could tell me a bit about yourself, where you grew up and where you live now? Do you live on your own or with family? Do you go to school? What subjects do you enjoy?

2. Could you talk me through a timeline of significant events in your life – If you can go back as early as you can remember.

- How did that make you feel at the time? (ask for each experience/memory)

- have these feelings changed over time? (ask for each experience/memory)

- do you think that experience had any an impact on who you are today/what you are doing today? (ask for each experience/memory).

Do you think any of these experiences set you back in life?

- In what way do you think they set you back?
- How has this impacted on how you see yourself/do things?

3. As I mentioned at the start, I'm interested in hearing about your experience of psychosis and your thoughts around your recovery from this. Could you start by telling me a bit about when you first noticed things changing for you?

- where were you?
- who was around?
- could you tell me a bit more about what happened? Describe the steps?
- how did you know things were changing?

4. What kind of things did you like doing back then? Before things started to change?

- what were your interests?
- how did you spend your time?
- could you walk back through a typical day?
- what did you see yourself doing for a living, uni etc.

5. How were you with other people?

- How would a good friend or family member have described you back then?
- could you give me 3 words that they might have used to describe you?
- could you give me an example to back up each of those words?

6. Would you be able to recall a memory of a stressful event back then?

- what happened and how did you react?
- how did others react around you?
- what did you learn from this?

7. If we move forward a bit, could you tell me about when you first had contact with CAMHS?

- when was this?
- what happened? Did you pursue help?
- what were the main thing you were concerned about at the time?
- could you describe a memory from this time?
- who was around to support you with this?
- if I had been a fly on the wall when that was happening, what would I have seen? -
- can you recall any emotions at that time?

8. You told me a bit about what you liked to do back then and how you spent your time. Could you tell me a bit about how that has changed, if it has changed?

- what are you doing differently now?
- could you describe a typical day for me?
- how would a good friend describe you now?
- how are you with other people?

- could you give an example, tell me more about that.

9. Apart from the memories we have been discussing, are there any significant memories over the past couple of years that stand out in your mind.

- again, if I was a fly on the wall, what would I see. Or if I was watching it on tv, what would it look like and how would I feel watching that?
- what do you think about that looking back on it?

10. Could you tell me a bit about how your recovery is going, or what you make of that word, recovery?

- what comes up for you when you think about that word?
- where would you say you are in your recovery just now?
- what are you doing differently now?
- what else would you be doing differently if you were recovered?
- where do you see yourself in a couple of years time?
- have you had any setbacks throughout your recovery journey?

11. What do you think you've learnt from the experiences you have told me about today?

- Do you think your earlier experiences have had an impact on who you are today?
- 'have you had any setbacks?
- Have these feelings changed over time?

- Do you think there is anything else which we have not spoken about, which would be helpful to speak about today?
- would you say that I have got a good account of your experience today?

Thank you very much for talking with me about that today. Do you have any questions before we finish the interview?

Complete CTQ Complete QPR

Appendix K – Line by Line Coding Example

Transcription		
Interviewer	What do you think that word (recovery) means to you?	
E002	I guess I feel from my experience that people expect that you take a magic pill and you are fine. But it's more like you have to learn to live with things. I guess it's more like not about getting rid of things but more like just learning to deal with things and to find a way.	Other's expectations of recovery. Learning to live with symptoms/acceptance of difficulties. Recovery journey.
Interviewer	Ok. Ye. And you said there that people expect that it should be a bit quicker? Where has that come from do you think?	
E002	Ye even like recently, my dad is like "oh you're still going to (service omitted) and still seeing a therapist? – when's that going to be over" and I'm like I don't know.	Others' expectations of recovery.
Interviewer	And what did you think about that?	
E002	I don't know, i just thought it was a bit unfair. But.	Others being unfair.
Interviewer	Uh huh. So you said there that you think this is something that you need to manage and find different ways of getting through things rather than it changing and getting rid.	
E002	Ye like i feel like you're never going to get rid of things – well that I'm never going to get rid of what's wrong with me so i just need to deal with it.	Never going to get rid of things. Learning to live with symptoms/ acceptance of difficulties.
Interviewer		

<p>E002</p>	<p>Where do you think you are in that process just now?</p>	
<p>Interviewer</p>	<p>Em. I'd say. . It's like going back and forth quite a lot. Cause like, it's a lot – this sounds stupid (laughs), so it's a lot easier to completely break something down rather than to build something up.</p>	<p>Going back and forth. Easier to break things down than build them up.</p>
<p>E002</p>	<p>Ok. What do you mean by that?</p> <p>I guess like you can spend ages and ages trying to recover but it's pretty easy just to completely ruin it.</p>	<p>Recovery takes time. Recovery is easily ruined.</p>

Appendix L – Personal Reflections on Grounded Theory Process

Being honest about my experience of the Grounded Theory research process would be that it has been extremely challenging at times but rewarding at others. Qualitative research was new to me and it felt daunting to take on a new approach on such a large scale and at such a critical point in my career. Meeting with the young people throughout the recruitment phase was a real highlight for me and for them to allow me to listen and ask more about such a significant experience in their lives was a privilege. I was moved by their stories and how the experience of psychosis affected them very differently in some ways but similarly in others and enjoyed ‘travelling a path through the interview’ with each of them (Birks & Mills, 2011).

Other parts of the research process were more challenging. Recruiting within a high-pressured team and when many changes were taking place was found to be a barrier to obtaining the numbers I required in a timely manner. I was required to work hard and be assertive in approaching busy clinicians regarding young people they were seeing for assessment and treatment. I became aware of how important this research was for expanding our knowledge within an emerging field of adolescent mental health; I also became aware, however, that it was not always possible for this to be a priority for others during busy periods. The use of Nvivo for qualitative research was a steep learning curve which I often felt blind in navigating. Seeking advice and direction with this was helpful when I was at the point of grouping together themes and analysing the data I had.

Overall, I enjoyed the process of gathering rich data from young people themselves and using this in conjunction with a more measurable quantitative approach. I felt immersed in this process and despite it feeling ‘never ending’ at times, found it enjoyable and an experience which has led to the development of many skills which I can hopefully take forward with me into a successful career as a qualified Clinical Psychologist.