Development and Validation of the Carer Adaption and Resilience Scale (CARS), Assessing Personal Recovery, Resilience and Growth for Carers of Those with Psychosis and Schizophrenia

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Abstract

INTRODUCTION: Caring for a relative with a diagnosis of psychosis or schizophrenia can be challenging and emotionally demanding, often with little training or support in managing difficult behaviours. Family carers provide invaluable support to their loved ones and save health services substantial amounts of resources. It is vital to support family carers so that they can support the service user they care for. To provide effective support it is important to gain a holistic view of carers' experiences. An under-researched area relates to the concept of personal recovery for carers. Personal recovery mainly relates to how service users experience personal or social recovery despite still experiencing symptoms. By understanding carers' experiences of personal recovery for themselves, we can promote this positive adaptation. OBJECTIVES: The main objective of this PhD was to explore personal recovery for carers and to develop a new outcome measure to evaluate it. METHODS: Personal recovery was explored by operationalising the concept for a carer population based on key literature. Mixed methods were employed to explore the concept of personal recovery using an exploratory sequential design. The exploratory phase of the PhD included a systematic review of relevant literature and a series of qualitative interviews with carers. The findings were then used sequentially to inform the development of a new outcome measure using cognitive interviews, and finally to validate the new measure by conducting a psychometric evaluation of the quantitative data gained from the larger questionnaire study. RESULTS: the systematic review of recovery related outcome measures showed no single measure is available to assess this for carers. In-depth qualitative interviews found that carers did not relate to the term personal recovery, however different facets of recovery were experienced such as acceptance, adaptation, resilience, and personal growth. This deviation from the expected findings showed the inductive nature of the qualitative study, and those results informed the development of the Carer Adaptation and Resilience Scale (CARS). The draft CARS was developed in conjunction with carers through a series of cognitive interviews. The validation study showed the CARS has a clear factor structure and good reliability and validity. CONCULSIONS: These findings expand our knowledge of carers' experiences, highlighting factors that could contribute to positive adaptation, resilience, and personal growth, and provide a way to quantify this.

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Declaration by Student

The entirety of this thesis is the work of Claire Alexandra Hilton, and no part of this thesis has been submitted in substantially the same form for the award of a higher degree elsewhere. Some sections of this thesis have been submitted for publication to academic journals.

Name: Claire Alexandra Hilton

Date: 21st July 2023

Statement of Authorship

The principal author of all these chapters is the PhD candidate, Claire Hilton (CH). The project's primary supervisor was Professor William Sellwood (WS), and the second supervisor was Steven Jones (SJ). Dr Katerina Panagaki and Dr Nadia Akers provided input to the systematic review paper.

Title of chapter: Self-Report Measures Assessing Aspects of Personal Recovery in Relatives and Other Informal Carers of Those With Psychosis: A Systematic Review

Authors, CH, WS, SJ had substantial contribution to the conception and design of the study. CH undertook the main tasks of the review: designing the protocol, conducting the literature searches, title and abstract screening, full text screening, data extraction, COSMIN analysis and levels of evidence analysis, writing the manuscript. KP and NA acted as second checkers on the title and abstract screening and data extraction phases of the review. The manuscript was critically assessed for academic rigour by WS, SJ, KP and NA.

Title of chapter: "You've Got To Put Your Own Oxygen Mask On First" – A Qualitative Study Looking At Personal Growth, Recovery, And Resilience For Carers Of Those With Psychosis And Schizophrenia.

Authors CH, WS and SJ had substantial contribution to the conception and design of the study. The principal author (CH) undertook all major tasks for the study such as: designing the protocol, topic guide, study documents, applying for ethical approval, recruitment, data collection, data analysis and writing up the manuscript. WS and SJ provided input on the study's analysis and interpretation of themes. WS and SJ also provided critical appraisal of the final manuscript.

Title of chapter: Carer Adaptation And Resilience Scale (CARS): Development Of A New Measure For Carers Of Those With Psychosis And Schizophrenia Using Cognitive Interviews

Authors CH, WS and SJ made substantial contribution to the concept and design of the study. CH undertook many of the main tasks of the study: designing the protocol, applying for NHS ethical approval, devising study materials, devising the draft CARS, setting up the Qualtrics survey pack, recruitment, conducting the cognitive interviews, data analysis and writing up the manuscript. CH and WS worked together on the data analysis. WS and SJ reviewed the final manuscript and provided important intellectual content to the work.

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Chapter 1: Introduction

Overview of chapter

This chapter will outline the main conceptual underpinnings and rationale for this PhD. Initially, the chapter will summarise what psychotic disorders are by providing current definitions, describe the main symptoms and prevalence rates of psychosis. Following this will be a brief discussion of the two main models used in health research to understand the potential causes of psychosis. I will also lay out the role that carers play in helping their loved ones with psychosis, how carers are defined for this PhD, what kind of care they provide, and how valuable this support is both for the service user and mental health services. Subsequently this chapter will explore in more detail the experiences that carers go through both in terms of negative experiences such as burden, burnout, and reduced quality of life; and in terms of the more positive aspects of caring, such as achieving a greater sense of meaning in their lives and being able to experience deeper personal connections. I will also introduce the concept of personal recovery and the rationale for applying this to a carer population. Finally, this chapter will layout the rationale and aims for this PhD and provide a summary of the study phases.

What is psychosis?

Psychosis is an umbrella term that incorporates any kind of psychotic experience ranging from an acute psychotic episode to a long-term diagnosis such as schizophrenia. Psychotic disorders have been defined as a major group of mental illness made up of several clinical symptoms (Gaebel & Zielasek, 2022). The main symptoms as defined by the DSM-5 (American Psychiatric Association, 2013) include: delusions, hallucinations, disorganised thinking, and speech, grossly disorganized or abnormal motor behaviour (including catatonia). The symptoms of psychosis are typically divided up into two main categories: positive symptoms are 'added on' to the persons experiences such as delusions or hearing voices, negative symptoms are ‘taken away’ from a person such as reduced motivation and emotional flatness (Early Psychosis Intervention, 2023). Other symptoms also play a role in the severity of a psychotic disorder, such as lack of insight, where the individual does not recognise that they are psychotic, having poor understanding about the condition, problems with communication, and reduced social adaptation (Gaebel & Zielasek, 2022). Psychotic symptoms can occur in several diagnostic categories such as schizophrenia, bipolar disorder, and unipolar clinical depression (National Insititute for Health and Care Excellence, 2014). For those with a diagnosis of psychosis and schizophrenia, recovery rates based on both clinical and social functioning criteria are estimated to be one in seven (Jääskeläinen et al., 2015) and psychosis is considered to be the 11th most severe cause of disability worldwide (Vos et al., 2015). Psychosis can cause significant distress to the person experiencing symptoms but also their family and friends, with long term treatment and support across a range of life domains being needed (National Institute of Care Excellence, 2014; Schizophrenia Commission, 2012; Sin et al., 2017; Sin & Norman, 2013). Data from the Global Burden of Disease Survey (Solomi et al., 2023) show that globally from 1990 to 2019 raw prevalence of schizophrenia increased by over 65%. There is a racial disparity in relation to the diagnosis rates for psychotic disorders such as schizophrenia. Data from the Adult Psychiatric Morbidity Survey (UK Government, 2021) show that a diagnosis of a psychotic disorder is relatively uncommon among all ethnic groups in England; however, there is a significantly higher percentage of black men (3.2%) who experience a psychotic disorder than white men (0.3%). Symptoms related to schizophrenia cause significant distress for the service user and their carers (Sin et al. 2017). Outcomes for those with a diagnosis of schizophrenia often require long term treatment and support across a range of life domains such as emotional support, financial support and practical assistance with activities of daily living (Sin et al. 2017; Schizophrenia Commission, 2012). Recommendations on treatments for schizophrenia include psychosocial and psychological interventions used in combination with antipsychotics to try to prevent the recurrence of psychotic episodes for the service user (Bighelli et al., 2021; NICE, 2014). Antipsychotics have been effective in the prevention of relapse; however, they are associated with unpleasant side effects which is one of the reasons for the development of a variety of psychological interventions to help prevent relapse

(Bighelli et al., 2021). Family interventions have been found to be particularly effective in improving the outcomes of schizophrenia and functioning for the service user, as well as equipping their carers with greater knowledge and insight into how best to care for the service user (Yesufi-Udechuku et al., 2015).

Family members and friends are often required to take on a caring role to provide emotional support, financial support, and practical assistance with everyday living activities (Sin et al., 2017; Lohrasbi et al., 2023). Current psychopharmacological treatments can help to reduce symptoms; however, they have little impact on the outcome of the illness (Millan et al., 2016). Those with psychotic disorders have an increased risk of mortality, more than twice that of the general population (Walker et al., 2015), and a heightened risk of suicide, twelve times greater than expected compared to the general population (Palmer, 2005; Saha et al., 2007). Psychosis is recognised as one of the most common forms of severe mental illness, often with poor recovery outcomes (National Institute of Care Excellence, 2014; Schizophrenia Commission, 2012) and there are thought to be 23.6 million people worldwide living with this condition (Vos et al., 2015). McGrath et al. (2016) found the projected lifetime risk of psychotic experiences to be 7.8% of the adult population, indicating that approximately 1 in 13 individuals can experience at least one psychotic experience before their 75th year. McGrath et al. (2016) also found the median age of newly diagnosed cases of psychotic experiences occur, to be 23 years. Symptoms of psychosis tend to emerge in late teenage or early adult years, for example, Hare et al. (2010) estimated the average age onset to be 21.44 years. This causes significant disruption just as these young adults are trying to make their way in the world, and has a huge impact on their life plans, but also their family members who often take on a long-term caring role for their loved one.

There is much debate about the causes of psychosis. The biomedical model provides explanations based on the individual’s biological make-up. Investigations into the genetic underpinnings of psychosis have found a vast array of genetic alterations that affect a wide variety of biological pathways (Giusti-Rodríguez & Sullivan, 2013; Sullivan, 2012). However, no clear replicable associations of specific genes have been linked with the specific clinical features of psychosis (Fanous et al., 2012). Other factors such as drug and substance abuse, and organic brain disorders may also lead to psychosis (Gaebel & Zielasek, 2022). The biomedical model does acknowledge the etiopathogensis of psychosis, that social and environmental factors could act to trigger neurobiological predispositions to psychosis (Gaebel & Zielasek, 2022; Haller et al., 2014). However, the prime focus remains on the biological nature of the condition. The biopsychosocial model (Engel, 1977) has become the dominant alternative to the biomedical model in that it incorporates the interconnection between the biological, psychological and socio-environmental factors that may lead to mental distress. Engel (1977) wanted a more holistic way to understand patients as more than their biological disorders, to look at their own thoughts, feelings and history and how this influenced their physical and psychological health. The biopsychosocial model places more focus on the systemic influences on an individual's mental health taking a holistic view of how external non-biological factors such as socioeconomic status, race, ethnicity, gender and sexuality can also be important components influencing health. This model provides an understanding that mental distress is a triggered response to life stressors with the individuals response influenced by their genetic 'vulnerability' at the time. In this regard it is said to be related to the vulnerability-stress model (Wong, 2014). This model highlights the outcomes of dynamic interactions amongst various dimensions of a person's life. An example being recent research looking at external environmental factors on the development of psychosis found that life trauma is associated with an increased risk of developing psychosis (Varese et al., 2012) with approximately 80% of patients with psychosis having a history of traumatic life events (de Bont et al., 2015; Hardy et al., 2016). The biopsychosocial model has been growing in recognition in medical and mental healthcare (Nakao et al., 2020) and has informed key health guidelines. This model has also informed clinical practice for both psychiatrists and clinical psychologists and informs current practice in case conceptualisation and formulation (Campbell & Rohrbaugh, 2013). This helps mental health professionals understand their patients as more than diagnostic labels, where the origins of symptoms can be explored in more depth so that more patient centred care can be provided. The work presented in this thesis has been guided by the biopsychosocial model.

Carers of those with psychosis

For this PhD carers have been understood as any family member, relative, partner or close friend that has provided informal and unpaid support to a loved one with any form of psychotic disorder. For clarity the bulk of the cited research presented in thesis relates specifically to carers of those with psychosis and schizophrenia. Research samples of carers from white European and North American samples show that carers are typically female (Brazil et al., 2009) and tend to be mothers of adult children (Sin & Norman, 2013; Yesufu-Udechuku et al., 2015) due to the average age of onset of psychotic symptoms. Carers also include fathers, partners, siblings, grandparents, children, and non-relatives such as close friends (Norton & Cuskelly, 2021). It is estimated that in the UK there are approximately 13.6 million (26% of the total population) informal carers of those with long term illness or disability, and these numbers have increased since the COVID-19 pandemic (Carers UK, 2020). There is estimated to be approximately 1.5 million carers of those with serious mental illness in the UK (Carers Trust, 2017; NICE, 2014; Schizophrenia Commission, 2012). Informal caregiving for all disorders has become an essential resource for health and social care services due to changes in the population, demography, related health problems, and limited financial resources (Cottagiri & Sykes, 2019; Pickard, 2008). It has been argued that carers of those with psychosis and schizophrenia are a hidden workforce (Eikemo, 2018), and the unpaid care they provide is said to save approximately £34,000 (over $43,000) per person with schizophrenia per year in the UK (Yesufu-Udechuku et al., 2015). There is a clear financial incentive to support carers wellbeing (Dillinger & Kersun, 2020). The support provided by carers can lead to superior recovery outcomes for those with psychosis. Carers can identify and respond to the early warning signs of relapse and facilitate access to appropriate care when needed (Fridgen et al., 2013; Kuipers et al., 2010), this in turn reduces relapse rates and the need for hospital care (Norman et al., 2005). Those who receive care have a better prognosis, enhanced quality of life (Pharoah et al., 2010; Sin et al., 2016) and improved mortality levels (Revier et al., 2015). This unpaid care is essential to those with a mental health diagnosis such as psychosis and schizophrenia, however, there is a great cost to the family member or friend who takes on this role.

Carers need support

Carers of those who experience psychosis must often step up to the challenge of providing care in a crisis situation and can find this very traumatic (Lovelock, 2016; Mork et al., 2022), especially after dealing with the adverse effects of the prodromal stages of their loved one's psychotic break when the situation is unclear, confusing and highly stressful (Shiraishi & Reilly, 2019). Carers have no preparation time and feel as though they have gone through a major life event without having the time or space to take stock or make sense of their experiences (Estradé et al., 2023). They are often exposed to extremely challenging and frightening behaviours, such as verbal and physical aggression (Onwumere et al., 2014), without any kind of training on how to manage these difficult and unpredictable situations (Jeon & Madjar, 1998; Schulze & Rössler, 2005; Kopelovich et al. 2021). Carers also deal with a significant change to their identity as they often take on the role without realising that they have become a carer (Dillinger & Kersun, 2019), and they struggle to reconcile being a carer and a parent, partner or sibling at the same time. Strong links have been found between experiencing lack of support and isolation and poor mental health for carers (Poon et al., 2017; Sin et al., 2021). This becomes more problematic when carers in poor health must relinquish their caring role, which can then lead to poorer outcomes for the service user (Onwumere et al., 2021). There have been many calls (Bademli & Lök, 2020; Boyer et al., 2016; Lök & Bademli, 2021; Onwumere & Kuipers, 2017; Poon et al., 2017; Wyder & Bland, 2014) for greater prioritisation and support for carers of those with psychosis to assist them in continuing this community-based care (Onwumere & Kuipers, 2017). There have also been calls for greater evidence based and targeted family focused interventions to support carers (Estradé et al., 2023; Dillinger & Kersun, 2019; Kopelovich et al., 2021). Carers often put their own needs last to provide good care; however, this increases the burden they experience. When they are able to attend to their own physical, emotional and spiritual needs often their problems seem more manageable (O'Grady & Skinner, 2012).

How carers experience support

Often carers' experience of support relates to the service user's care package that is often opaque, complicated to initiate, and typically involves a lot of time and emotional demands on the carer to arrange (Cheng et al., 2020; Estradé et al., 2023). Carers can find it stressful and frustrating trying to navigate the care system and push for a timely response for their loved one. NHS mental health services seem fragmented with contradictory messages and a lack of continuity of care being experienced (Estradé et al., 2023). Carers often feel excluded from their loved one's care and can feel as though they are treated as part of the problem, being seen as possibly causing the mental illness, sustaining the illness, or contributing to relapses (Cleary et al., 2020; Wyder & Bland, 2014). Carers of those with psychosis do not feel properly supported by Early Intervention Services (EIS) in the UK and have felt their own needs and emotions were not recognised by mental health services (Lavis et al., 2015). In the UK, the "Care Act 2014" (Department of Health, 2014) has legislated that all carers should receive a Carers Assessment to establish carer needs, however, this is only sporadically completed, and many carers are not aware that they are entitled to this assessment, and when assessments do take place carers needs are not always met effectively (Rowe, 2012).

Providing support to carers is not only important for their own wellbeing but is also seen as essential to service users' recovery outcomes (Cochrane et al., 2021) as carers assist with treatment compliance, social and financial support, and provide a level of continuity of care (Boyer et al., 2016). Support from carers has been found to reduce relapse rates and the need for hospital care for service users (Norman et al., 2005), improve mortality rates (Revier et al., 2015), and help service users access appropriate care when needed (Fridgen et al., 2013). Carers who experience difficult times related to their caring often have associated mental health difficulties which can negatively impact on their caring abilities (Bebbington & Kuipers, 1994; Cleary et al., 2020; Szmukler et al., 1996). This is because they may be less engaged and more likely to show critical or hostile behaviours towards those they care for (Cooper et al., 2010; Onwumere et al., 2014; Szmukler et al., 1996). Supporting carers is therefore vital to assist with their own wellbeing but also indirectly for the wellbeing of the service user (Dillinger & Kersun, 2019; Testart et al., 2013). The need for better support for carers has also been highlighted as a key policy recommendation in many Eurocentric western countries around the world. For example, the UK Government has published multiple policies and strategies to identify carers and provide them with support and interventions as soon as possible (Department of Health, 2014a; NICE, 2014; Yesufu-Udechuku et al., 2015), and family interventions have been recommended as best practice in the USA (Kreyenbuhl et al., 2010), Canada (Norman et al., 2017), Australia (Galletly et al., 2016), and is a recommendation of the NICE guidelines in the UK (National Institute of Clincial Excellence, 2014).

Interventions for carers

Health services and academic researchers have developed and trialled a range of interventions for families and carers of those with psychosis (Chien et al., 2020; Chiu et al., 2013; Lobban et al., 2020; Melamed & Gelkopf, 2013; Sin et al., 2022; Zhou et al., 2020). There have been a variety of different sorts of interventions, most focusing on psychoeducation primarily or as a subcomponent of the intervention. Initially family interventions focused on helping families to reduce levels of expressed emotion (critical comments, hostility and emotional over involvement) in the home environment. These interventions are now widely accepted to aid in the reduction of relapse rates and improve welling in carers (Bighelli et al., 2021; Lobban et al. 2013). New carers often have limited mental health literacy which can lead them to feel underprepared, not knowing how to respond or deal with difficult symptoms displayed by their loved ones (Bademli & Duman, 2016; Estradé et al., 2023). They also lack knowledge about the treatments for psychosis, how to provide care at home, manage difficult behaviours, and deal with treatment non-compliance (Tamizi et al., 2020).

Providing enough knowledge about psychosis is seen as essential to reduce their stress and burden (Bademli & Lök, 2020) and help them to develop effective coping strategies (Bademli & Duman, 2016; Raghavan et al., 2017).

Several recent novel eHealth interventions have incorporated psychoeducation and support for carers through online forums. Unfortunately, these online interventions have been found to have low efficacy rates (Batchelor et al., 2022; Lobban et al., 2019; Sin et al., 2019); however, this could be due to the online nature of the peer support offered and carers not having enough protected time to focus on the intervention. Other recent interventions have coupled psychoeducation with other psychological approaches, like problem-solving strategies (Barrowclough et al., 2001; Chien et al., 2020), or empowerment approaches through narrative therapy (Zhou et al., 2020). Such interventions have been found to improve carers quality of life and seem to reduce distress (Lobban et al., 2013; Yesufu-Udechuku et al., 2015), with some interventions finding a significant improvement in carer's inner resources and problem-solving abilities, perceived control of the situation and levels of hope (Chien et al., 2020; Zhou et al., 2020). Despite this, there is an ongoing implementation gap in identifying and providing support for carers (Sin et al., 2018). Despite Health Education England (HEE, 2020) implementing national training in family interventions in line with the recommendations made by NICE (National Institute for Clinical Excellence, 2014), family interventions have not been implemented to an adequate level yet (Mork et al., 2022). Clearly not only are psychological interventions for carers required but they also need to be implemented into routine care. To create more targeted support for carers it is important to have a holistic view of the multidimensional nature of their caring role, and as such, we need to understand both the negative and positive aspects to caring (Shiraishi & Reilly, 2019; Estradé et al., 2023).

Negative aspects to caring

Carers of those with psychosis report subjective burden of care and often face several challenges in many aspects of their lives: deterioration of their physical health and mental health, financial challenges, reduced quality of life, social isolation, feelings of grief and guilt (Charles et al., 2020; Jansen et al., 2015). Caring has been found to affect physical health with an increased risk of mortality (Caqueo-Urízar et al., 2014). Carers have been found to experience high levels of burden and emotional distress (Awad & Voruganti, 2008; Nordstroem et al., 2017; Poon et al., 2017). Roughly two-thirds of carers report depression, anxiety, or substance misuse (Pirkis et al., 2010), and carers have been found to meet the criteria for depression and stress related conditions such as anxiety (Birchwood et al.,2000; Cleary et al., 2020; Sadath et al., 2017). Carers of those with serious mental illness are more prone to developing a mental health condition themselves compared to relatives of those with other disorders, such as rheumatoid arthritis, multiple sclerosis, and epilepsy (Mittendorfer-Rutz et al., 2019). Carers are often exhausted, which can lower the threshold for losing their temper and they often have little respite time and can feel a sense of entrapment (Mork et al., 2022) especially as the service user becomes dependant on their care. Onwumere et al. (2018) found that approximately 60% of carers of those with first episode psychosis (FEP) scored over the threshold for emotional exhaustion with the potential to lead to burnout. This is especially marked for carers in the early years of the illness when related issues are new and they may not have developed coping strategies to manage difficult behaviours (Sadath et al., 2017). Posttraumatic stress disorder (PTSD) has been identified in carers, with 35% of carers of those with FEP, demonstrating symptoms (Barton & Jackson, 2008). Kingston et al. (2016) found that 44% of carers in their study met the threshold for posttraumatic stress symptoms (PTSS) and that this was strongly related to negative cognitions about the self, and self-blame often related to their caring role.

Carers of those with psychosis can experience financial burden as they often reduce their work hours or give up their day jobs to provide care. Carers commonly put their own lives on the back-burner to provide a calm, organised and supportive environment for their loved one, while being ‘on call’ at any moment (Lavis et al., 2015). Taking on a caring role has been linked to a reduced quality of life (Hayes et al., 2015; Sin et al., 2021). Carers have reported feeling angry, lonely, and socially isolated (Chien & Chan, 2004; Hayes et al., 2015; Jimena et al., 2024), with the load and responsibility of a long-term caring role causing fear and high levels of distress (Smith et al., 2014; Stansfeld et al., 2014). They can also experience strained family relationships and must deal with the stigma of mental illness in their family or close circle (Mackay & Pakenham, 2012; Magliano et al., 1998, Woodberry et al., 2021). Carers also experience high levels of grief and guilt. The grieving process occurs when carers try to reconcile their past hopes and dreams for their loved one with more realistic expectations (Wainwright et al., 2015; Mulligan et al. 2013). This grief and worry are compounded by the guilt that they should have recognised the illness sooner or done more to prevent it from developing in the first place (Estradé et al., 2023; Ward & Gwinner, 2014). Cherry et al. (2017) found that carers' feelings of guilt and shame are associated with emotional over-involvement, critical comments, and hostility in the family. Carers also worry about the future prospects for the person they care for and take on a high level of responsibility for this (Fortune et al., 2005; Jimena et al., 2024; Mulligan et al. 2013). Where families believe that the service user may not recover or that they believed that the treatments are not sufficient to help severe symptoms, they demonstrate high levels of stress (Gupta et al., 2015).

Positive aspects to caring

A large proportion of research about carers experiences has focused primarily on the negative impact of caring such as burden; however, other aspects of caring have largely been overlooked (Onwumere et al., 2018). Chen and Greenberg (2004) have argued that research focusing exclusively on family burden has missed a vital aspect of caregiving experience, the positive experiences. The positive aspects of caring include both personal and interpersonal gains for carers. The personal gains include perceived personal growth (Chen & Greenberg, 2004; Shiraishi & Reilly, 2019), a clearer sense of life priorities (Dillinger & Kersun, 2019; Marsh et al., 1996) a newfound sense of perspective and purpose, and positive life transformation that includes a greater sense of inner strength and satisfaction (Pickett et al., 1997; Winefield & Harvey, 1994). Estradé et al. (2023) found that carers were able to learn from their mistakes, enabling them to build resilience and hope which was found to be a key ingredient to keep moving forward. Other personal gains include greater self-confidence, personal resilience (Stanley & Balakrishnan, 2021), and enhanced coping effectiveness (Chen & Greenberg, 2004). Carers have also noted improved interpersonal relationships with the person being cared for but also other family members (Chen & Greenberg, 2004; Shiraishi & Reilly, 2019). Carers can experience greater interpersonal affection, a strengthened sense of love, appreciation, and support for their loved ones, increased compassion and appreciation with greater understanding and patience for others (Shiraishi & Reilly, 2019). Chen and Greenberg (2004) found that having greater reciprocity in relationships validated carers' efforts and promoted positive understanding of their caring experiences. The positive feelings identified by carers has been linked with lower burden scores and better self-assessed health (Cohen et al., 2002) and improved quality of life (Kate et al., 2013). Collaborative working with mental health professionals that looks holistically at all aspects of carers' experiences could provide more knowledge to the carer and in turn increase their sense of mastery (Birchwood et al., 1992; Reinhard, 1994) and feelings of self-efficacy and preparedness for caring (Stanley & Balakrishnan, 2021). It can also help to identify risk factors for negative carer outcomes (Cohen et al., 2002; Dillenger & Kersun, 2019) and help us understand more about healthy adjustment to caring, to promote resilience, positive adaptation, personal growth, and recovery. One aspect of carer experience that has received little investigation to date is their own personal recovery.

What is personal recovery?

Personal recovery has become the guiding approach influencing mental health policy and practices in many English-speaking countries globally (Price-Robertson, Obradovic, et al., 2017; Slade et al., 2014; Tew et al., 2012), as well as some regions of Asia such as Japan and Hong Kong (Mak et al., 2018). Personal recovery has mainly been understood as a process that service users navigate with a variety of different and contested definitions being presented (Shepherd et al., 2008). The most widely accepted definition comes from Anthony (1993) who saw personal recovery as:

> *"a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles…a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness".*

Andresen et al. (2003) explained personal recovery related to four key processes: finding hope, re-establishing identity, developing meaning in life, and taking responsibility for oneself. Leamy et al. (2011) conduced a systematic review and synthesized models of personal recovery. They outlined a framework of five key characteristics of personal recovery summarised using the acronym 'CHIME' (see Table 1). The CHIME framework has become widely used and influential and highlights the often-overlapping aspects of personal recovery (Leamy et al., 2011).

TABLE 1: *Summary of the CHIME Framework outlined by Leamy et al. (2011)*

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; 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

The origins of the personal recovery come from the consumer/survivor movement of the 1980's and 1990's and are based on self-help, empowerment, and advocacy (Shepherd et al., 2008). The recovery movement has been seen as a "grassroots movement of the disenfranchised that has placed itself apart from the human service professions, the academy, and the empirical research tradition" (Resnick & Rosenheck, 2006, p. 121), and emerged as an alternative discourse for understanding mental illness that emphasizes the holistic development of those in recovery (Leonhardt et al., 2017). This consumer-based understanding is understood as 'personal recovery' and represents a sharp move away from the idea of mental illness pathology and symptoms towards wellness despite symptoms (Shepherd et al., 2008). Personal recovery is thus distinctly different from the traditional notion of 'clinical recovery' that sees the importance of a reduction in symptoms, improved social functioning, relapse prevention and risk management (Slade, 2010). A useful conceptualization is to think about the service user being 'in' recovery as a journey, rather than recovery 'from' a mental illness (Davidson et al., 2008). Personal recovery is seen as a journey into life, not an outcome to be arrived at (Slade, 2010). This provides more agency and empowerment to the service user who can focus more on their abilities, interests, and possibilities for the future, gaining back their social roles and relationships that give their life value and meaning (Repper & Perkins, 2003). The concept of personal recovery has received a mixed reception from consumers. For example, there has been criticism by grassroots consumer groups arguing that personal recovery has become too professionalized and places a high level of responsibility on the service user to improve their situation and mental health when they are already vulnerable and unwell. For example, 'Recovery in the Bin' takes a critical theorist and activist stance seeing personal recovery as a way to discipline and control service users to accept intolerable and inhuman social pressures (Recovery in the Bin, 2023).

The role of families in recovery

Family carers are seen as integral to personal recovery for service users and should be included as partners in their care wherever possible (Mak et al., 2018; Shepherd et al., 2008). Families are increasingly being asked to provide recovery-orientated support while at the same time reconciling their own role, needs, and the needs of other family members (Wyder & Bland, 2014). The bulk of current research on personal recovery has focused mainly on the service users' experiences; however, there is now increasing recognition and calls to look at personal recovery for carers and family members (Norton & Cuskelly, 2021; Price-Robertson, Obradovic, et al., 2017). Some argue that the family's role is still ambiguous and is only understood as supporting the service users' recovery (Wyder & Bland, 2014). This shows that carers' experiences of recovery are intrinsically linked to the services user and cannot be understood in isolation (Wyder & Bland, 2014).

