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Major Research Project

Exploring the concept of ‘family recovery in families and individuals with lived experience of psychosis

Section A:

A systematic review of family recovery in psychosis

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Section B

Exploring service user and family member perspectives on ‘family recovery’: A qualitative study

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A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology

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Summary page

Section A: A systematic literature review

The aim of this review was to explore what research and models of family recovery have been developed in order to identify the core components of family recovery- the application of personal recovery ideas to families. Twelve papers were identified, four of which were empirical, the remaining six offering a descriptive model of family recovery. Family recovery reflected three key components: 1) how families promote the recovery outcomes of people with psychosis 2) the personal recovery needs of family members, and 3) promoting the recovery of the family system. The review recommends further research exploring family member perspectives on family recovery.

Section B: Empirical paper

Ten participants, six service users and four family members, took part in a qualitative research project exploring their perspectives on what family recovery meant to them. A mixed inductive/deductive thematic analysis was undertaken using the CHIME (connectedness, hope and optimism for the future, identity, meaning, and empowerment) components of personal recovery to explore their perspectives on family recovery. The CHIME model of recovery took on a particular family-orientated meaning. Connectedness centred on developing relationships within and outside of the family; hope related to hopes that their family would come or stay together; meaning and identity focussed on the roles that family members played within the family; and empowerment related to how families facilitated the personal recovery of their family member with psychosis and pursued their own recovery needs.

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Section A:

A systematic literature review of family recovery in psychosis

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Abstract

Introduction. Families play an important role in the clinical and personal recovery outcomes of people with lived experience of psychosis, yet they are also affected by their informal caregiving role. The contributions that families make to service user personal recovery outcomes, as well as to their own personal recovery journeys, has been referred to as ‘family recovery’. The aim of this review was to identify the core components of family recovery by reviewing the empirical research and existing models of family recovery.

Methods: A systematic literature review of peer reviewed published literature on family recovery was undertaken. Assia, CINAHL, psychinfo, Medline, and Web of Science bibliographic databases were searched.

Results: Twelve papers were identified that met inclusion criteria. These comprised eight descriptive models of family recovery and four empirical qualitative papers exploring staff and service user perspectives on family recovery. Family recovery reflected three key components: 1) how families promote the recovery outcomes of people with psychosis 2) the personal recovery needs of family members, and 3) promoting the recovery of the family system.

Conclusions: An understanding of the family experiences of recovery may help to facilitate improved personal recovery outcomes for families. However, the literature remains in its infancy and is hampered by a lack of empirical research. Implications for practice and further research are outlined.

Introduction

Psychosis has been broadly defined as losing contact with reality (Morrison, Renton, French, & Bentall, 2008) and can be associated with psychiatric diagnoses such as ‘schizophrenia’ and ‘bipolar affective disorder’. However, as a broad constellation of experiences, terms such as psychosis and diagnostic labels such as schizophrenia, are highly contested and significant debate continues as to the validity of these terms (Cooke, 2014), which some argue can imply a biomedical cause at the expense of psychosocial factors (Johnstone, 2000; Moncrieff, 2009). Throughout this review, terms such as psychosis and schizophrenia are used as labels by which to categorise a set of experiences and do not imply that they represent the existence of a disease entity. Furthermore, it acknowledges that the experiences of those with psychosis, and their family members, can also be understood from different perspectives which deliberately move beyond psychiatric terminology, such as a recovery perspective.

In exploring the prevalence of psychotic experiences, some argued that these experiences exist on a continuum (van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009), from transient and discrete psychotic experiences, to more persistent difficulties which affect cognition (e.g. deficits in speed of processing, attention, and concentration), thinking and perception (sometimes psychiatrically labelled as ‘delusions’ and ‘hallucinations’), affect (e.g. flat or blunted affect), and difficulties with motivation and daily functioning. As psychosis is reported to exist on a continuum, only some will meet a threshold which might require psychiatric support (van Os et al., 2009). One estimate suggests approximately 7.8 percent of the general population will meet this threshold, having an experience of psychosis before their 75th birthday (McGrath, et al., 2016). Research following a strict psychiatric definition of schizophrenia, argue that it is present in approximately 1 percent of the general population (Perälä et al, 2007).

The role of families in influencing the outcomes of people with psychosis

Research exploring factors associated with outcomes of those with psychosis suggest families play a significant role. Families can help identify the initial appearance of psychotic phenomena, help facilitate access to mental health services (Fridgen, et al., 2013; MacDonald, Fainman-Adelman, Anderson, & Iyer, 2018; O'Callaghan, et al., 2010) and identifying early indicators of relapse of significantly distressing experiences (Herz, et al., 2000).

More than four decades of research exploring 'expressed emotion' has shown that caregiving relationships characterised by high levels of criticism, hostility and/or emotional over-involvement are associated with an increased risk of relapse and rehospitalisation (Butzlaff & Hooley, 1998; Cechnicki, Bielańska, Hanuszkiewicz, & Daren, 2013). In contrast, warmth within family relationships appears to be protective against relapse within a first episode psychosis population (González-Pinto, et al., 2011; Lee, Barrowclough, & Lobban, 2014) and for those experiencing psychosis with longer-term needs (Bertrando, et al., 1992). Furthermore, positive family environments are associated with better functional outcomes, including quality of life and social adjustment, for people with ongoing experiences of psychosis (Greenberg, Knudsen, & Aschbrenner, 2006).

How are families affected?

Whilst families can influence the clinical outcomes of their relative experiencing psychosis, families are also affected by their informal caregiving role. Families report high levels of psychological distress (Kingston, Onwumere, Keen, Ruffell, & Kuipers, 2016; Poon, Harvey, Mackinnon, & Joubert, 2017), burden (Gupta, Solanki, Koolwai, & Gehlot, 2015) and poor quality of life (Caqueo-Urizar, Gutierrez-Maldonado, Miranda-Castillo, 2009; Gupta et al., 2015). Family members report emotional exhaustion, feelings of inadequacy, and express negativity towards the relative whom they care for, often known as 'carer

burnout' (Onwumere, et al., 2018). Family members also report feelings of grief and loss, alongside feelings of anger, despair, guilt, and shame (McCann, Lubman, & Clark, 2011; Patterson, Birchwood, & Cochrane, 2005; Riley, et al., 2010). There are also differential effects on the family, with different family members, such as siblings (Sin, Murrells, Spain, Norman, & Henderson, 2016) and spouses (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004), reporting unique challenges.

Finally, there is evidence suggesting that having a family member with psychosis can affect the family as a system. Research has shown that it can negatively impact family functioning, including reduced capacity to adapt to changing family circumstances, poorer family cohesion, higher levels of disengagement within relationships compared to before the appearance of psychotic symptoms, and poorer emotional connections (Gupta & Bowie., 2018; Koutra et al., 2014).

How are families supported? An overview of family focussed practice

Broadly defined, family focussed practice (FFP; sometimes called family inclusive or family sensitive practice) involves broadening the provision of care from a narrow focus on the individual with a mental health condition, to include the wider family and caregiver system (Foster, O'Brien, & Korhonen, 2012; Foster, et al., 2016). At the heart of FFP is a belief in adopting a 'whole family approach' (Figure 1). when supporting those with mental health needs (Foster, et al., 2016).

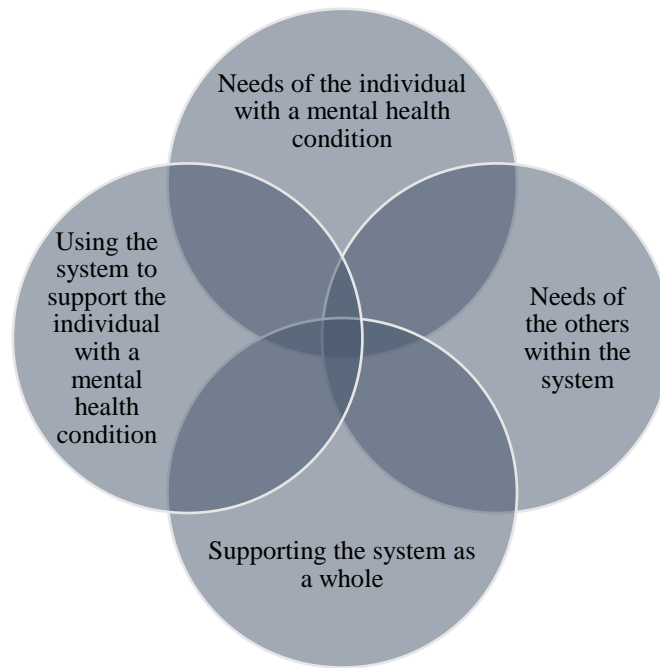


Figure 1. Overview of the whole family approach of family focussed practice adapted from Foster et al., (2016)

Yet FFP exists along a continuum (Dirik, et al., 2017), from providing basic advice and information, family and service liaison and family goal setting (Foster, et al., 2016), delivering complex psychosocial family interventions and therapy (McFarlane, 2016), to whole systems of care which can transcend the boundaries of families. In doing so, it takes a broad and inclusive approach to defining the family. A recent systematic review of family focussed practice for those experiencing psychosis identified three broad constellations of FFP models (Dirik, et al., 2017): 1) those adopting a diathesis-stress theory, 2) practices using systems theories and 3) models drawing on postmodernist theories.

Approaches using diathesis-stress theory largely used psychoeducative methods to influence the individual beliefs and behaviour of family members. In doing so, these approaches share a common focus on providing information about psychosis and wider services, altering problematic communication styles and appraisals around the causes and consequences of psychosis, and problem solving (McFarlane, 2016).

FFPs which draw on systems theories, generally conceptualise the family at a relational level, exploring how interactions within the family system shape its functioning (Cox & Paley; 1997; 2003). Professionals work with the whole family system to influence and alter interactions within the family and support improved function (Dirik, et al., 2017).

Postmodernist approaches to FFP have traditionally been seen to critique prevailing, largely biomedical, narratives of mental health conditions. These approaches have sought to position mental health conditions within a wider social framework, which are also seen as the source of possible solutions (Dirik, et al., 2017). This has largely been operationalised through the development of the Open Dialogue approach to acute psychosis, although this has also drawn on systemic and dialogical approaches (Seikkula & Olson, 2003).

Family inclusive practice: is there a role for recovery ideas?

Despite the proliferation of family-inclusive practices (Dirik, et al., 2017), there is a paucity of research exploring the potential relevance of personal recovery ideas as a framework for understanding the needs of families (Martin, Ridley, & Gillieatt, 2017; Wyder & Bland, 2014). In the context of supporting individuals, the personal recovery paradigm has become an important component of service design and delivery, and clinical practice (Anthony, 1993; Gilbert, Slade, Bird, Oduola, & Craig, 2013; Slade et al., 2014). Consequently, it has been argued recovery ideas have the potential to integrate the agenda of promoting family focussed practice with the existing recovery agenda within mental health services (Martin et al., 2017; Wyder & Bland, 2014). Before its potential relevance can be outlined, however, it is important to explore how recovery ideas have been defined.

What are recovery ideas?

Within the personal recovery literature, a distinction is often made between clinical and personal recovery. Clinical recovery is associated with symptom reduction, usually

assessed through the presence or absence of symptoms in a diagnostic checklist or symptom rating scale (Andreasen, et al., 2005; Jääskeläinen, et al., 2012). However, the personal recovery paradigm has emerged as an alternative means of understanding the experiences, aspirations, and outcomes of those experiencing mental health problems. Rooted in the emancipatory service user movement (Braslow, 2013), the personal recovery ethos represents a move away from clinical recovery to a more holistic, person-centred, individual, and subjective account of recovery (Slade, 2009). Since the 1990s personal recovery ideas have become an important organising framework for mental health service provision, professional practice, and research (Anthony, 1993; Gilburt et al, 2013; Slade et al., 2014).

Whilst definitions vary (Silverstein & Bellack, 2008; Warner, 2009), personal recovery from mental health problems has often been defined as a “deeply personal, unique process of changing one’s attitude, values, feelings, goals, skills, and/or roles...a way of living satisfying, hopeful, and contributing life, even with the limitations caused by illness” (Anthony, 1993). An influential systematic review of the personal recovery literature concluded there were often overlapping aspects to people’s accounts of their recovery journey (Leamy, Bird, Le Boutillier, & Williams, 2011). The review identified five key components, connectedness, hope and optimism for the future, identity, meaning, and empowerment, which has come to be known as the CHIME model of recovery. The components are outlined in greater detail in Table 1.

Table 1. *The 5 factor CHIME model (Leamy et al., 2011)*

Factor	Definition
Connectedness	Peer support and support groups; relationships; support from others; being part of the community
Hope and optimism	Belief in the possibility of recovery; motivation to change; hope inspiring relationships' positive thinking and valuing success; having dreams and aspirations
Identity	Dimensions of identity; redefining positive sense of self; overcoming stigma
Meaning	Meaning of mental illness experiences; spirituality; quality of life; meaningful life and social roles; rebuilding of life
Empowerment	Personal responsibility; control over life; involvement in decision-making; access to services and interventions; focussing upon strengths

Why take a recovery perspective for families?

Despite a range of governmental and national policy guidelines advocating the need to support families more (IRIS, 2012; National Collaboration for Mental Health, 2014; Worthington, Rooney, & Hannah, 2013), it has been argued the needs of families have been under acknowledged (Kuipers, 2010; Onwumere & Kuipers, 2017). Barriers to supporting families are complex and multifaceted (Eassom, Giacco, Dirik, & Priebe, 2014) and a recent review of barriers to family involvement highlighted a need for cultural change which better understands the needs of families (Martin et al., 2017). How then are families framed within the existing literature and what could the shift look like?

In reviewing how policy guidelines and research frames the needs of families, Bland and Foster (2012) argue families have largely been positioned in three ways 1) as potentially contributing to pathology through increasing the risk of relapse and inhibiting recovery 2) burdened through their caring responsibilities, and/or 3) obligated to support their relative in their role as informal carers. Consequently, this has led to an ambiguous understanding of families which can obscure their needs as well as the contributions they may make to their relative's wellbeing. In light of this, it has been argued 'family recovery' ideas have the potential to offer a framework for understanding the needs of families which move beyond

these unhelpful positions and allow families the opportunity to make meaning and explore their experiences together (Martin et al., 2017).

How might recovery ideas be relevant to the family?

If the recovery framework has the potential to capture the needs of families, including the person with psychosis, what evidence is there of its relevance? Whilst there is a paucity of direct research, there is indirect research which suggests it is of relevance. This research will be briefly reviewed, using the CHIME model to help organise the literature.

Connectedness. Some models of personal recovery see recovery as fundamentally embedded within, and actualised through, a network of interpersonal relationships (Topor, et al., 2006; Schön, Denhov, & Topor, 2009). In this context the family context can become a unique space in which a range of recovery needs can be met. Families can promote recovery by offering those with psychosis a sense of belonging and connection with people who are important to them (Piat, Sabetti, Fleury, Boyer, & Lesage, 2016) as well as emotional and practical support (Aldersey & Whiteley, 2015). Furthermore, those with psychosis can begin to enact roles within the family which transcend their 'illness role' through their position as a sibling, parent, or partner. There is also emerging research demonstrating that those with psychosis can contribute positively to family life, through reciprocal relationships including offering emotional and practical support (Allman, Cooke, Whitfield, & McCartney, 2018; Coldwell, Meddings, & Camic, 2011).

Notwithstanding these positive indications, it is important to note that for some people experiencing psychosis, family relationships can be difficult and problematic (Topor, et al., 2006; Young & Ensing, 1999). If the identity of family members with psychosis were largely defined by their psychosis, this could result in unhelpful linear service user-carer relationships within the family, whilst also fuelling resentment from family members who felt

obligated to offer help (Schön et al., 2009). Linear service user-carer relationships could have the effect of limiting the chances for more reciprocal, mutual, and enriching relationships which facilitate and sustain recovery (Schön et al., 2009).

Hope. Research exploring hope within a family context, highlights the important role it plays in sustaining the needs of family members (Bland & Darlington, 2002; Hernandez, et al., 2019). Furthermore, family members draw hope from the relationships they have within the family, as well as from those outside of it (Bland & Darlington, 2002) and holding on to a sense of hope has also been found to be associated with a reduction in subjective experiences of burden (Hernandez, et al., 2019). Yet families may also help to instil in their relative a sense of hope, including a steadfast belief in their ability to recover (Reupert, Maybery, Cox, & Stokes, 2015).

Identity and meaning. As mentioned earlier, it has been argued the family context allows those with psychosis to transcend an illness role to adopt other family roles, such as sibling, son/daughter, parent, or spouse (Reupert et al., 2015). This has been found to be particularly important in relation to the needs of parents who experience psychosis, who may see their identity as a parent, and their family life more broadly, as inseparable from their recovery journeys (Hine, Maybery, & Goodyear, 2019; Price-Robertson, Menderson, & Duff, 2017). Furthermore, family member's themselves may also experiences changes in their identity, which has been noted in parents (Milliken & Northcott, 2003), siblings (Newman, Simonds, & Billings, 2011) and the family as a system (Acero, Cano-Prous, Castellanos, Martín-Lanas, & Canga-Armayor, 2017).

Finally, family members can derive meaning from their experience of supporting their relative (Kulhara, Kate, Grover, & Nehra, 2012; Shiraishi & Reilley, 2018). This includes becoming more sensitive to persons with psychosis, clarity about their priorities in life, a

greater sense of inner strength, and they can experience a good relationship with their relative with psychosis.

Empowerment. A range of family interventions have been developed to reduce the effects of negative family relationships on the wellbeing of those with psychosis (McFarlane, 2016), but little research has explored how these interventions could maximise recovery (Glynn, Cohen, Dixon, & Niv, 2006; Gehart, 2012). Yet it has been suggested these interventions may be helpful in promoting whole family recovery through facilitating changes within the family system (Glynn et al., 2006).

The relevance of empowerment to family members may relate to their need to address their own mental health problems which can arise from their informal caregiver role (Gupta et al., 2015), to address social isolation (Hayes et al., 2015), and explore changes in self and relationships (Milliken & Northcott, 2003).

What do existing models of personal recovery say about families?