Personal recovery for carers

There has been very limited research about personal recovery for carers (Jacob et al., 2017; Scottish Recovery Network, 2016) and recovery informed practice has largely overlooked carers (Hungerford & Richardson, 2013). There has been a recent call to recognise that carers are on their own journey of personal recovery and that more should be done by health care services to promote and support this (Lavis et al., 2015; Norton & Cuskelly, 2021; Poon et al., 2017; Wyder & Bland, 2014). Carers' recovery should be understood as a unique and separate journey running in parallel to their loved one's recovery journey (Lovelock, 2016) to allow them to move forward with their own lives, developing a sense of meaning and purpose despite the on-going challenges that they may face (Deane et al., 2015; Norton & Cuskelly, 2021). O'Grady and Skinner (2012) describe this process as 'journeying on' where families move away from the preoccupation with the service user's journey to find the own separate recovery pathway, with an acceptance that they may not be able to fix or cure their loved one's illness. This acceptance can help carers to adjust and discover new possibilities, achieving a different life that goes beyond caring (Clarey et al., 2021). Carers' supporting role is not a static one and often must change due to changes in their loved one's symptoms (Wyder & Bland, 2014). Some have argued that carers experience secondary traumatisation where they share the trauma, isolation, and stigma of their loved one's mental illness (Clarey et al., 2021; Wyder & Bland, 2014) and this often subsumes their own identity (Lovelock, 2016). As the person they care for moves forward with their recovery journey, they may seek independence and freedom, and this could lead to tension as care roles need to be redefined and renegotiated and can negatively affect an already strained and enmeshed relationship (Lovelock, 2016). Because of this, it is important to consider the fluid and changing nature of the recovery journey for carers. Being able to assess this process over time would give greater insight into carer experiences and help better support them.

Rationale for the PhD

It is evident that to promote positive outcomes for carers, it is necessary to assess their experiences holistically, looking at both the negative and positive aspects to caring. There is already a considerable amount of research about the negative aspects to caring and the impact this has on carers. Research into the positive aspects to caregiving has been limited and has not been translated into any kind of family intervention tailored to support carers' recovery (Deane et al., 2015). Having a holistic picture of carer experiences could help clinicians and researchers understand the processes that underpin positive adjustment to caring, which in turn could help in the development of more targeted support for carers. One aspect to carer experience that is clearly under researched is their views of personal recovery and whether this could be a relevant concept to consider for their own experiences. To the author's knowledge, there is currently no empirical research investigating the personal recovery journey for carers.

One obvious way to investigate this would be through qualitative interviews, to gain an in-depth understanding of carers views and experiences of personal recovery for themselves. There is also a need to be able to assess personal recovery quantitatively using a self-report measure. One key reason for this relates to the changing nature of the recovery 'journey' for both the service user and the carer. The parallel nature of personal recovery for carers means that as the service user's mental health changes, this has a direct effect on the carer as well; so, it is important to be able to measure personal recovery for carers at different time points to get an idea about how their own recovery may be changing. An effective way to do this would be through a self-report measure as this would allow for longitudinal comparisons to be made. The bulk of outcome measures used to assess personal recovery have been developed for use with service users (Sklar et al., 2013). To date there is only one outcome measure that has been developed to assess personal recovery for carers

(Estrada, 2016), however, this is not available to clinicians or researchers as it was developed for use in a paid online intervention for carers in the USA called Families Healing Together (2018). There is a clear need to develop a measure looking at personal recovery for carers that can be made publicly available. Investigating personal recovery for carers is a complex task as the concept may not be valid for this population, however, it is worth investigating as it has been such an influential concept for service users.

Aims of the PhD

The key research question for this PhD was “what is the nature and experience of personal recovery for carers of those diagnosed with psychosis or schizophrenia?” The key objective of this PhD was to design and test a new outcome measure assessing carers’ own personal recovery. To address the research question and key objective, a four-phase approach was adopted for this PhD which is outlined in Table 2.

Rationale for Alternative Format

This thesis has been constructed using alternative format, comprised of four journal articles in published or publishable format. The decision to use this format was to maximise the dissemination of findings in a timely way, it was also felt to be a good fit for the nature of the research as each phase of research lends itself to being written up as a separate empirical journal article.

TABLE 2: *PhD Study phases*

Phase	Topic area	Chapter Number [output]
1	Systematic Review: A review of all available outcome measures that assess personal recovery (or any aspect thereof) for informal carers of those with psychosis. An assessment of the psychometric quality of any identified outcome measures using the COSMIN checklist	3 [paper already published]
2	Qualitative interview study: A series of in-depth interviews with carers of those with psychosis exploring personal recovery experiences using thematic analysis.	4 [drafted and ready for submission for publication]
3	Development of new outcome measure of personal recovery for carers: A draft measure was developed based on the findings from the qualitative interviews and literature on personal recovery. The measure was further refined through a series of cognitive interviews with carers and a matrix evaluation of the comments made.	5 [drafted and ready for submission for publication]

4	Psychometric evaluation and validation of the Carer Adaptation and Resilience Scale (CARS): An exploratory factor analysis and psychometric evaluation of the CARS.	6 [drafted and ready for submission for publication]

Chapter 2: Methodology

Overview of the chapter

This chapter will focus on the overarching methodological choices which guided the research design of this PhD. To understand the main philosophical assumptions behind this study, this chapter will review the main paradigms of positivism, postpositivism, interpretivism and pragmatism. Following this is a discussion of mixed methods research (MMR) and the rationale for selecting this approach for the current study. MMR has very clear research design frameworks, and it is recommended by key authors in this area such as John Creswell, Vicky Plano-Clarke, Charles Teddlie and Abbas Tashakkori. Research studies should make it explicit which research design is being followed. Therefore, the remainder of this chapter outlines the different phases of this PhD using an exploratory sequential research design as the framework. The main focus of this chapter is to provide an eagle eye's view of the main study design choices and philosophical assumptions behind this study. A more fine-grained summary of the individual methods used in this study are described in each of the research papers that follow this chapter.

Philosophical assumptions

Effective research design requires many considerations, and one of the fundamental concerns is the philosophical assumptions behind the research (Rolfe, 2013). Having a clear understanding about the nature of knowledge is important as this then dictates the most effective way to collect, analyse, and disseminate the data collected (Rolfe, 2013). Crotty (1996) provides a useful way to understand the four major elements to developing a study: firstly, at the broadest level are the philosophical assumptions such as the epistemology, ontology and beliefs about the nature of knowledge; secondly there is the theoretical lens that is informed by the philosophical assumptions such as the main social science theories, for example, interpretivism; thirdly there is the methodological approach taken, for example, quantitative or qualitative; finally, there are the individual methods of data collection, such as self-report measures or interviews.

All philosophical assumptions sit within a particular paradigm or worldview. A paradigm (Kuhn, 1970) encapsulates the philosophy, commitment, beliefs, assumptions, values, methods, outlook, and worldview of a particular group of researchers (Rychetnik et al., 2004). Each paradigm holds a different view about the nature of understanding and knowledge of reality that are packaged together with certain methodologies that are seen as the most appropriate fit to that paradigm. Different paradigms will have different ontological positions. Ontology relates to the understanding of the nature of reality and whether as scientists we are able to gather data that are objective and have an external view of social actors, or whether data are subjective, created within the individual with all experience being socially constructed through our perceptions and interactions with other social actors (Bryman, 2016). It is important to understand the epistemological position in research design (Rolfe, 2013). Epistemology is the understanding of what should be regarded as acceptable knowledge in a discipline (Bryman, 2016).

There are several paradigms or worldviews that influence how research is designed and conducted in the field of health research. Having a broad understanding of such paradigms helps researchers understand the different types of research design and methodology used to generate data. A summary of the main paradigms is presented below. In addition, a useful comparison table lists the key features and differences of the main paradigms (see Table 3).

TABLE 3: *Summary of the main paradigms in health research*

Paradigm *(worldview)*	**Ontological position** *(nature of reality/what is reality)*	**Epistemological position** *(nature of knowledge, how do we know something)*	**Main methodological approach** *(how we find out about it)*
Positivism	Purely objective: real-world objects are separate from the researcher so inferences can be objectively deduced. Reality can be accurately described, represented, and explained, also known as 'realism'. Aims to be value free. Reductionist	Deductive: top-down approach. Theories generate hypotheses that can be empirically tested and will allow for explanations of social behaviours to be assessed. Researchers can compare their claims against objective reality, allowing for prediction, control and empirical verification of theories.	Quantitative: Formal, objective, systematic process usually using numerical data
Postpositivism/ Critical Realism	Mainly objective. Social reality is external and independent and can be objectively studied. Acknowledges that reality can only be imperfectly understood and subject to change. Determinism: cause and effect thinking.	Deductive: top-down approach mainly. From theory to hypothesis to confirm or refute the theory. Detailed observations and the measurement of variables. Data can be generalised	Quantitative mainly but can use mixed methods.
Interpretivism/ Phenomenology	Constructionist: understanding the meaning of phenomena. Formed/constructed through participants subjective views.	Inductive: bottom-up that looks at individual perspectives to find broader patterns.	Qualitative: Conversational, subjective, organic process, usually using verbal interview

Paradigm *(worldview)*	**Ontological position** *(nature of reality/what is reality)*	**Epistemological position** *(nature of knowledge, how do we know something)*	**Main methodological approach** *(how we find out about it)*
	Meanings are shaped by social interactions with others and their personal histories. Meanings are continually being accomplished by 'social actors' and produced through social interactions. Acknowledges that researchers own accounts are also constructions of the social world.	Building broad themes from individual experience to generate theory. Promotes reflexivity in research.	data or text accounts of social experiences.
Pragmatism '3rd Research Paradigm'	Values both objective and subjective knowledge. Prioritises the research question as more important than the philosophical worldview behind the research. Seen as possible for researchers to have multiple worldviews, this should be explicitly expressed. Worldviews may change during the course of the project and maybe tied to different phases of the project.	Combination of deductive and inductive thinking. Practical and applied research philosophy should guide methodological choices. Focus on using the most effective methods to answer the research question. Frames procedures within philosophical paradigms and theoretical lenses. Focuses more on the consequence of research.	Mixed methods: Focus on multiple methods to best answer the research question. Mixes, integrates two forms of data concurrently by merging them or sequentially having one build on the other, or embedding one within the other.

Positivism

This paradigm holds a realist ontological position that how we perceive the world is an accurate understanding of reality thus allowing us to obtain accurate and direct knowledge of the world (Rolfe, 2013). Realism sees that social phenomena are external facts that are independent of social actors and beyond the influence of the researcher (Bryman, 2016). Because of this separation between real-objects and the observer, reality can be accurately described, represented, and explained in a value free and objective way (Rychetnik et al., 2004). The epistemological position held by positivists relates to deductivism or top-down research approaches, where theory generates hypotheses that can be tested empirically and allows explanations of laws to be assessed (Bryman, 2016). The main methodological approach used by positivists is quantitative and uses mainly numerical data collected in a systematic way, for example, through structured questionnaires.

Postpositivism and critical realism

These paradigms are mainly objective in that social reality is seen as external to the investigator, however there is an acknowledgement that reality can only be imperfectly understood and is subject to change (Rychetnik et al., 2004). Observations are seen as contextually bound and are therefore not generalisable to all cases and situations (Carpiano & Daley, 2006). Postpositivism holds a deductive epistemological position for the main part, empirically assessing theories using hypothesis testing. This approach does take on a more critical approach and incorporates ‘critical realism’ which has become a popular paradigm in more modern social science research as it provides a middle ground between naïve realism of ‘what you see is what you get’ and the scepticism of anti-realists for whom the entire social world is seen as socially constructed (Rolfe, 2013). Critical realism (Bhaskar, 1989, 2014) combines the realist ontological view of the positivists with a critical approach that sees research as conducted on, with and by people that is occurring within social structures and communities. This context can influence and distort the straightforward collection and interpretation of data (Rolfe, 2013). The fact that certain aspects of reality are not available for direct observation and can only be perceived indirectly (Bryman, 2016) means that there is then a requirement for the researcher to interpret a reconstructed reality, which provides a critique to direct realism and provides a strategy for overcoming the associated limitations (Bryman, 2016; Rolfe, 2013). The main methodological approach tends to be more quantitative but mixed methods and some qualitative methods are also employed.

Interpretivism

Interpretivism provides an alternative view to positivism. This paradigm takes a constructionist ontology seeing that the meaning of phenomena are formed and constructed through participants own subjective views (Cohen et al., 2008). Meanings are shaped by our social interactions with others and are continually ‘being accomplished’ and are subject to change (Bryman, 2016). There is an understanding that we cannot separate ourselves from what we know and that who we are and how we understand the world are intrinsically linked (Cohen & Crabtree, 2008). All interpretations are located within a particular context, setting and moment (Cohen & Crabtree, 2008). Knowledge is viewed as indeterminate and subjective (Bryman, 2016). Interpretivists also acknowledge that researchers’ own accounts are also constructions of the social world, and this is why reflexivity is so important (Rolfe, 2013), as researchers’ values are inherent in all phases of research (Cohen & Crabtree, 2008). Interpretivism includes the intellectual tradition of phenomenology that is concerned with how individuals make sense of their world and recognises that researchers should try to ‘bracket out’ their preconceptions or acknowledge any potential biases through reflexivity (Bogdan & Taylor, 1975). The epistemological position is inductive taking a ‘bottom-up’ approach as this looks at individual perspectives to find broader patterns and themes which are then aggregated to form theories. The main methodological approach used tends to be qualitative usually based on verbal interview data or textual accounts of social experiences.

Pragmatism

This paradigm takes on a practical approach to research. It acknowledges the value of both objective and subjective knowledge; however, it prioritises the research question and the best and most practical way this can be answered. Therefore, multiple worldviews can be held but it is advised that this is explicitly stated in the research design (Creswell & Plano Clark, 2011). It is also possible for world views to change in relation to the particular phase of the research, for example, if there is a qualitative component to the research, a more interpretivist paradigm and related methods would be appropriate. This approach looks at what works best in practice and combines both deductive and inductive thinking depending on what is the best approach at that point in the research. Pragmatists are typically associated with mixed methods research and will use the best methods to answer the research question, which might be quantitative or qualitative or a combination of both (Creswell & Creswell, 2018).

Mixed methods research (MMR)

MMR developed in the late 1980's and is based on the writings of sociologists, management scientists, nursing and education researchers in the USA, Canada, and the UK. It has been called the "third methodological movement" (Tashakkori & Teddlie, 2003) and has been formally linked to pragmatism (Tashakkori & Teddlie, 2003). This provides a practical and applied research philosophy where the research question is seen as of primary importance and argued that the forced choice dichotomy between postpositivism and constructionism should be abandoned (Bryman, 2016). Creswell and Plano Clark (2011) provide a good definition of MMR explaining how it mixes, integrates and links two forms of data concurrently by merging them, or sequentially by having one build upon the other, or embedding one within the other. MMR allows for one or both forms of data to be given priority depending on what the research is emphasizing. MMR frames the procedures within the most useful paradigm and theoretical lens to answer the research question. Multiple paradigms or worldviews can be used that best relate to the methods being used and Creswell and Plano Clark (2011) argue that the paradigm should become the guiding assumption that shapes how methods and procedures are selected, however, worldviews can change during the study, and this is acceptable but it must be made clear in the write up of the research.

Advantages and challenges of MMR

The main advantage of MMR is that it provides researchers with more methodological tools for data collection rather than being restricted to one methodological approach. This helps to answer questions that cannot be answered by one approach alone (Creswell & Creswell, 2018). By combining both it is seen as possible to overcome their respective weaknesses and draw on their strengths (Tashakkori & Teddlie, 1998). For example, quantitative methods can miss the in-depth and subjective meaning that a carer may have about personal recovery, but by running qualitative interviews, this can be overcome. Both approaches can be used to provide a comprehensive account of personal recovery and provides robust and credible research findings. MMR also provides a bridge across the sometimes adversarial divide between quantitative and qualitative researchers (Bryman, 2016). It encourages the use of multiple paradigms and to think about the most appropriate epistemological choices for the research, such as combining both inductive and deductive thinking at different phases of the study. It allows researchers to use both numerical and quantitative data and in depth verbal qualitative data in a pragmatic way. There are some challenges to this approach in that it requires the researcher to have a wide array of different research skills and experience. It also takes up more time and resources and effort on behalf of the research team. MMR can also be open to criticism from purist researchers who primarily follow one methodology as they may not agree with the combining of different philosophical positions (Creswell & Plano

Clark, 2011). A response to this would be that a pragmatist approach is not restricted or limited by philosophical assumptions as they prioritise the research question and what best methods can be used to answer the research question.

Philosophical approach of this PhD

This PhD has taken a pragmatic philosophical approach using MMR as this was seen as the best way to investigate the complex theoretical construct of personal recovery for carers. The theoretical lens has been personal recovery. Slade (2009) has argued that personal recovery is best understood from a constructionist perspective, as the theory lies between objectivism and subjectivism; as knowledge does not reflect external reality. Rather it is based on the intra and interpersonal experiences of the individual. Slade (2009) also argues that a constructionist ontology allows for the integration between the knowledge derived from the clinical models of mental health problems and the very idiosyncratic experiences of individuals. There has been a philosophical conflict to resolve in this research. Personal recovery is a very individual and subjective process that aligns more with the interpretivist paradigm. However, in order to create an outcome measure to assess personal recovery for carers quantitative methods needed to be employed which aligned more with a postpositive paradigm. There was clearly a difficulty in reconciling both paradigms and ontologies and hence a pragmatic approach was taken as it allowed for an interpretivist approach to be taken for the qualitative components and a postpositivist approach for the quantitative component of the PhD.

Research design of this PhD

MMR has very clearly defined research design frameworks, which have been outlined clearly by Creswell and Plano Clark (2011). There are several key decisions when designing a mixed methods study. First, decisions need to be made about the level of interaction between the quantitative and qualitative strands of the research. For example, are both strands independent of each other? Furthermore, what is the interaction level between the two strands? Moreover, can the findings from the two strands be combined before the final interpretation is made? Another consideration relates to the level of priority between the two strands. For example, do they have equal priority or is the qualitative component more of a priority. Thirdly, what is the timing of the implementation of each strand. What order do the researchers use to gather the data? For example, would concurrent data collection where both types of data are collected at the same time make sense, or is sequential data collection a better fit?

Exploratory sequential design

Based on Creswell and Plano Clark (2011) research design frameworks, an 'exploratory sequential design' was used in this thesis. This is the recommended research design for questionnaire development (Creswell & Plano Clark, 2011; DeVellis, 2012; Streiner et al., 2015). This design is recommended when exploration of a new theoretical concept is needed, or an outcome measure for the theoretical construct is not available. So, to relate this to the present study, there was a requirement to explore the concept of personal recovery for a new participant group (carers), and there was no outcome measure to assess this construct. This design takes an iterative approach and uses sequential timing, which begins with an exploratory phase and the collection and analysis of qualitative data. Building from these results, the second quantitative stage begins, where the data are tested out. The interpretation of the quantitative findings builds on the initial qualitative results. Creswell and Plano Clark (2011) recommend choosing this design when the research question is more qualitatively orientated and requires an exploratory stage because the researcher does not yet know what constructs are important to study. This design also needs enough time to conduct multiple phases sequentially. This did mean that this PhD had a very clear structure from the outset. However, it did run over time as each phase had to be completed before the next one could begin. The COVID-19 pandemic also delayed this study as well. Additionally, this design is helpful when there are limited resources, and where only one type of data is collected and analysed at a time. Because of the nature of a PhD, I was limited in terms of financial and human resources, with only myself collecting and analysing the data in a sequential process.

The philosophical assumptions of this type of design are pragmatic and allow different paradigms to be to be used as the research shifts between phases. Because qualitative methods take priority in the first phase, researchers tend to take on an interpretivist or constructionist approach to gain a deeper understanding of the research area from the subjective perspective of the participants. Then when researchers move to the quantitative phase, the philosophical assumptions may shift to those of postpositivism that would guide the identification and measuring of variables of interest. The strengths of this are that the separate phases make for a straightforward design that is relatively easy to describe, implement and report. It is also seen as more acceptable to both quantitative and qualitative research 'camps' because it integrates the findings from both and can be reported in separate publications relatively easily. There are also some challenges to this research design. For example, it requires considerable time to implement, it is often difficult to specify in detail the procedures that will be required for the subsequent phases of the study when ethical approval is being sought and two distinct samples should be used for each phase which makes recruitment more challenging. Creswell and Plano Clark (2011) also recommend that in addition to a research proposal any research design should be clearly outlined and recommend using flow charts to do this as this improves the transparency of the research. For this study, each phase has been summarised in flow charts based on the Creswell and Plano Clark (2011) recommended framework. A summary of each phase of the present study is detailed in Figures 1 to 3.

Researcher positionality

My position coming to this research was as a qualitative researcher with an interpretivist philosophical stance. My past qualitative research experience involved a mix of more interpretivist approaches such as social constructionism having conducted discourse analysis for my undergraduate dissertation, but also some more pragmatic qualitative approaches that involved working on a large-scale research trial and collecting and analysing following a more realist position. I came to this research favouring the qualitative element to the study and may have had a bias towards interpretivist methods because of this. It was important to take a pragmatic approach to the design and analysis of the qualitative interview data taking the approach that objective data could be sought. I had not had much experience of questionnaire design or quantitative methods and to address this I did a lot of reading around this area and attended training courses to fill in the gaps to my knowledge. I was also aware that both of my supervisors were clinical psychologists who valued mixed methods research and took a pragmatic approach to research. I realised it was important to make the philosophical position of this PhD very clear and to provide a clear description of mixed methods research within the thesis write-up.

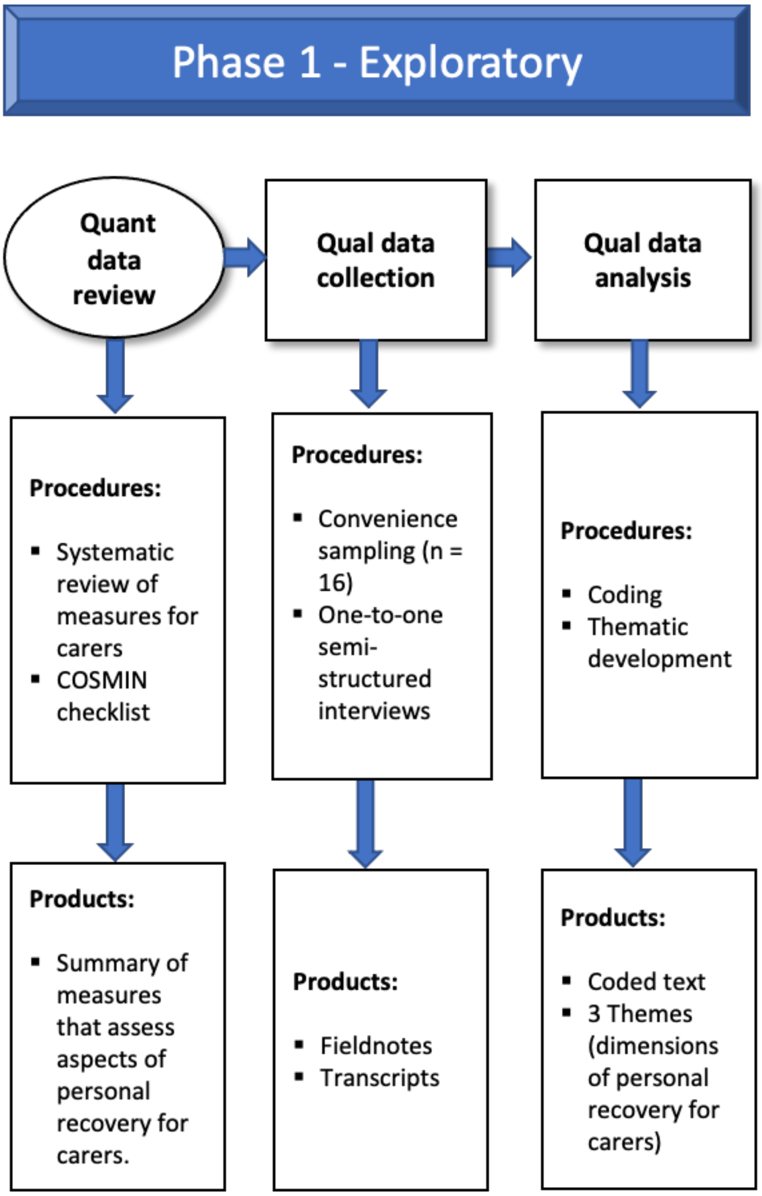
Another important element of my position as researcher relates to my lived experience of psychosis. I felt this was a strength as I had in depth knowledge and experience of the topic area and personal experience of seeing my family members becoming my carers. I was aware that this topic could become quite emotive for me, but I planned to raise any problems relating to this in my supervision. I also made sure to take a neutral position as much as I could as I understood that everyone’s experience of mental health is different. I was also aware that my characteristics as a female from white British ancestry, who grew up in a different country and who had young children would all affect the lens used to conduct and analyse this data. To address this bias, I made sure to write reflective notes throughout the interview stages of the PhD to help me consider my position and how this may be affecting my research.

PhD study stages

Exploratory stage

This stage involved both quantitative and qualitative methods. Initially a quantitative systemic review was conducted to explore outcome measures that may be related to personal recovery for carers. The COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist (Mokkink et al., 2010) was used to assess the methodological quality of the development of each measure and was based on a very structured checklist providing quantitative scores for each measure reviewed. Following this assessment, a descriptive account was presented summarising the key elements to each measure reviewed. The next part of the exploratory phase took a purely qualitative approach and involved a series of one-to-one semi-structured interviews with carers to discuss their experiences in-depth. A thematic analysis as outlined by Braun and Clarke (2006, 2013) was used to analyse the data resulting in 3 key themes that then fed into the next phase of the PhD. The end products of this phase are a published systematic review and a draft qualitative paper.

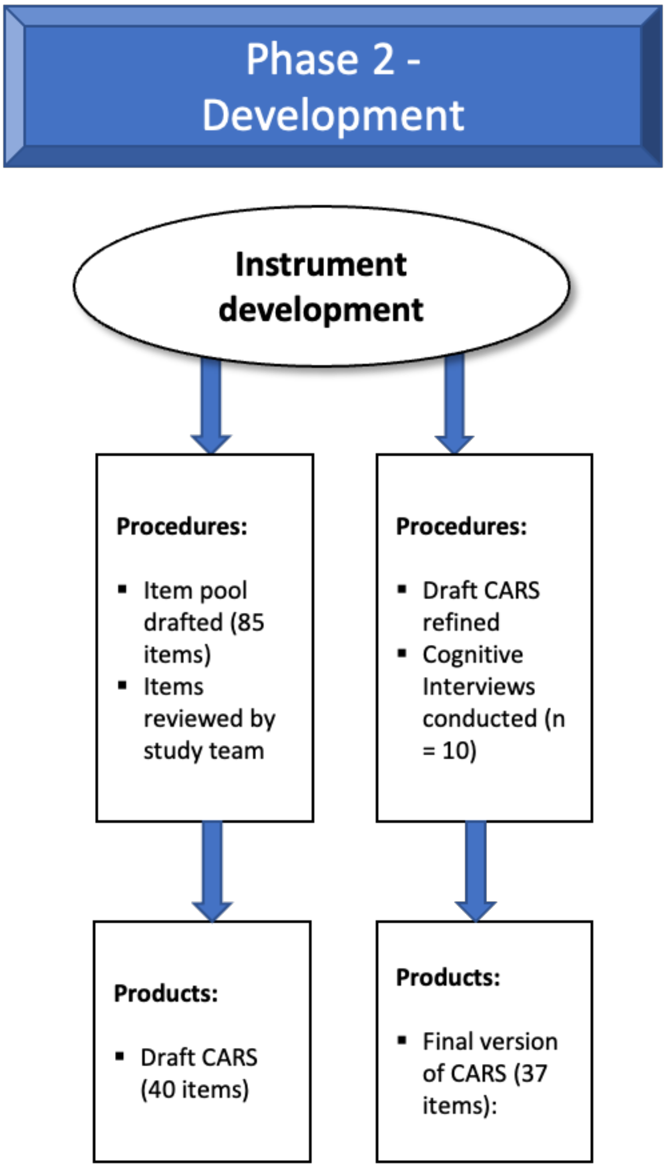
FIGURE 1: *Outline of Phase 1 of this PhD exploring the concept of personal recovery for carers*



Development stage

Phase two of this PhD related to the development of the new outcome measure called the Carer Adaptation and Resilience Scale (CARS). This phase represents the 'sequential' part of the research design as it is based mainly on the findings from the exploratory phase of the PhD. Phase two involved firstly the development of a pool of questionnaire items, which was then discussed in supervision resulting in the draft 40-item CARS. Following this a set of 10 cognitive interviews were conducted to discuss and refine the CARS with direct input from carers. Phase two of this PhD represents a primarily qualitative approach however a very systematic numerical approach was taken when refining the results from the cognitive interviews into the results matrix. This pooled the data into a set of 'problem categories' to be addressed. The end product from this phase was the final 37-item CARS ready for testing. Additionally, a paper has been drafted describing the development of the measure using a relatively novel qualitative method - cognitive interviewing.

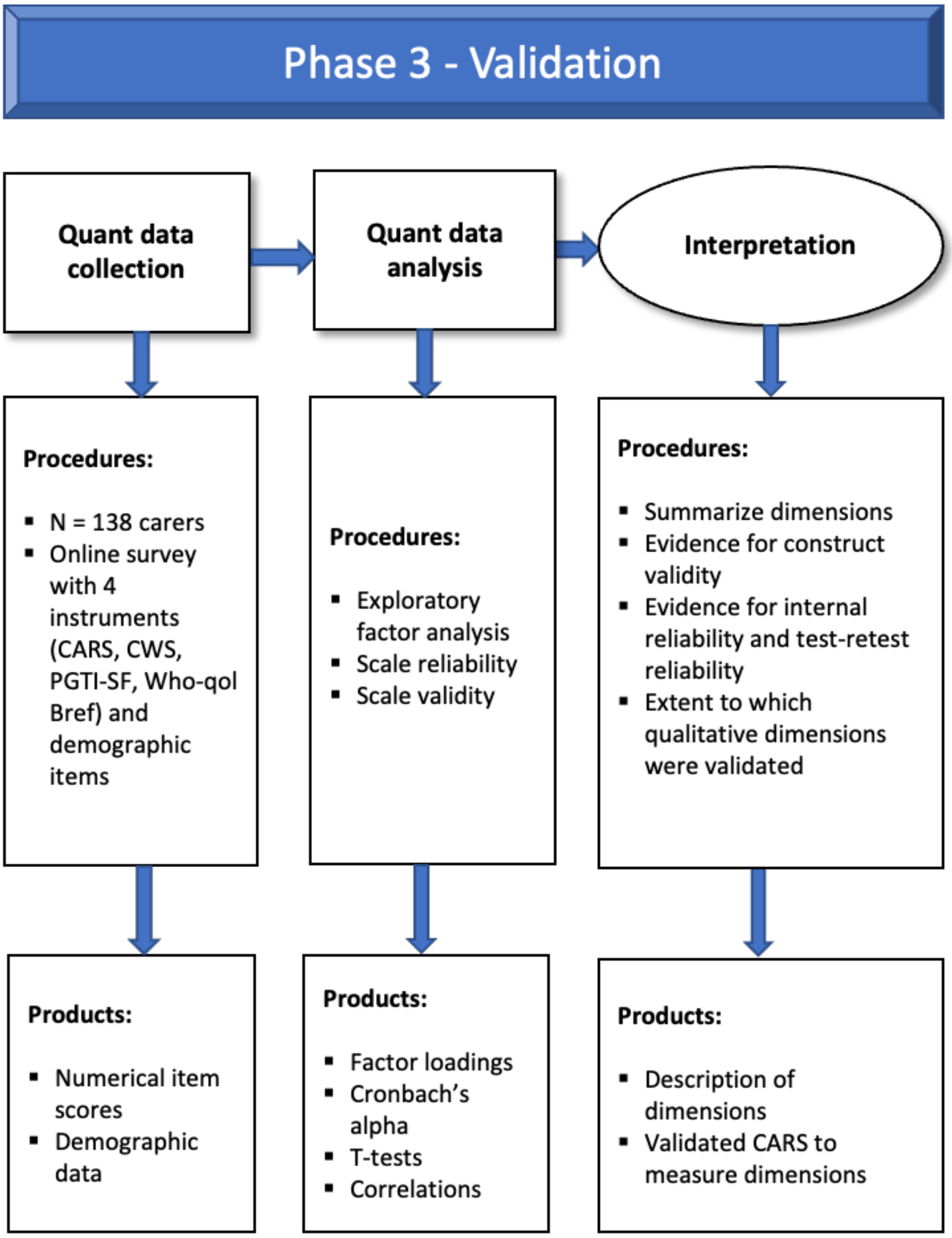
FIGURE 2: *Outline of Phase 2 of this PhD to develop the new outcome measure for carers*



Validation stage

Finally, phase three of this PhD related to purely quantitative methods. This final phase involved the psychometric testing of the CARS that was based on an online survey pack composed of quantitative measures, the CARS, the Carer Wellbeing and Support Scale (CWS), Posttraumatic Growth Inventory - Short Form (PTGI-SF) and the World Health Organisation Quality of Life - Brief version (WHOQOL-BREF). Full details are described in Chapter 6. The results from 138 carers were analysed using SPSS (IBM Corp, 2020) to assess the scale reliability, validity and to conduct an exploratory factor analysis of the CARS. This final phase has produced a validation paper ready for publication that details the psychometric evaluation of the CARS and outlines the different dimensions of this new measure. It has also produced a well validated new measure ready for use with carers of those with psychosis.

FIGURE 3: *Outline of Phase 3 of this PhD to validate the new outcome measure for carers*



Chapter summary

This chapter has outlined the main philosophical assumptions of various research paradigms such as positivism, postpositvism, interpretivism and pragmatism. It has also summarised the related ontologies and epistemologies of each of the major paradigms. This chapter has also presented the case for the use of mixed methods research as way to bridge the divide between quantitative and qualitative research methodologies. Finally, this chapter has clarified the choices made for this research, and the philosophical dilemma that needed solving which related to the need to create a quantitative outcome measure based on a highly subjective psychological theory of personal recovery. The solution was to follow a pragmatic paradigm and use a mixed methods research design that allowed for multiple paradigms to be used which allowed for the best methodologies to be used to answer the research question.

Chapter 3: Self-Report Measures Assessing Aspects Of Personal Recovery In Relatives And Carers Of Those With Psychosis: A Systematic Review

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Self-Report Measures Assessing Aspects of Personal Recovery in Relatives and Other Informal Carers of Those With Psychosis: A Systematic Review

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Hilton C, Jones S, Akers N, Panagaki K and Sellwood W (2022) Self-Report Measures Assessing Aspects of Personal Recovery in Relatives and Other Informal Carers of Those With Psychosis: A Systematic Review. Front. Psychol. 13:926981. doi: 10.3389/fpsyg.2022.926981

Background: Providing long-term care for a family member with psychosis can cause significant distress for informal carers due to the trauma of seeing their loved one in crisis, dealing with the difficult symptoms of psychosis and the burden of providing care. An important aspect of carers' adjustment can be construed as their personal recovery in relation to having a relative affected by psychosis. Self-report measures are increasingly used to assess personal recovery in service users, but less is known about the utility of such tools for carers.

Aims: This review aimed to identify all self-report measures assessing aspects of carers' personal recovery, and to quality appraise them.

Methods: Academic Search Ultimate, CINAHL, MEDLINE, PsychINFO and PubMed were searched for articles that reported the development of self-report measures created for carers of those with psychosis. Studies were appraised using the Consensus-based Standards for the Selection of health status Measurement INstruments (COSMIN) checklist. A Levels of Evidence synthesis provided overall quality scores for each measure.

Results: The search identified 3,154 articles for initial screening. From a total of 322 full text articles, 95 self-report measures were identified with a final 10 measures included for the quality assessment showing varying levels of psychometric rigor.

Conclusions: The results show that no single self-report measure is currently available for use to comprehensively assess personal recovery for carers, highlighting the need for further research in this area and the development of a new measure.

Keywords: caregivers, psychosis, schizophrenia, recovery approach, self-report measures, COSMIN checklist

INTRODUCTION

Taking on a long-term caring role for a family member who experiences psychosis or schizophrenia is associated with diminished psychological health, grief, social isolation and a poorer quality of life (Awad and Voruganti, 2008; Mulligan et al., 2013; Poon et al., 2017). The prevalence of psychosis is relatively common, with 7% of the adult population experiencing psychosis before their 75th birthday and 50% of these cases occurring before the age of 23 (Mcgrath et al., 2016). The Schizophrenia Commission (2012) have estimated that carers save £1.24 billion of public health funding per year, so it is essential to provide good support to carers. Family carers are also more likely to have financial problems and suffer from interpersonal stress (Mueser and Fox, 2002; Rose et al., 2002). The initial acute phase of treatment for psychosis can be overwhelming and has been compared to a bereavement for the relatives of the service user (Patterson et al., 2005). Carers of those with first episode psychosis have been found to burnt out—feeling exhausted, inadequate, and generally having negative appraisals of their caregiving ability (Onwumere et al., 2018). Carers have described feeling hopeless, depressed, and anxious and this has been conceptualized as a form of secondary trauma that is caused by the ongoing stress of providing long-term care (Wyder and Bland, 2014; Shiraishi and Reilly, 2019). Carers have been found to show symptoms of posttraumatic stress (PTSS) (Hanzawa et al., 2013) such as having intrusive thoughts about the event, feeling alert or on edge a lot of the time, and avoiding difficult thoughts and feelings about their loved ones mental health difficulties. Kingston et al. (2016) found that 44% of carers met the threshold for posttraumatic stress symptoms which was strongly related to negative thinking about themselves, self-blame, and trauma in relation to taking on a caring role. Poon et al. (2017) argue that it is important to acknowledge that families may be struggling with their caring role, and carers often feel isolated and alienated from their usual social support systems (Bland et al., 2009; Hayes et al., 2015). Carers often put their own needs last, but research suggests that when carers attend to their own physical, emotional, and spiritual health that many of their own problems become more manageable (O'Grady and Skinner, 2012). There has been a call for more supportive interventions to be provided for carers (Wyder and Bland, 2014; Poon et al., 2019) both for their own health and wellbeing but also to allow them to provide effective care for the service user (Reine et al., 2003; Testart et al., 2013). For example, recent novel eHealth interventions incorporating psychoeducation and peer support for carers have shown to have a positive impact on carer wellbeing (Lobban et al., 2019; Sin et al., 2019; Batchelor et al., 2022). Taking on a long-term caring role can also alter carers views of self-efficacy and in turn their coping capacity (Wilkinson and Mcandrew, 2008; Rowe, 2012), which may negatively affect both their caring abilities and personal lives (Wyder and Bland, 2014). To better understand and develop more targeted support for carers, it is important to understand their personal experiences (Zendjidjian and Boyer, 2014). Assessing carers experiences is also important in evaluating the treatment and management of care for the service user, as well as evaluating the wellbeing of the carer (Boyer et al., 2016).

An effective method of assessing the experiences of carers is through the use of self-report measures (Richieri et al., 2011) as they are relatively quick to administer and cost effective, which increases the feasibility of incorporating them into routine clinical practice. Self-report measures can also be used to measure the effectiveness of psychosocial and family interventions and can be a useful clinical tool, enabling carers a chance to reflect on their progress over time. The EUFAMI (2014) survey found that assessment of carers experiences was crucial in order to effectively support them, however, despite this need, self-report measures for carers are routinely underutilized in mental health services (Boyer et al., 2016). There are a plethora of measures to assess various aspects of carer experience (Harvey et al., 2005, 2008; Testart et al., 2013) with the majority of measures focusing on the negative aspects of caregiving such as burden, strain, reduced social networks and stigma. There are a few measures that investigate carer coping strategies, perception of need and quality of life (Zendjidjian and Boyer, 2014) and even fewer measures looking at the positive aspects of caring such as, developing greater compassion, finding greater meaning and purpose, and strengthened interpersonal relationships. Understanding the positive aspects of caring has been argued to be an important area to investigate to provide a holistic view of the caring process and to assess what progress is being made (Fulton Picot et al., 1997; Kate et al., 2013; Onwumere et al., 2018). A further important aspect of carer wellbeing that is linked to the positive aspects to caring is the concept of "personal recovery," conceptualized as living alongside the trauma, burden, stress of caring for a loved one experiencing a psychotic crisis. This is a facet of carers experience that is not assessed by any available measures used for carers but is now widely assessed for service users (Sklar et al., 2013).

The recovery approach has now become a guiding principle in mental health care delivery in most English-speaking countries across the globe (Tew et al., 2012; Slade et al., 2014; Price-Robertson et al., 2017) with the recovery approach being a key UK policy recommendation made by the Department of Health (2011). Personal recovery has been defined as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles" and "a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness" (Anthony, 1993). Personal recovery differs from clinical recovery in that it focuses on the unique personal journey that an individual with a mental health condition goes through in order to find new meaning and purpose in their lives, even in the presence of clinical symptoms (Anthony, 1993; Slade, 2009). There has been very limited research about the recovery approach and carers (Scottish Recovery Network, 2016; Jacob et al., 2017) and recovery informed practice has largely overlooked carers (Hungerford and Richardson, 2013). The bulk of current research has focused on service user recovery, however there is now increasing recognition of "family recovery" (Price-Robertson et al., 2017; Norton and Cuskelly, 2021). Recovery for service users does not happen in isolation and that it is dependent on family support (Wyder and Bland, 2014), and there is a need to understand and support families in their own recovery journey as distinct from the recovery of the service user (Norton and Cuskelly, 2021). It has been argued that carers are on a parallel journey of recovery (Wyder and Bland, 2014; Lovelock, 2016), and that the family recovery journey is intrinsically linked to the service user's journey thus neither can be understood in isolation (Wyder and Bland, 2014). Increasingly there is a call for more recovery focused support for carers and family members (Deane et al., 2015; Estrada, 2016; Poon et al., 2017; Norton and Cuskelly, 2021) and it is seen as important to support the carers recovery journey to assist them in moving forward with their lives by helping them to develop a sense of meaning and purpose despite ongoing challenges (Deane et al., 2015). In supporting carers to identify their own recovery journey, it is also more likely to deepen their understanding of their relatives' experiences of mental health problems by understanding their recovery journey (Lovelock, 2016), which may ultimately lead to improved relationships and a reciprocal support system within the family (Chen and Greenberg, 2004). Supporting the carer's recovery journey may also indirectly support service user's recovery because greater understanding of personal recovery processes gives carers greater confidence in their own "expertise-by-caring" (Fox et al., 2015). There are increasingly more recovery focused family interventions being developed and trialed (Deane et al., 2015; Estrada, 2016; Rue et al., 2016) and there are strong recommendations that carers must be included in recovery oriented social work practice (Poon et al., 2019) and in care planning with mental health professionals (Fox et al., 2015).

In light of the recommendations to provide more recovery-oriented support for carers, there is a requirement to identify self-report measures that may be used to assess personal recovery for carers. However, there are potential challenges in both defining and measuring personal recovery for carers. The primary challenge is that there is a limited literature on what personal recovery may mean for relatives themselves (Wyder and Bland, 2014; Lovelock, 2016). Despite recent systematic reviews of qualitative research examining carers' experiences (Mui et al., 2019; Shiraishi and Reilly, 2019), to date there is no qualitative research exploring specifically what personal recovery means for carers. This presents a potential challenge for this review, as the conceptual understanding of personal recovery will necessarily rely on personal recovery for service users as opposed to their carers. Because of the lack of conceptual literature on personal recovery for carers, there might also be a lack of measures assessing recovery for carers. To the authors' knowledge, there is currently only one measure, that is in the process of development, that focuses on family recovery in particular (Rue et al., 2016; [email] Personal correspondence with K, MacKinnon, 17 August 2016). This has presented a core conceptual problem for this systematic review in that if there is only one specific measure of recovery for carers, is there a need for the review? The authors felt that because of the compelling argument that personal recovery is an important aspect of carer wellbeing then a review looking at measures of various singular dimensions of recovery would reveal which outcome measures could be used together to assess the multi-dimensional nature of personal recovery. Previous systematic reviews looking at carer self-report measures have focused on measures that mainly assess the negative impacts of caring (Harvey et al., 2005, 2008; Testart et al., 2013), with many of the measures reviewed having been developed for the general population. This calls into question the validity of many of the measures in current use because it is difficult to adequately assess the experience of carers from the general population (Hilton, 2016). It is generally accepted to be good practice for self-report measures to be developed using the perceptions of the population they evaluate, to improve the relevance and validity of the measure (Slevin et al., 1988; Testart et al., 2013). In addition, previous reviews (Harvey et al., 2005, 2008; Testart et al., 2013) found a limited amount of self-report measures related to positive outcomes, such as quality of life, however, none of the reviews identified a measure that related to the concept of recovery. Therefore, there is a need for a more up to date review that focuses on aspects related to the recovery concept, and where the self-report measures reviewed have been developed specifically for the carer population.

The primary aim of this review was to identify all self-report measures that have been developed for use with carers of those with psychosis or schizophrenia, and that assess aspects of personal recovery. A quality appraisal of the psychometric properties of the self-report measures was carried out using the COSMIN checklist (Mokkink et al., 2010). This review had two further aims: to investigate and assess the level of carer involvement in the development of each self-report measure, and to explore how well personal recovery was assessed by each self-report measure.

METHODS

Protocol and Registration

This systematic review was registered on 22nd May 2018 with PROSPERO (CRD42018096020), and followed the PRISMA (Moher et al., 2009) guidelines.

Eligibility Criteria

Quantitative and mixed method studies that used a self-report measure(s) to assess the health and wellbeing of carers of those with psychosis or schizophrenia, were included. Carers included: parents, spouses, partners, grandparents, siblings, adult children, extended family and close friends in a caring role. Studies assessing paid carers, in-patient care staff and relatives under the age of 18 (young cares) were excluded. It was thought likely that adults and adolescents/children would have substantially different experiences because of varying levels of responsibility and role expectations. The clinical group of interest were service users who had received a diagnosis of psychosis (acute, chronic, first episode) or schizophrenia (all types). Service users who have experienced an episode of psychosis as part of another serious mental illness such as bipolar disorder or personality disorder were also included in this review, but only if the psychotic episode was the main focus of the article. See **Appendix A** for a full list of inclusion and exclusion criteria.

The self-report measures included any formally tested measure such as questionnaires, surveys, outcome assessments, instruments, and rating scales. Only self-report measures developed and validated in the English language and designed specifically to assess carers of those with a mental health diagnosis were included. There was no limitation on the date range of publication. Modified and brief versions of self-report measures were excluded from this review.

The conceptual challenge of this review has been the fact that there is limited research on personal recovery for carers, so particular attention was paid to operationalize this concept. Since there are no available self-report measures that primarily assess personal recovery for carers, several linguistic terms of recovery were collated from key authors on the topic of personal recovery (Anthony, 1993; Resnick et al., 2005; Slade, 2009; Leamy et al., 2011). These linguistic terms were discussed by the research team and a checklist of terms was created and incorporated as part of the search strategy for this review (see **Supplementary Material** for a copy of the checklist).

Information Sources

The following databases were searched in September 2017 with an updated search in March 2022: Academic Search Ultimate, CINAHL, MEDLINE, PsychINFO and PubMed. Additional searching strategies included checking the reference lists and citation tracking (using Web of Science) of the final papers. The search strategy involved setting out three distinct categories related to the key elements of the review: population, type of instrument and construct. Database specific search strategies were developed utilizing tools such as MESH headings (MEDLINE) and thesaurus terms (PsychINFO). See **Appendix B** for an example search strategy.

The following key word search terms were used to search all databases: [POPULATION] carer*, caregiver*, relative*, families, family caregiver*, psychosis, psychoses, psychotic, psychotic disorder, schizophren*, [TYPE OF INSTRUMENT] outcome measure, instrument*, assessment, measurement scale, rating scale, survey, questionnaire, patient reported outcome measure, self-report measure, [CONSTRUCT] recovery, mental health recovery, hope, optimism, goals, relationships, identity, meaning, personal responsibility, full engagement with life, empowerment, knowledge, life satisfaction, self-direction, full potential, person-driven, peer support, support groups, community, strengths, respect, motivation to change, positive thinking, valuing success, aspirations, positive sense of identity, quality of life, meaningful life, meaningful social roles, rebuilding life, employment, self-efficacy, coping, and adaptability.

Quality Appraisal

The COSMIN checklist (Mokkink et al., 2010) was used for this review as the gold standard for providing a comprehensive assessment of the psychometric properties of self-report measures (Rosenkoetter and Tate, 2018). The COSMIN checklist was developed by expert consensus (Mokkink et al., 2010), is freely available and includes a thorough user manual and scoring sheet and as such provides a consistent and transparent approach to systematic reviews of self-report measures.

Data Extraction

Online data extraction forms were created on DistillerSR (Evidence Partners, 2011) for the title and abstract screening and full text screening. Two independent reviewers (CH and NA) assessed all the title and abstracts against the inclusion criteria. Separate scoring sheets were used for the COSMIN 4-point checklist results, and for the assessment of quality of measurement properties per measure. CH carried out the COSMIN assessment, and then NA carried out a 20% check of the COSMIN results. Data were extracted by CH from the final 15 measure development or validation papers that related to: (1) details about the measures (2) characteristics of the study participants (3) details about the development of the measure and the psychometric properties required for the COSMIN assessment.

Synthesis of Results

The results of the COSMIN checklist were synthesized into two main results tables. The first table summarized the methodological quality of each study per measurement property (**Table 3**). Due to the comprehensive nature of the psychometric properties assessed, the COSMIN checklist does not provide one single overall score for each measure. Therefore, a second table (**Table 4**) was created to provide an overall assessment of the measurement properties for each outcome measure. The main psychometric properties assessed by the COSMIN checklist are: internal consistency, reliability (test re-test), content validity, structural validity and hypothesis testing. Certain psychometric properties assessed using the COSMIN checklist, such as cross-cultural validity, were not included in this review as no data were reported in the measure development papers.

RESULTS

Study Selection

The electronic database search identified 3,154 records with an additional 24 records identified through other search methods. The title and abstracts were screened by two reviewers independently (CH and NA) with good inter-rater reliability (Cohen's $\kappa = 0.78$). A total of 322 full text articles were selected based on the title and abstract screening. Of the 322 full text articles, 179 were excluded because they were based on a translated version of a measure, did not assess the psychometric properties of a measure or did not assess an aspect of recovery. This resulted in a total of 143 full text articles being screened to identify any potentially relevant outcome measures, of which 95 self-report measures were identified. Only 15 studies, covering ten measures, fulfilled the inclusion criteria. The main reasons for exclusion at full text stage are presente in **Figure 1**.

Table 1 shows the characteristics of included measures, **Table 2** shows the characteristics of the included studies, and **Table 3** details the COSMIN review carried out on the included studies to assess their methodological quality. No study was excluded based on methodological quality. A synthesis of the COSMIN results of all studies is summarized in a levels of evidence table (**Table 4**) where an assessment of all the measurement properties was carried out per measure.

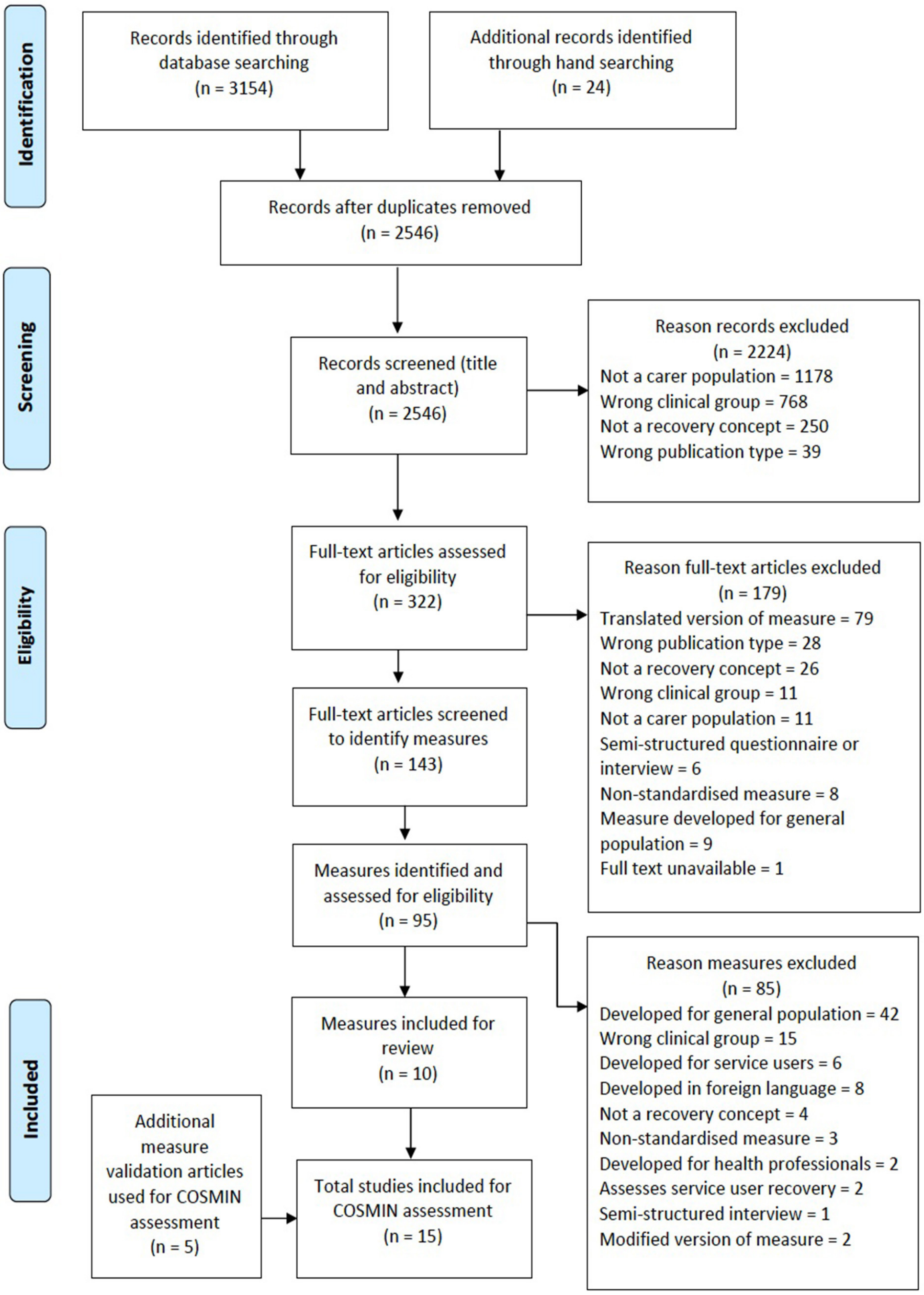

FIGURE 1 | Flow chart detailing the literature search.

Supplementary Material details the quality criteria used to assess the levels of evidence for each measure in **Table 4** and is based on Terwee et al. (2007) and de Vet et al. (2011) (see **Appendix C**).

Results of Individual Studies

Presented below are the summary findings of each measure, listed in alphabetical order by title of the measure. Each summary provides an overview of the constructs assessed by the measure, whether the constructs are based on theoretical model(s) and a summary of the theoretical model(s) used, the overall structure of the measure (domains and sub-scales), the response options, an assessment of the psychometric quality of the measure based on the COSMIN checklist, the level of public involvement in the development of the measure, and finally how the measure relates to the concept of personal recovery. All outcome measures assessed in this review have been specifically created for use with carers of those with psychosis and schizophrenia.

Carer Coping Style Questionnaire (CCSQ)

The Carer Coping Style Questionnaire (CCSQ; Budd et al., 1998) was designed to assess the coping styles of carers of those with schizophrenia and was based on two theoretical models; assessing the four dimensions of expressed emotion (Leff and Vaughan, 1985), and the seven coping styles identified by Birchwood and Cochrane (1990). The CCSQ has 89 items divided into nine subscales (collusion, reassurance, emotional over-involvement, constructive, resignation, passive, warmth, criticism/coercion and over-protectiveness). The response format of the CCSQ is a 5-point Likert scale. The CCSQ was tested on 91 carers of those with schizophrenia in the United Kingdom. It scored "poor" for internal consistency on the COSMIN checklist because the authors did not conduct a factor analysis or principal components analysis on the results despite a good alpha score for each subscale (Cronbach's alpha ranged between 0.69 and 0.87). Even if the authors had carried out a factor analysis, according to the COSMIN criteria, the CCSQ has a poor sample size ($n = 91$) for testing the unidimentionality of the factors as the population was below five times the number of items on the scale (89 items). The CCSQ scored "poor" on content validity because they did not involve carers in the development of the measure, meaning it is not possible to say that the items were relevant to the study population. The authors generated an item pool based on the theoretical models and then carried out a Q-sort with a team of health professionals to classify the items into discrete categories with the final item similarity matrix being subjected to a cluster analysis. Because no principal components analysis or factor analysis was carried out the CCSQ scored "poor" on structural validity. The CCSQ demonstrates "fair" hypothesis testing as the authors did not make it explicit how missing items were handled and it was unclear what a priori hypotheses were made. The CCSQ showed concurrent validity compared to the General Health Questionnaire (GHQ-28) (Goldberg, 1978), the Cost of Care Scale (CCS) (Kosberg and Cairl, 1992), and the Symptom-Related Behavioral Disturbance Scale (SBDS) (Birchwood, 1983).

The CCSQ does not seem to assess many aspects related to carer's personal recovery as the items assess carer coping styles in relation to their interactions with the service user and how this relates to expressed emotion. The CCSQ does not focus on the personal experiences of the carers, rather their interactions with the service user and because of this the CCSQ does not seem to fit well with the recovery framework.

Carer Wellbeing and Support Questionnaire (CWS)

The CWS (Quirk et al., 2009) assesses the well-being and support of carers of those with serious mental illness and dementia and was based on a pre-existing measure called the Carers' and users' expectations of services—carers' version (CUES-C) (Lelliott et al., 2003). The CWS consists of 49 items and is divided into two subscales: the carer well-being scale with 10 domains (your day-to-day life; your relationship with the person you care for; your relationships with family and friends; your financial situation; your physical health; your emotional wellbeing; stigma and discrimination; your own safety; the safety of the person you care for; your role as a carer), and the carer support scale with 5 domains (information and advice for carers; your involvement in treatment and care planning; support from medical and/or care staff; support from other carers; and taking a break (respite). The CWS sub-scales are scored using either a 4 or 5-point Likert scale depending on the specific subscale. The CWS was also validated with a large population sample of 361 carers from various centers across the United Kingdom. The CWS scored "excellent" on the COSMIN checklist for internal consistency as they reported high Cronbach's alpha scores for each subscale (0.96 and 0.97, respectively). The CWS scored "fair" for reliability on the COSMIN checklist only because the authors did not state the time interval between the two administrations of the test. The intra-class correlations for both subscales were high: $r = 0.92$ ($n = 91$) for the carer wellbeing scale and $r = 0.88$ ($n = 92$) for the carer support scale which demonstrates good test-retest reliability. The CWS showed "excellent" content validity as the measure went through a rigorous three phase construction process to make sure items were relevant to the constructs being assessed, and relevant for the target population. Carers were consulted regularly throughout the development and validation stages of the CWS construction which demonstrates excellent face validity and follows current good practice guidelines for questionnaire construction (Streiner et al., 2015). The CWS demonstrated "excellent" structural validity as the two-factor model accounted for over 50.8% of the variance. The CWS also showed "good" construct validity with all convergent hypotheses supported by moderately high correlations with the General Health Questionnaire (GHQ-12) (Goldberg, 1978) ($r = -0.66$, $n = 194$) and the Involvement evaluation questionnaire – European version (IEQ-EU) (Van Wijngaarden, 2003) ($r = -0.70$, $n = 122$).

The CWS covers a broad range of issues for carers and fits well with the recovery framework. The first sub-scale (Carer Wellbeing) is particularly relevant to the recovery framework as it covers carers personal experiences and looks at the various aspects of wellbeing such as physical health, mental health, financial resources, social networks, the carers own needs and how the carers view the future. The second sub-scale (Carer Support) is more focused on the level and quality of support

TABLE 1 | Characteristics of included measures.