Despite research demonstrating the important role families play in promoting the recovery of people with psychosis (Topor, Borg, Di Girolamo, & Davidson, 2011; Topor, et al., 2006), recovery models themselves do not sufficiently discuss the recovery needs of others nor their role in facilitating the personal recovery of those with psychosis (Reupert et al., 2015). In part this may reflect how personal recovery models have historically developed. It has been suggested that early definitions of recovery placed an emphasis on the importance of autonomy and self-determination (Lefley, 1997) which perhaps obscured the relevance of others to the recovery process (Wyder & Bland, 2014). Indeed, Anthony's (1993) definition of recovery was seen to frame recovery as a “deeply *personal*” (italics added) process (Rose, 2014), which posited recovery as a largely *intra*-psychic experience, involving alterations in thoughts, beliefs, and feelings in order to transcend the limitations imposed by an illness

(Price-Robertson et al., 2017). In the context of service users attempting to define their own criteria for recovery, this placed an emphasis on the individual and self-defined nature of recovery. However, as research began to elucidate factors which underpinned and sustained recovery, friendships, professionals, and family members were found to play an important role in a person's recovery (Reupert et al., 2015; Schön et al., 2009; Topor et al., 2011). Consequently, some saw a conceptual change in recovery which saw recovery as a relational experience, such that recovery was framed as both an *inter* and *intra* personal process (Price-Robertson et al., 2017). In doing so, some recovery authors began to argue for the need to incorporate the experiences of others into recovery models (Reupert et al., 2015). Consequently, some have begun to see some aspects of recovery, particularly in the context of families, as a bi-directional process with family members and those with psychosis in part influencing each other's recovery journeys (Reupert, 2017).

Rationale and aims of the review

Despite the significant role that families play in the lives of their relative with psychosis and their own significant need, it is widely acknowledged that more needs to be done to support families of people living with psychosis (Kuipers, 2010; Onwumere & Kuipers, 2017) and seek their perspective on their needs and experience. This has led some authors to suggest that a recovery paradigm can be a useful way of understanding and supporting families, promoting both the recovery needs of the relative with psychosis, as well as the recovery needs of the family (Martin et al., 2017; Wyder & Bland, 2014). To this end, there is an emerging literature on understanding the experiences of families (including the person with psychosis) from a recovery perspective and extending recovery principles to the family, which some have referred to as 'family recovery' (Price-Robertson et al., 2017; Spaniol & Nelson, 2015; Spaniol, 2010; Wyder & Bland, 2014), relational recovery (Price-

Robertson, Obradovic, & Morgan, 2017), or family focussed recovery (Waller et al., 2019; Ward et al., 2017).

If personal recovery can be understood as a concept relevant to the experiences of families, there is a need to review the literature to understand how family recovery ideas have been developed and applied, including what family recovery models have been developed, and how family recovery experiences have been researched. To this end, the following section seeks to provide a systematic and narrative review of the literature on family recovery to:

- 1) Explore what models of family recovery have been developed
- 2) Review the research on ‘family recovery’
- 3) Identify the core components of family recovery

Methodology

Eligibility criteria

The review sought to identify papers which described or developed a model of family orientated understanding of recovery from psychosis, and/or empirically explored an aspect of family experiences of recovery. The inclusion and exclusion criteria are listed in Table 2.

Table 2. *Inclusion and exclusion criteria*

Inclusion criteria:

- Studies which sought to understand family recovery from the perspective of service users with experience of psychosis, family members, or staff perspectives on family recovery. Studies were also included if they did not explicitly set out to explore family recovery/recovery from a family perspective, but this had emerged as a concept from their research on recovery or family experiences of supporting a relative with psychosis.
- Empirical studies providing an original model or framework of family recovery.
- Empirical studies providing extractable data on components or measurements of family recovery.
- Articles containing a description or model of family recovery.

Exclusion criteria:

- Studies focussing on clinical or functional recovery (i.e. reduction in psychiatric symptoms or functioning)
 - Studies of theoretical models focussing on family recovery in the context of non-psychosis populations, e.g. substance misuse or brain injury
-

Search strategy

A systematic search of the literature for relevant articles published from the database inception until 19th January 2019 was performed, searching the following five bibliographic databases: Applied Social Science Index and Abstracts (ASSIA; accessed via EBSCOhost), CINAHL; MEDLINE (accessed via OVID), PsycINFO (accessed via OVID), and the Web of Science. Results were limited to peer-reviewed English language journals. Key words, titles, and abstract were searched using search terms listed in Table 3.

The development of the search terms was an iterative process, derived from a range of sources. Search terms were taken from the key terms and titles of the initial papers found exploring family recovery. The search terms from published literature reviews in related areas were also reviewed, including literature reviews of carer/family research in the context of psychosis (e.g. Jansen, Gleeson, Cotton., 2015), reviews of recovery research (e.g. Leamy et al., 2014), and reviews of recovery in the context of psychosis (e.g. Scheyett, DeLuca, & Morgan, 2013). Finally, supervisors were also consulted for appropriate terms and reviewed the final search terms.

The search terms formed three clusters to reflect the three key areas of the review (psychosis, families, and recovery). Specific subtypes of recovery (e.g. “family recovery”) were used to ensure papers which explicitly used these terms were identified. This was on the basis that papers may have included the terms ‘famil*’ and ‘recovery’ as separate words in their key terms/title/abstract yet weren’t exploring family recovery as an idea (e.g. family perspectives on personal recovery from psychosis).

Table 3. *Search terms*

Psychosis OR psycho* OR schizophren* OR paranoi* OR delusion* OR hallucination* OR hallucina* OR mental illness* OR severe mental illness*

AND

carer* OR famil* OR sibling* OR parent* OR relative* OR spouse* OR partner* OR mother* OR father* OR wives OR son* OR daughter* OR brother* OR sister* OR cousin* OR wife OR husband*

AND

recovery OR “family recovery” OR “relational recovery” OR “family focussed recovery”

Web-based searching. Google and Google scholar were also used to search for articles, using the terms ‘families, recovery and psychosis’, and ‘family recovery’.

Citation searching. Citation searching was employed. This involved identifying potential papers by searching the reference list of papers previously identified.

Data extraction

All identified papers were downloaded onto Mendeley. Following the removal of duplicates, papers were initially screened by title and abstract only against the eligibility criteria by the author. Inclusion of papers for full extraction was undertaken by the author and the lead supervisor separately. Disagreements between reviewers were discussed with the author and both supervisors.

Quality assessment tool

To assess the methodological quality of qualitative studies, the Critical Appraisal Skills Programme (CASP) quality assessment tool for qualitative studies was used (Critical Appraisal Skills Programme, 2019). This is a 10-item tool which covers three broad areas in relation to a study's methodological quality: 1) are the results valid? 2) What are the results? 3) Will the results help locally? All studies were rated by an independent researcher (trainee clinical psychologist) to ensure the studies were assessed accurately. Where there were disagreements these were discussed until a consensus was reached.

Results

Overview of search strategy results

A total of 1238 papers were identified from the initial combined database, citation tracking, and google scholar searches. This was reduced to 1015 after duplicates were removed. A total of 985 papers were excluded after being screened by title and abstract, with 30 articles downloaded for full review against the inclusion and exclusion criteria. A total of 12 papers were included in the final review. Figure 2 shows the PRISMA flow chart (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

A brief description of the literature characteristics will be outlined, an appraisal of the literature, and then the reporting of the synthesised findings outlining the key components of family recovery.

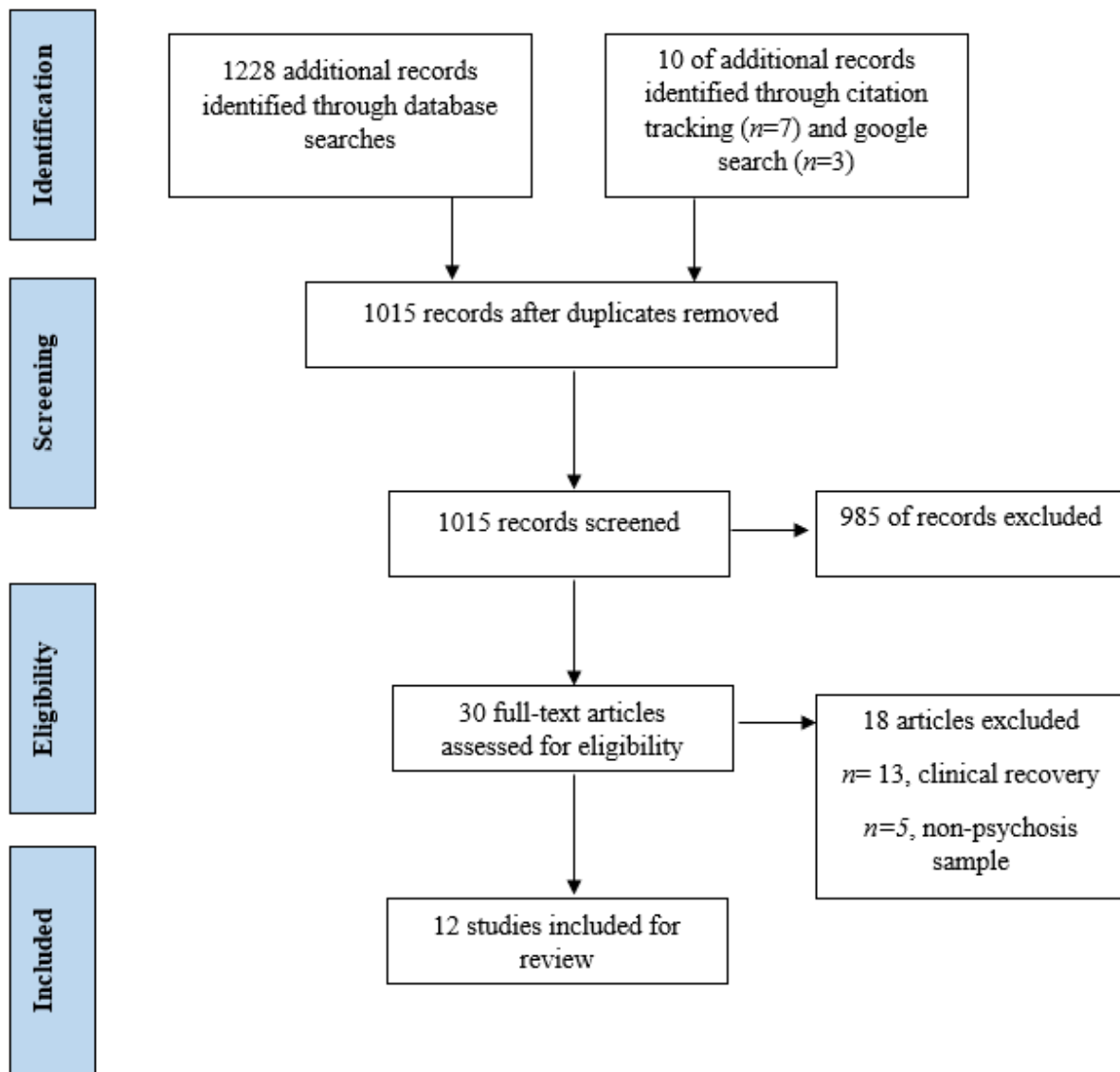


Figure 2. PRISMA diagram

Overview of papers found

Of the 12 identified papers, eight peer-reviewed articles containing models of family recovery were identified (Baxter & Diehl, 1998; Buckley-Walker, Crowe, Caputi, 2017; Chandler & Repper, 2011; Foster, Goodyear, Weiman, & Nicholson, 2019; Spaniol, 2010; Spaniol, & Nelson, 2015; Spaniol & Zippel, 1994; Wyder & Bland, 2014) and four peer-reviewed qualitative research articles (Foster & Isobel, 2018; Price-Robertson, Menderson, & Duff, 2017; Waller et al., 2018; Ward et al., 2017). The empirical papers provided service

user (Price-Robertson, Menderson, & Duff, 2017; Waller et al., 2018) and staff perspectives (Foster & Isobel, 2018; Ward et al., 2017) on family recovery and are presented in Table 5. The models of family recovery included a description of the key aspects of family recovery (see Table 4). The family recovery models were categorised into two groups: 1) phase-based approaches which saw family recovery unfolding over a series of non-linear stages (Baxter & Diehl, 1998; Spaniol 2010; Spaniol & Nelson, 2015; Spaniol & Zippel, 1994), and 2) process-based models which focussed on key recovery processes (Bukley-Walker et al., 2017; Chandler & Repper, 2011; Foster et al., 2019; Wyder & Bland, 2014).

Table 4. Overview of studies providing a model of family recovery

Study	Country	Type of model	Key components of the model
Baxter & Diehl (1998)	USA	Phase-based	Recovery for family members is defined as a transformative process of developing new meaning and purpose in their life in response to the ‘trauma’ of mental ‘illness’. This is achieved through a series of stages: 1) overcoming the shock of mental ‘illness’ and recognising their family member is in distress 2) coping by understanding that their relative’s psychosis may limit their life, altering expectations about goals, aspirations, and life, emotional catharsis including experiencing, guilt, grief, and anger 3) political advocacy by advocating for better services.
Buckley-Walker et al. (2017)	Australia	Process-based	Family recovery is defined as family members’ ability to live the lives they choose to live, which is consistent with their own values and goals, as well as striving to achieve their potential. Family recovery is comprised of two key components: personal and relational recovery. <ol style="list-style-type: none"> 1) Personal recovery is an <i>intrapersonal</i> process of feeling empowered to control one’s life, adapting one’s personal goals, clarifying values, alterations in one’s personal identity, and pursuing a meaningful life. 2) Relational recovery is an <i>interpersonal</i> process of developing relationships between the self and others. This involves developing meaningful and supportive relationships, connecting to one’s community, collaborating with others, and clarifying boundaries.
Chandler & Repper (2011)	UK	Process-based	Recovery is a shared experience between the person with psychosis, their family, and friends. Family recovery is a shared process of developing hope and empowerment together. Family relationships need to be underpinned by a sense of hope that the relationship will survive and that family members feel empowered to support each other.
Foster et al. (2019)	Australia	Process-based	Family recovery is a relational experience which emerges out of relationships within the family. Clinicians can therefore support families by: <ul style="list-style-type: none"> • Building relationships within the family system Identifying and promoting family strengths, the different valued family roles, and family hopes • Providing emotional and practical support, sign posting to relevant support agencies, and build relationships within the family • Providing psychoeducative material to help families feel empowered, develop shared plan to achieve family goals, leave families feeling hopeful.

Table 4 *Cont.*

Study	Country	Type of model	Key components of the model
Spaniol (2010)	USA	Phase-based	Family recovery is a painful, deeply emotional, yet ultimately transformative process of changing expectations, values, and attitudes, as well as a process of self-discovery, transformation, and renewal. Recovery unfolds over a series of four stages: 1) shock, discovery, and denial, 2) recognition and acceptance 3) coping, and 4) personal and political advocacy.
Spaniol & Nelson (2015)	USA	Phase-based	A further elaboration of the Spaniol (2010) model. Family recovery is facilitated through an acknowledgment of the emotional significance of having a relative with psychosis. This requires developing a good understanding of the mental health system, to overcome stigma, develop supportive relationships, and to move from feeling powerless to feel empowered.
Spaniol & Zippel (1994)	USA	Phase-based	<p>Family recovery is a transformative, yet deeply painful and emotional experience of changing one's expectations, values, and attitudes, as well as a process of self-discovery, transformation, and renewal. Family recovery occurs across four stages: 1) discovery/denial 2) recognition and acceptance 3) coping and 4) personal and political advocacy.</p> <p>Yet family recovery has six other characteristics: 1) recovery is a transforming process 2) experiences within the family differ 3) family members recover at their own rate 4) family members need to be aware of each other's phase of recovery 5) recovery is not linear 6) emotional reactions are a normal and understandable part of the recovery process.</p>
Wyder & Bland (2014)	Australia	Process-based	<p>Family recovery involves balancing multiple recovery needs and journeys including both the relative with psychosis and family members.</p> <ul style="list-style-type: none"> • Families can promote the personal recovery of their relative with psychosis through CHIME orientated 'recovery-promoting relationships' • The CHIME model is adapted to outline how family members experience their own personal recovery: connectedness focuses on promoting relationships within and outside of the family, hope relates to feeling hopeful for the future for themselves and their relative with psychosis; identity is framed in relation to developing relationships within the family which are not orientated around their relative's illness; meaning relates to pursuing activities which are important to the family and family members, and empowerment centres on feeling able to pursue these tasks • Families as a system navigate four recovery tasks: 1) overcoming secondary trauma 2) reconnecting 3) maintaining hope 4) moving from carer to family

Table 5. *Overview of empirical studies*

Study	Country	Methodology	N	Sample	Study aims	Key study findings	CASP score
Foster & Isobel (2017)	Australia	Individual interviews using thematic analysis	20	Staff	To explore staff perspectives on using family rooms in inpatient settings to promote family recovery	Promoting family recovery within an inpatient context is constrained through balancing risk and safety, but staff found it helpful to use family rooms as a space to hold family meetings. Key to staff perceptions of family recovery was the need to facilitate family connectedness.	12
Price-Robertson et al. (2017)	Australia	Individual interviews using ethnographic method	33	Service users	To explore how family life enables and impedes the recovery of fathers with psychosis.	Service users found it impossible to separate their own recovery experiences from the processes of family life. Family recovery is an emotional process which arises from relational processes linked to family life (attending a daughter's birthday, going on family trips); personal identity is inherently linked to service user's family whereby they derive meaning and value from their role within the family system; family recovery is a shared experience (dubbed 'distributive management') such that family life is organised to promote recovery and limit the chance of relapse.	11
Waller et al. (2017)	Australia	Individual interviews using thematic analysis	12	Service users	To explore the meaning of family recovery from the perspective of those with lived experience of psychosis.	Some service users felt that their family was important to their recovery, offering emotional and practical support, and adding meaning to their life. Service users reported that it was important that services support family members in their recovery.	13
Ward et al. (2017)	Australia	Individual interviews using thematic analysis	11	Staff	To explore staff perspectives on family-focussed practice within a recovery framework	Staff could not articulate how recovery ideas could be used in family-focussed practice. However, staff reported importance of helping to improve relationships and help families to feel empowered, primarily through the use of psychoeducation and holding family meetings.	13

Assessment of methodological quality

The CASP appraisal criteria were applied to the four empirical studies (see appendix A). Owing to the conceptual nature of the models of family recovery, no appraisal tool could be used to assess their quality.

Broadly speaking the studies obtained similar overall scores. Aims were generally clearly stated with an appropriate qualitative methodology and research design used. All four studies were rated as poor in how they reported their recruitment process with little information given as to how participants were recruited, levels of uptake, or barriers to recruitment. There was limited information across all studies on how rigorously the data were collected. Foster and Isobel (2017), Price-Robertson et al. (2017), and Ward et al. (2017) only made passing reference to how data were analysed, what methodology was used, and steps taken to ensure the process was rigorous. Similarly, only passing reference was made to ethical approval having been granted from a university. There was no consideration of the research relationship between the authors and the project. Studies offered a clear statement of findings which were of clear value.

In describing the development of the models of family recovery, all the models failed to provide a robust method by which the components were determined. Of the phase-based models, there was little discussion of how the different phases were developed, with little discussion of the relevant research on the needs of families who have a relative with psychosis, nor the wider literature on recovery. In comparison, some of the process-based models drew on well-established theories of recovery to help form the content of their models. Chandler & Repper (2011) and Wyder and Bland (2014) adapted the well-established and empirically validated CHIME model to inform their model of family recovery. Similarly, Buckley-Walker et al. (2017) drew on the CHIME model and other well-established explanations of recovery by Davidson (2003) to inform their model. Foster et al.