Instrument	Authors	Target population	Country of origin	Year of development	Constructs assessed	Domains	Number of subscales (number of items)	Response options	Full copy of instrument available
Carer Coping Style Questionnaire (CCSQ)	Budd et al.	Carers of those with schizophrenia	UK	1998	Coping styles	Copying style subscales—collusion; reassurance; emotional over-involvement; constructive; resignation; passive; warmth; criticism/coercion; over-protectiveness	9 (89)	5-point Likert scale	Yes
Carer Well-being and Support Questionnaire (CWS)	Quirk et al.	Carers of those with serious mental illness and dementia	UK	2009 and 2012	Wellbeing and support	Subscale 1—Carer wellbeing scale (10 domains): your day-to-day life; your relationship with the person you care for; your relationships with family and friends; your financial situation; your physical health; your emotional wellbeing; stigma and discrimination; your own safety; the safety of the person you care for; your role as a carer. Subscale 2 - Carer support (5 domains): information and advice for carers; your involvement in treatment and care planning; support from medical and/or care staff; support from other carers; and taking a break (respite).	2 (49)	4 and 5-point Likert scales	Yes

(Continued)

TABLE 1 | Continued

Instrument	Authors	Target population	Country of origin	Year of development	Constructs assessed	Domains	Number of subscales (number of items)	Response options	Full copy of instrument available
Care-related Quality of Life (CarerQol)	Brouwer et al.	Carers of those with serious mental and physical illness	Netherlands	2006	Quality of life	7 dimensions exploring burden: fulfillment, relational, mental health, social, financial, support, physical, and 1 dimension exploring happiness	2 (8)	Mixed format: single choice answers and a VAS	Yes
Carers' and users' expectations of services—carer version (CUES-C)	Lelliott et al.	Carers of those with serious mental illness	UK	2003	Experiences of caregiving	13 dimensions: help and advice, information about care workers, information about mental illness, involvement and planning of care, support for carers, own life, relationships, family and friends, money, wellbeing, stigma and discrimination, risk and safety, choice to care.	13 (26)	Normative statements with a 3-point rating scale, free-text response section	Carer Wellbeing and Support Questionnaire (CWS) replaced this.
Experience of Caregiving Inventory (ECI)	Szmukler et al.	Carers of those with serious mental illness	UK and Australia	1996	Experience of caregiving	8 negative (difficult behaviors; negative symptoms; stigma; problems with services; effects on family; the need to provide backup; dependency; loss), 2 positive (rewarding personal experiences; good aspects of the relationship with the patient)	10 (66)	5-point Likert scale	Yes
Family Mental Health Recovery Evaluation Tool	Rue et al.	Families of those with serious mental illness.	USA	2016	Positive aspects of caregiving, family recovery	Capacity to Support Family Member, Hopefulness toward Recovery, Mental Health Coping Skills, Boundaries and Role Clarification, Communication, Self-Efficacy toward Recovery	6 (46)	Mixture of 3 and 5-point Likert scales	No

(Continued)

TABLE 1 | Continued

Instrument	Authors	Target population	Country of origin	Year of development	Constructs assessed	Domains	Number of subscales (number of items)	Response options	Full copy of instrument available
Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIISS)	Friedrich et al.	Siblings of those with schizophrenia	USA	2002	Stress and caregiving	Primary stressors (caregiving roles, reactions to caregiving, disturbing behaviors, homelessness, alcohol, drugs, relationship with ill sibling). Secondary stressors (relationships with parents and family, relationship with other siblings, concerns about own children, relationship with spouse, relationship with friends, school performance, work performance and career). Mediators of stress: coping strategies (emotional/spiritual, relationships, cognitive and action) and social support (from friends, relatives, professionals and organized groups). Outcomes (effect on health, view of self)	5 (256)	Mixture of Likert scales, multiple choice answers and specific answers	Yes
North-Sachar Family Life Questionnaire (N-SFLQ)	North et al.	Carers of those with schizophrenia	USA	1998	Experience of caregiving	Coping strategies, knowledge of illness, communication, behavior management, employment	5 (11)	5-point Likert scale	Yes
Schizophrenia Caregiver Questionnaire (SCQ)	Gater et al.	Carers of those with schizophrenia	USA, and with an international validation	2015 and 2016	Experiences of caregiving	Two distinct constructs: "Humanistic impact"—social, emotional, daily life and physical impact; "Aspects related to caregiver role"—perceptions of caregiving, financial impact.	13 (30)	11-point numerical rating scale (NRS)	Yes
Social Network Questionnaire (SNQ)	Magliano et al.	Carers of those with schizophrenia	Across Europe	1998	Social networks	Quality and frequency of social contacts, practical social support, emotional support, the presence and quality of an intimate supportive relationship.	4 (15)	Not reported	Yes

TABLE 2 | Characteristics of included studies.

Study	Population	Sample size	Age, mean (SD or range)	Female (%)	Country
CCSQ Budd et al. (1998)	Carers of those with schizophrenia	91	59 (20–85)	71	UK
CWS Quirk et al. (2012)	Carers for those with mental health problems and dementia	361	65.5 (13.1)	65.3	UK
CarerQol Brouwer et al. (2006)	Carers of those with physical and mental health problems	175	60.8 (13.1)	75	Netherlands
Hoefman et al. (2011)	Carers of those with physical and mental health problems	275	58.74 (12.74)	74.3	Netherlands
Hoefman et al. (2013)	Carers of those with physical and mental health problems	1,244	<47.1–47.1%	58.3	Netherlands
CUES-C Lelliott et al. (2003)	Carers of those with mental health problems	243	60 (24–87)	Approx. 75	UK
ECI Joyce et al. (2000)	Cares for those with psychosis	69	Not reported	Not reported	UK
Szmukler et al. (1996)	Carers of those with mental health problems	626	1st sample−53 (+−30 years), 2nd sample - 46 (+−15 years)	66 (1st and 2nd samples combined)	UK and Australia
Family Mental Health Recovery Evaluation Tool Rue et al. (2016)	Carers of those with mental health problems	108	<40–86%	89.9	USA
FLIISS Friedrich et al. (2002) (Part 1 paper)	Siblings of those with schizophrenia	N/A*	N/A*	N/A*	USA
Rubenstein et al. (2002) (Part 2 paper)	Siblings of those with schizophrenia	761	39.7 (10.6)	73.7	USA
N-SFLQ North et al. (1998)	Carers of those with schizophrenia	56	Not reported	53	USA
SCQ Gater et al. (2015)	Carers of those with schizophrenia	19	51.63 (28–69)	79	USA
Rofail et al. (2016)	Carers of those with schizophrenia	358	Not reported	Not reported	Argentina, Brazil, Canada, Germany, Spain, France, UK, Italy
SNQ Magliano et al. (1998)	Carers of those with schizophrenia	236	Not reported	Not reported	UK, Greece, Italy, Portugal and Germany

TABLE 3 | COSMIN results showing the methodological quality of each study per measurement property.

Name of measure and study	Internal consistency	Reliability	Content validity	Structural validity	Hypothesis testing
CCSQ					
Budd et al. (1998)	Poor	–	Poor	Poor	Fair
CWS					
Quirk et al. (2012)	Excellent	Fair	Excellent	Excellent	Good
CarerQol					
Brouwer et al. (2006)	-	-	Excellent	-	Fair
Hoefman et al. (2011)	-	-	Fair	-	Fair
Hoefman et al. (2013)	-	-	Excellent	-	Fair
CUES-C					
Lelliott et al. (2003)	-	Fair	Good	Fair	-
ECI					
Szmukler et al. (1996)	Excellent	-	Excellent	Excellent	Good
Joyce et al. (2000)	-	-	-	-	Fair
Family Mental Health Recovery Evaluation Tool					
Rue et al. (2016)	Poor	-	Fair	Poor	-
FLIISS					
Friedrich et al. (2002) (Part 1 paper)	-	-	Excellent	-	-
Rubenstein et al. (2002) (Part 2 paper)	Poor	-	-	Poor	Good
N-SFLQ					
North et al. (1998)	-	-	-	-	-
SCQ					
Gater et al. (2015)	-	-	Excellent	-	-
Rofail et al. (2016)	Excellent	Good	-	Excellent	Fair
SNQ					
Magliano et al. (1998)	Poor	Fair	Fair	Fair	-

TABLE 4 | Quality of measurement properties per self-report measure.

Outcome measure	Internal consistency	Reliability	Content validity	Structural validity	Construct validity (Hypothesis testing)
CCSQ	+	N/A	-	-	+
CWS	-	+	+	+	+
CarerQol	N/A	N/A	-	N/A	+
CUES-C	N/A	-	+	-	N/A
ECI	+	N/A	+	+	+
Family mental health recovery evaluation tool	+	N/A	-	?	N/A
FLIISS	-	N/A	+	?	+
N-SFLQ	N/A	N/A	N/A	N/A	N/A
SCQ	+	+	+	?	+
SNQ	-	-	+	+	N/A

that carers receive from mental health services and is not as directly relevant to the recovery framework as it focuses more on the practical aspects of caring and not how the carer perceives or finds meaning in their role. The authors do suggest that the CWS can be used as in mix-and-match combinations and that the validated wellbeing and support subscales can be administered separately, which could mean that just the wellbeing sub-scale could be used to measure those aspects of recovery.

Care-Related Quality of Life (CarerQol)

The CarerQol (Brouwer et al., 2006) was developed to measure the quality of life of carers of those with physical and mental health problems. Eight items are divided into two subscales, with seven items relating to burden (fulfillment, relational, mental health, social, financial, support, physical) and one item to assess happiness. The response format is mixed, with single choice answers for the burden subscale, and a visual analog scale (VAS) for the happiness item. The CarerQol has been well-validated for content and construct validity with three validation studies (Brouwer et al., 2006; Hoefman et al., 2011, 2013) all based on data from carer populations in the Netherlands. It is unclear as to whether the data were collected using the English or Dutch version of the CarerQol, however, it was decided to include this measure in the review as the measure is available online in the English language. All three studies had large sample sizes (Brouwer et al., 2006, $n = 175$; Hoefman et al., 2011, $n = 1244$; Hoefman et al., 2013, $n = 275$). Based on the COSMIN criteria two out of the three studies scored "excellent" for content validity (Brouwer et al., 2006; Hoefman et al., 2013). The CarerQol scored less well for hypothesis testing with all three studies scoring "fair," the main reason being that the studies either failed to provide a description of how the missing items were handled or they failed to report on whether any a priori hypotheses were formulated. Even though three validation studies were carried out, there was no assessment of the measure's internal consistency, reliability or structural validity. The CarerQol did show some level of carer input in the development of the measure which is positive in terms of participant involvement. Carers were involved in some initial pilot testing and in commenting on the wording of the items, however, the researchers were solely responsible for devising the initial item pool.

The CarerQol does not fit well within the recovery framework despite purporting to assess carer quality of life. The bulk of the items relate to aspects of carer burden with only one item relating to happiness.

Carers' and Users' Expectations of Services—Carer Version (CUES-C)

The CUES-C (Lelliott et al., 2003) assesses the experience of caregiving based around 13 items (help and advice, information about care workers, information about mental illness, involvement and planning of care, support for carers, own life, relationships, family and friends, money, wellbeing, stigma and discrimination, risk and safety, choice to care). The response format involves three questions per item (which is worded as a normative statement). Part A questions ask whether the carers experiences matches the items normative statement, part B questions ask if the carer would like further support in that area, part C is a free text box for comments on that item. It was developed for use with carers of those with mental health problems in the United Kingdom. It is worth noting that this measure was deconstructed and used as the basis for the development of the CWS. The CUES-C was validated with a good size sample of 243 participants; however, it did not score well on the COSMIN checklist. The CUES-C scored "fair" for reliability on the COSMIN checklist because the authors did not report on how missing items were handled. Interclass coefficients were calculated for test-re-test reliability and were moderately good for both parts of the measure ($r = 0.61$, $n = 97$). The CUES-C was not based on any kind of theoretical model and as such it would be difficult to assess if all items together adequately reflect the construct being measured, which relates to content validity. Despite of this, the CUES-C scored "good" for content validity because they showed a very good level of carer involvement at all stages of the questionnaire development. An advisory panel worked with the authors throughout the development process providing feedback on the measure and the authors conducted focus groups and individual interviews on the draft measure. The CUES-C scored "fair" for structural validity on the COSMIN checklist because there was no description of how missing items were handled. The authors did carry out a comprehensive principal components analysis on both parts of the measure, part A includes 3 factors that account for 49% of the variance and part B includes 2 factors that account for 51% of the variance.

The CUES-C has several items that fit with the recovery framework, such as the statements about the carer's own lives, relationships with the service user, relationships with family and friends, their own wellbeing that includes both positive and negative elements, and their personal choice to care.

Experience of Caregiving Inventory (ECI)

The ECI (Szmukler et al., 1996) was the most commonly used measure in this review, being used in 20 of the 95 studies reviewed. The ECI provides a very broad view of the experiences of caregiving and is based on the stress-appraisal-coping framework (Lazarus and Folkman, 1984). It assesses both negative and positive aspects of caring with 66 items divided across 10 domains. There are eight domains covering the negative aspects of caring (difficult behaviors, negative symptoms, stigma, problems with services, effects on family, the need to provide backup, dependency, and loss), and two domains covering the positive aspects of caring (rewarding personal experiences, and good aspects of the relationship with the patient). The response format for the ECI is a 5-point Likert scale and it was developed by a team of researchers in the United Kingdom and Australia. The ECI has been validated by two studies, the original by Szmukler et al. (1996) that provided a good overall assessment of most of the psychometric properties of the measure, and a subsequent study by Joyce et al. (2000) that assessed hypothesis testing. On the COSMIN checklist, the ECI showed "excellent" internal consistency (Szmukler et al., 1996) as it had a large sample size ($n = 626$) and good Cronbach's alpha scores that were calculated for each dimension (ranging from 0.74 to 0.91). The ECI also demonstrates "excellent" content validity as it went through a rigorous five stage development process where carers had a high level of input at every stage of its development. For example, items were devised through a series of one-to-one interviews and focus groups with 120 carers. Szmukler et al. (1996) also ensured that the items were validated within the stress-coping model and found that the ECI predicted psychological morbidity. The ECI also scored "excellent" for structural validity because the authors carried out a comprehensive principal components analysis on a large sample of 626 carers. The initial 14 factor model accounted for 60% of the variance, and this was refined down to 10 factors for the final measure. The ECI scored "good" on the Szmukler et al. (1996) study and "fair" on the Joyce et al. (2000) study for hypothesis testing. This was because they did not state the expected magnitude of correlations or differences in the Szmukler et al. (1996) paper, and because only limited information was provided on the measurement properties of the comparator instruments in the Joyce et al. (2000) paper.

The ECI partially fits with the recovery framework because there are two dimensions that focus on the positive aspects of caring: "positive personal experiences" that assesses learning about oneself, having greater confidence, and being more understanding of others with problems; and "good aspects of the relationship" that assesses the relationship with the service user and whether the carer feels a sense of self efficacy in their care provision. However, a large portion of the ECI looks more at the burden of caring, such as stigma, dependency, and loss, and dealing with difficult behaviors and negative symptoms, which does not fit with the recovery framework.

The Brief Experience of Caregiving Inventory (BECI) (O'Driscoll et al., 2018) provides a shortened 19-item version of the ECI, which aims to provide a quicker and less burdensome version for carers to complete. The BECI was reviewed but excluded from the final COSMIN assessment for two reasons. First, the BECI has not been validated using a new sample population, as the authors carried out a Multidimensional Item Response Theory (MIRT) on the original data collected for the validation of the ECI in 1996. It is not possible to carry out a COSMIN assessment without a full validation paper with data collected from a relevant sample population. Secondly, part of the exclusion criteria for this review was to exclude modified versions of self-report measures.

Family Mental Health Recovery Evaluation Tool (Provisional Title)

The Family Mental Health Recovery Evaluation Tool (FMHRET; Rue et al., 2016) was developed to assess the wellbeing and recovery of family members who were taking part in an online family recovery intervention (Families Healing Together, 2018) in the USA and was validated by Rue et al. (2016). The intervention is based on the stress-appraisal-coping framework (Lazarus and Folkman, 1984) and the constructs assessed are the positive aspects of caregiving and family recovery. The measure contains 46 items divided into six domains (capacity to support family member, hopefulness toward recovery, mental health coping skills, boundaries and role clarification, communication, self-efficacy toward recovery). The response options are divided into a mixture of 3 and 5-point Likert scales. The FMHRET did not score well overall on the COSMIN checklist mainly because of the small sample size used to validate the measure. The authors used a sample of 108 carers, which is less than five times the number of items on the measure. To score anything above "poor" on the checklist, the measure should have had a sample size of more than 230 carers. The FMHRET scored "poor" for internal consistency but did demonstrate strong alpha values ($\alpha = 0.76$–0.86). It scored "poor" for its structural validation because of the small sample size. It should be noted that the authors only intended to carry out an exploratory factor analysis for this study, which may have been one of the reasons for the small sample size. The exploratory factor analysis of the FMHRET showed a five-factor model that accounted for 47% of the variance. The FMHRET scored "fair" for content validity, again because of the small sample size and because they didn't employ robust participant involvement in the development of the measure. According to the authors, the initial items were developed through a qualitative analysis of blog post entries from the "Families Healing Together" intervention, with a subsequent construct validity assessment with five "experts" to refine the conceptual definitions. It is not made clear who the "experts" were but following communication with one of the authors, it was clarified that only one of the "experts" was a carer (K. MacKinnon, personal communication, August 19, 2016)."

Of all the measures assessed in this review, the FMHRET is the most well-positioned within the recovery framework because it was developed to assess family recovery specifically. It looks at the positive aspects of caring as its primary construct but also includes other aspects such as coping skills and self-efficacy. Unfortunately, at the time of writing this review, the measure was not available for use outside of the "Families Healing Together" intervention.

Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLLISS)

The FLLISS (Friedrich et al., 2002) measures the stress of caregiving for siblings of those with schizophrenia and is based on the stress model of caregiving (Pearlin et al., 1990). The FLLISS was developed in the USA. It consists of 256 items across five domains that cover primary stressors, such as: caregiving roles, disturbing behaviors and their relationship to the ill sibling; secondary stressors such as: relationships with friends and family, work performance and career; the mediators of stress such as: coping strategies and social support; and outcomes such as: effect on health and view of self; and some demographic questions. The FLLISS uses a mixture of Likert scales, multiple and single choice answers. The FLLISS was validated in two parts, the first part reporting how the measure was devised (Friedrich et al., 2002) and the second part reporting the validation of the psychometric properties of the FLLISS (Rubenstein et al., 2002). The FLLISS scored "excellent" on the COSMIN checklist for content validity as the authors had a very rigorous approach in the development of the measure, basing the content of the items on a qualitative content analysis of interview data from 30 siblings. The authors also used some of the direct wording from the interview statements in the wording of the items which the authors claim increased the ecological validity and relevance of the measure for siblings, unfortunately they do not indicate which items are based on the interview statements in their published article. Siblings were also invited to comment on the final version of the measure before testing. The FLLISS scored "poor" for internal consistency because the sample size used was less than five times the number of items on the measure despite having a large sample of 761 participants. The FLLISS is the longest measure in this review with 256 items and the study would have needed a sample of over 1,280 to score over a "poor" rating on the COSMIN checklist. This sample size issue also affected the score for the structural validity of the FLLISS, which was also "poor" while all the rest of the scores were "good" to "excellent."

Even though the FLLISS is mainly concerned with assessing primary and secondary stressors, there are still elements to the measure that fit well with the recovery framework. Within those domains are items that assess the relationships between siblings, their family and friends, and topics like career and employment. Also, the FLLISS has a section that looks at the mediators of stress which is more relevant to the recovery framework as this assesses coping strategies and social support. The one concern in considering this measure for use to assess recovery is that it was specifically designed and validated for siblings of those with schizophrenia and as such it's unclear as to whether it could be used with other family carers.

North-Sachar Family Life Questionnaire (N-SFLQ)

The N-SFLQ (North et al., 1998) assesses the experience of caring for someone with schizophrenia and was not based on any sort of theoretical framework. It consists of 11 items set across five domains that cover: coping strategies, knowledge of the illness, communication, behavior management, and employment. It is rated on a 5-point Likert scale. The N-SFLQ was designed for and piloted in a small pilot study ($n = 56$) of a family intervention training program in the USA. No formal validation was carried out for this measure, which rendered it impossible to assess its psychometric properties using the COSMIN checklist.

This measure covers some of the aspects related to the recovery framework, such as coping strategies, communication and employment, however, it appears that there is also a large focus on the service user and their progress with items assessing number of hospital admissions and length of hospital stay. Additionally, this measure has no formal validation and because of these reasons, it is not recommended for use in assessing recovery in carers.

Schizophrenia Caregiving Questionnaire (SCQ)

The SCQ (Gater et al., 2015) was specifically designed for carers of those with schizophrenia and assesses their experiences of caregiving. It was not based on any theoretical framework but was developed from a commonly used burden measure called the Zarit Burden Interview (ZBI) (Zarit et al., 1980). The SCQ has 30 items spread across 13 domains grouped into two main constructs of the "humanistic impact" of caring, and "aspects related to the caregiver role." The response format is an 11-point numerical rating scale. The SCQ was validated in two parts. The first validation paper by Gater et al. (2015) assessed the content validity of the measure and outlined how the measure was devised. On the COSMIN checklist, the measure scored "excellent" for content validity. The authors describe a high level of participant involvement in the development of the measure as they carried out in-depth qualitative interviews with 19 carers to discuss the measure using a cognitive debriefing technique to assess their understanding of the measure and whether it was relevant and comprehensive for carers. The authors claim the measure demonstrates strong face validity. The second validation for the SCQ (Rofail et al., 2016) assessed the psychometric properties of the measure. The SCQ scored "excellent" for internal consistency with Cronbach alpha scores ranging between 0.80 and 0.96. Rofail et al. (2016) also assessed the test-retest reliability ($r = 0.75-0.87$) demonstrating "good" reliability on the COSMIN checklist. The SCQ showed "excellent" structural validity with a comprehensive factor analysis where 13 clear domains were identified. The SCQ scored "fair" for hypothesis testing. Even though the authors report that the item domain validity was fully satisfactory and that it showed good item convergent and divergent validity, according to the COSMIN checklist the SCQ scored "fair" because it was not made apparent what the a priori hypotheses were regarding the correlations or mean differences were.

In terms of the recovery framework, the SCQ seems to have a good fit. Even though it is based on a burden interview (ZBI) the domains assessed seem directly relevant to aspects of the recovery approach. For example, the SCQ assesses the "humanistic impact" of caring relating to the social, emotional, physical impacts on the carer's daily life, while the "aspects related to the caring role" investigates the carers perceptions of caregiving and the financial impact. It is a very well-validated measure with excellent participant involvement throughout the development process and as such would be a strong measure to use to assess aspects of carer recovery.

Social Network Questionnaire (SNQ)

The SNQ (Magliano et al., 1998) was designed to assess social networks and was developed for use with carers of those with schizophrenia. The measure was not based on any kind of theoretical framework but was based on the wider literature on social networks (L. Magliano, personal communication, August 2, 2016). The SNQ contains 15 items with four domains assessing the quality and frequency of social contacts, practical social support, emotional support, and the presence and quality of an intimate supportive relationship. The validation of the SNQ was discussed within a paper that reports the results of a large European research trial (Magliano et al., 1998) and as such there is limited detail about how the measure was developed. The SNQ scored "fair" for internal consistency on the COSMIN checklist primarily because the authors did not describe how missing items were handled. The SNQ had moderate Cronbach's alpha values ranging between 0.56 and 0.75 for each of the four factors. The test re-test of the SNQ was carried out with 50 carers 10 days apart however the SNQ scored only "fair" on the COSMIN checklist for reliability because it was not explained how missing items were handled. The SNQ scored "fair" for content validity as the authors did not describe whether they assessed all items as being relevant to the construct being measured and did not base the measure on a theoretical framework. There did not appear to be much participant involvement in the development of the measure apart from carers providing comments on the comprehensibility and relevance of the items on a trial version of the SNQ. To assess the structural validity of the SNQ the authors carried out a factor analysis and found four distinct factors that accounted for 56% of the variance, however, SNQ scored "fair" for structural validity as it was not clear how missing items were handled.

The SNQ is the only measure to provide a comprehensive assessment of social networks which fits well with this aspect of the recovery framework; however, this is only a part of the recovery journey that carers may travel. For example, it does not cover whether carers have developed a greater sense of meaning and purpose through caring, or whether they feel more confident and empowered to rebuild their lives. Because of the this the SNQ should not be used in isolation to assess recovery but could be used in conjunction with other measures to create a suite of questionnaires to comprehensively assess recovery for carers.

Additional Analysis

The overall findings from the COSMIN assessment of all 15 studies was synthesized into a levels of evidence table (**Table 4**) following the approach outlined in de Vet et al. (2011). This provides a good overall summary of the quality of each psychometric property for each of the 10 outcome measures reviewed. The quality criteria for each psychometric property used for this assessment were based on the recommendations by Terwee et al. (2007) and is outlined in **Appendix C**.

DISCUSSION

Summary of Evidence

The aim of this review was to identify self-report measures created for carers of those who experience psychosis that assess aspects related to the recovery approach. A total of 95 measures were found, a large proportion of which were not targeted for carers of those with psychosis or schizophrenia. Of the 10 measures considered relevant for this review, half were developed specifically for use with carers of those with psychosis or schizophrenia, 30% were developed for carers of those with a serious mental illness and 20% were developed for carers of those with a serious mental illness and either dementia or a physical impairment.

Recommendations for Instrument Selection

Out of the 10 measures, the CarerQol was the most frequently evaluated with three studies assessing its validity. However, these studies only assessed content validity and hypothesis testing and therefore did not score highly on the COSMIN checklist. Instead, the three measures that scored highly on the COSMIN checklist and thus showed the strongest psychometric properties were the CWS, the ECI, and the SCQ. The CWS was found to have excellent internal consistency, content validity and structural validity, with good hypothesis testing and a fair level of reliability. The ECI showed excellent internal consistency, content validity and structural validity, and good hypothesis testing. The SCQ demonstrated excellent internal consistency, content validity, structural validity, a good level of reliability and fair hypothesis testing. It should be noted that the COSMIN results only provide limited guidelines on instrument selection. There are two other important factors when considering instrument selection for this review, public involvement in the questionnaire design, and how well it assesses elements of personal recovery for carers.

Public involvement in the development of a measure, directly relates to the relevance and content validity of the measure (Slevin et al., 1988; Testart et al., 2013; Zendjidjian and Boyer, 2014). It is seen as good practice and crucial to current measure development processes (Sklar et al., 2013), as it adds to the robustness of the research and is recommended by policy and funding directives (Shippee et al., 2015). Public involvement in the development of the 10 measures was mixed: five showed "good" to "excellent" public involvement with only three demonstrating "excellent" public involvement by involving carers at every stage of the development process. The latter aligns with the recommendations made by Rat et al. (2007) who argue that it provides the most valid set of items for respondents. The remaining five measures showed either poor or no public involvement at any stage of the measure development. A similar comprehensive review of outcome measures for carers by Harvey et al. (2008) also found that a relatively low proportion of measures (8 out of 25) were developed with public involvement. Harvey et al. (2008) did note a greater level of public involvement in the more recently developed measures and it is clearly seen as good practice in measure development (Streiner et al., 2015). However, this was not echoed in the present review as some of the most recent measures like the Family Mental Health Recovery Tool developed in 2016 showed a limited amount of public involvement in the development process, and the measure that demonstrated one of the best levels of public involvement, the ECI, was developed in 1996.

The second important factor when considering instrument selection for this review is how well each measure fits within the recovery framework. The Family Mental Health Recovery Tool is the only measure that has a good fit with the recovery framework, however, it is not currently available for use outside of the "Families Healing Together" intervention (Rue et al., 2016). The CareQol, ECI and FLLISS all have a substantial focus on the burden and stress of caregiving and are therefore not considered useful in assessing recovery. Even though the ECI is one of the most comprehensively validated measures and scores highly on the COSMIN checklist, it only partially fits the recovery framework assessing only two positive aspects of caring; rewarding personal experiences, and good aspects of the relationship with the person being cared for. The CWS incorporates several aspects related to personal recovery in the carer wellbeing subscale such as: day to day coping, interpersonal relationships, physical and emotional wellbeing, and feelings of personal safety. The SCQ also provides a comprehensive set of items that assesses aspects relating to recovery such as: the "humanistic impact" on the social, emotional, and daily life of life of the carer, and the aspects and perceptions related to the caregiver role. Our recommendation of the best measures to use to assess personal recovery would be either the CWS or SCQ or a combination of the two as they show strong psychometric properties, cover a range of relevant aspects related to personal recovery, and demonstrated a good level of public involvement in the development of the questionnaires. However, using multiple measures to assess personal recovery still does not assess the multi-dimensional nature of the recovery concept, and it could become burdensome for carers to complete. A solution to this would be the development of a new outcome measure with a specific focus on recovery for carers that could be used in future research studies as a more appropriate way to assess this construct.

Strengths and Limitations

The COSMIN has several strengths as a robust and rigorous assessment tool that was developed by an international team of experts (Mokkink et al., 2010). It is becoming recognized as the "gold standard" and is a popular tool for many health-related systematic reviews (Rosenkoetter and Tate, 2018). Thus, this review has used the strongest quality appraisal possible. This review is also strengthened by the fact that it goes beyond reporting on the COSMIN findings, by assessing another important aspect of good practice in questionnaire design, public involvement in research.

This review presented a challenge in trying to apply the concept of personal recovery to a carer population, which has been both a strength and limitation. Because of the complex nature of how to define personal recovery, the research team devised a way to operationalize the concept by reviewing the definitions of recovery as outlined by the key authors in this area: Anthony (1993), Resnick et al. (2005), Slade (2009) the CHIME framework outlined by Leamy et al. (2011). The key concepts and linguistic terms were then incorporated into a checklist (see **Supplementary Material**) and formed the basis of the search terms of this review. This can be seen as a strength as it provides a transparent overview of our understanding of the key features of recovery for carers.

However, by focusing on elements of recovery we may have been overly inclusive in terms of papers identified as being potentially relevant. Note that 95 measures were identified initially, but only ten of these could be related directly to recovery in some way. This may raise questions about the focus of our search strategy. In the searches, the terms used to describe the target population brought back results for carers from different clinical populations (physical and mental health). Two searches were used with the Boolean operator "AND," however, this still brought back irrelevant studies for this review. On a positive note, this means that it is unlikely that any relevant studies were missed.

A limitation of this review is a potential selection bias due to the choice to only include English language measures due to lack of funding to employ translators. This review also excluded translated versions of measures originally developed in English, and measures that were developed in a foreign language, as there appeared to be many non-English language measures that this would warrant a separate review. However, there were two potentially relevant measures that were excluded because they were developed and validated in a non-English language sample. The Scale for Positive Aspects of Caregiving Experience (SPACE) (Kate et al., 2012) was validated in Hindi, and the Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQol) (Richieri et al., 2011) was validated in French. This review did not include short form measures either as it was felt that the reduced number of items would affect the content validity of the measure and considering that measures only partly assess aspects of recovery this would prove to be problematic. A further limitation of this review was that it was not possible for the second reviewer to carry out the full COSMIN assessment on all papers due to time constraints, however, the second reviewer carried out a 20% check of the work with a good level of agreement to the first author.

CONCLUSION

This review set out to identify all self-report measures that have been developed for use with carers of those with psychosis or schizophrenia and that assess aspects of personal recovery. It seems that in fact, there may be no measure targeting carers' recovery per se, despite its potential importance. The authors therefore set out to examine carer measures that to some extent measure specified aspects of "carer recovery" and attempt to encapsulate this issue across available instruments. A small number of measures are available that combined, could be used to assess personal recovery for carers. The only measure specifically developed to assess recovery, the Family Mental Health Recovery Evaluation Tool is not currently available to clinicians or researchers. To get the most comprehensive assessment of recovery using the measures that are currently available would mean that a selection of measures would need to be used together which would be time consuming and burdensome for respondents to complete. For example, if the CWS, the ECI, SCQ, and the SNQ were to be used as a set of questionnaires to assess recovery, this would involve the participants completing an approximate total of 160 items. One solution would be to combine selected subscales from each of the various measures to form a new measure, however, this would still need to be validated as a separate measure and would still not cover all the aspects related to the concept of personal recovery. This review highlights the need for further research in this area, and the potential development of a new measure that is specifically focused on assessing personal recovery for carers especially considering the recent call for more support for carers on their "parallel" recovery journey (Wyder and Bland, 2014; Lovelock, 2016; Poon et al., 2017). The COSMIN checklist provided a useful quality assessment for this review despite some failings. It enabled an overall quality assessment of the psychometric properties of each outcome measure to be assessed. It is also clear that public involvement is important at every stage in the development of a measure if this is to provide a tool that is valid and relevant for the target population.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author/s.

AUTHOR CONTRIBUTIONS

CH designed the study, wrote the protocol, carried out the literature searches, screened the articles, carried out the data extraction, completed the COSMIN checklist analysis, and wrote the manuscript. WS and SJ provided input into the study design and protocol, contributed to, and approved the final manuscript. NA screened articles, contributed to the analysis, contributed to, and approved the final manuscript. KP contributed to and approved the final manuscript. All authors contributed to the article and approved the submitted version.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2022.926981/full#supplementary-material

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Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The supplementary material for this published paper is located in the Appendix of this thesis.

APPENDIX F: *Inclusion and exclusion criteria for title and abstract screening of systematic review*

APPENDIX G: *Example search strategy for systematic review*

APPENDIX H: *Quality criteria for good measurement properties modified from Terwee et al. (2007) and DeVet et al. (2011) used in systematic review*

Chapter 4: "You've Got To Put Your Own Oxygen Mask On First" – A Qualitative Study Looking At Personal Growth, Recovery, And Resilience For Carers Of Those With Psychosis And Schizophrenia

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Abstract

INTRODUCTION: The family members of those with psychosis and schizophrenia can be exposed to highly distressing events and often take on the primary caring role for their loved one. This leads to substantial stress and burden and their mental and physical health is often negatively affected. Carers provide an essential part of supporting those with serious mental illness; however, there is frequently little support for them to do this. Family interventions are being developed to assist carers in reducing their psychological distress; however, there has been limited focus on personal recovery for carers. The 'recovery approach' has been an important community movement started by service users that has now becoming a guiding principle in mental health services. Personal recovery is seen as a journey, distinctly different from 'clinical recovery' in that service users are still able to lead a meaningful and fulfilling life despite still experiencing symptoms.

METHOD: This study aimed to qualitatively explore this concept with carers of those with psychosis and schizophrenia; whether they may be able to lead a fulfilling life alongside their caring responsibilities. Seventeen family carers were interviewed, and a thematic analysis of the transcripts was conducted.

RESULTS: The analysis found three main themes: 'Carers' Personal Recovery'; 'Building Resilience'; and 'Personal Growth'. Overall, 'personal recovery' was not seen as an appropriate term that carers could relate to. However, some of the concepts behind 'personal recovery' were evident, such as a changed outlook on life, finding greater meaning and purpose, improved relationships, strength, and empowerment.

DISCUSSION: It was apparent that carers go through a process of building resilience, and adapting to their caring role, which can lead to transformative growth. The results were considered in the context of developing an outcome measure to evaluate these aspects of caring and whether this could be used to bolster current interventions.

Introduction

It is well documented that psychosis or schizophrenia not only have a substantial impact on the individual with the diagnosis, but also their family members (Boyer et al., 2016). They often take on a vital role as primary caregivers (Caqueo-Urízar et al., 2009; Ochoa et al., 2008; Reine et al., 2002). Informal carers are said to save £1.24 billion of public health care funds per year in the UK (Schizophrenia Commission, 2012). Darmi et al. (2017) argue that people with psychosis can become very dependent on the informal care and the support provided by family members due the often-recurrent cycles of relapse and the high demands caused by the symptomology of psychosis and the limited amount of day-to-day care offered by mental health services. There is a clear need to support carers' well-being and to support them in their caregiving role. Efforts have been made by health services and researchers to develop family interventions to help families cope with the challenges of caring for the service user (Lobban et al., 2020; Melamed & Gelkopf, 2013; Norton & Cuskelly, 2021; Sin et al., 2022). A review by Sin et al. (2017) found that psychoeducational interventions for carers reduced their global morbidities, perceived burden, negative caregiving experiences and expressed emotion, which is the global index of the emotional climate of the familial group (Cherry et al., 2017). It is argued that the involvement of carers is essential to enhance treatment gains for those they care for (Kuipers et al., 2010) and can lead to better outcomes, reduction in relapse rates and the need for hospital treatment for the person they care for (Norman et al., 2005). Carers are instrumental in supporting service users by promoting treatment adherence, social support, accessing appropriate mental health treatment when needed (Fridgen et al., 2013), and pushing for continuity of care for their loved one (Boyer et al., 2016). Carers' negative experiences may also impact on their ability to care (Reine et al., 2002), so supporting carers is of the utmost importance both for their own wellbeing and indirectly for the service user too (Testart et al., 2013). Carers' own needs and emotions can often be overlooked as they are not directly involved with mental health services for themselves but in a supportive capacity for the service user; for example there is often an emphasis by mental health staff on stress reduction in the home; however, this relates more to the well-being of the service user in having a calm environment rather than the wellbeing of their carer (Lavis et al., 2015).

Caring for someone with psychosis has been found to have a negative impact on carers (Rofail et al., 2016) including high levels of burden and emotional distress (Awad & Voruganti, 2008; Dillinger & Kersun, 2020; Glozman, 2004; Li et al., 2007; Poon et al., 2017) and increased depression and anxiety compared to the general population (Boydell et al., 2014; Kuipers et al., 2010; Sadath et al., 2017). Carers have a higher risk of mortality (Harvey et al., 2002), show deterioration in physical health (Caqueo-Urízar et al., 2009), and reduced quality of life (Boyer et al., 2016; Poon et al., 2017). Compared to the general population carers report elevated feelings of social isolation and loneliness ((Hayes et al., 2015; Vasileiou et al., 2017), feel embarrassed, ashamed, and guilty (Boyer et al., 2016; Cherry et al., 2017) due to the social stigma of being related to someone with a mental health problem. Informal carers are often faced with taking on a caring role in a crisis situation (Lovelock, 2016) and some have argued that they go through highly traumatic experiences (Darmi et al., 2017; Shiraishi & Reilly, 2019) and display symptoms of PTSD (Barton & Jackson, 2008; Kingston et al., 2016). The bulk of research into carer wellbeing has focused on carer burden, however, the impact of other aspects and experiences of caring has been overlooked (Onwumere et al., 2018).

There has been a call for researchers to better recognise the positive aspects of mental health caregiving as this provides a more holistic picture of the caregiving experience (Fulton Picot et al., 1997; Kate et al., 2012). Caregiving can promote a sense of accomplishment, companionship, fulfilment, improved self-esteem, and closer family relationships (Chen & Greenberg, 2004; Cohen et al., 2008) and having positive caregiving experiences has been associated with better quality of life outcomes for carers (Kate et al., 2014). Research into the positive aspects of caregiving has been limited and has not translated into interventions tailored to support relatives’ recovery (Deane et al., 2015). It seems evident that to promote positive outcomes for carers, it is necessary to assess both their positive and negative experiences to understand the mechanisms behind those experiences, and ultimately to inform more effective support.

A potentially important aspect in understanding carer wellbeing is the concept of 'personal recovery'. The recovery approach has become one of the most influential paradigms in mental health policy and practice across the English-speaking world (Price-Robertson, Manderson, et al., 2017) and represents a shift in focus away from traditional 'clinical recovery' which focuses on symptom, relapse reduction, and medication adherence; to 'personal recovery' which supports the service user in working towards their own goals and in taking responsibility for their own life (Slade, 2009). Personal recovery has been defined as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles" and "a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness" (Anthony, 1993). The terms 'recovery' and 'personal recovery' are often used interchangeably but generally relate to the concepts of 'personal recovery'. The bulk of research on the recovery approach has focused on service user recovery. However, there is now increasing recognition that recovery for service users does not happen in isolation and is dependent on family support (Wyder & Bland, 2014), and that personal recovery processes are dispersed across a wider interpersonal network rather than resting solely with service users (Price-Robertson, Manderson, et al., 2017). There has been limited research about the personal recovery for carers (Jacob et al., 2017; The Scottish Recovery Network, 2009) and recovery informed practise has largely overlooked carers (Hungerford & Richardson, 2013). It has been argued that carers are on a parallel journey of recovery (Lovelock, 2016; Wyder & Bland, 2014) and that the family recovery journey is intrinsically linked to the service user's journey, thus neither can be understood in isolation (Price-Robertson, Manderson, et al., 2017; Wyder & Bland, 2014).

Increasingly there is a call for more recovery focused interventions for carers and family members (Deane et al., 2015; Estrada, 2016; Norton & Cuskelly, 2021; Poon et al., 2017) to support carers in moving forward with their lives by helping them to develop a sense of meaning and purpose despite ongoing challenges (Deane et al., 2015). In supporting carers to identify their own personal recovery journey and to reconnect with wellness, it is more likely to deepen their understanding of their relative's experiences of mental health problems (Lovelock, 2016), which may ultimately lead to improved relationships and a reciprocal support system within the family (Chen & Greenberg, 2004). Supporting carer recovery may also indirectly support the service user's recovery journey because greater understanding of personal recovery processes gives carers greater confidence in their own 'expertise-by-caring' (Fox et al., 2015). There are increasingly more recovery focused family interventions being developed and trialled (Deane et al., 2015; Estrada, 2016; Rue et al., 2016) and there are strong recommendations that carers must be included in care planning with mental health professionals (Chien et al., 2020; Fox et al., 2015). However, there is a limited literature on what personal recovery may mean for relatives themselves (Lovelock, 2016; Wyder & Bland, 2014) and to date there is no qualitative research exploring what personal recovery means for carers. The aim of this study was to explore the positive experiences of caring for a loved one with psychosis, in particular carers' understanding of personal recovery for themselves.

Methods

This interview study was conducted as part of a larger research project looking to develop a new outcome measure for carers to assess their personal recovery. The qualitative interview data were used to explore personal recovery and directly informed the creation of questionnaire items on a draft of the new measure.

Participants and recruitment

A purposive sampling strategy (Ritchie et al., 2003) was used to ensure data were captured from those with direct and current caring experience and thus could provide expertise in this topic (Flick, 2008). The inclusion criteria included any adult relative or close friend who provided informal and unpaid care and support to someone with a diagnosis of psychosis, schizophrenia, schizoaffective disorder, or delusional disorder. The recruitment strategy was focused on 3rd sector charities and carers groups, social media, and word of mouth. The lead researcher (CH) circulated information to local charities and carers groups and attended carers meetings to discuss the study and hand out information. Study advertisements were also placed on social media with links to the study website. Full ethical approval was given by the Lancaster University Faculty of Health and Medicine Research Ethics committee (project code: FHMREC16113 - see Appendix J). All participants were provided with an information sheet and had the opportunity to ask questions about the study. Participants also gave informed consent prior to the interviews taking place. All interviews were conducted during working hours on weekdays. To thank participants for their time they were given a £10 gift voucher. Please see Appendices L to O for copies of the advertising materials, participant information sheet, consent form and debrief form.

Data collection and analysis

The interviews followed a semi-structured format using a topic guide (Appendix A). The topic guide was developed by the lead researcher (CH) and discussed with the project supervisors (BS & SJ). Questions on the topic guide were guided by the academic reading on the experiences of carers of those with psychosis for example, two key qualitative research studies conducted by Lavis et al. (2015) and Wainwright et al. (2016). The topic guide was used flexibly with the interviewer (CH) exploring different topics as they arose organically. The aims of the interviews were to explore the concept of ‘personal recovery’; however, this phrase was never explicitly stated during the interviews but only at the end as the authors did not want to directly impose any a priori theoretical concepts. Participants were asked to discuss their experience of caring for someone with psychosis and how this may have impacted on their wellbeing. Interviews lasted an average of 70 minutes and were conducted both face to face (10 interviews) or remotely (7 interviews) via Skype, MS Teams or telephone. Due to the COVID-19 pandemic, the final three triangulation interviews were completed remotely as it was not possible to meet in person due to the UK government restrictions at the time (December 2020). Despite this restriction it was still possible to gather rich data and allowed the researcher to recruit from a wider geographic area.

All interviews were audio recorded, transcribed verbatim and coded using NVivo 12 (QSR International, 2018) by the lead author (CH). The analytical methodology used was based on thematic analysis (Braun & Clarke, 2006, 2013) which offered a flexible way to identify, analyse and interpret patterns in the interview data. The analysis was conducted by the lead author (CH) with regular analysis meetings with the project supervisors (BS & SJ) to discuss the theme structure. The analytic approach was inductive to explore the data in a 'bottom up' manner based directly on what the carers shared in the interviews; however, the topic guide was driven by the concepts outlined by the theory of personal recovery and in that respect, it also followed a deductive approach. This duality of analytic approaches can be combined effectively within an analysis to allow for a theoretical concept to be explored (Braun & Clarke, 2013). One way to operationalise the analytic method used for this study was to explore how both deductive and inductive reasoning were to be used to explore recovery in carers. In terms of deductive reasoning, the theoretical and conceptual understanding of the 'personal recovery' was explored by the research team prior to devising the topic guide. This included reading academic material by key authors (Anthony, 1993; Estrada, 2016; Leamy et al., 2011; Lovelock, 2016; Slade, 2009, 2010; Slade et al., 2014) on this topic. Because the bulk of research on personal recovery has related to service users, the research team operationalised key terms and phrases that could be related to carers and relatives, for example: the category 'hope' included terms like 'optimism', 'positive thinking', 'full potential', and 'aspirations'. This checklist of phrases formed the basis for a systematic review of personal recovery measures that could be used to assess recovery, see Hilton et al. (2022) Chapter 3, and Appendix B. The interview questions were open ended and explored a variety of aspects related to the concept of personal recovery. The three triangulation interviews at the end of the study acted as a more deductive way to double check certain points about carers understanding of personal recovery specifically.

The analytic process included coding the anonymised transcripts, refining and grouping codes into subthemes and themes through thematic mapping and selecting exemplar quotes. Particular attention was paid to the various aspects of personal recovery and whether the carers saw this for themselves. Themes were discussed and refined by the research team in an iterative process.

Reflexivity

The main researcher (CH) also kept a reflective journal throughout the data collection and data analysis process. This provided a tool to review how the researcher's positionality may have subjectively influenced the analysis. My positionality coming to this study was as an academic researcher with lived experience of acute psychosis and who's family had become my carers while I was unwell. This meant that I had first-hand experience as a service user but also, I had seen the dramatic impact this had on my family. Consideration should be made to my position as a white female living in a first world country who is also a parent. I was cognisant that I would not be able to fully understand the experiences of carers from different ethnic backgrounds, other genders, other sexualities, other socio-economic statuses or countries. I do feel that my position as a parent provided me with valuable insight into the high levels of emotions that carers carry when their child is acutely unwell. A fuller summary of this is provided later in the discussion section of this paper.

Results

Demographic characteristics

A total of 17 carers were recruited, with 16 being interviewed for the main part of the study. Three triangulation interviews were carried out after the main data collection with two carers from the original interview set and one additional carer being interviewed. The majority of those interviewed were female (13) which represented 76% of the sample. The carers' relationships to service users were predominantly parental. Of the carers interviewed, 11 were mothers, two were fathers, three were partners/spouses, and one was a sibling. The length of time that carers had been providing care ranged from three and a half years to approximately 50 years. Eighty percent of the sample were from a White British ethnic background; however, two carers (20% of the sample) were from Australia and New Zealand respectively as they had heard about the study via social media and wanted to take part. The mean age of the carers was 56.8 years with an age range of between 29 years and 77 years. Of the 16 carers who took part in the first set of interviews, 9 carers were living separately from the person they cared for, while 7 carers were living with the person they cared for. The carers described the mental health difficulties of their loved ones as all being related to a form of psychosis (psychosis – 2; psychosis and schizophrenia – 4; psychosis and another serious mental or physical illness; schizophrenia – 5; schizoaffective disorder – 2). See Table 4 for further demographic characteristics.

TABLE 4 *Sociodemographic characteristics of participants for the qualitative interview study*

Participant characteristic	*n* (%)	M (SD)
Gender		
Female	13 (76.5)	
Male	4 (23.5)	
Age		57.9 (15.8)
Ethnicity		
White British	15 (80)	
White Australian European	1(10)	
White New Zealand European	1(10)	
Caring relationship to person being cared for		
Mother	11 (64.7)	
Father	2 (11.8)	
Sibling	1 (5.9)	
Partner	3 (17.6)	
Diagnosis of person being cared for *		
Psychosis	4 (23.5)	
Psychosis/Schizophrenia	4 (23.5)	
Psychosis & PTSD & Personality disorder	1 (5.9)	
Schizophrenia	6 (35.3)	

Schizoaffective disorder	2 (11.8)	
Length of time providing care (in years)		13 (11.0)

Interview themes summary

Four main themes were identified that explored personal recovery for carers which were: ‘Carers’ Personal Recovery’, ‘Building Resilience’ and ‘Personal Growth’ and ‘Negative Aspects to Caring’. The first theme, ‘Carers’ Personal Recovery’, comprises of four subthemes: ‘Latent Recovery’, ‘Recovery Terminology’, ‘Parallel Recovery’, and the final subtheme ‘Recovery, Grief and Loss’. The second main theme, ‘Building Resilience’, highlights how carers had put in place adaptations to their lives to help them cope better with their caring responsibilities. This theme includes the subthemes of: ‘Being positive’, ‘Acceptance’, ‘Rationalising’, ‘Work Adjustments’, ‘Keeping Busy’, ‘Getting Support’, ‘Self-care’, and ‘Self-protection’. The third theme of ‘Personal Growth’ explores the process of longer-term changes that impacts on carers’ personality and outlook on life. The subthemes include: ‘Changed outlook on life’, ‘Strength and Empowerment’, Campaigning and Complaining’, ‘Deeper Personal Connections’, and ‘Hope and Gratitude’. The final theme of ‘Negative Aspects of Caring’ looks at the strain of providing care to someone with psychosis. The subthemes include: ‘Losing Identity and Confidence’, ‘Emotional Strain’, ‘Strained Relationships’, and ‘Grief and Guilt’. See Table 5 for a summary of the main themes, definitions, and subthemes.

TABLE 5: *Summary of qualitative interview themes*

Main theme	Definition	Sub-themes
Carers' Personal Recovery	Whether carers recognise that they are on a journey of personal recovery for themselves or not. Suggestions of latent recovery for carers that they are not aware of their recovery until some time has passed. Often carer recovery is dependent on the recovery of the service user in parallel, if the service user is well then, some of the burden of care may lift off the carer. The terminology of 'recovery' is problematic for carers to identify with, it is often understood as 'clinical recovery' and they see that they have not been the ones with an 'illness'. Recovery for carers is also associated with feelings of grief and loss, even when things are better, they will always feel sadness about what has happened.	Latent Recovery Recovery Terminology Parallel Recovery Recovery, Grief and Loss

Building Resilience	Carers finding ways to cope better with their caring responsibilities by making positive adaptations, getting support and improving their self-care. What helps carers appears to be having a positive attitude, accepting the situation, rationalising that they are dealing with a mental illness, and keeping busy as a distraction and to feel like they are being proactive. Accepting support from others, making sure they take care of themselves through self-care are also important. Carers described strategies that can be understood as ways to protect themselves emotionally.	Being positive Acceptance Rationalising Work adjustments Keeping busy Getting support Self-care Self-protection
Personal Growth	Positive changes to carers outlook on life despite experiencing negative aspects to providing long term care. Includes a more positive outlook on life, feelings of strength and empowerment, the motivation to complain and campaign for better services and to help other carers and service users. Evidence of carers creating deeper personal connections with the person they care for and other carers. Care's describe elements of hope and gratitude that things can improve.	Changed outlook on life Strength and empowerment Campaigning and complaining Deeper personal connections Hope and Gratitude

Negative aspects of caring	The burden of providing long term care can be significant for carers. Carers describe losing their identity and confidence and feeling less empowered. They describe high levels of emotional strain, mental health difficulties for themselves and having to take sick leave from work. Personal relationships also become strained through the stigma of caring for a relative with a serious mental health problem. High levels of grief for the relative they once knew and they life they had been planning for themselves. Feelings of guilt that they should have been able to spot the illness sooner or done more to help.	Losing identity and confidence Emotional strain Strained relationships Grief and Guilt

Theme One – Carers' Personal Recovery

Overall, carers had mixed views about whether they go through a process of personal recovery, with several carers not being able to identify with this concept. When carers did discuss recovery, it was mainly to do with the service user's recovery. Carers described 'parallel recovery' as they acknowledged that when the service user was doing well, then that had a knock-on positive effect for them as well. It became apparent as the interviews progressed that there was a problem with the sematic meaning of the term personal recovery. Because of this a further three carers were interviewed to specifically discuss what personal recovery meant for them, the main finding being that there is a form of recovery that takes place, but the term personal recovery is not valid for carers themselves.

Subtheme: Latent Recovery for Carers

The first subtheme shows how some carers did see that carers could recover however this was: "really not recovery in a definable sense but certainly finding a position whereby you can manage the problem better." Q009. Recovery did not seem to be an accurate description of what carers experience. The component parts of the concept of 'recovery' were discussed in the interviews and there was evidence from the quotes to support the theory of recovery however it would be remiss to ascribe the theory of personal recovery in a top-down way onto this population. There is a quality of latent recovery where carers do go through a process of change, but they would not class themselves as 'recovered' or in 'recovery'. Some carers understood that some form of 'recovery' was a possibility for them, but it was still in progress, that relief was not there yet, and it was a gradual process that might only become apparent with hindsight.

> *"I think it's still ongoing…it'll be something that all of sudden I'll think oh yeah I don't do that anymore, or I am less anxious about that, I think it'll just be a very gradual thing, but I am a lot lot better than I was, definitely." Q002*

This quote show's how carer recovery could be seen as an implicit process that is sometimes not apparent until they look back on how far they have come.

Subtheme: Recovery Terminology

It became apparent that there was a problem with personal recovery terminology. Many carers understood recovery in a literal sense, with one carer explaining it well using the example of 'economic' recovery:

> *"Recovery seems to imply like an economic recovery that the indices will return to what they were before the event." T001*

Even when asked if there was a better term that could be used, carers found it difficult to pinpoint. "I'm sure there is a better phrase, can't think what it is but I think there is a better phrase." Q015. It was apparent that the concepts behind the theory of recovery were present with phrases such as "rebuilding your life" Q015, "learning to accept the situation" T001 and even 'post-traumatic growth' being discussed.

> *"That is a perfect description; posttraumatic growth! Because it is traumatic…it's actually describing what happened, the trauma to the carer, and the growth post the trauma…that's a clearer description, than recovery." T003*

This subtheme highlights how many carers struggled to understand personal recovery for themselves: "I don't feel like I need to recover anything really" Q008. This relates to the carers understanding of recovery in terms of 'clinical recovery' and how they felt that they had not been ill themselves, so they did not need to 'recover'. This was explored in more detail in the triangulation interviews.

> *"So, I think this recovery idea is the problem? I dealt with somebody with psychosis. And I don't feel I had to be looked upon afterwards as somebody who needed to recover." T003*

As the interviews progressed it became apparent that the term ‘recovery’ was a problematic concept for many carers and some even felt it was in fact ‘misleading’:

> *“Recovery in a sense is misleading, it's a little bit of a euphemism for a return to an acceptable, tolerable day-to-day life [without] some traumatic disaster suddenly plunging into the middle of your day.” T001*

Subtheme: Parallel Recovery

‘Parallel Recovery’ encapsulated how carers noted that their recovery is dependent on their loved one’s recovery and are “linked” Q007.

> *“I think for me the only way that I would go on a journey to recovery is if my brother was as well…I think the two things are just so connected, … my recovery depends on his recovery.” Q007*

This highlights how recovery can be thought of as running in parallel to the recovery of the service user. Many carers described waiting to ‘rebuild’ their lives once the person they cared for was well.

> *“My recovery and rebuilding my life back to a social life and hobbies and my career would only really start once I know he’s stable and on his feet again.” Q011*

There were differences between carers dealing with short term acute psychotic episodes compared to those caring for a loved one with a long-term diagnosis such as schizophrenia who “due to their loved one’s condition, [other carers] probably never escape and never rebuild their lives.” Q009.

Subtheme: Recovery, Grief and Loss

Throughout the interviews themes of grief and loss permeated what carers were expressing. Juxtaposing this to the ‘theory of recovery’ their grief and loss could be understood and accepted by carers to an extent. It became apparent that this may not be a 'positive' recovery journey, but a process that would always hold sadness and loss.

To return to the quote mentioned above, T001 describes their understanding of 'recovery' from on economic sense but goes on to describe the 'permanent damage' that has been done. This demonstrates a high level of loss that the carer cannot see as ever changing.

> *"Recovery seems to imply like an economic recovery that the indices will return to what they were before the event. This is not going to happen. The permanent…damage…has been done in some cases." T001*

Carers also felt that if they did 'recover' then they would never be able to return to their old selves or lives and that they are forever changed, living with constant worry that they cannot see ever lifting.

> *"I don't think I will ever be in that place that I was before, 'cos I'll always have the worry at the back of my mind, that's something that will never leave me, no matter how well [service user] is doing" Q003.*

Some carers even felt angry about the term, feeling that they should be returning to a better place or back to 'normal' but that this might never be the case. This added to their sense of loss and grief.

> "Recovery is a strong word…certainly feels 'well it's OK now'. It's not OK.' It's just, the process continues really." T001

It became evident through the interviews that carers generally did not understand that they were going through a 'personal recovery journey', however, it did become evident that they had been going through a process of change, building resilience that supported them with their caring responsibilities.

Theme Two - 'Building Resilience'

This theme explains the process that carers go through to build up resilience and cope better with their caring responsibilities. All carers described adaptations and coping tools that they used to help them mentally, emotionally, and practically. Building resilience was also facilitated by getting both formal and informal support and learning that self-care was important to keeping themselves well so that they could effectively care for their loved ones.

Subtheme: Being positive Carers described emotional adaptations such as learning to be positive, realising that small victories need to be celebrated, and to be hopeful that even if things "dip" things will be better. There was also the recognition to look back and realise how far carers had come in learning to deal with difficult situations.

> *"Things will get better, things will improve, even if they're very small things, each day is different and if things are really bad, tomorrow might be a bit better…keep looking back at where you've come from. So, when you think things are really bad again, look back and remind yourself about how far you've come." Q002*

Some carers also described a coping tool of trying to be in 'good place' emotionally. This also helped the service user, to help them feel better and less of a burden, however, this often comes at the expense of the carer as they hide and suppress their own negative emotions:

> *"Carers are quite good at hiding [things] because they don't want the person they're caring for to feel as though they're a burden." Q011*

Subtheme: Acceptance

The concept of acceptance was also very important for carers cognitive adaptation. This relates to acceptance of their loved one's mental health diagnosis, but also an acceptance of their caring responsibilities. Carers described having emotional relief and being able to mentally 'move on' once they had accepted their loved one's mental health diagnosis.

> *"I had to accept the illness, and the situation, and once I accepted that … and came to terms with that, I found things a lot easier for myself to move on." Q003*

Many carers explained that a process of acceptance that their loved one may never return to how they were before their psychotic episode, and that this acceptance, although heart breaking, helped their own mental health. There was also the recognition that they could not control the situation, and that there was only so much they could do to help:

> *"You realise that actually you have to learn to live with it, you're not going to get it ticked off, you're not going to get it better … you didn't cause it, you can't control it and you can't cure it. That's quite helpful to bring into that." Q013*

Another aspect related to cognitive adaption related to how carers had learned that 'stepping back' and detaching from the situation helped both their mental state and the relationship with the person they care for.

> *"I've taken a step back from the whole issue to reflect and tolerate 'well this is how things are', there's nothing I can really do much directly about it except support and accept and intervene when I can, and also to think rather than of myself and the impact on me, well what can I do to support and maintain the person you're caring for, what's the best thing for them?" Q009*

Some carers also discussed how important it had been to recognise and 'see' the person rather than their diagnosis and to accept that they had an illness, and it was the symptoms of the illness that had changed them.

> *"I've realised, seeing my son, that it's not just the diagnosis, they're still a person. You know there's more to it than just the illness…I think people need to look beyond the diagnosis." Q003*

One long term carer also spoke with great conviction: "don't give up on the person that's ill, work with them work together and you can work it out" Q005, that the person they loved was still there and they had managed to "live as pretty much a normal life" Q005, despite the illness.