(2019) drew on a recently developed relational-recovery framework (Price-Robertson, Obradovic, & Morgan, 2017) to help guide their components of family recovery. However, this model lacks much empirical validation (Price-Robertson, Menderson, Duff, 2017).

Synthesis of findings

To develop an initial synthesis of the findings, each paper was summarised. This included identifying the methodology of the paper (whether the studies were descriptive or empirical in nature), description of participants, the key study questions/aims, and the paper's primary outcome or finding. Initial patterns were identified in terms of the nature of the papers (i.e. descriptive models of family recovery vs empirical research into family recovery), papers which focussed on the experiences of staff or service users, and an emerging sense of family recovery having multiple components which varied according to who within the family was being considered.

The relationships between the papers and their findings were then explored to develop the initial core components of family recovery. This was achieved by grouping the findings according to patterns within the studies' findings. To help characterise the findings further, it was then noted whether the components had their basis in empirical research and/or theoretical models.

The final synthesis involved incorporating the initial observation that different papers explored family recovery from different perspectives within the family. Prior to this, the core components of family recovery amounted to a list of synthesised findings. Consequently, organising the core components by the superordinate categories of 'promoting the recovery of the relative with psychosis', 'promoting the recovery of family members', and 'promoting the recovery of the family as a whole' allowed for more meaningful and helpful distinctions to be made around what the core components of family recovery could be.

What are the core components of family recovery?

In carrying out a narrative synthesis of both the empirical and conceptual literature, the author organised the core components of family recovery into three categories: 1) the family as a space for promoting the recovery of service users 2) promoting the recovery of family members 3) promoting the recovery needs of the family as a whole. These components are summarised in Table 6 below.

Table 6. *Summary of models and research on family recovery*

Components of family recovery	Support from models of family recovery	Support from empirical papers	Core components
Promoting the recovery of the relative with psychosis		✓	Families promote recovery by offering emotional and practical support (Waller et al., 2018, Ward et al., 2017)
		✓	Service users derive meaning from their families (Waller et al., 2018) and value the opportunity to connect with meaningful non-illness related family roles, such as being a parent (Price-Robertson et al., 2017).
	✓		Family members can support the recovery of their family member by developing 'recovery promoting relationships' (Wyder & Bland, 2014) including 'learning to "let go" of trying to "fix" (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015).
Promoting the recovery of family members	✓		Developing awareness of their own needs (Baxter & Diehl, 1998; Buckley-Walker et al., 2017; Spaniol 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994).
		✓	Addressing practical needs such as learning about mental illness and mental health services (Baxter & Diehl, 1998; Foster et al., 2019; Spaniol, 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994; Wyder & Bland, 2014) and developing skills to support their own wellbeing and to cope with the challenges of their relative's mental illness (Baxter & Diehl, 1998; Spaniol, 1994; 2010; 2015; Wyder & Bland, 2014).
		✓	Addressing psychological needs such as overcoming feelings of loss and grief for their relative's life and their own, and allowing an emotional catharsis (Baxter & Diehl, 1998; Buckley-Walker et al., 2017; Spaniol 2010; Spaniol & Nelson, 2015; Wyder & Bland, 2014).
		✓	Addressing recovery needs, such as connecting with their own values and aspirations, exploring alterations in identity, pursuing meaning, and moving beyond a carer role (Buckley-Walker et al., 2017; Wyder & Bland, 2014).

Table 6 *cont.*

Components of family recovery	Support from models of family recovery	Support from empirical papers	Core components
Promoting the recovery of the family as a whole	✓	✓	Promoting family connectedness (Foster & Isobel, 2017; Ward et al., 2017; Waller et al., 2019; Wyder & Bland, 2014)
	✓	✓	Developing relationships within the family which transcended an ‘illness’ or caregiving role (Price-Robertson et al., 2017; Wyder & Bland, 2014)
	✓		Promoting hope (Chandler, & Repper, 2011; Foster et al., 2019; Wyder & Bland, 2014)

The family as a space for promoting the personal recovery of service users. Some of the family recovery literature focussed primarily on promoting the recovery needs of service users through the support of the family. In part this literature focussed on parents (Price-Robertson et al., 2017), although not exclusively (Waller et al., 2018; Ward et al., 2017; Wyder & Bland, 2014). This literature saw the family context as inseparable to the recovery needs and journeys of service users. This context was broadly defined in two ways: 1) family members provide instrumental support to their relative by offering practical and emotional support, 2) family life as a space for personal recovery to unfold.

In relation to providing practical support, empirical literature from both staff and service users highlighted how families may offer important instrumental support, such as encouragement, practical help (e.g. attending appointments etc), and emotional support (Waller et al., 2018; Ward et al., 2017). Yet service users also acknowledged how family life could potentially impede recovery, particularly if they felt families were overinvolved or dismissive of their aspirations (Waller et al., 2018).

Wyder and Bland (2014) offered a systematic framework for outlining how families could promote the recovery journeys of their relative. Key to this were what Wyder and Bland (2014) called ‘recovery-promoting relationships.’ Drawing on the CHIME model as a framework, they argue families can help service users to develop a sense of connection and belonging within the family, as well as help facilitate access to other relationships within the wider community. Family members could help promote and hold a sense of hope for the future, acknowledging strengths and progress. A positive sense of identity can be developed through developing a relationship with their relative such that their mental health problems only became one aspect of their relationship. Families can promote their relative’s sense of meaning by helping them access activities which provide it. Empowerment relates to navigating responsibility between family members and their relative. This may involve family members ‘letting go of trying to fix their relative’ (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015; Wyder & Bland, 2014).

Yet family life took on a broader meaning in some of the models and empirical research. For some, the family offered participants meaning, and their relationships with family members were profoundly important to them (Price-Robertson et al., 2017; Waller et al., 2018). The family space allowed those with psychosis to enact non-illness related roles within the family system (parent) which allowed them to make positive contributions to family life (Price-Robertson et al., 2017). For some service users, their hope for the future was orientated around family life, such as wanting to celebrate family events together, being a good parent, or helping their family members to succeed and progress in their life (Price-Robertson et al., 2017). The responsibility for their personal recovery was seen as shared, what Price-Robertson et al (2017) termed ‘distributed management’. This meant family life, such as a child care and work, was organised in such a way as to maximise recovery whilst reducing the possibility of external pressures triggering a possible relapse. For example, a

mother working full time to allow her husband (who experiences psychosis) to concentrate on fathering and avoid the stress of working life which could negatively impact on his mental health (Price-Robertson et al., 2017).

Promoting the recovery of family members. None of the empirical literature directly explored the recovery experiences or outcomes of family members themselves. However, papers exploring the perspective of service users and staff acknowledged the importance of supporting the emotional and personal recovery needs of family members (Price-Robertson et al., 2017; Waller et al., 2018; Ward et al., 2017). This was consistent with the conceptual models which all argued family members should be supported in their own recovery (Baxter & Diehl, 1998; Buckley-Walker, Caputi, Crowe, 2017; Spaniol, 2010; Spaniol & Nelson, 2015; Wyder & Bland, 2014). Fundamental to all of the models was helping family members to develop an awareness of their own needs which were argued to be often overlooked or downplayed as family members primarily focussed on the needs of their relatives (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994;). The needs of family members were framed in three ways 1) practical needs 2) psychological needs and 3) personal recovery needs.

Practical needs were largely framed in relation to psychoeducation about mental health problems and how to access support (such as carer groups and mental health service) and developing practical coping strategies for managing their own wellbeing (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994; Wyder & Bland, 2014). This was corroborated by staff who found helping educate family members about mental health problems to be a key way of working with families (Ward et al., 2017).

Both phased based models (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015) and process-based models (Buckley-Walker, et al., 2017; Wyder & Bland, 2014) argued family members may need to address a range of psychological needs. In particular

addressing the potential trauma of having a family member with psychosis, addressing feelings of loss and grief for both their own and their relative's life, and experiencing an emotional catharsis. This recognises the possibility for suffering and pain as a part of the process of recovery.

In outlining the personal recovery needs of family members, the family recovery models outlined several different key components. All models were premised on a belief that a relative developing psychosis offered an opportunity for family members to reflect on themselves and explore meaning in their life, such that recovery could be an inherently transformative process (Baxter & Diehl, 1998; Buckley-Walker et al., 2017; Spaniol, 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994; Wyder & Bland). The personal recovery needs of family members could be organised into two categories of 1) interpersonal recovery needs and 2) intrapersonal recovery needs.

Interpersonal recovery needs focus on the relational aspect of the recovery journey. All family recovery models acknowledged the importance of relationships to the needs of family members. Relationships could be considered those which are helpful and supportive, which may be embedded within a shared experience such as attending carer groups (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015), or based on existing family relationships or friendships. This may also involve reorientating family members' relationships with their relative with psychosis, moving between a caring to a family relationship based on mutuality and reciprocity (Wyder & Bland), as well as establishing clarity around boundaries (Baxter & Diehl, 1998; Buckley-Walker, Caputi, Crowe, 2017; Spaniol, 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994).

Intrapersonal recovery processes may focus on the different aspects of a family member's sense of self which may, or may not, change following a relative developing

psychosis. Wyder and Bland (2014) adapted the CHIME model as a framework for understanding the personal recovery needs of family members, offering a systematic overview of recovery for family members which is outlined in Table 8 below. Wyder & Bland (2014) offered the only model to emphasise hope, whilst the remaining models saw it as exploring identity and deriving meaning from the experience of supporting a relative with psychosis. This could include identifying personal strengths, clarifying personal values, exercising control over one's life, and pursuing a life which is meaningful and enjoyable (Baxter & Diehl, 1998; Buckley-Walker, Caputi, Crowe, 2017; Spaniol, 2010; Spaniol & Nelson, 2015; Spaniol & Zippel, 1994).

Table 7. *Adapting the CHIME model to understand the recovery needs of families taken from Wyder & Bland (2014)*

CHIME principles of recovery	Families' recovery: central elements
Connectedness	Relationships and support from others; Peer support and support groups; being part of the community
Hope and optimism about the future	Maintaining hope for themselves; maintaining dreams and aspirations for themselves
Identity	Redefining their caring role as simply one aspect of their life; overcoming own sense of stigma, guilt and shame
Meaning in life	Balancing the limitations imposed by their caring responsibilities with their goals for their own life; expanding their social role beyond that of being a carer to occupy normal, functional social roles and activities; pursuing and achieving new life goals; spirituality; making worthwhile contributions to a community of one's choice
Empowerment	Assuming control of own lives and developing a life that extends beyond their caring role; learning to manage own levels of distress; feeling empowered to change their and their loved one's situation

Promoting the recovery needs of the family as a whole. The empirical research on family recovery acknowledged supporting the family as a system, which went beyond the individual needs of family members or relatives (Foster & Isobel, 2018; Waller et al., 2017; Ward et al., 2019). This was also reflected in two models of family recovery offered by Wyder and Bland (2014) and Chandler & Repper (2011). Within the empirical literature, both staff and service users spoke of the importance of promoting a sense of family connectedness (Foster & Isobel, 2018; Foster et al., 2019; Waller et al., 2018; Ward et al., 2017). This was achieved by promoting family relationships, facilitating the family's ability to communicate with one another, helping them to pursue family events which helped foster a sense of a shared identity, and developing family orientated goals (Foster & Isobel, 2018).

Promoting the recovery of the family as a whole was also implicit in the Wyder and Bland's (2014) idea of 'recovery promoting relationships.' For example, identity was framed in relation to family members and service users developing relationships whereby the relative's mental illness and the family member's caregiving role only became one aspect of their relationship. Furthermore, empowerment became a shared endeavour whereby family members shared responsibility for their relative's wellbeing, which echoed Price-Robertson, Menderson, and Duff's (2017) notion of 'distributive management'.

This dynamic and inter-dependent framing of recovery was justified for some in framing recovery as a relational process, rather than a journey to be pursued by an individual. This was perhaps made most explicit by Chandler and Repper (2011) who located the experience of recovery in the social context of people's lives and embodied relationships. Consequently, family recovery was largely seen as a shared experience that emerges out of mutually sustaining relationships.

The inter-dependent nature of family recovery was also apparent in Wyder and Bland's (2014) four family recovery tasks: 1) maintaining hope 2) reconnecting 3)

overcoming secondary trauma 4) journeying from carer to family. Hope related to family members and service users holding on to a belief that the family would survive and stay together, in the face of a potentially traumatic experience of having a family member develop psychosis ('overcoming secondary trauma'). At the heart of family recovery is the importance of family relationships ('reconnecting') which involve balancing multiple types of relationships, which are flexible enough to provide support when needed but not to be defined by this caregiving role (moving from carer to family).

Discussion

This review explored what models and research have been undertaken on 'family recovery' to help elucidate its core components. Two sets of models were identified, conceptualising family recovery as either process-based or phase-based. Only four studies empirically explored family recovery, however, this was only from the perspective of staff and service users; family members themselves were noticeably absent, which represents a significant gap within the literature. In reviewing the available literature, 'family recovery' is a broad term encompassing a range of different needs within the family system, including how to promote the personal recovery of the person experiencing psychosis, supporting the recovery of family members, and promoting the recovery of the family as a whole.

Given the variation in the different components of family recovery, these findings should be interpreted with caution. Many of the key components were derived from conceptual papers lacking a robust methodology for determining the core principles which fundamentally lack empirical validation. This calls into question the validity of the components outlined in this review. Furthermore, the papers were largely developed in the USA and Australia and failed to acknowledge the possibility of cultural differences, which have been explored in the wider personal recovery literature (Tse & Ng, 2014; Tuffour, Simpson, & Reynolds, 2019). Whilst this review has provided some conceptual distinctions

which were hitherto lacking in the literature, the core components outlined here should only be seen as tentative or preliminary expressions of what family recovery may consist of, given the lack of empirical evidence present in the literature and the methodological weaknesses of the conceptual papers. Therefore, there is an urgent need to undertake further research to explore the experiences of families, to understand their perspectives on the content of family recovery.

Family recovery and the wider literature on families and psychosis

Much of the clinical and research literature on the role families play in the outcomes of those with psychosis has focussed on their role in influencing clinical outcomes (Cechnicki et al., 2013), whilst interventions designed to support the needs of the family have largely focussed on reducing expressed emotion to reduce distress and the chances of relapse in people with psychosis. Notwithstanding the importance of reducing distress for service users and families, it is important to note that this only focusses on one aspect of families' experiences (Kulhara et al., 2014). It is possible, therefore, that a family recovery framework may offer a non-pathologizing framework which moves away from deficits towards strengths (Bland & Foster, 2012). As recovery ideas have been seen as a potentially useful framework for supporting family interventions in psychosis, including promoting systemic change (Gehart, 2012; Glynn et al., 2006) there is potential for a family recovery framework to support the development of recovery orientated family interventions.

One significant contribution of the family recovery literature to the wider recovery literature is the extension of recovery ideas to the individual needs of family members. So far, the wider recovery literature has largely focussed on the needs of service users (Leamy et al., 2011; Slade, 2009). Yet the family recovery literature is hampered by a lack of empirical research into the personal recovery experiences of family members; at present there are only anecdotal accounts of recovery from family member's perspectives (Chandler, Bradstreet,

Hayward, et al., 2013; Parr, 2009). Yet like the wider recovery literature (Mead & Copeland, 2000), family member experiences are likely to vary. Whilst there was some acknowledgement that the experiences of family recovery may vary within the family (Spaniol, 1994; Wyder & Bland, 2014), there was little attempt to explore how experiences may be different and how this is reflected in their models. Yet evidence from the wider literature on psychosis and families suggests the experiences within families vary greatly. For example, whilst siblings report similar levels of carer burden, grief-reactions, and psychological distress in comparison to parents (Patterson et al., 2005; Sin et al., 2017), siblings express specific concerns in relation to survivor guilt, concerns around heritability of psychosis, pressure to provide support, altered roles within the family unit, and can report poorer quality of relationship with their sibling who is experiencing psychosis (Bowman et al., 2014; Sin et al., 2016). This underscores the need for possible family recovery models or research to acknowledge the differing needs and experiences of family members, and how recovery ideas could be used to support them. In particular, some family recovery models used the CHIME model as a framework for families, yet this remains unsubstantiated against the experiences of families. If the CHIME model was to be used it would need to consider some of the criticism of this model of recovery, in particular whether it completely describes the recovery process, emphasising the positive experiences of recovery at the expense of more negative experiences (Stuart, Tansey, & Quayle, 2016). This is important as some family recovery models (e.g. Spaniol & Nelson, 2015) emphasise the importance of recovery as a deeply painful experience.

In reviewing the papers, the models and empirical papers provided little insight into how family recovery may unfold over time, although the phase-based models suggest the phases are non-linear, implying change over time (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015). Examining change over time may be important as evidence

suggests the wellbeing of family members can vary, with distress peaking during the early phase of the condition (Jansen, Gleeson, & Cotton, 2015; Sadath, Muralidhar, Varambally, Gangadhar, & Rose, 2017). Consequently, family members may have different recovery needs depending on how long they have been supporting a relative with psychosis. As suggested by Buckley-Walker et al. (2017), the early stages of family recovery may need to focus on stabilisation and the provision of practical support, before families can engage with their personal recovery journey, should they need to.

The family as a particular context where recovery unfolds

The family recovery literature suggests the family may be a unique context where recovery could unfold. The literature exploring how families promote the recovery of people with psychosis has largely focussed on the instrumental and emotional support they provide (Aldersey & Whitley, 2015). Whilst one paper acknowledged this (Waller et al., 2018), the work of Price-Robertson et al. (2017) focussed on how recovery is promoted through their wider role within the family and their contribution to family life. There is an emerging literature exploring how family members with psychosis contribute positively to family life, but this can be overlooked by clinicians (Allman et al., 2018; Coldwell et al 2011). This suggests that in thinking about how families promote recovery, the focus may need to broaden to include not just the instrumental role that families play in the recovery of their relative with psychosis, but also how the personal recovery of those with psychosis is facilitated through their role and contribution to family life.

Promoting positive interaction within the family may also have additional benefits, in particular increased caregiver gains. There is some evidence to suggest how much help a parent provided to their relative significantly correlated with the amount of assistance the relative provided to the parent, which suggests the importance of promoting reciprocity within family relationships (Aschbrenner, Greenberg, Allen, & Seltzer, 2010). This in turn

may be significant as quality interaction between family members may be protective against a re-emergence of distressing psychotic experiences and rehospitalisation (González-Pinto, et al., 2011; Lee et al., 2014). Furthermore, there is also evidence to suggest the likelihood of sibling-carers to provide long term support may be influenced by the quality of their sibling relationship and positive experience of personal caregiving gains (Smith, Greenberg, & Seltzer, 2007).

Family recovery may also be relevant in understanding the positive experiences of caregiving (Kulhara et al., 2012). A family recovery approach may be helpful in explore how family members derive meaning from their experiences and how this may influence their priorities and values in life (Kulhara et al., 2012). Furthermore, a family recovery framework may also explore and emphasise family strengths and resilience, such as how family relationships may help to promote and sustain feelings of hope (Bland & Darlington, 2002) as well as the opportunity to recognise the contributions those with psychosis can make to their families (Allman et al., 2018).

Supporting the recovery of the family system

The family recovery literature also begins to explore the wider family system. Perhaps understandably, this is related primarily to the quality of relationships within the family system and the need to develop a sense of family connectedness. There is research which suggests families can struggle with reduced flexibility within the system, the capacity to adapt to changing family circumstances (Gupta & Bowie, 2018; Koutra et al., 2014). Whilst family interventions in psychosis (FIP, McFarlane, 2016) may help promote family relationships, only limited evidence exists on how they promote recovery outcomes which is largely from the perspective of service users (Allen, Burbach, & Reibstein, 2013). Yet the recovery benefits of FIP may extend to other areas of family recovery, such as helping to promote a shared family identity (Acero et al., 2017), facilitate a shared sense of meaning,

and help family members to balance their own recovery needs with those of their relative (Wyder & Bland, 2014).

Limitations

The small number of papers which were largely conceptual limits the ability to draw strong conclusions about the core components of family recovery. The absence of formal tools to assess the methodological quality of the descriptive models of family recovery means that a judgment cannot be made about the quality of these models. The use of the CASP tool also has some limitations. The absence of clear criteria for scoring each item means scoring can feel subjective and arbitrary, calling into question the accuracy of the scoring, although this was somewhat mitigated through the use of a second scorer.

It is possible papers were missed as only a selection of databases were used. Whilst the search terms could have been broadened to search, this was not possible owing to the large number of articles that this would have returned. Future reviews may wish to do a more exhaustive search of all aspects of recovery for family members, based on the individual components of the CHIME model.

Implications for practice

Whilst the personal recovery movement has become significant within the theory and practice of clinical psychology, particularly when working with people lived experiences of diagnoses of psychosis and schizophrenia (Brabban, Byrne, Longden, & Morrison, 2017; Hamm, Hasson- Ohayon, Kukla, & Lysaker, 2013; Hodgkins & Fowler, 2010), its relevance to families has largely been overlooked. Theoretical models of carer and family distress largely focus on the role that specific cognitive appraisals play in the maintenance of distress (Kuipers, Onwumere, & Bebbington, 2010) yet this could be expanded to explore the role of specific recovery related beliefs.

As recovery ideas become important for service design and development (Slade, et al., 2014), family recovery ideas have the potential to ensure families are included in this development. Yet concerns have been raised about how families have been framed within existing policy and practice guidelines (Bland & Foster, 2012), namely that families are seen as either contributing to mental health problems, burdened, or obligated to support relatives with psychosis which has created an ambiguous understanding of the role of the family in some aspects of practice and policy. Family recovery ideas may have the opportunity to open discussions around the experiences and needs of families, which recognises the diversity of family experiences (Bland & Foster, 2012). As Chandler and Repper (2011) argue this would afford families the agency to describe and define their experiences and needs.

Despite commentary highlighting the potential relevance of recovery ideas to family interventions in psychosis (Allen et al., 2013; Gehart, 2012; Glynn, et al., 2006), there is a paucity of research on how recovery ideas could be applied. Further research could explore the relevance of recovery ideas to family interventions in psychosis, which includes the recovery needs of both service users and families, given there is some preliminary evidence suggesting family interventions are helpful for service user personal recovery (Allen et al., 2013).

Further research

The different models outlined in the review represents an emerging literature exploring the relevance of recovery to the family, which some have begun to call ‘family recovery’. Given the findings of this review, including the limitations outlined above, further research in family recovery processes are indicated.

To support the development of our understanding of family recovery, further research into the experiences of family members from a recovery perspective is needed. Importantly,

the experiences of a range of family members (e.g. siblings, partners) and different ethnic groups should be explored to ensure this reflects the experiences of all family members. Furthermore, as some models argue for the inclusion of the experiences of the service user into family recovery models (e.g. Wyder and Bland, 2014), further research would need to ensure their voices are included.

The models and research undertaken so far have focussed on the content of what they believe to be key components of family recovery. However, it is unclear whether they reflect the experiences of families. Furthermore, there is little research exploring how the processes unfold, for example how is the experience of navigating empowerment experienced by families?

At present there is little research exploring what might facilitate family recovery. This has relevance to how systems of support and specific interventions could be designed or developed to address the recovery needs of families. Consequently, further research could explore how family orientated interventions facilitate or impede family recovery.

The research conducted so far has focussed on qualitative accounts of family recovery. The literature could be developed further through quantitative research such as the use of a Delphi methodology (Okoli & Pawlowski, 2004) to explore the perspective of clinicians, researchers, service users and family members on what they believe to be the core components.

Conclusion

As families and those living with psychosis face multiple challenges, the family recovery literature is beginning to offer a framework which moves beyond a focus on clinical outcomes for families, yet the literature remains in its infancy. Identifying and understanding the needs of families from a recovery perspective may be important to understanding how

this framework can be advanced to help facilitate improved outcomes for those with psychosis and their families.

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Section B

Exploring service user and family member perspectives on ‘family recovery’: A
qualitative study

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Abstract

Aims: Families have been shown to influence the clinical and personal recovery outcomes of family members with psychosis, yet they too can also be profoundly affected as a result of their informal caregiving roles. Given the close relationships between families and their relative with psychosis, there is emerging literature extending recovery ideas to the family, which some have called ‘family recovery’. However, there is a paucity of research directly exploring the experiences and perspectives of families on what family recovery may mean. This study used the CHIME (connectedness, hope and optimism for the future, identity, meaning, and empowerment) model of personal recovery (Leamy et al., 2011, pp 445-452) to explore accounts of ‘family recovery’.

Methods: Six participants with lived experience of psychosis, and 4 family members were interviewed. A mixed inductive/deductive thematic analysis was undertaken using the CHIME components of personal recovery as a framework for understanding ‘family recovery’ narratives.

Results: The CHIME model of recovery took on a particular family-orientated meaning. Connectedness centred on developing relationships within and outside of the family; hope related to hopes that their family would come/stay together; meaning and identity focussed on the role’s family members played within the family; and empowerment related to how families facilitated the personal recovery of their family member with psychosis and pursued their own recovery needs.

Conclusion: The study found that the CHIME model was a useful framework for exploring ‘family recovery’ albeit with the core components taking on a family-orientated meaning.

Introduction

Towards a family perspective in personal recovery models

Research exploring the epidemiology of psychosis suggests approximately 7.8 percent of the general population will have an experience of psychosis before their 75th birthday (McGrath, et al., 2016) and 1 percent of the population will receive a diagnosis of schizophrenia (Perälä et al., 2007). Whilst research and clinical practice has traditionally focussed on exploring clinical (i.e. symptom reduction) and functional (e.g. employment or educational) outcomes of those with psychosis, the personal recovery paradigm (e.g. Anthony, 1993; Leamy, Bird, Le Boutillier, & Williams, 2011) has been seen by some to offer an alternative framework for understanding the needs, aspirations, and outcomes of people with psychosis. Whilst definitions vary, it has been argued ‘personal recovery’ encompasses a more holistic, person-centred, and subjective definition of recovery, which ultimately involves pursuing a meaningful life even with the limitations caused by illness (Anthony, 1993). In reviewing the lived experience of service users’ personal recovery and a range of different models of personal recovery, Leamy and colleagues (2011) developed the CHIME model of recovery which conceptualised personal recovery as unfolding over five domains: connectedness, hope and optimism for the future, identity, meaning, and empowerment (see Table 1).

Whilst the CHIME model has become a key framework for understanding personal recovery, several limitations have been identified. One line of critique has focussed on the empirical basis of the CHIME model. A systematic review by Stuart, Tansey, and Quayle (2016) explored whether the CHIME was a ‘best fit’ against the personal recovery accounts of service users. Whilst the model accurately captured 70% of service user personal recovery narratives, the model often missed the practical, emotional, and financial difficulties people experiences, the importance of support from professionals, accepting limitations, having

patience, and learning to focus their attention on the present, not the past or future, and finally a wish by some to return to, or desiring, normality. Scepticism around the concept of recovery has become a key critique of some service users. Concerns have been raised about the professionalisation of the term which undermines its origins within the emancipatory service user movement (Rose, 2014). Finally, some have critiqued CHIME for the individualisation of the framework, often decontextualizing recovery from wider social, economic, and relational contexts (Harper & Speed, 2014; Price-Robertson, Obradovic, & Morgan, 2017).

Table 1. *The 5 factor CHIME model (Leamy et al., 2011)*

Factor	Definition
Connectedness	Peer support and support groups; relationships; support from others; being part of the community
Hope and optimism	Belief in the possibility of recovery; motivation to change; hope inspiring relationships, positive thinking and valuing success; having dreams and aspirations
Identity	Dimensions of identity; redefining positive sense of self; overcoming stigma
Meaning	Meaning of mental illness experiences; spirituality; quality of life; meaningful life and social roles; rebuilding of life
Empowerment	Personal responsibility; control over life; involvement in decision-making; access to services and interventions; focussing upon strengths

Despite the personal recovery paradigm becoming an important part of clinical practice (Brabban, Byrne, Longden, & Morrison, 2017; Hamm, Hasson-Ohayon, Kukla, & Lysaker, 2013; Hodgekins & Fowler, 2010), research (Slade, Adams, & O'Hagan, 2014), and service design (Slade, et al., 2014), little research has explored the relevance of recovery ideas to the family. Indeed, the CHIME model of recovery has yet to be applied to families and therefore questions remain as to the relevance of this model, especially given the criticism levelled at it by Stuart et al (2016). Yet evidence suggests families can influence

both the clinical (Cechnicki et al., 2014; González-Pinto, et al., 2011; Lee, Barrowclough, & Lobban, 2014) and personal recovery outcomes of people experiencing psychosis (Reupert, Maybery, Cox, & Scott Stokes, 2015). Therefore, there is an absence in the literature around the relevance of recovery to families, including the relevance (or not) of CHIME as a model.

Family members themselves can also be profoundly affected by their caregiving role, with evidence of high levels of psychological distress (Kingston, Onwumere, Keen, Ruffell, & Kuipers 2016; Poon, Harvey, Mackinnon, & Joubert, 2017), experiences of grief and loss (Patterson, Birchwood, & Cochrane, 2005), poor quality of life and burden (Gupta, Solanki, Koolwai, & Gehlot, 2015) and social isolation (Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, 2015). Furthermore, there is indirect evidence to suggest recovery ideas are relevant to individual family members. Research has found hope is an important aspect to the needs of family members (Bland & Darlington, 2002; Hernandez et al., 2019) family members can derive positive meaning from the experience of supporting a relative with psychosis (Kulhara, Kate, Grover, & Nehra, 2012), and they can also experience profound changes in their sense of identity (Milliken & Northcott, 2003; Newman, Simonds, & Billings, 2011). Yet families are also affected as a system, with research demonstrating family functioning, in particular cohesion and flexibility, can be affected (Gupta & Bowie, 2018), as well as families' sense of identity (Acero et al., 2017). There is also evidence demonstrating those with psychosis contribute positively to family life (Coldwell, Meddings, & Camic, 2011), yet this can get overlooked by clinicians (Allman, Cooke, Whitfield, & McCartney, 2018).

There is also emerging interest in the relevance of recovery ideas to family interventions in psychosis (FIp) (Gehart, 2012; Glynn, Cohen, Dixon, & Niv, 2006). FIp are one of the primary means by which the needs of families are addressed within mental health services owing to a strong evidence base for reducing rehospitalisation and relapse of psychiatric symptoms of those experiencing psychosis (Pharoah, Mari, Rathbone, & Wong,

2010) as well as helping to improve carer wellbeing and reduce negative caregiving experiences and expressed emotion (Lobban, et al., 2013; Sin, et al., 2017). Glynn et al. (2006) argue FIp could be developed by adopting more of a recovery focus, expanding the definition to the family as a whole, exploring how to instil hope, develop collaborative and shared goals, improve the relationships within the family system, and help them to feel more empowered to meet their needs. However, at present little research has directly explore how FIp maximise a shared experience of recovery (Allen, Burbach, & Reibstein, 2013).

As families both influence the personal recovery outcomes of their family member, and they themselves could be seen to experience their own process of recovery, there is an emerging literature which explores recovery from a family perspective (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015; Wyder & Bland 2014) which some have seen as a potential framework for supporting family-recovery orientated practice (Foster & Isobel, 2018; Foster et al., 2019; Wyder & Bland, 2014).

Models of family recovery

As a developing literature, ‘family recovery’ has been conceptualised in a variety of ways, which broadly fall into three categories: 1) how families can promote the recovery needs of those experiencing psychosis. This sees the role of families as offering instrumental support through emotional and practical support (Ward, Reupert, McCormick, Waller, & Kidd, 2017; Waller, Reupert, Ward, McCormick, Kidd, 2018). For some with psychosis, family life also takes on a broader meaning, such as their personal recovery goals related to aspects of family life such as being a good parent or celebrating family events (Price-Robertson, Menderson, & Duff, 2017). 2) Family members experience their own recoveries. This includes addressing practical needs, such as learning about mental health conditions and mental health services, addressing psychological needs, such as overcoming grief and loss, and pursuing their own recovery, including developing a sense of hope, identifying meaning in

their experiences, (re)connecting with their own personal values, and moving beyond their role as a carer (Baxter & Diehl, 1998; Spaniol, 2010; Spaniol & Nelson, 2015; Wyder & Bland 2014). 3) How the family can be supported as a system by promoting family relationships and a sense of hope for the future (Chandler & Repper, 2011; Wyder & Bland, 2014; Foster & Isobel, 2018). The multiple proposed components of family recovery are elaborated on in Table 2.

As an emerging literature, family recovery literature has been under researched. Research so far has largely focussed on the experience of staff and their understanding of family recovery practice (Foster & Isobel, 2018; Ward et al., 2017) and the role of parenting as a focus for family recovery (Price-Robertson et al., 2017; Reupert, Price-Roberston, and Maybery, 2017). Whilst one paper has directly explored the experiences of those with severe and enduring mental illness (Waller et al., 2018), this focussed largely on how families supported service user recovery, yet there was a recognition from service users that family members need support with their recovery. Furthermore, studies and models have drawn from a variety of clinical populations (Reupert et al., 2017), and little is known about the relevance of family recovery to families and service users with psychosis. Given the absence of empirical research, a significant question remains as to how those with psychosis and family members understand and describe ‘family recovery’.

Table 2. *Summary of models and research on family recovery*

Components of family recovery	Core components
Promoting the recovery of the relative with psychosis	<p>Families promote recovery by offering emotional and practical support (Waller et al., 2018, Ward et al., 2017).</p> <p>Service users derive meaning from their families (Waller et al., 2018) and value the opportunity to connect with meaningful non-illness related family roles, such as being a parent (Price-Robertson et al., 2017).</p> <p>Family members can support the recovery of their family member by developing 'recovery promoting relationships' (Wyder & Bland, 2014) including 'learning to "let go" of trying to "fix" (Baxter & Diehl, 1998; Spaniol 2010; Spaniol & Nelson, 2015).</p>
Promoting the recovery of family members	<p>Developing awareness of their own needs (Baxter & Diehl, 1998; Buckley-Walker et al., 2017; Spaniol, 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994).</p> <p>Addressing practical needs such as learning about mental illness and mental health services (Baxter & Diehl, 1998; Foster et al., 2019; Spaniol 2010; Spaniol & Nelson, 2015; Spaniol & Zipple, 1994; Wyder & Bland, 2014) and developing skills to support their own wellbeing and to cope with the challenges of their relative's mental illness (Baxter & Diehl, 1998; Spaniel 1994; 2010; 2015; Wyder & Bland, 2014).</p> <p>Addressing psychological needs such as overcoming feelings of loss and grief for their relative's life and their own, and allowing an emotional catharsis (Baxter & Diehl, 1998; Buckley-Walker et al., 2017; Spaniol, 2010; Spaniol & Nelson, 2015; Wyder & Bland, 2014).</p> <p>Addressing recovery needs, such as connecting with their own values and aspirations, exploring alterations in identity, pursuing meaning, and moving beyond a carer role (Buckley-Walker et al., 2017; Wyder & Bland, 2014).</p>
Promoting the recovery of the family as a whole	<p>Promoting family connectedness (Foster & Isobel, 2017; Ward et al., 2017; Waller et al., 2019; Wyder & Bland, 2014).</p> <p>Developing relationships within the family which transcended an 'illness' or caregiving role (Price-Robertson et al., 2017; Wyder & Bland, 2014).</p> <p>Promoting hope (Chandler, & Repper, 2011; Foster et al., 2019; Wyder & Bland, 2014).</p>

Study rationale

To advance our understanding of what family recovery may mean, the literature would benefit from further research directly exploring family recovery narratives, which includes both those with psychosis and family members, whose opinions and experiences have not yet been adequately researched. To this end, this study has used the CHIME model as a framework for understanding experiences of family recovery as reported by family members and people with lived experience of psychosis. In doing so, this enables the study to draw on well established, clearly defined, and evidence-based definition of recovery whilst also exploring the relevance of CHIME to families given its limitation (Stuart et al., 2016).

This project set out to address the following two questions:

- To what extent does the CHIME model of recovery help explain the family recovery experiences of those with lived experience of psychosis and family members?
- Do family members discuss themes of recovery outside those of CHIME?

Methodology

Participants

Twelve participants were originally recruited, six family members and six service users, all of whom were unrelated. Unfortunately, two carer interviews were lost due to problems with audio recordings. The final 10 family members and service user characteristics are summarised in Tables 3 and 4 respectively. Participant characteristics were collected through a questionnaire administered prior to the interview (see Appendix B). Participants were not asked if they had received family interventions for psychosis.