Subtheme: Rationalising

Some carers also seemed to find comfort by rationalising their loved one's illness: "when you love someone, you make a lot of reasonings in your own head…like we put it down to stress initially." Q014. Rationalising severe mental illness as akin to a serious physical health problem helped to reduce their guilt at seeking professional help and supporting their loved one to go into hospital, which many carers felt guilty about.

> *"My cousin said to me you know if he [service user] had appendicitis you wouldn't be trying to pull his appendix out would you, so you have to hand him over to the professionals." Q014*

Subtheme: Work adjustments

There were also examples of more practical adaptions that some carers had made, such as to their employment. Many carers discussed having to take time off work to allow them to care for their loved one during their crisis, with many returning to work on part time hours to allow them more flexibility. Other carers left their jobs permanently to devote more time to being a carer:

"I even packed in my job…to give more time to my son. They were aware what I was going through, and probably it was starting to impact a little bit on my performance. So, got a decent payoff, packed it in and devoted a lot of that time, to looking after him [son]" Q004

Subtheme: Keeping busy

Despite high demands on their time, many carers found it helpful to keep busy. There seemed to be two reasons for this: to distract themselves from the situation, but also to feel proactive in trying to make a difference and help their loved one in the only way they know how.

> *"The way I deal with it is to be proactive and try and make a difference and I start writing loads of complaints and speaking to people and feeding it back to everybody." Q014*

Attending support groups and doing charity work also appeared to be another way to keep busy while also getting support.

Subtheme: Getting Support

All carers discussed 'Getting Support' which is the next subtheme relating to 'Building Resilience'. This included informal and formal support. Some carers explained how talking to friends and family had "kept me sane" (Q014) and that they found it good to share their worries and 'offload'. Some carers mentioned that it's good to be open and honest about the illness as often they found other people were dealing with similar situations and this was comforting: "I don't try and keep it a secret no, because you talk to people and straight away nine out of ten people will come back with a little something that we're not so different." Q013. Many carers commented that it is important to accept help, not only to find out "what the hell's going on" Q009, but also to know how best to deal with things such as: the symptoms of psychosis, or how to apply for state benefits for the person they care for, and deal with difficult behaviours. There was also a feeling that carers should not feel too proud to accept help and that it wasn't a sign that they were failing in any way.

> *"If somebody offers you help, don't be proud and say no I'm fine, if somebody asks you who's a professional or who's there to help you, I would say take that help and if you're feeling that you're struggling and you're down and it's becoming too much, that's not a failing in you, let somebody know 'cos there should be some help somewhere." Q011*

There were mixed views about carer support groups. Some carers found them extremely helpful and described positive experiences of support groups. "I just found this as a bit of a refuge for me to come here and relax and unwind and talk to like-minded people" Q004. There was a strong sense of community with other carers, "there was this incredible sense of commonality in the room" Q001, where other carers understood their situation because: "they know what the dark days feel like and they know what the good days feel like" Q011 and it was 'okay' to be open and honest about things in a safe space. Some carers found attending support groups cathartic because "you come away from that place thinking, phew I'm not on my own there's lots of other people in the same boat as me" Q004. Not all carers found carers support groups helpful, however. Some described the groups as depressing "it's like a competition to see who's had the worst experience sort of thing" Q008. Some carers felt hearing other stories could drag them down, and that they didn't find the groups that helpful the further into their caring journey they were: "I felt I was helping other people more than I was receiving help" Q002. Others described not having the time to attend groups and felt like it was just a place for "tea and sympathy" Q006, which they didn't find helpful.

Subtheme: Self-care

The subtheme 'Self-care' was seen as an important part of building resilience. All carers mentioned some form of self-care that helped them, for example having friendships and maintaining a life outside of caring: "friendships and contacts are very very important, and to have a life outside… ‘Cos otherwise I think it would be very easy to turn in on yourself and to just be swamped by it.” Q016. A lot of carers understood that if they did not look after themselves then they would not be able to care for their loved one.

> *“you must put on your own oxygen mask first…It’s no good going to pieces because you’ve worn yourself ragged looking after someone else ‘cos it’s not helpful in the end … make sure that you keep yourself as healthy as you can and as happy as you can.” Q013*

Most carers were aware that they should take care of themselves, and this seems to be general advice to carers, however carers expressed that it is much harder to do with all the other life stressors going on: “also take care of yourself, which I didn’t, people told me that I had to make time for myself and that was the hardest thing to do.” Q002. There was recognition that if they did not protect their own health then they could become “part of the problem rather than part of the solution.” Q011

Some carers also mentioned that finding an outside source of comfort to be tremendously beneficial in relation to caring for themselves: “know where your well is, know where you can go for a source of comfort, inspiration or whatever like that when things get a bit full of angst.” Q013. There was a religious or spiritual element to this understanding where some carers felt that if things were becoming too much they could “hand over” Q013 to a higher power and this comforted them.

Subtheme: Self-protection

Carers also described other ways of protecting their mental health. Making mental space was a way for carers to detach from the situation and put up a protective barrier which allowed them to be less emotionally invested because the situation they were dealing with was just too overwhelming. Carers described how to make mental space by just focusing on one thing at a time “my coping strategy really is to exclude everything else and just concentrate on that” Q014. Another carer described learning to ‘compartmentalise’ their caring responsibilities with a life outside caring: “you learnt to compartmentalise, and switch off at times, right she’s ill so ok we concentrate now, ok she’s not ill, I go off and do things." Q016. Making mental space has clearly been a helpful adaptation for many carers in helping them cope with extremely high stress situations. Another more practical form of self-care was discussed, and this related to making physical space for the carer.

Most longer-term carers found it had been very beneficial for their loved ones to live independently, which offered carers some respite.

> *"If we'd had the person we were caring for staying with us, I think the close proximity … the almost unbearably claustrophobic emotional challenges that that presented would in fact be destructive … everybody needs their space." Q009*

Getting physical space allowed the carers to also make mental space and have time to emotionally repair themselves. The benefit of getting physical space was not limited to their loved one living independently, even going back to work helped carers recover: "I think with my recovery it definitely helped me to get away and have a job and 'cos I was in a better place myself" Q007

Another self-protection strategy described in the interviews related to when carers described anticipating the worst possible outcome for the person they care for, as a way to emotionally prepare for potential negative outcomes.

> *"There becomes a point where it's a protection, there's a barrier comes down … so many times I'd expected to find him dead shall we say, then that one day it won't surprise me, … it sounds an awful thing to say but that is the way I feel" Q011*

Theme Three – 'Personal Growth'

The final theme is 'Personal Growth' that shows that despite carers not connecting with the term personal recovery many described elements of recovery that show a process of personal growth, for example many carers described quite fundamental changes to their outlook on life: “I feel like my life was shaken to the core, [caring] has kind of changed me fundamentally,” Q001.

Subtheme: Changed outlook on life

Many carers went on to explain how they feel they’ve become more altruistic, introspective, understanding, and compassionate towards others, more knowledgeable about mental health issues, more confident and empowered in order to fight for better mental health services.

> *“My whole outlook on life has altered and it does make it feel … far more introspective, you look at yourself closer, you know analyse things a bit more deeply and I think you care for other people a lot more than what you have done in the past” Q004*

Other carers felt that they had gained clarity about their life priorities “I’m a lot clearer about my priorities.” Q012. Some carers described being far less materialistic and described a longing for a “simple, uncomplicated” Q011 lifestyle. Changing expectations about their loved ones’ recovery seemed to help some carers “you learn to take shallower steps and that helps you get through it.” Q002. There is also evidence that carers have built emotional resilience in dealing with someone with a serious mental illness: “nothing really surprises me anymore with regards mental health or medical conditions or I’m not fazed by anything.” Q011. As with any form of growth, there needs to be a catalyst for change, a difficult journey to travel and for all carers this related to the difficulties they had in caring for their loved one.

Carers discussed other adaptations they had made to their thinking patterns, like learning to be more flexible in their attitude to when situations do not work out as planned.

> *“I’m more flexible, because a lot of the things that we had planned just had to go. So I’m much more ‘if it doesn’t happen it doesn’t happen’.” Q002*

Subtheme: Strength and empowerment

Many carers talked about how they have emotionally grown from their experiences. Many felt stronger and more empowered through their experience: “it’s made me a stronger person.” Q003. Some carers described having great strength because it was their child that needed caring for: “you get some sort of superhuman power … where your children are concerned.” Q002 and becoming more empowered to fight for better mental health services for their loved ones. Some carers did manage to regain their confidence as the service user was recovering and stabilising. This allowed the carers to rebuild their confidence gradually: “it’s a process of little steps that rebuild your own confidence that he’s going to be ok.” Q002. Carers that took on a more of ‘campaigning’ role to push for system wide change, found this boosted their confidence and they felt more empowered because they had “emotional energy to knock harder on doors, shout louder at meetings, write strong letters and protest and kick back.” Q015.

The interviews also highlighted how carers had developed greater purpose and meaning in their lives. Carers described wanting to use their negative experiences to help other carers and improve mental health services.

> *“I really wanted to use all the negative experiences that I’d had to make a difference for others, because I was just so acutely aware of how damaged I’d felt, how difficult it was to access the support and services that I that me and my family needed.” Q001*

Some carers have found their experience meaningful but painfully so: “Certainly meaningful but it’s not what I would choose. I wouldn’t recommend it.” Q009

Subtheme: Campaigning and complaining

Many carers described ‘complaining and campaigning’ for better mental health services because of their experiences. This process also seems to provide a cathartic experience which helps carers “let off steam”. Q009. In the situation where they felt powerless to help their loved one, this gave them something constructive to do to try to help the situation, not just for the person they care for but also for others who have been struggling to get support from services.

> *"I'm trying to make it better for him, I don't want him to be ill again and have 53 hours on the A&E so I'll do what I can to prevent that happening and things have changed because of my feedback." Q014*

Subtheme: Deeper personal connections

Many carers described how their friendships have "certainly strengthened and deepened." Q001. Indeed, carers did describe being able to form deeper personal connections as the joint experience of going through such a difficult experience together as a family had brought them closer together. A lot of carers felt that they had a closer relationship to the person they were caring for: "We've become incredibly close because of all this … that's one of the plus sides," Q002

Some carers they felt that because they had sought out support from other carers that they had managed to create deep personal connections that would not have been there before.

> *"I'm in communication with some other carers now … I'm developing some friendships that will probably last for quite a long time, they're actually based on around coping with living with these conditions." Q001*

Carers felt that they had learned to communicate better, they were able to pick up on subtle things like "non-verbal facial expressions" Q012 that helped them to "connect with what they're [the person they care for] experiencing" Q012. Carers also felt they were more patient, compassionate and had greater empathy for others. "It's made me a more caring, kind, understanding person, I have more patience and compassion towards others." Q003

Subtheme – Hope and Gratitude

Carers also described feelings of 'Hope and Gratitude' that the future would be better "there is light at the end of the road" Q003, this was particularly relevant for those carers that could see signs of recovery in their loved one. The concept of gratitude also came up in the interviews. This related to carers recognising that things could have been worse for them, and with hindsight they see they have coped well and had it 'easier' compared to other carers. Where the service user seemed to be improving and in a period of recovery, carers described life becoming more settled and a period of respite where they could recuperate "we're just really breathing, we're happy." Q012. There was the feeling to enjoy those moments while the service user is well and not to take it for granted because things can change easily:

> *"We don't know when things will change for [person they care for], and to enjoy that window of opportunity, to feel close as a family, grab it, enjoy it, because this time next year it could be different again, you know so if you have that time don't take it for granted" Q006*

Subtheme: Negative aspects to caring

Despite descriptions of positive change and growth carers still describe 'Negative Aspects to Caring' such as the overwhelming burden of caring for a loved one with psychosis with some carers explaining how they became completely preoccupied with the illness to the point that they felt "all consumed" by it: "I'm lost in that illness with him I think." Q014. They also felt that their lives were put on hold and "on the back-boiler" Q011 with their plans and priorities disrupted while they care for their loved one. "My plans will start when

I’ve got my time back, which I think a lot of carers are like that, for the carers that I know find that it’s quite intense” Q011

Subtheme: Loss of identity and confidence

Carers also explained how they felt less empowered and for some this has led to a loss of personal identity: “I feel less empowered…I feel like my identity’s been taken, I don’t really know who I am or what I want or I’m just the carer.” Q003. Other carers described having lost their confidence particularly in social situations. One of the reasons for this is that they did not have much to discuss outside of their caring responsibilities:

> *“I’d lost all my confidence, I found it difficult to go into a social situation, I found I had nothing to talk about because my life was surrounding [person they cared for], and it wasn’t appropriate to talk about [them] socially …I couldn’t keep a conversation going, I just lost my social confidence completely,” Q002*

This also implies an element of stigma around talking openly about mental health. Most carers felt “a bit lost in it all” Q014, that they had no certainty about the future and therefore could not make plans for their life – their lives were on hold.

Subtheme: Emotional strain

Carers also described their mental health as having deteriorated, feeling completely overwhelmed with the great emotional strain “my well was just running dry in terms of being able to cope” Q001, with some of them describing being at “screaming point” in desperation and that they felt “there’s times when I wanted to give up, just felt like I couldn’t do it anymore, I either wanted to run away or like take my own life because I just couldn’t yeah.” Q003. Some carers recounted having extreme mental and physical exhaustion “sometimes I just reach a point where I’m just exhausted, mentally and physically exhausted and I just want to shut off.” Q014, and how they felt like they were always on alert for the “tiny little symptoms” Q016 that their loved one was relapsing. While anxiety and depression were discussed by several carers, some carers had found some improvement to their mental health as their loved one was recovering “I’m much better than I was but…I have to make myself search for, it’s a conscious thing that I do, to look for positives.” Q002 which shows evidence of parallel recovery.

Many carers describe having to go “off sick” with their own mental health problems “I had a bit of a breakdown” Q01, and then for some not being supported to return to work because of their caring responsibilities.

Subtheme: Strained relationships

Many carers described a strain on family relationships both close family and extended family. “But it certainly the impact is very great. It has a distorting and traumatic effect on family relationships, and everybody tries to tackle it and is affected in a different way” Q009. Carers discussed how relationships were affected because they need to focus on the person that was ill and tended to neglect the other family members:

> *“I’d say my relationship with my husband might have been affected at times because I get very focused on [person being cared for] when he’s ill, and I find I totally forget about him [husband].” Q014.*

There is also the recognition that the siblings of those that are unwell are affected as well: “certainly, it has put tremendous pressures on the family and you know my other children and their relationships, undoubtedly.” Q016

Some carers described feeling “incredibly lonely” Q012, because they had lost their social life: “I’d gone from seeing loads more of my friends … to zero.” Q002, and how “you find out who your friends are most definitely” Q009. Carers also described negative changes to their relationship with the person they care for. Some felt the service user became “resentful” of their carer for nagging them to take medication for example. Other carers felt that their loved one had become a “bit too close…and very dependant” Q001 on the carer which was overwhelming.

Subtheme: Grief and Guilt

All carers described a sense of grief and guilt for their loved one: “you’ve lost that person and you don’t know whether you’ll ever get them back” Q006. There is also a grief for a lost future of the service user, as many of those interviewed were parents of young adults who had become unwell: “this kind of illness happens right when they should be at the beginning of their prime, you know and all these opportunities should be occurring to set them up for the rest of their life,” Q012. Some carers were grieving about the loss of their own future plans, with some coming to the sad realisation that they were now facing a long-term caring role as their loved one may never fully recovery to be able to live independently. One carer dealt with this by lowering their expectations about their loved one’s future:

> *“it’s a terrible thing to say but I don’t have aspirations or expectations for [the person they care for] that a parent would normally have. I’m happy for [them] to be stable and involved in family life and have some friends…and that’s enough for me.” Q009*

Many carers felt a strong sense of guilt that they should be able to help their loved one more: “I feel guilty that I can’t cure him.” Q014. Many parent carers blamed themselves for their loved one’s mental ill health wondering if they had done something wrong when raising their child, or if there was a genetic link that had caused their mental illness.

> *“You feel guilty, you feel somehow you’re to blame, … you’re looking for the reason why this has happened. When you look back at how were when he was little, did I spot it early enough?” Q006*

Throughout the interviews there was a great sense grief and sadness that even though carers might have learned to be stronger and become more knowledgeable about mental health this was not through choice and it was certainly an unwanted hardship that was thrust upon them.

> *"You probably will end up stronger and more knowledgeable as a person as a result of this. It isn't a strength and a knowledge that you would actually seek out to be honest with you. You wouldn't wish it, it's not 'well I'm really glad I went through that trauma', no." T001*

Discussion

The present study aimed to gain a more in depth understanding of the role of 'personal recovery' for carers for those with long term psychosis. The interview data were explored through this 'recovery' lens and three themes were identified. Some surprising conclusions were made, mainly that carers do not recognise personal recovery as valid for themselves. Instead, there seemed to be other more relevant processes at play such as carers building resilience by putting in place coping strategies related to getting support and self-care, which helped them adapt to their caring role. Many carers described a journey of personal growth rather than personal recovery. The linguistic term 'personal recovery' did not seem to be readily accepted by most carers, however the themes identified in the data did show a number of elements of 'personal recovery' are relevant for carers but that an alternate and more specific term(s) should be found to describe the process they go through in adapting to their caring role.

Carer Recovery

Some carers did see recovery as possible, but this related to a latent process that became evidence when they looked back on how far they had come. The bottom-up data from the participants quotes did not adequately support that carers are on a 'recovery journey' in the same way that service users are. Carers did seem to recognise the concept of 'parallel recovery' as Lovelock (2016) described, where carer 'recovery' is contingent upon the recovery of the person being cared for. This parallel recovery seems impermanent with carer wellbeing narrowing and being continually 're-sited' depending on the service user's health (Lavis et al., 2015; Poon et al., 2017). It became evident through the interviews that carers felt the terminology of recovery for themselves was invalid and in fact misleading. This prompted running further triangulation interviews to specifically discuss the concept of personal recovery with carers. This data supported the finding that the terminology of personal recovery seemed problematic, with carers aligning the term more with clinical recovery, or even economic recovery, and felt that they had not been unwell themselves so what did they have to recovery from. Clearly the term 'recovery' is problematic, however, the underlying concepts of personal recovery as defined by the (Leamy et al., 2011) CHIME framework do still fit the main findings of this study. One example of this is that the CHIME framework outlines 'Connectedness', which relates to the subthemes 'Deeper Personal Connections' and 'Getting Support' and the sense of community that some carers felt as described in the data. In addition, the increased connectedness described tended to relate primarily to their identity as a carer and bearing the care burden, rather than concerning a more general sense of increased social connectedness. In addition, for some, the increased opportunities to meet others in the same position were seen as rather negative as not all carers found benefit from attending support groups.

Some carers felt the term 'recovery' could be detrimental as it could spark a sense of grief in carers. The theme 'Recovery, Grief and Loss' attempted to capture this dichotomy that even if things had improved there was always an overtone of loss and grief that for some felt like a permanent change. The sense of loss also became apparent by the anger that some carers demonstrated when thinking of the term 'recovery' which highlighted to them that that things should have returned to how things were before and that they should be ‘recovered’ and better by now.

So, if the term ‘recovery’ is invalid for carers, could there be more applicable terminology?

Building Resilience

‘Resilience’ has been defined as the “adaptation and swift recovery after experiencing severe adversity during life” (Davydov et al., 2010), and has been conceptualised for those carers who overcome adversity to survive the day-to-day burden of caring for a loved one with a mental illness and also to grow stronger, be more flexible and thrive as a healthier person (Van Breda, 2001). Links have been made between the concepts of ‘personal recovery’ and ‘resilience’ in the literature looking at service user recovery (Echezarraga et al., 2019). There is also a strong emerging literature showing how resilience in carers can help them to overcome the stress and burden of care (Lök & Bademli, 2021; Zauszniewski et al., 2015) and that positive adaption to their caring role can lead to positive changes, such as reduced burn out, improved quality of life and better family functioning (Amagai et al., 2016; Mannion, 1996). Resilient carers have better mental health and perform well when dealing with a variety of emotional, behavioural, cognitive, and social problems (Chen et al., 2016; Fitryasari et al., 2018; Wang et al., 2020; Zauszniewski et al., 2015).

The theme ‘Building Resilience’ seemed to depend upon several coping tools identified by carers such as: being positive, learning to be more flexible and being open and honest about their loved one’s mental health problems. These findings mirror those of Amagai et al. (2016), who also noted that carers who were more positive in their outlook were better able to control their emotions which showed an adaptation of resilience. Positive emotions are vital to counteract stressful experiences related to caring and have been found to be strongly related to having a sense of meaning and purpose in life (Rutten et al., 2013). Another important aspect of ‘Building Resilience’ relates to an adaptation that carers made to accepting the situation and how this often was the key to help carers cognitively adjust to their caring role and appeared to bring them a sense of peace. Similar findings were highlighted by Bishop and Greeff (2015) who found that when carers were able to accept the diagnosis of their loved one and evaluate a crisis situation passively, they were able to find different ways of adapting to their situation. Social support was another important sub-theme relating to 'Building Resilience', which showed that in general, carers valued both informal and formal support that they received from friends and family or support groups and how this acted to provide them with a sense of community and comfort in knowing they were not alone, which acted to reduce their social isolation. Similar findings were reported by Chen and Greenberg (2004) who found that informal support validates carers' experiences and that the mutually supportive environment promotes personal growth.

Another important sub-theme of 'Building Resilience' was self-care which many carers acknowledged was very important for keeping themselves well so that they could continue caring, however this was easier said than done. Despite self-care being a recommendation to take time for themselves, to promote psychological, physical, and social wellbeing, and build resilience (Onwumere et al., 2018), many found it difficult to prioritise their self-care because they were so focused on prioritising the needs of those they care for. Another important theme noted from the interview data was that of 'self-protection' which was a way for carers to set boundaries both emotionally and physically to better help them manage. The findings from this study are supported by literature looking at 'resilience' for carers and the positive aspects of caregiving. However, the data show that many carers go through a dynamic process of change and that many of the strategies they use to build resilience led to 'personal growth'. Rutten et al. (2013) note how the term resilience ranges from the prevention of mental health problems to the successful adaptation and recovery after experiencing adversities in life, including posttraumatic growth as an adaptation where the person has gained a better understanding of life with new perspectives and is able to respond well to similar challenges in the future. This shows well, the link between building resilience and personal growth.

Personal Growth

This theme encapsulates the longer-term changes to carers' cognitions, behaviours, and outlook on life and shows how their negative experiences can lead to positive personal transformation. It is important to note that carers still go through a traumatic experience, and this is more a process of trying to reduce their negative experiences that then lead to adaptations and latent personal growth. Personal growth occurs over a long period of time, which links to the findings of Lavis et al. (2015) who found carers go through a slow process of change, where distress solidified and settles in many areas of carers daily lives even after the person they care are for has 'recovered'. This finding links to the idea of a 'latent recovery' as discussed in theme 1, where we can see how despite positive changes or a kind of recovery occurring for carers that they are not aware of this until they have had time to reflect. Lavis et al. (2015) found that this happens because carers have "embodied vigilance" which is hard to let go of, and carers find their lives have been hugely reshaped by their experiences. This links to the findings of this study, that carers lives have been 'shaken to the core' and many of them have been through a major life transformation.

The theme of 'Personal Growth' also links to literature looking at the positive aspects to caregiving such as Chen and Greenberg (2004) findings that carers perceived personal growth and enhanced interpersonal relationships which supports the finding from these interviews that carers can experience 'Deeper Personal Connections'. Caring has also been found to be a potential source of positive transformation that provides carers with a sense of inner strength and satisfaction (Mackay & Pakenham, 2012; Pickett et al., 1997; Winefield & Harvey, 1994). This theme is also supported by the findings of Shiraishi and Reilly (2019) qualitative meta-summary that found carers can go through positive impacts from caring such as family solidarity, admiration, affirmation, affection, compassion, learning new knowledge and skills, self-confidence, personal growth, and appreciation. The theme of

‘Personal Growth’ does seem to be a double edge sword however, as the cause for the growth comes at a cost.

The interview data highlighted how carers experience ‘Negative Aspects to Caring’ which is the final theme presented in this paper. Carers describe how they have endured a trauma or repeated traumas and have experienced negative effects to their mental health and interpersonal relationships, lost their identity and confidence, felt disempowered, and suffered from feelings of grief, guilt, and shame. These findings link to the literature on the negative aspects of caring and carer burden (Boyer et al., 2016; Onwumere et al., 2018; Poon et al., 2017; Shiraishi & Reilly, 2019), and the literature on the grief experiences of carers (Godress et al. 2005; Patterson et al. 2005; Mulligan et al. 2013) highlighting how grief can often be prolonged as carers are not only mourning the loss of the person as they used to know them, but also the loss of hopes, wishes and aspirations caused by the disabling nature of psychosis. Godress et al. (2005) also note how the experience of grief changes over time as the nature of the illness ‘unfolds and changes’ and this reinforces the theme of ‘Recovery, Grief and Loss’ that highlights that even when the carer and service user have moved to a more ‘recovered’ period the sense of sadness remains

Carers go through a traumatic experience and research suggests that carers show symptoms of posttraumatic stress (Barton & Jackson, 2008; Darmi et al., 2017; Hanzawa et al., 2013; Kingston et al., 2016). Lavis et al. (2015) found evidence of carers having a delayed reaction to trauma, with carers only feeling the full force of affective challenges long after the service user’s illness onset. Shiraishi and Reilly (2019) mirror these findings and go on to note a cyclical structure between the service user relapsing and the return of the trauma for carers. There is an alternative concept that may be more applicable for carers that incorporates many of the core concepts of the ‘personal recovery’, acknowledges that personal growth can occur as a result the traumatic experience that carers endure. The concept of ‘posttraumatic growth’ (PTG) (Tedeschi & Calhoun, 2004) suggests that individuals can experience positive change because of struggling with difficult life crises, and this is expressed in various ways, such as: increased appreciation and gratitude for life, more meaningful interpersonal relationships, greater sense of personal strength, a change in life priorities, and a richer existential and spiritual life. PTG also links to personal recovery as they both describe positive growth as an ongoing process or ‘journey’ that does not have a static outcome. The growth that occurs is not as a direct result of the trauma, but rather through individuals’ struggle with a new reality in the aftermath of the trauma. PTG fits well with the main findings of this paper, for example, the three domains as outlined by Calhoun and Tedeschi (2014a) of: ‘changed perception of self; relating to others; and changed philosophy of life’, were all themes present in the interview data. The concept of PTG also recognises importance of resilience whereby individuals are better prepared and able to re-experience subsequent traumas (Janoff-Bulman, 2014) because they have become stronger and wiser individuals.

It is important to realise that even though carers may go through a growth process, this happens through a traumatic process and carers’ experience show considerable heterogeneity (Chen & Greenberg, 2004), with good experiences intermingled with bad (Dohrenwend et al., 2004). Carers may look back and see their personal growth journey, but they acknowledge that this was never by choice. A poignant reminder of this comes from one carer: “…you probably will end up stronger and more knowledgeable as a person as a result of this. It isn't a strength and a knowledge that you would actually seek out to be honest with you. You wouldn’t wish it, it's not ‘well I’m really glad I went through that trauma’, no.” T001

Strengths and Limitations

This study provides a holistic view of carer adjustment and wellbeing by investigating the positive aspects of caring and is consistent with a paradigm shift away from focusing on the mechanisms that determine a vulnerability to mental health problems towards resilience factors that encourage individuals towards remaining healthy and being able to bounce back when facing life adversities (Rutten et al., 2013). This study strengthens the argument for family interventions that increase the experience of positive emotions and promote the building of resilience (Rutten et al., 2013; Wang et al., 2020; Zhou et al., 2020) and links to the call for more of ‘family recovery’ interventions (Maybery et al., 2015; Nicholson et al., 2014; Norton & Cuskelly, 2021) which is gaining currency. This study provides novel data about how carers conceptualise their own personal recovery or not. It highlights the problems with the term ‘personal recovery’ and provides new more relevant concepts to carers such as: ‘resilience’, ‘personal growth’ and ‘posttraumatic growth’. A further strength of this study is that it highlights areas promoting carer wellbeing that can inform further interventions for carers. In accord with intervention studies, it shows the importance of self-care, getting support, how acceptance of the situation can help to build resilience, which can lead to positive personal transformation. A further strength relates to the methodology of conducting further ‘triangulation’ interviews with carers to allow an open space to debate the terminology of ‘personal recovery’ which strengthened the methodological quality of the study, providing clarification of the data using a deductive approach.

The limitations of the study relate mainly to the homogeneity of the study sample being made up of participants who were from a White British or Other White European ethnic background. Issues around homogeneity of carer samples have been commented on in other research studies so does seem to be a frequent problem with this population (Gallagher & Wetherell, 2020; Hazell et al., 2020; Smith et al., 2014) The findings would have been far more representative if data from carers of different ethnicities and racially minoritised groups was used. Another limitation relates to the fact that convenience sampling was used for this study, so the data are not representative in terms of a sample of carers from different socio-economic backgrounds, or carers of service uses who are at different stages of mental health care for example, those service users that are in-patient or being cared for by a community mental health team. Another limitation was that the sample was mainly recruited via carers support groups which may have influenced the findings, by providing an overrepresentation of carers who access peer support and have different coping strategies compared with carers who do not attend support groups. Recruitment for this study proved to be quite challenging and it was difficult to recruit those from ethnic minorities. The geographic locations of the local carers’ groups used for recruitment were not situated in multicultural centres of the UK and this made recruiting a diverse sample difficult. The implication of this is that the findings from this study cannot be seen to represent the experiences of all carers of those with psychosis. It is also important to note that data collection was hampered by the COVID-19 pandemic, which meant that interviews had to move to remote means which may have impacted the interview rapport.

However, it did mean that carers from a wider geographic area were able to be involved in the study.