Table 3. *Family member characteristics*

Participant ID	Age	Gender	Relationship to service user	Marital status	Employment status	Ethnicity	Age family member first experience psychotic symptoms	Age family member first accessed mental health services	Length of time supporting family member
1	32	Male	Sibling	Married	Employed full time	White-British	20	20	17
2	71	Female	Parent-mother	Married	Retired	White British	27	27	15
3	63	Female	Parent-mother	Married	Employed part time	White British	20	20	15
4	71	Female	Parent-mother	Married	Employed part time	White British	18	18	27

Table 4. *Service user participant characteristics*

Participant ID	Age	Gender	Living status	Relationship status	Employment status	Ethnicity	Currently supported by mental health services	Self-reported Length of time in years of support from mental health services	Age of onset of psychosis symptoms	Age at first contact with mental health services
5	51	Male	Living with family	Single	In receipt of benefits	Black British – Caribbean	Yes	32	17	20
6	56	Female	Living with family	Single	Seeking employment	White British	Yes	27	31	31
7	32	Male	Living with family	Single	Volunteer	Black British – Caribbean	No	4	27	27
8	36	Male	Living independently	Single	Mixed- employed part time, in receipt of benefits, volunteering	White British	Yes	13	24	24
9	47	Male	Living with family	Single	Volunteer	Black British – Caribbean	No	26	22	22
10	53	Female	Living alone	Single	Seeking employment	White- other	No	1.5	48	49

Procedure

Recruitment. Service users and family members were recruited independently of each other, from separate sources, and families. Service users were recruited through the host Trust's database of participants who had volunteered to be contacted directly for research purposes. Family members were recruited through the host trust's carer forum and advertising through carer forums outside of the trust. Inclusion and exclusion criteria are outlined in Table 5 below.

Table 5. *Participant inclusion and exclusion criteria*

Inclusion criteria:

- Adult (aged 18 or older) individuals with lived experienced of psychosis currently under the care of a community mental health team or have given approval to be contacted about research projects through the Trust's research participant database
- Informal carers are those who assume a caregiving role for the service user for at least three months prior to entry to the study and satisfied any one of the following criteria: 1) they are a parent, spouse or partner of someone with lived experience of psychosis; 2) they live with the service-user and are willingly classified by themselves as being a carer; or 3) they do not live with their family member who experiences psychosis, but maintain at least one weekly contact with them, which might include a phone call.
- Sufficient command of written and spoken English to provide informed consent and participate in an interview without the need for an interpreter.
- Participants who can provide informed consent to take part in the study.

Exclusion Criteria

- Carers of service users with mental health difficulties other than psychosis.
 - Service users with mental health problems other than psychosis
 - Service users who are currently psychiatric inpatients
 - Participants who are unable to provide informed consent.
 - Inadequate command of the English language to participate in interviews and requires the use of an interpreter.
 - Service users with a primary diagnosis of alcohol or substance dependency
 - Service users with a primary diagnosis of organic syndrome or learning disability
-

Ethical approval. The research project was conducted in line with the BPS Code of Human Research Ethics (British Psychological Society, 2014). The project was given favourable NHS ethical and HRA approval (see Appendices C and D), and the host Trust gave Research and Development approval (see Appendix E). A summary of the results was written for all participants who requested a copy (see Appendix F) and the host trust (see Appendix G).

Informed consent. To aid participants in providing informed consent (Appendix H), a participant information sheet was developed (see Appendix I). Participants were given multiple opportunities to ask questions and clarify their understanding of the project. Participants were made aware of their rights within the project, including their right to withdraw.

Data protection and confidentiality. All transcripts were anonymised to maintain confidentiality and were stored on a password protected computer. Interviews, transcripts and other study information were stored in locked electronic or filing cabinets.

Interviews. All interviews took place on a research site. Participants were informed of their right to pause and end the interview at their discretion. Whilst some interviews were paused, no one terminated the interviews prematurely. All participants were debriefed following the interview to explore their wellbeing and experience of the interview. The author received regular supervision to explore the personal and professional implications and execution of the project.

Design

A qualitative methodology was chosen allowing for an in-depth exploration of recovery experiences within a family (Ritchie, 2003). One off interviews with service users and family members were undertaken. To address the first research question, a deductive thematic analysis was undertaken, exploring evidence of themes consistent with the CHIME model. For the second research question, an inductive thematic analysis was undertaken to identify themes which did not fit within the CHIME model.

Thematic analysis (Braun, Clarke, Hayfield, & Terry, 2019) was chosen as it allowed for the use of pre-existing themes to be searched within the data (deductive analysis), whilst also searching for themes which did not fit with the CHIME model (inductive analysis).

Whilst grounded theory (Glaser & Strauss, 1999) could have been adopted as an alternative methodology to help develop a theory of family recovery, this methodology was not adopted on the grounds that pre-existing models were already available in the wider literature. Furthermore, the methodology was consistent with past qualitative research validating the CHIME model against the experiences of service users (Bird et al., 2014).

The study adopted a critical realist stance. Unlike naïve realist approaches which assume the immediate and direct accessibility of reality, critical realists argue reality is continuously construed (as opposed to constructed in the social constructionist (Burr, 2006) sense) and mediated by the experiences of those construing it (Sayer, 2000). Consequently, accounts of reality (such as the experiences of participants in qualitative research) are seen as real, albeit informed by their past experiences, research contexts, and wider social, cultural, and political factors (Sayer, 2000).

Interviews

A semi-structured interview schedule was developed, using open ended questions to facilitate in depth exploration of family recovery (see appendix J). Interviews lasted between 45 to 75 minutes. As the project focussed on family experiences, the initial question invited participants to talk about who they considered to be in their family. From there 10 questions followed which focussed on aspects of family recovery, including their beliefs about family recovery as an idea. All interviews were audio recorded and later transcribed, and brief notes were taken during and after the interviews to note any salient ideas and/or possible themes within the interview.

Quality assurance

Yardley (2000) argues there are roughly four key components of good qualitative research: 1) sensitivity to context 2) commitment and rigour 3) transparency and coherence, and 4) impact and importance (see Table 6).

Table 6. *Yardley's (2000) key components of qualitative research*

Components of qualitative research	How this was achieved
Sensitivity to context	Open-ended questions were developed, which allowed participants to challenge the premise of questions. For example, participants were allowed to define who they felt were members of their family and what recovery meant to them and their family, rather than impose definitions.
Commitment and rigour	Braun and Clarke's (2006) six stages of data analysis was followed. Note taking during and after the interviews, as well as verbatim transcription, allowed for immersion into the data and formed the premise of initial theme development.. To ensure the interviews were analysed in a rigorous way which did not simply reflect the opinions of the lead researcher, two transcripts were reviewed by an independent researcher.
Transparency and coherence	A thematic map of the key themes and exemplar quotes are provided, along with a narrative of how the themes unfold (see results section below). To support reflective engagement with the research project and transparency, a reflective diary was kept throughout the research (see Appendix K). This was supported through ongoing reflective discussions with the project supervisors.
Impact and importance	This aspect of good qualitative research is concerned with the utility and influence of the project on future research and clinical practice. Exploring the applicability of recovery ideas to the family represents a novel extension of recovery ideas which could enable a more nuanced understanding of how families could be supported, and new avenues of research developed

Reflexivity

The author approached this project having worked with families in an early intervention in psychosis service and during a research project on crisis teams prior to beginning training as a clinical psychologist. These experiences led the author to develop an awareness of the often-overlooked experiences of families, but also concern for the individualised nature of treatment. This in part led to an interest in exploring family experiences from a recovery perspective. A research diary (see Appendix K), along with

reflective discussion with the project supervisors, aided reflections on the authors possible assumptions.

Data analysis

The data were initially analysed inductively following Braun and Clarke's (2006) methodology, allowing space for themes to be identified prior to the deductive analysis. The data were then reanalysed using a deductive approach with *a priori* themes generated from the CHIME model in line with Hayes's (1997) guidelines. The results of both analyses were discussed with the project supervisors to explore differences and similarities between the two analyses. It was felt that inductive themes could be subsumed under the deductive themes, with no significant divergence from the original CHIME components (see appendix L-O).

Inductive analysis. The inductive analysis followed Braun and Clarke's (2006) six stages of data analysis (see Table 7; see appendix L).

Table 7. *Six stages of thematic analysis (Braun, & Clarke, 2006)*

Stage 1: familiarising yourself with the data	This began during the interview process whereby notes focussing on particular salient ideas which emerged during the interview, or upon reflection, were taken at the end of interviews. Again during the transcription process, notes were taken with regards to any areas of interest and preliminary patterns were noted down. Transcripts were then 'actively read' multiple times to help familiarise and engage with the data. Informal observations were noted down.
Stage 2: Generating initial codes	Initial codes were noted across all transcripts which included both descriptive and interpretative codes. Two transcripts were also shared with one of the study supervisors who provided detailed line-by-line reflections on possible codes.
Stage 3: Searching for themes	The initial codes were clustered into themes pertinent to the research question.
Stage 4: Reviewing potential themes	An initial set of five themes was developed on the basis of the initial codes. In reviewing these themes against the whole data set, the themes were reordered and reduced to 4 final themes (see appendix L).
Stage 5: Defining and naming themes	The final set of themes were named and defined
Stage 6: Producing the report	A detailed report was produced outlining the findings of the analysis

Deductive analysis. The deductive analysis was undertaken following Hayes's (1997) eight stages of deductive thematic analysis (see Table 8; appendix M). In doing so, transcripts were searched for evidence of connectedness, hope, identity, meaning, and empowerment. As with the inductive analysis, a second person examined the coding. There were no disagreements on the allocation of CHIME themes except that both found identity and meaning difficult to distinguish (see Table 8).

Table 8, *Eight stages of deductive analysis (Hayes, 1997)*

Stage 1: Establishing the themes of the analysis	Five themes were developed from the CHIME model of personal recovery (Leamy et al., 2011).
Stage 2: Transcribing the interviews	Interviews were verbatim transcribed by the author.
Stage 3: Identify all attributions made during the interview related to the themes	All transcripts were individually read and re read with the CHIME relevant attributions (statements) in mind. CHIME relevant attributions were then noted on the transcripts.
Stages 4 & 5: Extract and sort all attributions into a list according to the themes of the analysis	All attributions from across the different participants were extracted and sorted according to the five CHIME themes.
Stage 6: Examine the attributions within each thematic category and identify their general orientation	Each CHIME theme was reviewed to characterise their overall content. Subordinate themes were identified. This led to the themes of meaning and identity being classified as inter-related. Participant statements seemed to have elements of both together, so they were difficult to separate out (as illustrated in the results section).
Stage 7: Compare the attributions within one category made by one set of research participants with those in a similar category made by another set	This involved cross checking the attributions of participants to ensure consistency within the theme.
Stage 8: Identify the general themes and conclusions which may be drawn from the analysis	The general themes and conclusions were identified and discussed within the final report.

Results

Evidence for all five CHIME themes were found across all transcripts, which included 11 subordinate codes (see Table 9). Owing to meaning and identity being closely related, these two were consolidated into one theme, ‘meaning and identity’. Illustrative anonymised quotes for all themes and subordinate codes have been included. There were no inductive themes that could not be fitted within the CHIME framework. Rather, they suggested an elaboration of it, as shown in the sub-themes.

Table 9. *Themes and codes extracted from the 10 transcripts*

Theme	Subordinate codes
Connectedness	Connections within the family: strained relationships
	Connections within the family: growth and staying together
	Connections outside of the family: feeling alienated from the wider family and community
	Connections outside of the family: importance of non-family connections
Hope and optimism for the future	The family coming together
	Lost hopes
Identity and meaning	Moving beyond an ‘illness role’ within the family
	Preferring another family role to that of a carer
Empowerment	How families empower service users
	Disagreements and different perspectives about how best to support their relative’s recovery
	What helps and hinders family members to empower themselves

Connectedness

Connectedness centres on developing relationships with others, feeling supported, and being a part of a community. Within the context of families, connections took on a particular

focus on family relationships, how relationships within the family had changed, but also with the wider family and community.

Connections within the family: strained relationships. For some participants, experiencing psychosis caused a major rupture in their relationship with their family members, with some service users feeling rejected or abandoned by their families, and losing a sense of togetherness.

Pt 7, service user *“since I became unwell my relationships with [my family] deteriorated...it deteriorated a lot.”*

Pt 3, family member *“It’s a bit like a spider and we’re on a different leg of spider. We don’t really do anything together.... I always imagined we’d always be together more than we are [as a family].”*

Connections within the family: growth and staying together. Yet for some, family relationships had not changed, and the family remained as they were. There was a sense, for some, of relationships growing together as a shared journey of growth.

Pt 6, service user *“[me experiencing psychosis] has brought them together in that they’re... more supportive of me and understanding of me... I think we’ve grown together as a family unit and I think that they have grown with me”.*

Pt 1, family member *“[my sister’s psychosis] made us closer.”*

For some family members and service users, there was a sense recovery centred on reconnecting with relationships within the family.

Pt 4, family member *“[my husband and I] we’re now enjoying each other’s company, we’re enjoying life together.”*

Pt 5, service user *“I’m finding it easier to reconnect with my family now.”*

Service users expressed a desire to be included in family life, which meant family members understood how their mental health conditions could act as a barrier to inclusion.

Pt 6, service user *“I’ve always been included ...they’ve always said come along, even if I just sit on the sofa and fall asleep on the sofa. They’ve always wanted me to participate in the family situation. They’ve never said “you know what, sort yourself out and leave me” they’ve always included me.”*

Pt 5, service user *“my cousin saying “thanks for coming [to my birthday party], because I know that sometimes it’s hard for you to come to things like that”, that helps.”*

To help feeling included within the family, this meant the family went through a process of learning how to support their family member who had experienced psychosis and accepting them for who they are.

Pt 8, service user *“I’ve taken [my family] on a journey. Like my nanna for example, she generationally isn’t in the generation where people understand mental illness all that well, she’s gone away and informed herself and done the best she can to learn about it. The same goes for my sister.”*

Pt 6, service user *“in the beginning they didn’t know how to react, they are a lot more calmer and collective and they don’t think it’s the end of the world if I do have a crisis...But now I have periods of recovery and I’m okay and stable, so it has changed in that they don’t panic as much, and they don’t think it’s an absolute write off.”*

Connections outside of the family: feeling alienated from the wider family and community. Families reported the experience of having a family member with psychosis had caused them to feel alienated and let down by their wider community, who they felt could have supported them.

Pt 3, family member “*[I was asked if I was] still involved in the church goings on. I said not as much as I used to be, but one of the reasons is because I was so disappointed that the parish didn’t really help us in anyway whatsoever. Not us, not our son, not anybody.*”

Pt 7, service user “*yeah it was tough for [my family] to deal with like, especially in terms of how [psychosis] is looked upon by the black community.*”

For some this also meant feeling unsupported by their wider family.

Pt 2, family member “*... at the beginning at the illness I think I would say [stigma] was a factor...because at the same time our nephew [became unwell], and everyone knew about it and was asking about it and oh dear poor so and so, but no one asked about ...[our].daughter, yet we were really going through absolute hell. But they kept asking about the nephew, but they never asked about our daughter. At that time, it was hard.*”

Connections outside of the family: importance of non-family connections. Service users also spoke of the importance of relationships outside of the family, which were often seen as being like family, including adopting family roles.

Pt 6, service user “*I have a very close friend, we’ve been friends since school and she’s almost like a sister to me because we’ve been together for such a long time. I’m her daughter’s godmother. She calls me aunty, so I have another niece.*”

Pt 8, service user “*I’ve got friends that have formed part of my family since my relationship with my parents has broken down. There are people in my life who I’ve now given lasting powers of attorney, so they are as close as they can be to me.*”

For some, family was extended even further to incorporate their wider community and neighbourhood.

Pt 8, service user *“part of my family would be the people at the gym who make me feel welcome there....people I’ve called my family...for me it’s more community than family. It’s more about having a recovery that’s based on positive interactions with people. Love support and caringness [sic], being able to share, being open... people in the neighbourhood who can keep yourself out of yourself, for me that’s what I see as a family.”*

Hope and optimism for the future

Hope relates to believing recovery is possible, motivation to change, and a sense of optimism for the future. Within a family context, participants spoke primarily of their hope in relation to the family as a whole being able to come or stay together. Yet family members and service users acknowledged they had to face lost hopes and expectations about the future.

The family coming together. Family members and those who had experienced psychosis expressed a sense of hope the family may come together.

Pt 3, family member *“For the family to recover it would be lovely to do more things together, to do more things or even just to have a weekend away. Or a day trip, you know.”*

Pt 9, service user *“[I’d like] for everyone to get on better and be happy with one another...make it a family unit again. Because I want us to be a family again.”*

Given the rupture in family relationships, some service users spoke of hope for reconciliation.

Pt 8, service user *“I’m also holding a space in my heart for reconciliation, because that’s what I want...because I think that’s the right thing to do.”*

For some participants who had experienced psychosis, they spoke of a hope that they would maintain what they had.

Pt 6, service user *“I hope that we still remain close, or we’d even maintain what we have and not saying things will get better, but I’d hope that we would maintain where we are. To maintain that level of closeness, support, and love, and being there for each other, most importantly.”*

Pt 5, service user *“[I hope] that the family sticks together like they have done over the years.”*

But it was also recognised that family life is reciprocal, and staying together, or reconnecting, would only emerge if it was mutually desired.

Pt 6, service user *“But it’s a two-way street because it would have to be me and them who would want to make that connection.”*

Pt 7, service user *“for anyone that’s in [a] family or creates a family you want the best as you see it, but at the end of the day for that to happen it takes more than just you.”*

Lost hopes. In speaking of the future participants inevitably reflected on the past, and they described a sense of having to alter their expectations and hopes about what could have been and what the future might have looked like. For some this meant facing loss for themselves and their relative.

Pt 2, family member *“I think life hasn’t unfolded how we wished for her really....We’ve got a daughter who probably would have wished to have met a partner and got married or had children, and a nice career, but none of that has happened for her.”*

Pt 6, service user *“because they thought, I thought, that I was going to get a decent job and you know live a traditional life....But I haven’t gone down that road.”*

Yet the experience of having a close relative who has experienced psychosis also meant changes in family members’ own expectations for their life and their relative, which could be upsetting.

Pt 2, family member *“we’ve had a mentally ill daughter living with us at the time of our lives when we were hoping to have a bit of freedom and I suppose us as a married couple we haven’t had much freedom ... I try not to worry about what might have been because it tends to make you sad really. But so life is really very different to how we think our life would be.”*

Identity and meaning

Identity is about developing a multifaceted sense of self, whilst *meaning* can be about developing meaningful activities, hobbies, and social roles. Service users reported how they enjoyed enacting family related roles such as being an uncle, aunt, or godmother, which contributed to their sense of identity. Service users derived significant meaning from these identities within the family. Although for some service users these roles were lost when they developed psychotic symptoms.

Moving beyond an ‘illness role’ within the family. For some service users, they derived meaning from their ability to enact family roles which went beyond an ‘illness role’, adopting trusted and valued family roles.

Pt 6, service user *“I help with babysitting, even when I was depressed and whatever they didn’t say to me “you’re not well enough to look after the children” They’d say “she’s my sister and I trust her to look after my children” ...If they wouldn’t leave their children with me, it would almost feel like I wasn’t a proper family member, as if I was set apart, that I...wouldn’t be part of the family almost. Somebody who was just ill and put in the corner... I think [my family] are able to see me as a sister, as an aunt...there is acceptance of who I am and what position I play in the family...which is incredibly important to me.”*

Pt 8, service user *“[Being an uncle] gives me a different role, it gives me something else that I can be doing, and I enjoy being that person in their lives.”*

Some family members expressed a desire for their relative to be more involved in other family responsibilities.

Pt 4, family member *“it would be nice if the [grand] children did see their uncle a bit, as at the minute they don’t know him at all.”*

Pt 1, family member *“I’d probably like [my sister] to be more involved in my family.”*

Preferring another family role to that of a carer. For family members there was a sense that they could see themselves as adopting a ‘carer’ role within the family, but they also expressed a desire for alternative roles and relationships.

Pt 3, family member *“It would be nice not to have that caring role, but it’s up to me to take the hat off.”*

Pt 2, family member *“I can’t remember the last time I went out and had a lovely lunch with her, like mums and daughter do. Very occasionally, but I don’t think I have for a while.”*

Pt 1, family member *“I’m just thinking about the future and it would be nice if [my mum and sister] could talk and be somewhere closer to a traditional relationship with her daughter, rather than just a carer-parent-best friend rapport all rolled up into one, closer to a traditional relationship.”*

Empowerment

Empowerment relates to a sense of agency over life, taking personal responsibility, as well as being supported by systems and services to pursue one’s aspirations and hopes. This aspect of participants’ narratives remained close to the original definition- how families promoted the recovery needs of service users, but also the need for family members to pursue their recovery needs.

How families empower service users. People who had experienced psychosis valued the support that their family offered them.

Pt6, service user *“I know that there are quite a few people who don’t have family support and they haven’t got what, well the family support that I have. So...regardless of all the time I’ve been in hospital they [the family] have been there for me, visiting all the time and helping me out.”*

There was a sense families offer love and support, and could be reliable and dependable, especially during times of potential crisis.

Pt6, service user *“[my family] support me, they love me, they are there for me if I need them. They are there for me in a crisis... And I know that at any time I can call. Anytime I can, whenever day or night, they are there for me and...if I need to call them it’s something serious and it’s not something that I’m playing out. So, recovery for me is about knowing I can rely on them...knowing that I can rely on my family so that they can support me.”*

Pt 7, service user *“they [the family] are there to help and support you obviously, that’s the part they play in your recovery...as a form of support they’re trying to help and not give up on that person, that’s the most important thing.”*

Families empower their relative by offering support without judgement.

Pt 6, service user *“if I had to do something and I can’t do it, they’re not going to say “why can’t you do it?” and start going on. They’ll say, “Okay, we’ll do it together, or I’ll help you do it”. They help me out.”*

Family members spoke of the need to promote independence and for their relative to have a happy and fulfilling life.

Pt 1, family member *“our goal for everyone, for my sister [who has experienced psychosis], is for her to be more independent. We’re the only ones really that understand her and are able to know, to read her mood, and understand how she’s feeling. I...have been pushing for her to do more activities independently and possibly a bit of volunteering, or something like that.”*

Pt 2, family member *“As a family we...know that her condition isn’t going away but we want her to...have a bit more independence and a fulfilling life...we just want her to manage by herself a bit, with the help of medication, and kind of support groups, and for her to be happy, that’s the main thing.”*

Family members also spoke of helping their relative engage in everyday activities.

Pt 4, family member *“[my husband] meets her for coffee frequently, and goes for walks and is very supportive generally.”*

Pt 3, family member *“[my husband and son] they go watch cricket and hockey and have coffee together which is nice.”*

For those who had psychosis, they appeared to value a shared understanding of how best to be supported.

Pt 6, service user *“in the beginning they [family] didn’t know how to react, they are a lot calmer and collective now, and they don’t think it’s the end of the world if I do have a crisis.”*

Pt 8, service user *“they know what the plan is they’ve been to the psych appointments, so that is out in the open and that’s something everyone is aware of.”*

Disagreements and different perspectives about how best to support their relative's recovery. Family members and service users spoke of the disagreements within the family of how best to support their relative with their recovery.

Pt 1, family member *“I think there's been some disagreement about what my sister should do. We still think that she should volunteer...but she's never done that, I mean just doing a day, but my mum doesn't think she's ready for it.”*

Pt 7, service user *“Some people [in my family] would be like, “what do you need to go to therapy for?” no one shared my opinion.”*

What helps and hinders family members empowering themselves. Family members spoke of their own recovery needs, in particular looking after their own needs.

Pt 2, family member *“I think I've learnt this from my carers' groups that you do have to learn to think of yourself a bit as well as the person you care for and probably we, or me, I haven't probably thought of myself a lot.”*

Pt 3, family member *“anything to have a break is good.”*

But this could be a struggle, with feelings of guilt or obligation acting as a barrier.

Pt 3, family member *“we don't relax. We don't go on holiday, we don't go anywhere... we'll always worry. But that's what everyone keeps saying, don't worry.”*

Pt 2, family member *“[what makes it hard is] probably a feeling of guilt possibly sometimes, you know that the person that the person you care for is on their own and they've got nothing to do today and they have no activities and you know that you might have to pick up the pieces when you get home because they'll be in an awful mood or a stressed state. So, there's a bit of guilt in there actually.”*

In helping with their own needs, family members often spoke of the importance of having social support.

Pt 2, family member *“with our neighbours...they’ve been extremely supportive, right since the start... My husband has a lot of friends, and that’s important I think.”*

Pt 4, family member *“I have a group of friends, [they help by] being there so you can talk and you can hear their problems.”*

This also included the importance of being supported within the family.

Pt 2, family member *“I feel that we’re very lucky, we have got a lot of family support and I do feel supported by, you know, the wider family, my son and sister-in-law especially. I always ring my son for help and support if I need to...I don’t know what I’d do without it really.”*

Discussion

The central question of the study centred on understanding the family recovery experiences as described by family members and those with psychosis. In doing so, the project used the CHIME model (Leamy et al., 2011) as a way of identifying aspects of what could be considered family recovery in the accounts of family members and service users.

Whilst participants provided accounts consistent with the CHIME model, the model’s core features of connectedness, hope, identity, meaning, and empowerment took on a particular meaning within a family context. Connectedness centred around relationships within and outside of the family, hope related to hopes the family would come/stay together, meaning and identity focussed on the roles those with psychosis and family members played within the family and the personal meaning they derived from this, and empowerment related

to how families facilitated the personal recovery of their family member with psychosis, and pursued their own recovery needs.

Family recovery: developing relationships within the family

Central to personal recovery models are the importance of connections- developing relationships with others, feeling supported, and being a part of a community (Leamy et al., 2011). The narratives of those with psychosis and family members echoed these sentiments, focussing on a sense of growth within the family, an ability to stay together, and they felt able to (re)connect and enjoy their relationships. The significance of improved relationships has come to be seen as a fundamentally important aspect of recovery, with service users reporting they value the support of their family (Topor et al, 2011). Within some theories of recovery, there is a move towards viewing recovery as a relational process built on reciprocal and mutual relationships (Chandler & Repper, 2011; Price-Robertson et al., 2017). As such, family recovery could be seen as a particular form of relational recovery built on a shared sense of family identity (Acero et al., 2017). In doing so it also acknowledges the important contributions some people with psychosis make to family life by offering emotional and practical support to their family (Allman et al., 2018; Coldwell et al., 2011). As such a ‘recovery task’ (Wyder & Bland, 2014) or a recovery orientated family goal (Maybery, Reupert, & Goodyear, 2013) for families may relate to developing family relationships and supporting a shared sense of ‘togetherness’. This is consistent with research exploring staff accounts of family recovery practice, where facilitating family relationships and a sense of connectedness is seen as an important component (Foster & Isobel, 2017; Ward et al., 2017).

There were also reports from family members and those with lived experience of psychosis of strained and difficult relationships within and outside of the family, highlighting the variation in family experiences. Whilst it was unclear from the results why this was the case, the wider literature indicates this is a common experience for families (Koutra et al

2015; Koutra et al., 2014a; Koutra et al., 2014b) and service users (Topor et al., 2011). This highlights the need to support improving relationships within the family, perhaps through the use of family interventions in psychosis (Allen, Burbach, & Reibstein, 2013; Claxton, Onwumere, & Fornells-Ambrojo, 2017; Pharoah, Mari, Rathbone, & Wong, 2010). Furthermore, helping to build positive family relationships may also help to increase caregiver gains and improve family member wellbeing (Chen & Greenberg, 2004; Maglino, et al., 2003). Given that high expressed emotion (e.g. criticism) has been found to be related to poor family outcomes (Gupta & Bowie, 2018; Koutra et al., 2014a), increased carer distress (Jansen, Gleeson, & Cotton, 2015), and is associated with an increased risk of relapse for service users (Cechnicki et al., 2014), interventions designed to help reduce elevated expressed emotion are likely to be beneficial to families.

Family recovery: holding on to hope that the family can come/stay together

Hope within the recovery literature has often been conceptualised as a largely intrapsychic phenomena orientated around believing recovery is possible, motivation to change, and positive thinking (Rose, 2014). Yet within a family context, hope can become a more relationally infused concept, orientated around developing or maintaining relationships within the family (Price-Robertson, Obradovic, & Morgan, 2017). Whereas personal recovery has been argued to unfold in the ‘everydayness’ of life (Borg & Davidson, 2008), this too was also expressed by families, but related to the everydayness of family life and the pursuit of ordinary family activities.

Whilst hope has consistently been seen as a key aspect of recovery (Sælør, Ness, Holgersen, & Davidson, 2014), it may also have important implications for the wider functioning of the family. Higher levels of hope can be associated with a reduction in distress for family members who have a relative with psychosis (Hernandez, et al., 2019) and facilitating a sense of hope may support wider family resilience by enabling them to see

beyond the immediate stressful experience of supporting a relative with psychosis (Hernandez et al., 2013). How and where families derive hope from remains largely unexplored, but consistent with the findings of this study, there is some evidence to suggest families can draw hope from emotional support they receive from within their families (Bland & Darlington, 2002) highlighting the importance of facilitating relationships within the family. Yet there is also evidence to suggest hope is likely to be culturally contingent, shaped by religious-social-and-cultural practices (Hernandez, et al., 2019). Therefore, future research may need to explore further both the sources of hope for families, but also the role of cultural factors in shaping both its form and content.

Family recovery: meaning and roles within the family

In exploring meaning and identity within a family context, these CHIME concepts took on a particular shared meaning. For service users', identity related to enacting non-illness related roles, which they derived significant meaning from. For some family members, their identity could be related to their caregiving role, which some expressed a wish to move beyond.

Meaning within the wider recovery literature has focussed on service users enacting meaningful social roles (Leamy et al., 2011). Within a family context, it is possible this may relate to the particular roles within the family. Whilst family recovery models have focussed on parenting in particular (Reupert et al., 2017), the findings of this study have widened the focus to other, albeit closely related, roles such as being an uncle, aunt, or godparent. As one participant said, their identity as an uncle gave them a "different role". Some family members wished for their relative to be more involved in their family, whilst family members reported a wish to move beyond their caregiving role, a key aspect of several models of family recovery (Buckley-Walker et al., 2017; Wyder & Bland, 2014).

Yet for some participants who had experienced psychosis, their role was lost when they began to develop symptoms. As a result, their contributions and role in family life, as well as their personal strengths, became obscured by their family seeing them as a “sick person”. This may be explained by what Allman et al. (2018) call an ‘illness paradigm perceptual filter’ which can result in families and those with psychosis overlooking the positive contributions they can make to family life. This highlights the need to explore the contributions and roles those with psychosis play within the family and/or how service users and families may want this to change (Maybery, Reupert, & Goodyear, 2013).

Helping service users to explore their roles within the family may also have wider implications. Some research suggests the experience of psychosis may result in a need to adapt one’s sense of identity (Morin & St-Onge, 2017). Difficulties in adapting one’s sense of identity may occur when new experiences (such as psychosis) become too incongruent with existing models of the self and the world (Joseph & Linley, 2005). Consequently, helping those with psychosis to connect with the role within the family (such as uncle, brother, parent), may help them to ground their identity in a pre-existing model of the self. Furthermore, it was clear some with psychosis valued these roles, in part allowing them to transcend their identity as a person with psychosis (Reupert et al., 2015).

Family recovery: empowering service users and family members

Empowerment within the CHIME model relates to a sense of agency over life, taking personal responsibility, as well as being supported by systems and services to pursue one’s aspirations and hopes. For participants empowerment related to how families promote the recovery needs of service users, whilst family members spoke of pursuing their own recovery.

The study findings are consistent with previous studies which have found that those with psychosis value the contributions the family make to their recovery through the emotional, practical, and social support they offer (Aldersey & Whitley, 2015). The current findings suggested families offer ongoing emotional support by ‘being there’ for their relative, whilst also promoting empowerment through supporting and not judging. There is an absence of research exploring family member perspectives on how they promote the recovery of their relative, yet the finding of this study suggests there is a convergence of perspectives between family members and those with psychosis. Future research may benefit from a more in-depth exploration of the perspectives of those with psychosis and their family members on how their recovery is best supported.

Family members also described the need to pursue their own recovery. Whilst there is anecdotal evidence of carers reporting their own personal recovery (Chandler, Bradstreet, & Hayward, 2013; Parr, 2009), there is little research which directly explore the relevance and applicability of recovery ideas to families. Family recovery models (Wyder & Bland, 2014; Spaniol & Nelson, 2015) suggest family members should be supported to help them pursue a life beyond their caregiving responsibilities, which was partially confirmed by the accounts of family members.

As described by the family members of this study, feelings of guilt may act as a potential barrier to families actualising their own recovery needs. Research exploring feelings of guilt within family members has found it to be associated with a range of clinical outcomes, such as heightened expressed emotion (Cherry, Taylor, Brown, Rigby, & Sellwood, 2017). This research highlights its role in potentially impeding recovery, in part because of the tension between balancing their needs with that of their relative. This highlights the important need for clinicians to explore with family members their caregiving responsibilities, helping them balance their wellbeing with that of their relative. There is

some evidence to suggest carer led interventions may be a helpful means of helping to improve carer wellbeing (Roddy, Onwumere, & Kuipers, 2015) but could be a means to help them explore their own recovery.

Strengths and limitations

One of the limitations of the current study is the small sample size, particularly in relation to the number of family member interviews. Whilst qualitative research does not necessarily intend to produce generalisable findings (Gheondea-Eladi, 2014), the small sample size brings into question the possibility of missed experiences which may contradict the findings of this study or offer additional insights. Furthermore, bar one sibling, family members were all white British mothers of a similar age who were recruited through a similar setting (an NHS Trust carers' forum). Consequently, it is highly likely that the results of the study are not representative of the wider caregiving population. In contrast, there was more diversity with regards to age, gender, and ethnic background of service user participants.

One significant limitation of the study may have been the design, in particular interviewing people who were not related. The recruitment of participants from the same families may have allowed for a richer exploration of family recovery ideas and perhaps allowed for a more in-depth exploration of the similarities and differences, as well as tensions and areas of agreement, between family members. Indeed, as Wyder and Bland (2014) argue, family recovery is likely a case of balancing multiple needs which perhaps individual interviews may not have as fully captured.

The project took a broad approach to exploring the relevance of recovery ideas to the family, asking questions within the interviews which elicited responses across different aspects of family life (e.g. relationships, the future, hopes, and identity). In doing so, this may have limited the possibility of exploring these aspects of family recovery in greater depth,

such as why relationships had worsened within families, and sources of hope. Furthermore, the limited sample size and similarity within family member participants meant it was difficult to explore in greater detail the differences and similarities in how family recovery was conceived in comparison to participants who had experienced psychosis.

The use of the CHIME model as a framework for exploring family recovery came with advantages and disadvantages. Using the CHIME model allowed for a clear and operationalizable set of definitions by which to explore family recovery ideas in depth, and therefore explored a well-established model in a different context. Furthermore, the CHIME model is perhaps the most empirically robust model of recovery, having been developed through a robust review of the existing literature (Leamey et al., 2011), and having been broadly shown to accurately reflect personal recovery narratives, albeit with some notable exceptions (Stuart et al., 2016). However, it is possible that the use of the CHIME model to explore family recovery limited the scope for other aspects of recovery to emerge. However, the sub-themes did incorporate ideas which haven't traditionally been included within CHIME research (Stuart et al., 2016) such as loss, tensions within family relationships, and the sense of disagreement which can emerge within the family around what recovery may involve.

Future research

In order to further elucidate the conceptual and empirical underpinnings of family recovery, future research could explore in greater depth specific aspects of family recovery. For example, what helps families to develop and sustain feelings of hope? Future research would benefit from exploring a range of family member experiences, including siblings, fathers, partners, and children. This is important as research into the experiences of different family members highlight different experiences and concerns (Bowman, Alvarez-Jimenez, Wade, McGorry, & Howie, 2014; Fraser & Warr, 2009; Jungbauer, Wittmund, Dietrich, &

Angermeyer, 2004). Furthermore, given the evidence suggesting personal recovery ideas are shaped by cultural factors (Hernandez et al., 2013; Tuffour, Simpson, & Reynolds, 2019), it would be important to explore how social-cultural factors may shape notions of family recovery. Given the limitations around this study's design, future research could adopt a different approach, such as recruiting participants from the same family to explore how family recovery ideas may be understood by different family members. Furthermore, future research could adopt a different methodological approach to family recovery experiences, such as multifamily family member interviews (Reczek, 2014) or dyadic family interviews (Eiskovits & Koren, 2010).

One potentially fruitful area of research may be the overlap between family interventions in psychosis and family recovery. Given there is significant overlap between the goals of family interventions and family recovery, this could be more directly explored in a future research project. This could include interview family members and those experiencing psychosis, as well as interviewing family intervention practitioners to explore how they use recovery ideas in their work, if at all, and how family members are incorporated into their understanding of recovery.

Practice implications: towards family recovery

The study findings highlight the potential for clinicians and mental health service providers to extend personal recovery ideas beyond the individual with psychosis, to both family members and the wider social system. The CHIME model potentially offers clinicians and services a helpful framework for identifying and working with the recovery needs of families (Wyder & Bland, 2014) yet further research into what constitutes family recovery is needed. In exploring the recovery needs of families, the findings of this study suggest clinicians should explore and promote relationships within the family system. Furthermore, clinicians should explore family hopes for the future, which may enable practitioners to

develop recovery-orientated goals (Maybery et al., 2013). The findings of this study also suggest those experiencing psychosis derive meaning from the roles they play within the family, yet past research suggests this can go unnoticed by clinicians (Allman et al., 2018). Therefore, it may be important for services, families, and those experiencing psychosis to be aware of the multiple roles held by those experiencing psychosis and their relatives that goes beyond the primary role of ‘patient’, ‘carer’, and sibling of person with psychosis. Facilitating greater awareness of these additional roles, and support to take on other roles is indicated.