Reflective summary

There was a strong component of reflexivity throughout this study, enabling transparency of the findings as any 'a-priori' assumptions were discussed between the research team throughout all phases of the study. Reflexivity is the recognition that a researcher’s past background can affect the lens through which they perceive and understand the data. Finlay and Gough (2008) highlight how the subjective nature of qualitative analysis may impact the research findings indicating the importance of reflexivity. CH (the first author) has direct experience and extensive knowledge of the impact psychosis can have on family members and carers. It must be noted that CH’s positionality in this study as of a White British female with lived experience of psychosis and this will have had an influence on the analysis and interpretation of the interview data. SJ and WS are both Professors of Clinical Psychology and have worked as clinical psychologists in the NHS. SJ has extensive experience in developing and delivering recovery focused interventions for those with bipolar disorder and psychosis. WS has extensive experience in working with the carers of those with serious mental illness and took a more critical approach to the concept of personal recovery and its application to a carer population. It is positive to note that although thematic analysis usually relies on inductive data collection and analysis, in this study there was a pre-conceptualised focus on recovery for carers. The fact that carers rejected this terminology, and this was included in the formation of the themes, indicated that the reflexive process seems to have been robust.

Conclusion

This study shows that the term ‘personal recovery’ is not valid from carers’ perspectives and that it could in fact cause more harm and grief to carers by suggesting an expectation for carers to return to the life they had before their loved one became unwell. By unpacking the component parts of the term ‘personal recovery’, this study has found evidence that carers see themselves on a ‘parallel’ journey of recovery with the person they care for. This study suggests better concepts to understand carer wellbeing: how carers are able to build resilience, adapt to their caring role and go through a process of posttraumatic growth rather than a journey of ‘personal recovery’.

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Appendices

APPENDIX A – *Qualitative Interview Topic Guide*

Interview topic guide

Opening:

- This is an open interview where I would like you to feel open to talk about issues that you think are important about your caring role.
- I've got a list of questions to work through, but they are more of a prompt.
- You can speak for as long or as short as possible and if you don't want to answer any questions then please let me know and we can skip that question.
- We can take a break at any time during this interview, and we can also stop this interview at any time if you don't want to continue.
- Could you just confirm that you've received a participant information sheet and signed the consent form.
- Just to remind you that this data will be transcribed and analysed and some of the quotes from this interview may be used in my thesis and in academic papers.
- I will be anonymising all identifiable data, such as names of people and place names. I'd like you to feel open to mention names because I will be changing these on the transcripts.
- Are you ready to begin?

Initial questions:

- Can you tell about who you care for?
- What is their diagnosis?
- How long have you been caring for this person?
- Where were they when you were caring for them?
  - In your house/with you?
  - In supported housing?
  - On an in-patient unit?
- What is or has your caring role been for this person?

Early days:

- In the beginning, how did you feel when your relative became unwell?
- How did you feel when you first heard that your relative had a mental health diagnosis?
- How did your life change? *[prompt: can you give an example?]*

- Do you think you changed as a person after hearing of the diagnosis/taking on a caring role for your relative? *[prompt: how did you change? Was there a change in your identity?]*

Present:

- And now? Do you think you've changed over time? Since hearing of the diagnosis and providing care*? [prompt: how did you change? Was there a change in your identity?]*
- Do you feel you have adapted/adjusted to your caring role? *[prompt – how?]*
    - What has helped you to adjust?
    - What coping strategies have you used?
    - How do you look after your own mental health? *[prompt – can you give me an example?]*
- Have your views about mental health changed since taking on this caring role?

Emotions:

- What were your feelings about taking on a caregiving role? Have your feelings changed over time? *[prompt – How have they changed?]*
- Do you think this has been a positive experience for you? How?
- Through the journey of caring for your relative, have you found it a meaningful experience? *[prompt – In what way?]*
- Do you feel that your philosophy of life has changed/deepened due to this? *[prompt – In what way?]*
- Have you gained a greater sense of purpose in your life from your caring role?
- Would you say you feel more empowered through this experience? *[Prompt – could you give me some examples?]*
- Do you think you've had personal growth through this experience?

Social life:

- What support did you access to assist you with your caring role? Did you attend support groups/speak to friends? How did it help you?
- Was your employment affected by your caring for you relative*? [prompt: in way?]* And what about now?
- Did your social life change after taking on a caring role? How did it change? And what about now?
- Do you feel more connected in your relationships?
    - with the relative/friend you care/ed for?
    - other family/friends? *[prompt – could you give me an example?]*

Looking to the future:

- Do you still feel a sense of responsibility for caring for your relatives?
- At the time of the diagnosis, what were your feelings about your future? [probe - for the service user?] Have your feelings about the future changed? If so, how have they changed?
- What goals have you got for the future?
- Would you say your feel satisfied with your life? [prompt – Could you tell me more?]
- What would you advise to a new carer about their journey?
- *[Give brief summary of 'recovery']* Do you think you've been on a journey of recovery or a process of rebuilding your life?

Closing:

- We are now coming to the end of the interview.
- Is there anything else you want to mention about your experience of providing care?
- Have you got any questions for me?
- Thank you very much for you time.

APPENDIX B – *'Personal Recovery' checklist of terms*

One aim of the review was to include those measures that had at least some potential focus on personal recovery. This raised the question as to how this factor should be appraised when selecting papers. To this end, a checklist was developed which aimed to cover items or subscales pertaining to personal recovery. Looking at definitions of recovery and recovery outcomes allowed the development of such a checklist. Sources for this checklist included: Anthony's (1993) definition, the CHIME framework outlined by Leamy et al. (2011) and the descriptions by Resnick et al. (2005); Slade (2009). (See the main paper for the full references).

Key terminology was extracted from the texts outlined above. These were then grouped by the lead author into categories. All of the terminology identified formed the basis of the search strategy and inclusion and exclusion criteria for this review.

TABLE 6: *Checklist for Personal Recovery concepts*

Outcome measures will need to address aspects related to personal recovery as it relates to the 'recovery approach' and 'mental health recovery'

Category	Aspects/key terms
Hope	Relating to ideas of optimism, 'positive thinking', valuing success, full potential, aspirations
Goals	Goals for the future, self-direction, full potential, person-driven, motivation to change, rebuilding life, aspiration, full potential, employment
Relationships	Relating to family relationships, social networks, meaningful social roles, family adaptability, family cohesion, respect
Support	Peer support, peer support groups, community support, social support, interpersonal support, employment
Meaning	Spirituality, meaningful life, meaningful social roles, personal growth, quality of life

Identity	Change in identity, understanding oneself, personal responsibility, empowerment, self-aware, self-direction, person driven, positive sense of identity, self-efficacy
Adaptation	Coping, adaptability, rebuilding life, quality of life, strength, gaining knowledge, empowerment, life satisfaction

Chapter 5: Carer Adaptation And Resilience Scale (CARS): Development Of A New Measure For Carers Of Those With Psychosis And Schizophrenia Using Cognitive Interviews

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Key words: Personal recovery, resilience, posttraumatic growth, carers, caregivers, psychosis, schizophrenia, scale development, cognitive interviews

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Abstract

INTRODUCTION: Family carers often provide vital support for loved ones diagnosed with a serious mental illness such as psychosis or schizophrenia. Carers often manage chronic, challenging, and unpredictable behaviours with little or no training. Many carers suffer from significant burden, anxiety, depression, grief, stigma, and shame. Understanding how carers adjust and adapt to their caring role can assist in developing more targeted interventions and support to promote greater resilience and personal recovery for carers. Carer recovery has been conceptualised in a variety of ways, but generally it is understood that carers go through a unique 'parallel' recovery journey alongside the person they care for. Despite the importance of understanding personal recovery for carers, there is currently no available outcome measure to assess this. To fill this gap, the Carer Adaptation and Resilience Scale (CARS) was developed. Draft items of the CARS were developed based on a series of qualitative interviews with carers exploring the difference facets of personal recovery.

METHOD: This paper describes the next phase of CARS development, which was to gain detailed feedback from carers to assess the content validity of the items through a series of 10 cognitive interviews. Cognitive interviews are increasingly recognised as an effective evidence based qualitative method for testing new outcome measures in health research. The process involved in-depth one to one interviews and utilised both 'think aloud' and 'verbal probing' techniques to gain detailed feedback about all aspects of the questionnaire being assessed. Data from the interviews was pooled into a summary matrix of comments and suggestions for improvement.

RESULTS: Comments were made on 90% of the 40 items, the questionnaire instructions and response options. The issues raised by carers were grouped into three problem categories: 'specificity' (items not being specific enough for carers), 'semantic' (the meaning of items were unclear due to wording), 'conceptual' (problems understanding the underlying concept of the item). This informed the refining of the CARS: three items were removed, 13 items

were retained, 22 items were rephrased, and two items were merged. The resulting 37-item draft measure went on for a full psychometric evaluation.

Introduction

Psychosis includes a range of symptoms affecting approximately 7% of the adult population before their 75th year, with 50% of newly diagnosed cases occurring by the age of 23 years old (McGrath et al., 2016). It is an umbrella term for a group of symptoms and experiences such as hallucinations, delusions and thought disorder that can occur within different diagnostic categories such as schizophrenia, bipolar disorder, and unipolar psychotic disorder (National Insititute for Health and Care Excellence, 2014). The symptoms of psychosis often cause significant distress and individuals may need long term support in many life domains such as emotional, financial, and practical support for everyday tasks (Schizophrenia Commission, 2012; Nice, 2014; Sin et al. 2017). Relatives and family members of those with psychosis often provide this important informal care and support (Caqueo-Urízar et al., 2009; Ochoa et al., 2008; Reine et al., 2002). A carer can be understood as a relative or family member who has taken on an unpaid and informal caregiving role, who often must manage chronic and behaviours that challenge, with unpredictable psychological symptoms with little or no training or support for their role (Schulze & Rössler, 2005; Winefield, 2000). Carers are often forced to take on a caring role in a crisis situation (Lovelock, 2016) where they may have witnessed highly distressing symptoms such as verbal and physical aggression directed towards themselves by their loved one (Onwumere et al., 2014) and have to deal with the increased risk of self-harm and suicide for the person they care for (Challis et al., 2013; Harvey et al., 2008).

Taking on such a caring role has been associated with deterioration in carers' physical health (Caqueo-Urízar et al., 2009), increased depression and anxiety (Kuipers et al., 2010; Sadath et al., 2017) and reduced quality of life (Boyer et al., 2013; Sin et al., 2017). Onwumere et al. (2018) found carers of those in Early Intervention Services, suffer from emotional exhaustion and burnout. Taking on a caring role is seen as traumatic (Darmi et al., 2017; Lovelock, 2016; Shiraishi & Reilly, 2019) and carers have also been found to suffer from posttraumatic stress symptoms (PTSS) (Hanzawa et al., 2013; Kingston et al., 2016) related to carers experiencing negative cognitions about themselves and self-blame for trauma linked to their caring role. There is a clear need to support carers, and this is a key policy recommendation made by the UK Schizophrenia Commission (2012). Carers in the UK provide unpaid care and save the health services approximately £34,000 (over $43,000) per person per year (Yesufu-Udechuku et al., 2015) so there is a clear financial incentive to support the wellbeing of carers (Dillinger & Kersun, 2020). Carers' negative experiences are not only highly disrupting and distressing for the individuals but also may impact on their ability to care for their loved one (Barrowclough & Parle, 1997; Reine et al., 2002) so supporting carers is important for both their wellbeing but also the wellbeing of the person they are caring for (Testart et al., 2013).

To support carers' wellbeing there is a need to understand their experiences in a holistic way (Zendjidjian & Boyer, 2014). One way to do this is to understand how they adjust to their caring role; however, there is limited literature on the process of adjustment in families after the onset of psychosis. Understanding carer adjustment would potentially help support better targeted interventions for carers to help reduce their vulnerability to burnout (Onwumere et al., 2018). Additionally, understanding the positive aspects of caring may show how carers have learned to adapt and cope in a well-adjusted way with their caring role (Kate et al., 2013) and this can also help in the development of targeted interventions. Positive aspects to caring include increased family solidarity, admiration, affection, compassion, learning new knowledge and skills, personal growth, appreciation, and better self-confidence (Chen & Greenberg, 2004; Shiraishi & Reilly, 2019). It has also been found that if carers can recognise the positive experiences of their caring role, this can improve their quality of life (Kate et al., 2013) and that recognising positive experiences counteracts stress (Rutten et al., 2013). These concepts link to the theory of resilience, understood as how carers find the emotional strength to help them manage the burden of care better, by overcoming adversity to survive and go beyond the day-to-day stresses of caring which helps them become more flexible and a healthier person (Van Breda, 2001). Helping carers to build resilience has been found to bring about positive change in the family through constructive adaptions which reduce carer burnout, promotes family recovery, and optimises family functioning (Amagai et al., 2016).

The concept behind family recovery is related to the recovery approach which has been defined as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles" and "a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness" (Anthony, 1993). A key difference between personal recovery and clinical recovery is that it conceptualises the individual 'journey' of recovery despite the presence of clinical symptoms, and this allows service users and carers to find meaning, purpose, and empowerment despite still living with the experiences of a serious mental illness (Anthony, 1993; Slade, 2009). The recovery approach has become one of the most influential paradigms shaping mental health policy and practice in most English-speaking countries globally (Price-Robertson, Manderson, et al., 2017) and has been a key policy recommendation in the UK (Department of Health, 2011).

There has however been limited research into carer recovery (Jacob et al., 2017; The Scottish Recovery Network, 2009) and recovery informed practice has largely overlooked carers and families (Hungerford & Richardson, 2013; Norton & Cuskelly, 2021). Recently, it has been argued that carers are on a 'parallel' recovery journey alongside the service user (Lovelock, 2016; Wyder & Bland, 2014), where they both experience a similar albeit separate recovery journey. Wyder and Bland (2014) acknowledge that families experience a unique recovery experience with similarities but also points of tension in each respective recovery journey, with carers responding to their role in a dynamic and multi-layered way. Price-Robertson et al. (2017) have made the case for 'relational recovery' arguing that the recovery approach takes on a highly individualised view of personal recovery, failing to acknowledge the importance of human interdependence which obscures the importance of the social connection, environmental and socio-political influences of the time. It is clear from the literature that the concept of 'personal recovery' for carers is understood in a variety of different ways and a variety of different terminology has been used to explain their unique recovery experiences. Despite this, helping carers gain an understanding about their own personal recovery can help them to move forward with their lives by assisting them to develop a greater sense of meaning and purpose despite the ongoing challenges of caring they face (Deane et al., 2015; Norton & Cuskelly, 2021).

To develop more targeted interventions for carers it is important to gain a deeper understanding of the factors that would support positive adaptation to caring, build greater resilience and personal recovery for carers. There is limited literature in this area and no way to measure carer adaptation or recovery using a single formalised self-report measure. A systematic review (Hilton et al., 2022, see Chapter 3) of outcome measures related to recovery for carers, found that several different measures would need to be used to fully assess recovery for carers. This would be very taxing for carers to complete in a research study or clinical setting. Through a series of studies, we are focussing on the development of a single scale that will assess carer recovery.

Hilton et al. (see Chapter 4) conducted a series of qualitative interviews to explore the concept of carer recovery and adaption. The findings from the interviews showed that some carers do go through a 'recovery journey' where they have learned to positively adapt to their caring role, build up resilience and show aspects of personal growth and increased knowledge and wisdom, which was related to the concept of Posttraumatic Growth (Tedeschi & Calhoun, 2004). A key finding from the qualitative interviews was that most carers did not like the term 'recovery' in relation to themselves as they did not feel they were 'recovering' from an illness. This showed two things, first, that carers generally understood the concept of recovery in terms of the 'clinical' meaning of the term, and that secondly, it would not be an acceptable term to use as the primary focus of a new outcome measure despite carers discussing how they had experienced difference aspects of personal recovery. The findings of the qualitative study informed the development of the questionnaire items for the Carer Adaptation and Resilience Scale (CARS). This study aims to assess the first draft of the CARS with carers to measure the content validity, item wording and response options of the questionnaire, following the cognitive interview method of scale development (Willis & Artino Jr, 2013; Wright et al., 2021). The finalised version of the CARS will then be fully validated by investigating the psychometric properties and factor structure of the new scale in a subsequent publication.

Methods

Research design

Cognitive interviews are recognised as an evidence based qualitative method for testing the validity of new outcome measures (Willis & Artino Jr, 2013; Wright et al., 2021), and to provide insight into the mental processes as the participant goes through each item of the new measure or survey, providing rich insight into their attitudes and understanding of the constructs being tested in real time (Willis, 2004). Cognitive interviewing as a method is becoming a well-established and widely used method in health research (Wright et al., 2021) and is often used as part of a multistage, mixed methods approach in questionnaire design and validation (Wright et al., 2021). This interviewing technique is underpinned by cognitive theory, with a commonly used method based on Tourangeau's four-stage model of cognitive processing (Tourangeau & Rasinski, 1988). This model explains how a participant firstly comprehends the question, the retrieval of the necessary information from their long-term memory, their judgement on how to answer the question based on long-term memory, and finally providing a response. Based in Tourangeau's model, two techniques are used during the interviews which are: the 'think aloud' and 'verbal probing' techniques. For the 'think aloud' technique, participants are trained at the start of the interview to verbalise all thoughts and feelings they have about each questionnaire item. The 'verbal probing' technique requires the interviewer to ask further questions based on what the participant has told them about each questionnaire item, which gives the interviewer more control during the interview and allows them to clarify points as they are discussed. Many studies used a hybrid method that combines both the 'think aloud' and 'verbal probing' method (Beatty & Willis, 2007; Conrad & Blair, 1996), and this was the approach taken for the present study. The design and reporting are also based on The Cognitive Interviewing Reporting Framework (CIRF) outlined by Boeije and Willis (2013), which was developed to improve the transparency of reporting of the methods and procedures used in this type of study. The CIRF was based on several existing quality checklists for reviewing and reporting qualitative research (Boeije & Willis, 2013).

Study participants and recruitment

This study gained ethical approval from the NHS (REC reference: 21/SC/008, dated: 01/03/2021), see Appendix K. The study participants recruited were informal carers from across England. The primary inclusion criteria were, any informal carer of someone who had experienced at least one episode of psychosis in their lifetime, the carer being over the age of 18 years old, and able to provide consent. Any paid or professional carers were excluded, as were young carers below the age of 18 years. Participants were recruited during the summer of 2021 primarily through various NHS Trusts across England, mental health charities, carer support groups, and social media. A sample size of 10 participants was chosen based on guidance from (Willis, 2008) who suggests that sample sized of between 8 – 12 participants is adequate to allow for efficient and timely development and evaluation of new questionnaires. See Appendix P for study advertising materials, Appendix V for a screenshot of the study blog, and Appendices Q and R for the participant information sheet and consent form.

Item pool and draft questionnaire

The item pool was based on the findings of qualitative interviews with carers investigating carer recovery, resilience, adaptation, and posttraumatic growth (see Chapter 4). The study team initially devised an item pool of 85 items based on the themes and subthemes of the qualitative findings. The item pool was then reviewed to assess the item wording, comprehensibility and reading level. This resulted in the first draft of the CARS questionnaire containing 40 items, which was subsequently assessed during the cognitive interviews. The draft CARS questionnaire had a Flesch-Kincaid score of 74 which was determined using average sentence length and calculating the average number of syllables per word, indicating the US Grade 6 level (equivalent of a 12-year-old reading level) that equated to being ‘fairly easy to read’. The response option of the draft questionnaire was a

5-point Likert scale of how far the participants agreed with the item statement (“1 - Not at all” to “5 - A lot”).

Data collection

All interviews were conducted by remote means due to UK government restrictions linked to the COVID-19 pandemic. Seven interviews took place over Microsoft Teams, while the remaining three interviews were conducted by telephone. All participants had access to an online device, allowing them to see the online survey during the interview. The interviewer (CH) briefed the participants about the study, took verbal consent and then explained the ‘think aloud’ technique that participants were asked to use. Participants discussed all items on the draft CARS questionnaire, the response options, and demographic questions to be used in the larger survey study to assess the psychometric properties of the CARS questionnaire. All interviews were audio recorded, and the interviewer took supplementary field notes during interviews.

Data analysis

The audio recordings were analysed along with the interviewer’s field notes to extract the comments and suggestions made by participants about the individual items on the questionnaire and the survey pack as a whole. A summary matrix was created using Microsoft Excel that included each item of the questionnaire and all the comments made about that item from each of the participants. A written summary of their comments was noted on this matrix. Two researchers (CH and WS) then carried out a joint content analysis of the data matrix discussing the comments and suggested changes. Any changes and revisions to items were then discussed with the final member of the research team (SJ).

Results

Participant characteristics

Ten carers were interviewed for this study. The bulk of the carers were female (80% of the sample). The age range was between 45 and 84 years old with most of the sample being married (70%). All of those interviewed came from a White British ethnic background. Many of the carers were retired (60%) or worked part-time (30%). Most of the carers (80%) interviewed were parents of someone who had experienced an episode of psychosis, and the average duration of providing care was 14.6 years (range 4 – 25 years). Carers provided on average 12.3 hours of care per week, however, this ranged from between 0 hours to 40 hours. Four carers interviewed did not have primary caring responsibilities because the person they cared for was on an inpatient unit. There was an even split between those caring for someone with a diagnosis of psychosis or a diagnosis of schizophrenia and four carers reported that the person they cared for was currently having symptoms of psychosis. Further details of the participant characteristics can be found in Table 7. The cognitive interviews lasted on average for 50.5 minutes, the longest interview being 1 hour 19 minutes, while the shortest one was 32 minutes.

TABLE 7: *Sociodemographic and caring characteristics of participants for the CARS development study*

Participant Characteristic	*n* (%)	M (Range) in years
Gender		
Male	2 (20)	
Female	8 (80)	
Age		
45 - 54	3 (30)	
55 - 64	2 (20)	
65 - 74	3 (30)	
75 - 84	3 (20)	
Ethnicity		
White British	10 (100)	
Highest level of education		
Completed secondary school	1 (10)	
Completed some college/university	5 (50)	
Completed undergraduate degree	1 (10)	
Completed a postgraduate qualification	3 (30)	
Employment status		
Full-time	1 (10)	
Part-time	3 (30)	
Retired	6 (60)	
Marital status		
Single	1 (10)	
Married	7 (70)	
Divorced	2 (20)	

Caring characteristics		
Duration of care responsibilities (years) [mean (range)]		14.6 (4 – 25)
Care provided each week (hours) [mean (range)]		12.3 (0 – 40)
Relationship to person cared for		
Parent	8 (80)	
Adult child	1 (10)	
Friend	1 (10)	
Diagnosis of person cared for		
Psychosis	5 (50)	
Schizophrenia	5 (50)	
Symptomatic at time of interview	4 (40)	
Mental health service supporting person cared for		
In-patient ward	4 (40)	
Community Mental Health Service	5 (50)	
Discharged from services	1 (10)	

Summary of findings

Carers provided a combination of general feedback about the questionnaire as a whole and specific comments per item. See Appendix C for the list of 40 items assessed during the cognitive interviews. Over 90% of the items discussed during the interviews received constructive feedback and recommendations about how to improve the question, while only three items received no comments from participants. The issues discussed about each item related to three problem categories. The first problem category 'specificity' related to the questions not being specific enough for carers or not being generalised for carers across the span of their caring journey, it also related to questions being too broad and vague. The second problem category was 'semantic' which related to how the items were worded or if they were confusing. The third problem category 'conceptual' incorporated problems around understanding the underlying concept or construct of the question and how this might relate to caring. The following section expands on each problem category further. A summary of the comments made by carers is provided in Table 8.

TABLE 8: *Summary of results matrix of initial 40 items of the CARS*

Item number	Number of comments	Problem category	Summary of comments	Outcome category
I have a more positive outlook on life	2	Specificity	General dislike of question, not what they were expecting, confusing and too broad.	Removed
I have learned to take time for myself	0	N/A	N/A	Retained
I have found things that comfort me when my life gets difficult	1	Semantic	Problem with the clarity of question. Discussed best way to rephrase during interview.	Rephrased
I have accepted in a positive way that my loved one has a serious mental health diagnosis	5	Semantic	Rejected phrase 'in a positive way'. Felt it was too positive for what is a difficult life situation.	Rephrased
I have accepted in a positive way that I have become a carer for my loved one	3	Semantic	Rejected phrase 'in a positive way'. Felt it was too positive for what is a difficult life situation.	Rephrased
I have made peace that my loved one's future plans may have changed	3	Semantic	Question instils sadness, dislikes phrase 'made peace with', difficulty understanding phrasing.	Rephrased
I have made peace that my future plans may have changed	3	Semantic	Question instils sadness, dislikes phrase 'made peace with', difficulty understanding phrasing.	Rephrased
I have learned to deal with difficult situations	1	Specificity	Too broad, clarify that this relates to caring responsibilities.	Rephrased
I feel I can handle things if my loved one becomes unwell again	2	Conceptual	Challenging question to answer as psychosis/schizophrenia is so unpredictable.	Rephrased

Item number	Number of comments	Problem category	Summary of comments	Outcome category
I feel more resilient	2	Conceptual	Difficulty with concept of ‘resilience’ - seen as quite complex.	Rephrased
I have learned to manage my stress levels better	1	Specificity	Needs to be more specific to caring role.	Retained
I have realised that I’m stronger than I thought I was	2	Specificity	Clarify that this relates to ‘emotional strength’ and specifically to caring role	Rephrased
I have become more understanding of others	4	Specificity	Links this to being more understanding to other’s mental health problems, comments about feeling the opposite, more resentful.	Retained
I have more empathy for others	3	Semantic	One carer questioned the semantic meaning of term of ‘empathy’. Other carers accepted term as valid and felt it should be retained	Retained
I am more patient	2	Specificity	Difficult for newer carers to see a change to how patient they are because of their caring role.	Retained
I try to use my knowledge and experience to help others	1	Specificity	Needs to be more specific to caring role.	Rephrased
I have learned more about myself	5	N/A	Generally agreed with this question, liked phrasing.	Retained
I am more confident	4	Specificity	Question too broad, difficult to relate to how this has changed because of caring.	Removed

Item number	Number of comments	Problem category	Summary of comments	Outcome category
I feel more able to stand up for myself and the person that I care for	1	Specificity	One carer felt this related to their personality rather a change because of their caring role.	Retained
I have a greater sense of direction in life	6	Semantic	Multiple interpretations of question, related to life stage. Needs clarifying that it relates to caring role. Changed phrasing from ‘direction in life’ to ‘purpose in life’.	Rephrased
I feel a greater sense of purpose in life	6	Semantic	Multiple interpretations of question, related to life stage. Needs clarifying that it relates to caring role. Changed phrasing from ‘direction in life’ to ‘purpose in life’. Merged with item 20.	Merged
I have become wiser	2	Specificity	Quite broad, needs to be more specific to caring role/mental health issues.	Rephrased
I am better at communicating with others	3	Specificity	Question too broad, needed further clarification. Recommended it was rephrased to be more specific about communication with ‘close friends and family’ rather than ‘others’.	Rephrased

Item number	Number of comments	Problem category	Summary of comments	Outcome category
I have stronger relationships with others	3	Specificity	Question too broad, needed further clarification. Recommended it was rephrased to be more specific about communication with ‘close friends and family’ rather than ‘others’.	Rephrased
I have a stronger relationship with my loved one because I have become their carer	1	N/A	Generally agreed with this question, liked phrasing.	Retained
I am able to make deeper personal connections with others	3	Specificity	Question too broad, needed further clarification. Recommended it was rephrased to be more specific about communication with ‘close friends and family’ rather than ‘others’. Prompted deeper thought on the topic, seen as good question.	Rephrased
I am more hopeful about the future	3	Specificity	Question is ambiguous, clarify that it’s about the carers future. Life stage and other factors also place a role here.	Rephrased
I feel grateful because things could have been worse for me	4	Semantic	Mixed views, some carers like the positive phrasing, other carers found this upsetting and rejected the term ‘grateful’.	Retained
I really appreciate when things are going well in my life	3	Conceptual	Seen as redundant question, all carers will always agree with this question, so it does not tell us anything.	Removed
I have become more spiritual	1	Specificity	Needs to be more specific to caring role.	Rephrased

Item number	Number of comments	Problem category	Summary of comments	Outcome category
I feel that when the person I care for is better, then things for me will be better *[Negatively scored]*	3	Conceptual	Difficulty understanding the concept of 'parallel recovery' behind the question.	Rephrased
I have developed my own interests alongside being a carer	3	Semantic	Expand this to include 'retained' own interests and not just 'developed' own interests.	Rephrased
My loved one's mental health problems are no longer the main focus of my life	3	Semantic	Negative wording of question creates confusion. Difficulty understanding concept. Does not align well with response options.	Rephrased
I have been through a process of rebuilding my life	3	Semantic	Difficulty with phrasing of concept. Recommended changing 'rebuilding life' to 're-establishing life'.	Rephrased
I have regained my social life despite my caring responsibilities	4	Specificity	Question too narrow, makes the assumption that everyone loses their social life. Recommended rephrasing to 'maintained social life'.	Rephrased
I have grown as a result of the traumatic experience of my loved one's mental health crisis	3	Semantic	Mixed views, some felt question was quite long, and phrasing was too positively loaded. Other carers liked question.	Retained
I feel overwhelmed by my caring responsibilities	3	Specificity	Debates about how applicable this is to all carers at different time points of their caring journey.	Retained
I feel anxious about my caring responsibilities	0	N/A	N/A	Retained

Item number	Number of comments	Problem category	Summary of comments	Outcome category
I feel depressed about my caring responsibilities	3	Specificity	Debates about how applicable this is to all carers at different time points of their caring journey. Some felt the wording was too negative.	Retained
I feel I did my best to help my loved one when they were in crisis	1	Semantic	Response options did not align well to the wording of the question.	Retained

Problems with the specificity of items

Eighteen out of the 40 (45%) items discussed during the interviews had problems relating to specificity. The comments made related mainly to questions either being too broad and difficult to answer, or not applicable to carers specifically. Participants also highlighted how some of the questions were not applicable to all carers because a lot of them were at different stages on their caring journey. For example, one carer was quite new to caring and explained how it was difficult to understand whether caring had changed them or not because it was too soon to tell. The questionnaire can be understood as a measure of change over time to see if carers have adapted to their caring role, so this raised an important point, which is to clarify with respondents that the questionnaire is taking a snapshot of the carers' situation at a certain point in time. Where carers highlighted problems with questions, they usually offered a solution as to how to make it more specific, for example, item 23 and 24 asked about having better communication and relationships with "others" which carers found confusing and suggested narrowing the wording to specify "close family and friends". A further suggestion made by carers related to questions being more specific about carers experiences. Because of these comments, all related items were rephrased to include a reference to being a carer, for example the phrase "since becoming a carer" was added to many items on the survey.