Family recovery ideas may also have important implications for family interventions in psychosis. Indeed, there is significant scope to explore how family recovery ideas are integrated into FIPs given the overlap, such as emphasising the importance of developing relationships within the family system, helping to develop a shared understanding of differing family needs, and help families to move beyond linear service-user and carer family roles. Yet there is an absence of recommendations for how family interventions could more fully integrate recovery ideas which includes the family (Gehart, 2012). This is particularly important given the developing nature of family interventions for psychosis. As models move away from framing psychosis as a "serious and persisting psychiatric illness" (Glynn et al., 2006) towards a focus on strengths and the inclusion of multiple perspectives (Burbach, 2018), family recovery ideas may help to develop FI by moving away from clinical definitions of recovery towards emphasising hope, relationships, and a shared sense of empowerment.

Conclusions

In exploring the CHIME model as a means of understanding aspects of ‘family recovery’, this study found how the core components took on a more family embedded meaning, highlighting how recovery happens in families, for both service users and family

members. Identifying and understanding the stories, experiences and meaning of recovery in families may be central to facilitating improved outcomes for people with lived experience of recovery and their family networks.

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Section C: Appendices

Appendix A: CASP scores

Table 5. Overview of CASP* quality assessment tool for qualitative studies

	Clear state ment of the aims ?	Qualita tive method ology approp riate?	Appro priate research design	Appro priate recruit ment strateg y?	Conside ration of data collecti on	Conside ration of research h relation ship	Ethica l issues consid ered?	Rigo rous data anal ysis	Clear state ment of findi ngs?	Valu e of rese arch	to tal
Foste r & Isobe l (2017)	2	2	2	1	1	0	1	1	1	1	12
Price- Robe rtson et al (2017)	1	2	2	1	1	0	1	1	1	1	11
Walle r et al (2018)	1	2	2	1	1	0	1	2	2	1	13
Ward et al (2017)	2	2	2	1	1	0	1	1	2	1	13

*Whilst the CASP checklist uses three scoring criteria: yes, no, unable to determine, this was replaced with a numerical scoring system of 0 if the criterion was not met, 1 if partially met, 2 if fully met, this enable

Appendix B: Demographics questionnaire



Participant Study Identification number:

Exploring the concept of 'family recovery' in families and individuals with lived experience of psychosis.

'Family recovery and psychosis' V 1.2 1st June 2017

Age:.....

<i>Gender (please tick):</i>	
Male	<input type="checkbox"/>
Female	<input type="checkbox"/>
Transgender	<input type="checkbox"/>

<i>Living status (please tick):</i>	
Living independently	<input type="checkbox"/>
Living with family	<input type="checkbox"/>
Living in supported accommodation	<input type="checkbox"/>
No fixed address	<input type="checkbox"/>

<i>Relationship status (please tick):</i>	
Single	<input type="checkbox"/>
Married	<input type="checkbox"/>
Civil partnered	<input type="checkbox"/>
Long-term relationship	<input type="checkbox"/>
Divorced	<input type="checkbox"/>
Widowed	<input type="checkbox"/>

<i>Employment status (please tick):</i>	
Employed full time	<input type="checkbox"/>
Employed part time	<input type="checkbox"/>
Carer	<input type="checkbox"/>
In receipt of benefits	<input type="checkbox"/>
Retired	<input type="checkbox"/>
Volunteer	<input type="checkbox"/>
Seeking employment	<input type="checkbox"/>

<i>Ethnicity (please tick):</i>	
Arab	
Asian or Asian British – Indian	
Asian or Asian British – Pakistani	
Asian or Asian British – Bangladeshi	
Asian or Asian British – any other Asian background	
Black or Black British – Caribbean	
Black or Black British – African	
Black or Black British – any other Black background	
Chinese	
Mixed – White and Black Caribbean	
Mixed – White and Black African	
Mixed – White and Asian	
Mixed – Any other mixed background	
White – British	
White – Irish	
White – any other White background	
Any other ethnic origin group	
Prefer not to disclose	

Are you currently in contact with specialist (secondary care) mental health services?

<i>Yes</i>	
<i>No</i>	
<i>I have never been in contact with mental health services</i>	

For how long have/did you use mental health services?

.....

At what age did you, or our relative, begin to experience mental health problems:

.....

At what age did you, or our relative, first access mental health services:

.....

If you are a relative, for how long have you supported your family member with experience of psychosis?

.....

Appendix C: Health Research Authority approval letter

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Appendix D: NHS ethical approval

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Appendix E: R&D approval

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Appendix F: Summary of report for participants



Summary of research findings: Exploring the concept of ‘family recovery’ in families and individuals with lived experience of psychosis

Dear [Participant]

I am writing to you because you took part in a research project looking at the relevance of recovery ideas to the family, and you expressed an interest in hearing about the result of the study. As the study is now complete and the information that you and others provided has been analysed, I would like to tell what the study found and the implications for this.

Why do the study?

Families can be important to the lives of people who experience psychosis. Yet family members are also affected themselves. In recent years people have spoken about the importance of recovery ideas to people who experience psychosis. Recovery ideas meant different things to different people, but they often involve living a meaningful life, despite the limitations of their difficulties. Research has found that recovery can be defined according to 5 key themes: connectedness (the relationships we have with other people), hope and optimism for the future, identity, meaning, and empowerment. This has been called the CHIME model of recovery. Whilst people have spoken about the relevance of these ideas to people with psychosis, there isn’t much research in relation to the family. Therefore, we wanted to explore the experiences of family members and those with psychosis of family life, to see if recovery ideas are relevant.

What did the study do?

10 participants were interviewed- 6 who had experienced psychosis, and 4 family members. I asked them questions about how family life had changed since they or their relative first developed psychosis, as well as questions about relationships within the family had changed, hopes for the future, and if they thought recovery ideas were relevant. The answers which were given by the participants were analysed using a research method called ‘thematic analysis’. This involves looking through all the interviews for common themes. We also looked through the interviews to see if there was evidence in people’s stories which were consistent with the CHIME model.

What did you find?

We found that people’s experiences could broadly be categorised into the themes outlined in the CHIME model. As this is a summary, there may be some aspects of this which you feel doesn’t reflect your experience. The themes were:

Connectedness

Connectedness centres on developing relationships with others, feeling supported, and being a part of a community. Within the context of families, connections took on a particular focus on family relationships, how relationships within the family had changed, but also with the

wider family and community. People talked about how relationships within the family had become strained since they or their family member first experienced psychosis. Yet others spoke about how relationships had stayed strong and they felt as if they had grown together as a family. Service users appeared to value being included in family life, which meant family members understood how their mental health conditions could act as a barrier to inclusion. Relationships outside of the family also changed, and family members and service users felt they had been let down by their community.

Hope and optimism for the future

Hope relates to believing recovery is possible, motivation to change, and a sense of optimism for the future. Within a family context, participants spoke primarily of their hope in relation to the family as a whole being able to come or stay together. Yet family members and service users acknowledged that they had to face lost hopes and expectations about the future.

In speaking of the future participants inevitably reflected on the past, and they described a sense of having to alter their expectations and hopes about what could have been and what the future might have looked like. For some this meant facing loss for themselves and their relative.

Identity and meaning

Identity is about developing a multifaceted sense of who we are as a person, whilst *meaning* can be about developing meaningful activities, hobbies, and social roles. For some service users, they derived meaning from their ability to enact family roles which went beyond an ‘illness role’, adopting trusted and valued family roles, such as being an uncle, babysitting, and supporting other family members. For family members there was a sense that they could see themselves as adopting a ‘carer’ role within the family, but also expressed a desire for alternative roles and relationships, such as spending time together as a ‘mother and daughter’ or their relative being more involved in family life.

Empowerment

Empowerment relates to a sense of agency over life, taking personal responsibility, as well as being supported by systems and services to pursue one’s aspirations and hopes. This aspect of participants narratives remained close to the original definition- how families promoted the recovery needs of service users, but also the need for family members to pursue their recovery needs.

People who had experienced psychosis valued the support that that their family offered them. They felt that families helped them to feel loved, supported, and accepted. Family members spoke of the need to promote independence and for their relative to have a happy and fulfilling life. But there were times when there were disagreements about the best way to pursue recovery.

Family member’s spoke of their own recovery needs, in particularly looking after their own needs, taking a break from supporting their relative, seeing friends, and doing activities which they enjoy. But this could be a struggle, with feelings of guilt or obligation acting as a barrier.

What is the significance of the findings?

To help make sense of the findings, they were understood in the context of the wider research on families, psychosis, and recovery. In particular the study thinks there are four significant findings 1) helping to support relationships within families, where possible 2) exploring the hopes that family members have for the family, including helping the family to grow 3) exploring roles within the

family, including helping those with psychosis to explore what they contribute to family life and how family members can step outside of a 'caring role', 4) using the family as a potential resource for service users as part of their recovery, but also helping family members to pursue their own recovery.

The research also point out the need to do more research in this area as it is new topic of research. The project acknowledge that not all people have a good experience of family and this needs to be taken into consideration as well. If you would like a copy of the fully write up of the research, please get in touch. Thank you so much for your invaluable contribution to the project and I hope that it can make a difference for other families and how mental health services support them.

Yours sincerely

Edward Mundy

Trainee Clinical Psychologist and Principle Researcher

Appendix G: Report for local Trust R&D and HRA

Health Research Authority

DECLARATION OF THE END OF A STUDY

(For all studies except clinical trials of investigational medicinal products)

To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee (REC) that gave a favourable opinion of the research within 90 days of the conclusion of the study or within 15 days of early termination.

For questions with Yes/No options please indicate answer in bold type.

1. Details of Chief Investigator

Name:	Edward Mundy
Address:	Salomons Institute for Applied Psychology 1 Meadow Road Tumbridge Wells TN1 2YG
Telephone:	
Email:	E.g.mundy502@canterbury.ac.uk
Fax:	

2. Details of study

Full title of study:	Exploring the concept of ‘family recovery’ in families and individuals with lived experience of psychosis
Research sponsor:	Dr. Fergal Jones
Name of REC:	London-Surrey
REC reference number:	18/LO/0202

3. Study duration

Date study commenced:	25/5/2018
Date study ended:	11/02/2018
Did this study terminate prematurely?	No

4. Recruitment

Number of participants recruited	
Proposed number of participants to be recruited at the start of the study	
If different, please state the reason or this	

5. Circumstances of early termination

What is the justification for this early termination?	
---	--

6. Temporary halt

Is this a temporary halt to the study?	
If yes, what is the justification for temporarily halting the study? When do you expect the study to re-start?	<i>e.g. Safety, difficulties recruiting participants, trial has not commenced, other reasons.</i>

7. Potential implications for research participants


Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	
--	--

8. Final report on the research

Is a summary of the final report on the research	Yes
--	-----

enclosed with this form?	
--------------------------	--

9. Declaration

Signature of Chief Investigator:	
Print name:	Edward Mundy
Date of submission:	11 th April 2019



Dear [REC chair /R&D manager]

Re.: End of study and summary of research findings

Study title: Exploring the concept of ‘family recovery’ in families and individuals with lived experience of psychosis

IRAS code: 234044

REC reference: 18/LO/0202

I am writing to inform you that the above research project is now complete, with no concerns raised. Outlined below is a summary of the research projects findings and implications.

Please do not hesitate to contact me should you have any questions.

Summary of the research

Introduction

Families can be important to the lives of people who experience psychosis. Yet family members are also affected themselves. In recent years people have spoken about the importance of recovery ideas to people who experience psychosis. Recovery ideas meant different things to different people, but they often involve living a meaningful life, despite the limitations of their difficulties. Research has found that recovery can be defined according to 5 key themes: connectedness (the relationships we have with other people), hope and optimism for the future, identity, meaning, and empowerment. This has been called the CHIME model of recovery. Whilst people have spoken about the relevance of these ideas to people with psychosis, there isn’t much research in relation to the family. Therefore, we wanted to explore the experiences of family members and those with psychosis of family life, to see if recovery ideas are relevant.

Methods

12 participants were originally recruited, 6 family members and 6 service users. Unfortunately, 2 service user interviews were lost due to problems with audio recordings. Questions were asked in relation to participants understanding of recovery and its relevance to the family. To analyse the results an inductive and deductive thematic analysis was used.

The data were initially analysed inductively, allowing space for themes to be identified prior to the deductive analysis. The data were then reanalysed using a deductive approach with a priori themes generated from the CHIME model. In doing so, transcripts were searched for evidence of connectedness, hope, identity, meaning, and empowerment, as well as themes which did not fit within the CHIME model. The results of both analyses were discussed with the project supervisors to explore differences and similarities between the two analyses. It was felt that inductive themes could be subsumed under the deductive themes, with no significant divergence from the original CHIME components.

Results

Evidence for all five CHIME themes were found across all transcripts, which included 11 subordinate codes (see Table 1). Owing to meaning and identity being closely related, these two were consolidated into one theme, 'meaning and identity'. Illustrative anonymised quotes for all themes and subordinate codes have been included. There were no themes that could not be easily fitted within a modified CHIME framework.

Table 1. Themes and codes extracted from the 10 transcripts

Theme	Subordinate codes
Connectedness	Connections within the family: strained relationships
	Connections within the family: growth and staying together
	Connections outside of the family: feeling alienated from the wider family and community
Hope and optimism for the future	The family coming together
	Lost hopes
Identity and meaning	Moving beyond an 'illness role' within the family
	Preferring another family role to that of a carer
Empowerment	How families empower service users
	How family members empower themselves
	Disagreements and different perspectives about how best to support their relative's recovery
	What helps and hinders family members empowering themselves

Connectedness

Connectedness centres on developing relationships with others, feeling supported, and being a part of a community. Within the context of families, connections took on a particular focus on family relationships, how relationships within the family had changed, but also with the wider family and community. People talked about how relationships within the family had become strained since they or their family member first experienced psychosis. Some participants reported:

Service user: “*since I became unwell my relationships with [my family] deteriorated...it deteriorated a lot.*”

Family member: *“It’s a bit like a spider and we’re on a different leg of spider. We don’t really do anything together.... I always imagined we’d always be together more than we are as a family.”*

Yet others spoke about how relationships had stayed strong. Some participants reported:

Service user *“[me experiencing psychosis] has brought them together in that they’re more supportive of me and understanding of me... I think we’ve grown together as a family unit and I think that they have grown with me”.*

Service users appeared to value being included in family life, which meant family members understood how their mental health conditions could act as a barrier to inclusion.

Service user *“they’ve always included me...they’ve always said come along, even if I just sit on the sofa and fall asleep on the sofa. They’ve always wanted me to participate in the family situation. They’ve never said “you know what, sort yourself out and leave me” they’ve always included me.”*

To help feeling included within the family, this meant the family went through a process of learning how to support their family member who had experienced psychosis and accepting them for who they are.

Service user *“I’ve taken [my family] on a journey. Like my nanna for example, she generationally isn’t in the generation where people understand mental illness all that well, she’s gone away and informed herself and done the best she can to learn about it. The same goes for my sister.”*

Relationships outside of the family also changed, and family members and service users felt they had been let down by their community.

Family member *“[I was asked if I was] still involved in the church goings on. I said not as much as I used to be, but one of the reasons is because I was so disappointed that the parish didn’t really help us in anyway whatsoever. Not us, not our son, not anybody.”*

Hope and optimism for the future

Hope relates to believing recovery is possible, motivation to change, and a sense of optimism for the future. Within a family context, participants spoke primarily of their hope in relation to the family as a whole being able to come or stay together. Yet family members and service users acknowledged that they had to face lost hopes and expectations about the future.

Family member *“For the family to recover it would be lovely to do more things together, to do more things or even just to have a weekend away. Or a day trip, you know.”*

Service user *“[I’d like] for everyone to get on better and be happy with one another...make it a family unit again. Because I want us to be a family again.”*

In speaking of the future participants inevitably reflected on the past, and they described a sense of having to alter their expectations and hopes about what could have been and what the future might have looked like. For some this meant facing loss for themselves and their relative.

family member *“I think life hasn’t unfolded how we wished for her really.... We’ve got a daughter who probably would have wished to have met a partner and got married or had children, and a nice career, but none of that has happened for her.”*

Identity and meaning

Identity is about developing a multifaceted sense of identity, whilst *meaning* can be about developing meaningful activities, hobbies, and social roles.

For some service users, they derived meaning from their ability to enact family roles which went beyond an ‘illness role’, adopting trusted and valued family roles.

Service user *“I help with babysitting, even when I was depressed and whatever they didn’t say to me “you’re not well enough to look after the children” They’d say “she’s my sister and I trust her to look after my children” ...If they wouldn’t leave their children with me, it would almost feel like I wasn’t a proper family member, as if I was set apart, that I...wouldn’t be part of the family almost. Somebody who was just ill and put in the corner... I think [my family] are able to see me as a sister, as an aunt...there is acceptance of who I am and what position I play in the family...which is incredibly important to me.”*

Service user *“[Being an uncle] gives me a different role, it gives me something else that I can be doing, and I enjoy being that person in their lives.”*

For family members there was a sense that they could see themselves as adopting a ‘carer’ role within the family, but also expressed a desire for alternative roles and relationships.

Family member *“It would be nice not to have that caring role, but it’s up to me to take the hat off.”*

Family member *“I can’t remember the last time I went out and had a lovely lunch with her, like mums and daughter do. Very occasionally, but I don’t think I have for a while.”*

Empowerment

Empowerment relates to a sense of agency over life, taking personal responsibility, as well as being supported by systems and services to pursue one’s aspirations and hopes. This aspect of participants narratives remained close to the original definition- how families promoted the recovery needs of service users, but also the need for family members to pursue their recovery needs.

People who had experienced psychosis valued the support that that their family offered them.

Service user *“I know that there are quite a few people who don’t have family support and they haven’t got what, well the family support that I have. So...regardless of all the time I’ve been in hospital they [the family] have been there for me, visiting all the time and helping me out.”*

Family members spoke of the need to promote independence and for their relative to have a happy and fulfilling life.

Family member *“our goal for everyone, for my sister [who has experienced psychosis], is for her to be more independent. We’re the only ones really that understand her and are able to know, to read her mood, and understand how she’s feeling. I...have been pushing for her to do more activities independently and possibly a bit of volunteering, or something like that.”*

But family members and service users spoke of the disagreements within the family of how best to support their relative with their recovery.

Family member *“I think there’s been some disagreement about what my sister should do. We still think that she should volunteer...but she’s never done that, I mean just doing a day, but my mum doesn’t think she’s ready for it.”*

Service user *“Some people [in my family] would be like, “what do you need to go to therapy for?” ...no one shared my opinion.”*

Family members spoke of their own recovery needs, in particularly looking after their own needs.

family member *“I think I’ve learnt this from my carers’ groups that you do have to learn to think of yourself a bit as well as the person you care for and probably we, or me, I haven’t probably thought of myself a lot.”*

Family member *“anything to have a break is good.”*

But this could be a struggle, with feelings of guilt or obligation acting as a barrier.

Family member *“we don’t relax. We don’t go on holiday, we don’t go anywhere... we’ll always worry. But that’s what everyone keeps saying, don’t worry don’t worry.”*

In helping with their own needs, family members often spoke of the importance of having social support and from within the family.

Family member *“with our neighbours...they’ve been extremely supportive, right since the start... My husband has a lot of friends, and that’s important I think.”*

Family member *“I have a group of friends, [they help by] being there so you can talk and you can hear their problems.”*

family member *“I feel that we’re very lucky, we have got a lot of family support and I do feel supported by, you know, the wider family, my son and sister-in-law especially. I always ring my son for help and support if I need to...I don’t know what I’d do without it really.”*

Discussion

To help make sense of the findings, they were understood in the context of the wider research on families, psychosis, and recovery. In particular the study thinks there are four significant findings 1) helping to support relationships within families, where possible 2) exploring the hopes that family members have for the family, including helping the family to grow 3) exploring roles within the family, including helping those with psychosis to explore what they contribute to family life and how family members can step outside of a ‘caring role’, 4) using the family as a potential resource for service users as part of their recovery, but also helping family members to pursue their own recover.

The research also points out the need to do more research in this area as it is new topic of research. The project acknowledge that not all people have a good experience of family and this needs to be taken into consideration as well. If you would like a copy of the fully write up of the research, please get in touch. Thank you so much for your invaluable contribution to the project and I hope that it can make a different for other families and how mental health services support them.

Arrangement for publication and dissemination

The project authors are in the process of exploring appropriate journals to submit the findings of this study too.

Feedback to participants

All participants were offered a summary of the findings of the project. Of those who requested a summary, a copy was sent to them.

Yours sincerely

Edward Mundy

Trainee Clinical Psychologist and Principle Researcher

Appendix H: consent form



CONSENT FORM

IRAS code: 234044
 'Family recovery and psychosis' 28th May 2017, V.1.2

Title of Project: Exploring the concept of 'family recovery' in families and individuals with lived experience of psychosis.

Name of Researcher: Edward Mundy

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 26th February 2018 (version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I agree for the interview to be audio recorded.
4. I agree that anonymous quotes from my interview may be used in published reports of the study findings.
5. I agree to take part in the study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

STUDY SUMMARY

For those who have taken part in the study, we are offering them a summary of the study’s findings. If you would like copy of this document, please tick this box

If you would like a copy of the study’s findings, please indicate how you would like the findings to be sent to you (please ensure you provide this information in the above contact details section):

Email

Post

CONTACT DETAILS

Mobile:.....

Email:.....

Home address:.....

.....

Appendix I: Participant information sheet



Information about the research

Exploring the concept of 'family recovery' in families and individuals with lived experience of psychosis.

IRAS code: 234044
 'Family recovery and psychosis' 26th February 2018, V.1.5

Hello, my name is Edward Mundy and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study I am conducting. Before you decide if you want to take part, it is important that you understand why the research is being done and what it would involve for you, should you take part in it. If you have any questions, please feel free to talk with me about it, my contact details are below.

What is the purpose of the study?

Though we know that many people with experience of psychosis are supported by their families, there is very little research about the family perspective on 'recovery'. The phrase recovery is used a lot, and in different ways by different people. But, how do families understand the idea of family recovery? Is it even relevant? If so, what does it look like and mean for families? To help us answer these questions, we would like to ask those who have experienced psychosis, as well as family members who support someone who has experienced psychosis, to take part in the study.

Why have I been invited?

You have been invited to take part in the study because of your lived experience of psychosis or you have a relative with experience of psychosis who you have supported.

Do I have to take part?

No. Taking part in this study is entirely voluntary, and therefore it is up to you whether you take part. You are free to withdraw at any time, without giving a reason. This would not affect any care you or your relative receives.

What will happen to me if I take part?

If you decide to take part, you would meet with me to discuss the research in more detail and for you to have the chance to ask questions. If you decide to take part in the research you will be asked to sign two short consent forms, of which you will keep one copy.

You would then be invited to take part in a face-to-face interview lasting about 1 hour, where questions about yours and your family's experiences of psychosis and beliefs about family recovery will be asked. This interview will be audio recorded, and later transcribed for analysis. The interview will take place in a clinical (National Health Service) or university site.

We will also ask you some background information about yourself, such as your, age, gender, ethnicity, and your or your relatives use of mental health services.

In total, your involvement with the study should take no longer than 2 hours.

What are the possible disadvantages and risks of taking part?

It is our opinion that taking part in the research should not cause any direct harm to you. It is possible, however, that discussions about family experiences of psychosis and recovery may be upsetting. Should you find the interview upsetting, you have the right to pause it, as well as end it should you feel like you don't want to continue.

What are the possible benefits of taking part?

Whilst we cannot promise that this study will help you, hopefully your experiences will help us to develop a better understanding of family recovery.

To compensate you for your time, we can offer you £10.

Will information from or about me from taking part in the study be kept confidential?

All information that you provide during your time with the research project will be kept strictly confidential. To ensure confidentiality of your information, all physical documents, such as consent forms and audio transcript, will be stored in locked filing cabinets at Canterbury Christ Church University, and will only be accessible by the research team. Transcripts of interviews will be transcribed by me, and names and any personally identifying information will be omitted from the transcripts. Audio recordings will be stored on an on a password protected Canterbury Christ Church University computer.

Following completion of the study, all the anonymised data will be stored for 10 years on a password protected and encrypted USB device within a locked cabinet at Canterbury Christ Church University. After 10 years, the data will be destroyed.

Are there any limits to confidentiality?

Yes, but only if it is felt that someone's safety may be at risk; this may relate to a historical issue, a current concern, or relate to an issue in the future. In these circumstances, the study may be obliged to contact an appropriate third party.

What will happen to the results of the research study?

The findings of this study will be written up in partial fulfilment of my doctorate in Clinical Psychology.

We also intend to publish selected findings from the study in a peer reviewed academic journal and presented at academic/ mental health conference. This would involve using some anonymised quotes from interviews.

A summary of the study's findings will be made available to those who have taken part in the study. All quotes used will again be anonymised.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any point. You may wish to withdraw partially, and have no further contact with the study once the interview has taken place, but are happy for us to use the information obtained during the interview, or you may withdraw completely, whereby your answers will be removed from the study. However, please note that once the findings of the study have been published and extracts from interviews used, you would not be able to withdraw your answers. If you wish to withdraw, there is no expectation that an explanation is given, and it will not affect any services that you or your relative receives.

To withdraw from the study, please contact me (contact details below), informing me that you would like to withdraw from the study, and whether you are happy for your answers to be used or not.

Who is organising and funding the research?

This study is organised and funded by Canterbury Christ Church University.

Who else is involved in the study?

In addition to the lead researcher, Edward Mundy, the study is being supervised by Dr. Juliana Onwumere (lead supervisor), and Dr. Sue Holttum (second supervisor, Canterbury Christ Church University).

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London-Surrey Research Ethics Committee (REC reference 18/LO/0202)

What if there is a problem or I want to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

If you have a concern about any aspect of this study, you should ask to speak to the lead researcher, Edward Mundy, who will try to address your concerns (contact details are at the end of the document). If you wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology, Canterbury Christ Church University 1 Meadow Road, Tunbridge Wells, TN1 2YG – paul.camic@canterbury.ac.uk, tel: 01227 927114.

Further information and contact details

If you have any questions or concerns about the study and/or would like more information, please contact the lead researcher, Edward Mundy, at e.g.mundy502@canterbury.ac.uk.

Appendix J: Interview schedule

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Appendix K: Abridged reflective diary

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Appendix L: Inductive analysis

Inductive analysis:

Initial themes

1. Family relationships
 - a. Strained relationships within the family
 - b. Growth and staying together
 2. Family life
 - a. Life not unfolding as expected
 - b. Feeling alienated from the wider family and community
 3. How families promote recovery
 - a. Support, acceptance, love, and inclusion
 - b. Empowerment
 4. Family recovery
 - a. Hope for the family coming/staying together
 - b. Family members own recovery needs
 - c. Importance of support
 - i. Family support
 - ii. Non family support
 - d. Balancing multiple recovery needs
 5. Family roles
 - a. Beyond an illness role
 - b. Beyond a caring role
-

In the initial themes there was an emerging overlap with some of the CHIME themes. Perhaps not unsurprisingly, there was a strong theme around relationships within families, which overlapped with the CHIME theme of ‘connectedness’. Yet this theme incorporated both the challenges within family relationships as well as the challenges, which aren’t typically as well reported in the recovery literature. Whilst I suspected the theme of family relationships would come up, I wasn’t expecting families to talk so much about the wider family system nor the community. Whilst CHIME notes the importance of being connected to a sense of community, the initial themes within the accounts of participants was around a sense of alienation/separateness from the community. The theme of hope was also apparent, yet again took on a more collective family orientated meaning, rather than a focus on the family person with psychosis recovering.

*Evidence of initial themes*Final four themes

1. Family relationships
 - a. Strained relationships within the family
 - b. Growth and staying together
 - c. Feeling alienated from the wider family and community

 2. Family life
 - a. Life not unfolding as expected
 - b. Family roles
 - i. Beyond an illness role
 - ii. Beyond a caring role

 3. How families promote recovery
 - a. Acceptance, love, and inclusion
 - b. Support
 - c. Empowerment

 4. Family recovery
 - a. Hope for the family coming/staying together
 - b. Family members own recovery needs
 - c. Importance of support
 - i. Family support
 - ii. Non family support
 - d. Balancing multiple recovery needs
-

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Theme definition

1. Family relationships

This theme focussed on how both family members and those with lived experience of psychosis saw relationships both within the family and external to it, including the wider family and their community. Participants spoke primarily of how the presence of psychosis in the family had caused tensions within family relationships, in part as a result of the caring responsibilities which some family members experienced. Tensions could also emerge out of a misunderstanding by family members of the needs of the family member with psychosis. Yet both family members and those with psychosis spoke of experiences of growth in family relationships, or that psychosis had not caused the breakdown of relationships.

2. Family life

This theme focussed on the internal and external relationships, experiences, and expectations of families. Families spoke of 'life not unfolding' as expected, which related to how psychosis had caused family members and those with psychosis to re-evaluate their expectation for themselves and/or the family as a whole. This often related to expectations around relationships, jobs, and moving out of the family home. Included within this was a sense of loss around what could have been or was expected. Families and those with psychosis also spoke of the roles they played or would like to play in the family. Families spoke of wanting to move beyond their 'caring role', whilst those with psychosis spoke of wanting to move beyond an 'illness role'. This largely reflected a desire or actual experience of relationships which wasn't orientated around the presence of psychosis, either as a 'carer' or some with psychosis. For example, those with psychosis spoke of being an aunt, uncle, and of caring and supporting other family members.

3. How families promote recovery

This theme focussed on how both those with psychosis saw their family as supporting their recovery and family members perceptions of their role. Both family members and those with psychosis spoke of the importance of practical support, such as supporting them to leave the house and to eat dinner, and engaging in social activities, such as having coffee. Those with psychosis spoke of the importance of acceptance, love, and inclusions. This related to how they felt a sense of acceptance from family members in terms of their needs and what they could/couldn't do. This was accompanied by a sense of love. Finally inclusion involved being incorporated and seen as part of the family, such as being invited to family events. Family members and those with psychosis spoke of the importance of empowerment, such as helping them/their family member to be more independent.

4. Family recovery

This theme incorporated experiences of both those with psychosis and family members which could be seen as 'family recovery'. There was a theme of family members and those with psychosis expressing a desire for the family to either come together or stay together, to maintain or develop a sense of 'the family' as a unit. Family members spoke of their own recovery needs, such as seeing friends. There was a sense from all participants of the importance of support, from both within and outside of the family. There was also a sense

that there was a need to balance multiple needs and differences of opinion around how best to support the family and the person with psychosis.

Appendix M: Deductive analysis

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Appendix N: Merging inductive and deductive themes

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Appendix O: Instructions for authors Community Mental Health Journal

Manuscript Submission

Authors should submit their manuscripts online. Electronic submission substantially reduces the editorial processing and reviewing times and shortens overall publication times. Please follow the hyperlink “Submit online” on the right and upload all of your manuscript files following the instructions given on the screen. <http://comh.edmgr.com>

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Inquiries regarding journal policy, manuscript preparation, and other such general topics should be sent to the Editor-in-Chief:

Jacqueline M. Feldman, M.D.

Patrick H. Linton Professor

Department of Psychiatry & Behavioral Neurobiology

University of Alabama at Birmingham

CCB 4th Floor, 1530 3rd Avenue South

Birmingham, AL 35294

Email: jfeldman@uabmc.edu

- <http://comh.edmgr.com>

Manuscript Preparation

Manuscripts should be submitted in Word.

- Use 10-point Time New Roman font for text
- Use italics for emphasis
- Use the automatic page numbering function to number the pages
- Do not use field functions
- Use tab stops or other commands for indents, not the space bar
- Use the table function, not spreadsheets, to make tables
- Save your file in doc format. Do not submit docx files.

Adhere to Journal style and include the following sections: Abstract, Introduction, Methods, Results, Discussion, and References.

All studies must be approved by human subjects committees (also known as institutional review boards). At the end of the Methods section, authors must state which human subject committee (institutional review board) approved the study.

The title page should include:

- The names(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address, telephone, and fax numbers of the corresponding author

Please provide an abstract of 100 to 150 words. The abstract should not contain any undefined abbreviations or unspecified references.

Please provide 4 to 6 keywords which can be used for indexing purposes.

Limit Articles to 16 pages of text, double spaced per APA guidelines, exclusive of references, tables, and figures. Brief Reports should be no longer than 10 pages of text, and should not include any tables or figures.

Abbreviations should be defined at first mention and used consistently thereafter.

Tables:

- All tables are to be numbered using Arabic numerals
- Tables should always be cited in text in consecutive numerical order
- For each table, please supply a table heading. The table title should explain clearly and concisely the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table heading.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

For the best quality final product, it is highly recommended that you submit all of your artwork – photographs, line drawings, etc. – in an electronic format. Your art will then be produced to the highest standards with the greatest accuracy to detail. The published work will directly reflect the quality of the artwork provided.

References

List alphabetically, adhering strictly to APA style (Publication Manual of the American Psychological Association, 4th or 5th edition). Authors are responsible for providing accurate references.

Conflict of Interest

Authors must address possible conflicts of interest which can include (a) consulting fees or paid advisory boards for the past two years or known future; (b) equity ownership and/or stock options in publicly or privately traded firms; (c) lecture fees from speaking at the invitation of a commercial sponsor, for the past two years or known future; (d) employment by the commercial entity that sponsored the study; or (e) patents and/or royalties from, service as an expert witness to, or performance of other activities for an entity with a financial interest in this area. Authors should include a sentence toward the end of the Methods section listing possible conflicts of interest or stating that there are no known conflicts of interest.

Authors must certify their responsibility for the manuscript. In so doing, the authors certify (a) that they accept responsibility for the conduct of the study and for the analysis and interpretation of the data, (b) that they helped write the manuscript and agree with the decisions about it, (c) that they meet the definition of an author as stated by the International Committee of Medical Journal Editors, and (d) that they have seen and approved the final manuscript. In certifying responsibility for the manuscript, authors also certify that neither the article nor any essential part of it, including tables and figures, will be published or submitted elsewhere before appearing in the Journal. Authors should include a sentence at the end of the Methods section saying that all authors certify responsibility.

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The Journal is dedicated to rapid dissemination of research on therapeutic treatments or preventive interventions. Supplements to the Journal can be used to publicize findings newly presented at conferences or symposia.

Please contact the Managing Editor for information about supplemental issues of the Journal.

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This journal is committed to upholding the integrity of the scientific record. As a member of the Committee on Publication Ethics (COPE) the journal will follow the COPE guidelines on how to deal with potential acts of misconduct.

Authors should refrain from misrepresenting research results which could damage the trust in the journal, the professionalism of scientific authorship, and ultimately the entire scientific endeavour. Maintaining integrity of the research and its presentation is helped by following the rules of good scientific practice, which include*:

- The manuscript should not be submitted to more than one journal for simultaneous consideration.
- The submitted work should be original and should not have been published elsewhere in any form or language (partially or in full), unless the new work concerns an expansion of previous work. (Please provide transparency on the re-use of material to avoid the concerns about text-recycling ('self-plagiarism').
- A single study should not be split up into several parts to increase the quantity of submissions and submitted to various journals or to one journal over time (i.e. 'salami-slicing/publishing').
- Concurrent or secondary publication is sometimes justifiable, provided certain conditions are met. Examples include: translations or a manuscript that is intended for a different group of readers.
- Results should be presented clearly, honestly, and without fabrication, falsification or inappropriate data manipulation (including image based manipulation). Authors should adhere to discipline-specific rules for acquiring, selecting and processing data.

- No data, text, or theories by others are presented as if they were the author's own ('plagiarism'). Proper acknowledgements to other works must be given (this includes material that is closely copied (near verbatim), summarized and/or paraphrased), quotation marks (to indicate words taken from another source) are used for verbatim copying of material, and permissions secured for material that is copyrighted.
- **Important note: the journal may use software to screen for plagiarism.**
- Authors should make sure they have permissions for the use of software, questionnaires/(web) surveys and scales in their studies (if appropriate).
- Authors should avoid untrue statements about an entity (who can be an individual person or a company) or descriptions of their behavior or actions that could potentially be seen as personal attacks or allegations about that person.
- Research that may be misapplied to pose a threat to public health or national security should be clearly identified in the manuscript (e.g. dual use of research). Examples include creation of harmful consequences of biological agents or toxins, disruption of immunity of vaccines, unusual hazards in the use of chemicals, weaponization of research/technology (amongst others).
- Authors are strongly advised to ensure the author group, the Corresponding Author, and the order of authors are all correct at submission. Adding and/or deleting authors during the revision stages is generally not permitted, but in some cases may be warranted. Reasons for changes in authorship should be explained in detail. Please note that changes to authorship cannot be made after acceptance of a manuscript.

Upon request authors should be prepared to send relevant documentation or data in order to verify the validity of the results presented. This could be in the form of raw data, samples, records, etc. Sensitive information in the form of confidential or proprietary data is excluded.

*All of the above are guidelines and authors need to make sure to respect third parties rights such as copyright and/or moral rights.

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- If the manuscript is still under consideration, it may be rejected and returned to the author.
- If the article has already been published online, depending on the nature and severity of the infraction:
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