Problems with the semantic meaning of items

Approximately a third of the items' meanings were unclear. Some phrasing caused an emotive response in some carers, for example, item 4: "I have accepted in a positive way that my loved one has a serious mental health diagnosis" did not sit well with many carers as they disagreed with the term "in a positive way". Many felt this was phrased too positively when trying to describe a very upsetting life situation that they were dealing with, so that question was rephrased to more neutral terminology. Another suggestion made by participants related to item 20 that asked about having greater "direction in life". Many carers struggled to interpret this question as for many this related more to an earlier life stage of having a career for example. Participants suggested changing this to having a greater “purpose in life”. There were mixed views about some items on the questionnaire and whether carers found them acceptable. Item 28 “I feel grateful because things could have been worse for me” was received well by many interviewed, however some carers found the term “grateful” upsetting as it seemed completely opposite to how they viewed their caring role, and it made them feel as though they ‘ought’ to feel grateful when they still felt desperate about their situation. Despite the negative comments, this item was retained as it tells us something about how the carer views their situation at the time, which provides insight for researchers or clinicians.

Problems with the conceptual understanding of items

Some of the concepts behind certain items were seen as complex and difficult to understand. Five out of the 40 items were found to have problems relating to the concept behind the question. An example being item 10: “I feel more resilient”, which relates to the psychological construct of how able a person is to bounce back after a setback. Carers found it difficult to answer as some felt it was very much dependant on the person’s situation at the time, while another carer felt it was a complex concept for just one question. Despite these comments the item was retained, albeit, in a rephrased form as it was felt that on balance carers did understand the concept and it provides insight about their level of resilience and emotional strength. Another latent concept that was difficult for carers to understand related to the idea of ‘parallel recovery’; where if the person being cared for is recovering from their psychotic symptoms, then this has a positive knock-on effect, and the carer is able to recover alongside the person they care for. The initial item 31: “I feel that when the person I care for is better, then things for me will be better” tried to explore this concept of ‘parallel recovery’ but had mixed comments. Some carers found it a redundant question as for them it was obvious that when the person they cared for was well then they would be well, however, they were not recognising that for some long term carers who’s loved one has been unwell for some time, that they may have had to find a way to build a life for themselves away from their caring responsibilities as a way to cope with their long term caring responsibilities. This item was rephrased to clarify the concept of a parallel journey of recovery for the carer with the final wording of: “My wellbeing is directly related to the wellbeing of the person I care for”.

General comments

Some carers commented that they found the questionnaire quite emotionally difficult to answer as it “brings things home” (CI002) and makes them think about their life situation and mental wellbeing. Some carers found completing the questionnaire quite “cathartic” (CI008) and that the questions were “relatable” (CI003) to their situation. They felt that completing the questionnaire gave them clarity about where they were with their own mental health. In relation to the opening instructions of the questionnaire, one carer did not feel comfortable with the term “loved one” to describe the person that they care for as they felt that this was too close to being ‘in love’ with their family member or friend. Therefore, the term was changed throughout the questionnaire to “family member or close friend”. A total of 3 items (numbers 18, 29 & 39) were removed from the draft questionnaire, 13 items were retained with limited re-wording to include the phrase “since becoming a carer”, and 22 items had substantial rephrasing, while 2 items (numbers 20 & 21) were rephrased and merged. See Table 8 for a full breakdown of the outcomes for each item. All participants accepted the response options proposed so these were not changed. The final questionnaire with all the recommended changes is detailed in Appendix D. The final version of the CARS Flesch-Kincaid score dropped from 74 (US Grade 6) to 64.7 which is classed as US Grade 9 or 14-year-old reading level, this was due to the lengthening of each sentence to include more specific reference to being a carer. None of the carers mentioned that they felt the reading level of the questions was too difficult. The final CARS measure was incorporated into a larger survey study to assess the psychometric properties of the final questionnaire, the results of which will be published in a separate article.

Discussion

Carers generally accepted the concept behind the CARS which was to assess carer adaptation, resilience, and recovery, which also supports the findings of the qualitative study (Hilton et al. in preparation, see Chapter Four). There was an overwhelming sense that carers appreciated that research was being done to develop the survey to try to improve support structures and promote carer wellbeing as many felt let down by mental health services in general. The cognitive interviews successfully highlighted three problem categories that needed to be addressed: specificity, semantic and conceptual. This informed the refining of the CARS by removing 3 items, retaining 13 items, rephrasing 22 items, and merging 2 items together resulting in the 37-item measure for full validation.

This study fulfils the recommendations to gain a more holistic picture of caring and to focus on the positive experiences and not just the negative aspects such as carers' burden (Onwumere et al., 2018). Often carers put their own needs last to prioritise the needs of the person being cared for (Lavis et al., 2015). If carers are supported to take care of their own wellbeing and identify the positive aspects of caring, this may increase their satisfaction about their caring ability, which could reduce rates of carer burnout (Onwumere et al., 2018). The concepts explored in the CARS are also supported by previous findings that carers reported personal resilience, improved personal relationships, personal growth, enhanced coping effectiveness and a reassessment of life priorities (Chen & Greenberg, 2004; Marsh et al., 1996). The findings also raise the concept of whether carers go through a process of posttraumatic growth, which is defined as the experience of positive change occurring as a result of a personal struggle with a highly challenging life crisis (Calhoun & Tedeschi, 2001). Carers clearly go through a traumatic experience that for some starts even before the psychotic crisis occurs and then continues in a cyclical structure depending on whether the person they care for has a relapse (Shiraishi & Reilly, 2019).

It has been found that carers who are more resilient have better mental health and are better able to deal with various cognitive, emotional, behavioural, and social problems (Hashemi et al. 2010) and this is something that should be promoted.

Although the primary focus of the present study was to ensure that questionnaire items were clear and understandable to participants, it goes some way to fulfilling the call for more research into family recovery (Norton & Cuskelly, 2021; Price-Robertson, Manderson, et al., 2017) and also confirms the concepts behind 'parallel recovery' (Deane et al., 2015; Lovelock, 2016) as carers recognised that their wellbeing was linked to the person that they cared for. It is important to note that the findings from the qualitative study (Hilton et al. in preparation, see Chapter Three) showed that the semantic understanding of recovery was difficult for carers to accept, and this is why there was no mention of the term 'recovery' in any of the items on the draft CARS. However, the underlying concepts behind recovery such as having a greater sense meaning and purpose in life, better self-confidence in day-to-day caring, a greater sense of strength and empowerment, positive personal growth and better interpersonal relationships are assessed by the CARS.

Strengths and limitations

The original design for this study had outlined setting up two face-to-face focus groups to help with the development of the CARS, however, this could not go ahead due to the COVID-19 pandemic, so cognitive interviews were chosen as these could be conducted as remote one-to-one interviews more easily than larger online focus group. There were several benefits to using cognitive interviews. First, they have been seen as providing richer data compared to focus groups, as the interviews are done one-to-one and seem more intimate potentially eliciting more honest answers through the combined techniques of 'think aloud' and 'verbal probing' (Beatty & Willis, 2007; Tourangeau et al., 2000). Secondly, this allowed the refinement of items on the CARS in an iterative approach, where initial suggested changes outlined in earlier interviews were changed and presented to later participants for comment. This would have been more difficult to do using the focus group approach. A third advantage to using online cognitive interviews is that it allowed for recruitment from a wider geographic area (Donnelly & Heaton, 2022) which presents the opportunity to access carers who are more widely dispersed and less likely to engage with research. The data generated by the cognitive interviews provided invaluable insights into carers' views of the items showing the value of public involvement in research, which is a key recommendation in the literature on questionnaire development (DeVellis, 2012; Streiner et al., 2015). Having direct feedback from carers enables the testing of content validity and the creation of questionnaires that are seen as valid to the population being tested (ecological validity).

A limitation to this study mainly related to the homogeneity of the study sample as 100% of the sample came from a White British ethnic background. Issues around homogeneity of carer samples have been commented on in other research studies so does seem to be a frequent problem with this population (Gallagher & Wetherell, 2020; Hazell et al., 2020; Smith et al., 2014). This was partly due to difficulties with recruitment due to the COVID-19 pandemic, and restrictions of the researcher's time and budget. Because of these challenges it was not possible to stratify the sample to ensure that carers from different ethnic backgrounds were included. Many of the carer's groups were closed due to COVID-19 so even if the researcher had targeted recruitment at different carers groups in more ethnically diverse geographic locations this would have proved very difficult. Because of this it is difficult to generalise the findings for all carers of those with psychosis. It must also be recognised that there may also be a self-selection bias as the carers who took part had been caring for a number of years and were probably more interested in concepts of adaption and resilience compared to new carers dealing with a relative who has recently gone through their first psychotic episode.

Conclusions

The use of cognitive interviews to assess the content validity of the CARS was highly effective in providing rich insights that led to valuable changes to the measure. It allowed for in-depth real time data to be gathered directly as participants were thinking about the question. It also allowed the researcher the ability to verbally probe for more detail and to clarify points. Using cognitive interviews was found to be very effective in dealing with a sensitive topic such as the mental health of carers of those with serious mental health problems. The findings support the concepts behind the CARS such as adaptation, resilience, and recovery as valuable to carers.

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Appendices

APPENDIX C – *Draft CARS used for the cognitive interviews*

Carer Adaptation and Resilience Scale (CARS) [WORKING TITLE]

Thinking about how things have been since your loved one was in crisis and they needed extra support from you:

1. I have a more positive outlook on life
2. I have learned to take time for myself
3. I have found things that comfort me when my life gets difficult
4. I have accepted in a positive way that my loved one has a serious mental health diagnosis
5. I have accepted in a positive way that I have become a carer for my loved one
6. I have made peace that my loved one's future plans may have changed
7. I have made peace that my future plans may have changed
8. have learned to deal with difficult situations
9. I feel I can handle things if my loved one becomes unwell again
10. I feel more resilient
11. I have learned to manage my stress levels better
12. I have realised that I'm stronger than I thought I was
13. I have become more understanding of others
14. I have more empathy for others
15. I am more patient
16. I try to use my knowledge and experience to help others
17. I have learned more about myself
18. I am more confident
19. I feel more able to stand up for myself and the person that I care for
20. I have a greater sense of direction in life
21. I feel a greater sense of purpose in life
22. I have become wiser
23. I am better at communicating with others

24. I have stronger relationships with others
25. I have a stronger relationship with my loved one because I have become their carer
26. I am able to make deeper personal connections with others
27. I am more hopeful about the future
28. I feel grateful because things could have been worse for me
29. I really appreciate when things are going well in my life
30. I have become more spiritual
31. I feel that when the person I care for is better, then things for me will be better [Negatively scored]
32. I have developed my own interests alongside being a carer
33. My loved one’s mental health problems are no longer the main focus of my life
34. I have been through a process of rebuilding my life
35. I have regained my social life despite my caring responsibilities
36. I have grown as a result of the traumatic experience of my loved one’s mental health crisis
37. I feel overwhelmed by my caring responsibilities [negatively scored]
38. I feel anxious about my caring responsibilities [negatively scored]
39. I feel depressed about my caring responsibilities [negatively scored]
40. I feel I did my best to help my loved one when they were in crisis

* This has a Flesch-Kincaid *score* of 74 – which is classes as equivalent to 6th Grade (12 yrs) and equates to being ‘fairly easy to read’.

Response options

5-point Likert scale

A lot Quite a bit Moderately A little Not at all

Appendix D – *Final version of the CARS for validation*

Carer Adaptation and Resilience Scale (CARS) Version 1.9

This questionnaire is all about you as someone who supports a family member or close friend with psychosis and/or schizophrenia. It is about **YOUR** mental and emotional wellness. We do understand that how you feel is often closely linked with how the person you care for is feeling, but for this scale we are interested in **YOUR** wellbeing and not that of the person you care for.

Please try to answer every question. Every answer is valuable and there is no right or wrong answer. If you are unsure of an answer, choose the one that seems the most appropriate which can often be your first response to the question.

Thinking about **how things have been for you** since your family member or close friend was in crisis and they needed extra support from you:

1. Since becoming a carer, I have learned to take time for myself
2. I have found engaging hobbies and activities that help me switch off from my caring responsibilities
3. I have accepted that my family member or close friend has a serious mental health diagnosis
4. I have accepted that I have become a carer for my family member or close friend
5. I have come to terms that my family member or close friend's future plans may have changed
6. I have come to terms that my future plans may have changed because of my caring responsibilities
7. Being a carer has helped me learn how to deal with difficult situations
8. Since becoming a carer I feel more confident that I can handle things if the person I care for becomes unwell again
9. Because of my caring experiences, I feel more resilient
10. Since becoming a carer I have learned to manage my stress levels better
11. Since becoming a carer I have realised that I'm emotionally stronger than I thought I was

12. My outlook on life has become more positive as a result of being a carer
13. Since becoming a carer I have become more understanding of others
14. Since becoming a carer I have more empathy for others
15. Since becoming a carer I have become more patient
16. I feel overwhelmed by my caring responsibilities [negatively scored]
17. I feel anxious about my caring responsibilities [negatively scored]
18. I feel depressed about my caring responsibilities [negatively scored]
19. Since becoming a carer I have learned more about myself
20. As a carer I try to use my knowledge and experience to help others
21. I feel more able to stand up for myself and the person that I care for
22. Being a carer has given me a greater sense of purpose in life
23. Being a carer has helped me to become wiser
24. Since becoming a carer I am better at communicating with family and close friends
25. Since becoming a carer I have stronger relationships with family and close friends
26. I have a stronger relationship with my family member or close friend because I have become their carer
27. I am able to make deeper personal connections with other carers
28. I am more hopeful about my future as a carer
29. I feel grateful because things could have been worse for me as a carer
30. Since becoming a carer I have become more spiritual
31. My wellbeing is directly related to the wellbeing of the person I care for [negatively scored]
32. I have managed to pursue my own interests alongside being a carer
33. My family member or close friend’s mental health problems are no longer the main focus of my life
34. I have managed to re-establish my life since the person I care for had their mental health crisis
35. I have managed to maintain or regain my social life despite my caring responsibilities
36. I have grown as a result of the traumatic experience of my family member or close friend’s mental health crisis

37. I feel I did my best to help my family member or close friend when they were in crisis

** This has a Flesch-Kincaid score of 64.7 – which is classes as equivalent to 9th Grade (14 yrs)*

Response options

5-point Likert scale

Not at all (1) A little (2) Moderately (3) Quite a bit (4) A lot (5)

Chapter 6: Carer Adaptation and Resilience Scale (CARS): Development And Validation Of A New Measure For Carers Of Those With Psychosis And Schizophrenia

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Key words: Personal recovery, resilience, posttraumatic growth, carers, caregivers, psychosis, schizophrenia, scale development

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Abstract

INTRODUCTION: Family members are often required to provide informal and unpaid care when their loved one has experienced psychosis. This role can be highly challenging as the carer has to deal with difficult symptoms and behaviours often with little training or support for themselves. Carers can experience high levels of emotional distress and burden, a negative effect on their physical health and quality of life as they experience feelings of inadequacy and exhaustion. This in turn can affect the quality of care they provide to their loved one. The care provided by family members has been found to improve outcomes for service users and saves the health services money, so supporting carers is important. To fully support carers, we need to understand their experiences holistically, which means looking at both the negative and positive aspects to caring. By looking at the positive aspects of caring we can promote more comprehensive family interventions and psychoeducation to support carers. Understanding how carers adapt and adjust to their caring role can help us understand how carers are able to build resilience and manage their own day-to-day burden of caring. An under researched area of carer experience has been their own personal recovery, which relates to how carers can find greater meaning and purpose in their life with improved hope of optimism despite the ongoing challenges of providing long term care. Personal recovery is closely linked to positive adaptation and resilience and should be promoted to improve carers quality of life. There is currently no outcome measure that assesses personal recovery, adaptation, or resilience for carers of those with psychosis. This is what this research aimed to address.

METHOD: The development of the Carer Adaptation and Resilience Scale (CARS) followed a multistage mixed methods development process. Phase one involved item generation using data from qualitative interviews. Draft items were then refined based on detailed feedback from carers. Descriptions of the phase one development of the CARS are detailed in separate papers. This paper describes phase two of the development process and details the psychometric validation of the final 29-item CARS.

RESULTS: Carers were recruited from several NHS Trusts across the UK and were asked to complete a survey pack that included the CARS and secondary measures. Data analysis included Exploratory Factor Analysis (EFA) to assess the factor loadings of items on the CARS. Reliability was assessed by looking at Cronbach's alpha scores, item-total correlations, split-half Spearman Brown correlations, and test re-test reliability. Validity of the CARS was also measured to look at the ecological validity and convergent validity compared to secondary measures. Data from 138 completed survey packs showed an initial 9-factor model of the 37-item CARS. This was refined using item-total correlation analysis and the removal of 8 items that did not perform well. This produced the final 29-item CARS based on a 6-factor model. The final version of the CARS has 5 domains: personal growth, adaptation and resilience, personal recovery, mental health concerns, understanding and empathy. The CARS demonstrated excellent internal consistency, high split-half reliability, and good test re-test reliability. The CARS also showed significant correlation with the three other related measures with a medium effect. The CARS shows strong psychometric properties and was developed with a high level of input from carers themselves demonstrating excellent ecological validity.

DISCUSSION: The CARS can be used to assess aspects of carers psychological wellbeing, their adaptation to their caring role, their level of emotional resilience and if they have been through a process of personal growth. The CARS would prove highly useful in both clinical and research settings.

Introduction

A diagnosis of a psychotic disorder such as psychosis or schizophrenia can be very distressing for both the individual with the condition but also their family members. There is no single definition for psychosis, but it generally denotes an array of symptoms including hallucinations, delusions, thought disorder, anxiety, and depression (Gaebel & Zielasek, 2022). Psychotic disorders like schizophrenia are said to be prevalent with 23.6 million cases worldwide (Vos et al., 2015). Clinical recovery rates are 1 in 7 (Jääskeläinen et al., 2015) and psychotic disorders are seen as the 11th cause of disability worldwide (Vos et al., 2015). McGrath et al. (2016) reported prevalence rates of approximately 7% of the adult population before their 75th year, with 50% of newly diagnosed psychotic episodes occurring by the age of 23 years old. The symptoms of psychosis often cause significant distress where long term treatment is required and support is often needed across a range of different life domains requiring practical, financial, and emotional support to assist the individual with daily living activities (Kuipers et al., 2014; Schizophrenia Commission, 2012; Sin et al., 2017; Sin & Norman, 2013). Often relatives and family members step up during a crisis to provide informal and unpaid care for their loved one (Mork et al., 2022).

It is estimated that there are approximately 1.5 million people providing care to a family member or friend with mental illness in the UK (Carers Trust, 2017; Schizophrenia Commission, 2012). The unpaid care that family members provide is said to save the UK health services approximately £34,000 (over $43,000) per person per year (Yesufu-Udechuku et al., 2015), so there is a clear financial incentive to support the wellbeing of carers (Dillinger & Kersun, 2020). Carers not only represent a core component of the health and social care systems (Onwumere et al., 2021) but the care they provide to the service user improves their illness prognosis and enhances their quality of life (Pharoah et al., 2010; Sin et al., 2016). Carers can find the load and responsibility of their role highly distressing and overwhelming which affects their own mental health (Singleton et al., 2002; Smith et al., 2014). Carers have been found to have high levels of depression and anxiety (Kuipers et al., 2010; Pirkis et al., 2010;

Sadath et al., 2017), reduced quality of life (Boyer et al., 2016; Sin et al., 2021) and a negative effect on their physical health (Caqueo-Urízar et al., 2009).

Carers can also suffer from grief, feeling a sense of loss because their loved one may have a chronic and disabling mental health condition, and both the service user and their own life trajectories may have changed drastically (Mulligan et al., 2013; Patterson et al., 2005; Wainwright et al., 2015). Carers have also reported elevated feelings of guilt (Cherry et al., 2017), anger, loneliness, and social isolation (Chien et al., 2016; Magliano et al., 1998). The caring role is often highly taxing as carers have to deal with chronic, challenging and unpredictable behaviours (Mackay & Pakenham, 2012). Carers are often exposed to verbal and physical aggression (Dean et al., 2007; Onwumere et al., 2014) often without any formal training and limited support from mental health professionals. Onwumere et al. (2014) found that patient-initiated violence was associated with poorer carer wellbeing and an increase in negative appraisals of caregiving by the carer (Smith et al., 2019). This can lead to a drop in confidence about their ability to cope, heightening distress and feelings of inadequacy. Carers of those with first episode psychosis can suffer emotional exhaustion and burnout (Onwumere et al., 2018) and have been found to exhibit symptoms of posttraumatic stress symptoms (PTSS) (Hanzawa et al., 2013; Kingston et al., 2016). Taking on a caring role often happens in response to crises and can be highly traumatic (Darmi et al., 2017; Lovelock, 2016). Lavis et al. (2015) found that carers often showed a delayed reaction to the trauma as they often put their own needs last in order to care for their loved one.

Poor carer mental health and wellbeing can also affect the service user as it can negatively affect the care provided (Bebbington & Kuipers, 1994; Reine et al., 2002; Szmukler et al., 1996). Carers who are under strain with poor mental health can be less engaged and more likely to show critical or hostile behaviours towards the person they are caring for (Lee et al., 2014; Szmukler et al., 1996). Providing early support for carers has been recognised as important globally with several policies and strategies to identify and provide support to carers (Australian Government, 2010 ; Center for Mental Health Services, 2009; Department of Health, 2014; National Insititute for

Health and Care Excellence, 2014; Pharoah et al., 2010; Yesufu-Udechuku et al., 2015), however there is still an ongoing implementation gap (Sin et al., 2018).

Past research has paid much attention to the negative aspects of caring, however, there are other aspects of caring that have largely been overlooked (Onwumere et al., 2018) that can provide insight into the caring experience and identify any risk factors that could lead to negative carer outcome (Cohen et al., 2002). Positive aspects to caring have been identified such as: greater personal resilience, improved interpersonal relationships, the development of adaptive coping strategies, reassessment of life priorities, and personal growth (Chen & Greenberg, 2004; Kate et al., 2013; Shiraishi & Reilly, 2019). Positive appraisals of caregiving experiences can lead to improved quality of life for carers (Kate et al., 2013) reduced carer burden and better self-assessed health (Cohen et al., 2002). Exploring the process of adjustment in families could help minimise carers' vulnerability to burnout (Onwumere et al., 2018). To promote positive adaptation to caring we need to understand more about how carers build resilience to help them overcome the adversity and manage the day-to-day burden of caring. Van Breda (2001) suggests that understanding personal resilience could show how carers could grow stronger, learn to be more flexible and become physically and mentally healthier. Promoting resilience has been found to bring about positive change, adaptation, and recovery to the family (Amagai et al., 2016).

Personal recovery for carers?

Carers themselves may go through a process of personal recovery, however, this has been little researched to date (Jacob et al., 2017; The Scottish Recovery Network, 2009). The recovery approach has been one of the most influential paradigms shaping mental health policies and practice in most English-speaking countries (Price-Robertson, Manderson, et al., 2017). The concept of 'personal recovery' developed out of the consumer movement (W. W. Mak et al., 2018) as a way to understand how service users can live a meaningful and satisfying life despite still showing symptoms of mental illness. It differs from the idea of 'clinical' recovery that looks only at the reduction of symptoms and improved social functioning, and denotes an end point to be reached. Personal recovery is seen as a journey, with service users being ‘in’ recovery rather than ‘recovered from’ mental illness. Personal recovery has been defined as: “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles” and “a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness” (Anthony, 1993). Leamy et al. (2011) synthesized the models of personal recovery and outlined five processes known by the acronym CHIME (i.e., connectedness, hope and optimism about the future, identity, meaning in life, and empowerment). Recovery informed practice has largely overlooked carers (Hungerford & Richardson, 2013) despite arguments being made that they are on a parallel journey of recovery (Lovelock, 2016; Wyder & Bland, 2014), and that neither recovery journey can be understood in isolation. There has been a call for more attention to be given to carer and family recovery to enable unique and tailored interventions to be developed (Norton & Cuskelly, 2021; Price-Robertson, Manderson, et al., 2017).

Understanding personal recovery for carers could help researchers and clinicians promote better resilience and positive adaptation and adjustment to the caring role. There is however a gap in empirical research on personal recovery for carers and this formed the basis of this study. A systematic review of outcome measures for carers (Hilton et al., 2022) found that there is no single measure assessing personal recovery for carers, rather a combination of several measures could be used to measure different aspects of personal recovery. However, this would be burdensome for carers to complete. The systematic review showed the need for a new measure to assess personal recovery for carers. A follow-on inductive qualitative study (see Chapter 4) explored the topic of personal recovery with 17 carers. This included using the concept of personal recovery and the constituent processes as the framework to the topic guide. The main themes were: ‘Carers Personal Recovery’, ‘Building Resilience’, and ‘Personal Growth’. The overall finding was that the terminology of personal recovery was not acceptable for many carers and could in fact be detrimental in that it might be perceived as highlighting that they should be 'recovered' and that things should be back to 'normal' for them. Despite this, the processes behind personal recovery were identified as relevant, such as finding greater meaning and purpose, adaptation, and adjustment to caring, increased functioning despite the ongoing challenges on care. There also seemed to be a process of building resilience that for some lead to personal growth. All carers noted the negative aspects of care and how, if they had experienced personal growth this was not out of choice but was as a result of trauma. This linked to the concept of posttraumatic growth (PTG) outlined by Tedeschi and Calhoun (2004). The findings from the qualitative interviews directed the development of items for the Carer Adaptation and Resilience Scale (CARS) as it became apparent from the interview data that processes such as adaptation and resilience and personal growth were also important considerations for carer wellbeing.

The CARS was developed in two phases. Phase one involved item generation and refinement using data generated by the qualitative interviews and direct input from carers using cognitive interviews (see Chapter 5). Cognitive interviewing is becoming a well-established qualitative method in health research and is often used in a multistage mixed methods approach to questionnaire design and validation (Wright et al., 2021). Cognitive interviews were conducted with ten carers as they reviewed the 40 item draft CARS. Interviews lasted on average for 50 minutes where the interviewer (CH) used the ‘think aloud’ and ‘verbal probing’ techniques as outlined in Tourangeau and Rasinski (1988) four stage model of cognitive processing. Carers provided detailed comments on 95% (38 out of 40) of the CARS items. These were grouped according to three different problem categories: specificity (items were not specific enough about the carer experience), semantic (item wording was confusing or needed clarifying), conceptual (the psychological concepts or processes being addressed by the item were confusing or too complex for carers). Adjustments were made considering these comments to produce the final 37-item CARS ready for larger scale psychometric testing.

This study represents phase two of the CARS development with the aim of conducting an Exploratory Factor Analysis (EFA) on the CARS to investigate the underlying factor structure and whether this aligns to the findings from the qualitative study, followed by a psychometric evaluation to assess the reliability and validity of the CARS.

Material and Methods

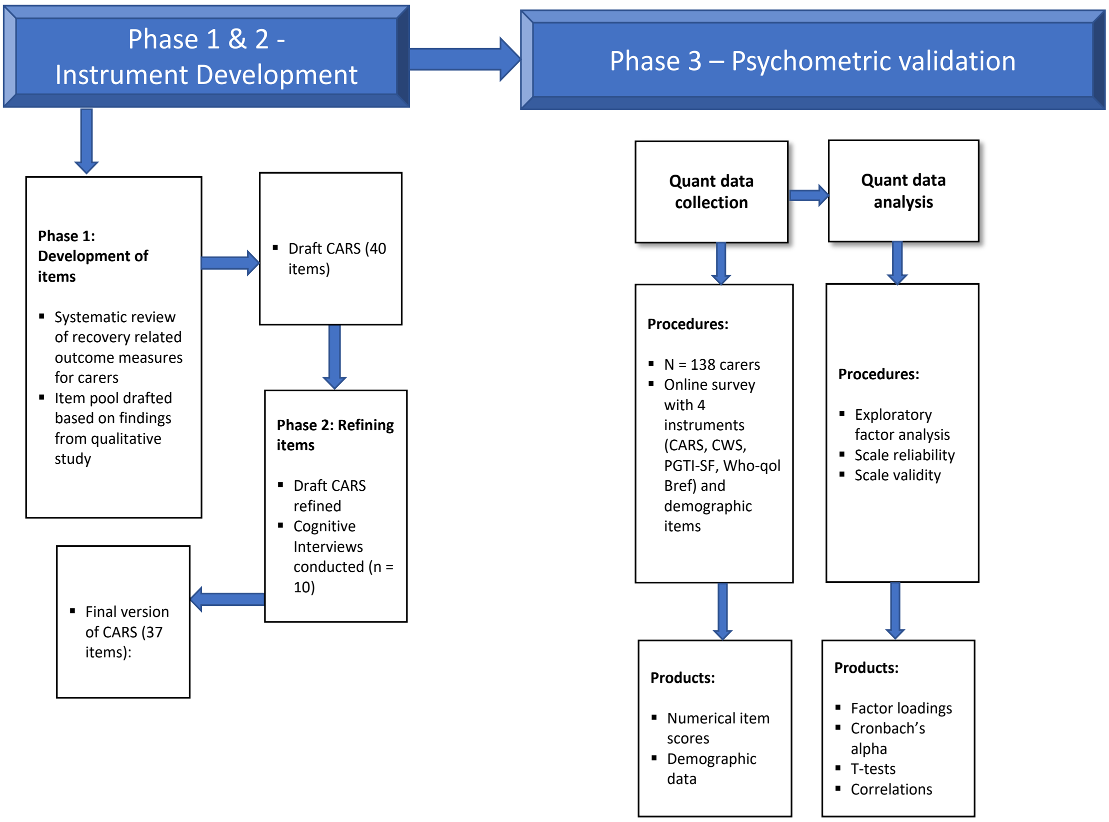
The CARS followed a detailed multistage, mixed-methods development process, with regular input from carers as experts by experience. The development of this measure was seated within a larger research project looking at the process of personal recovery for carers of those with psychosis and schizophrenia. The initial research question was to explore whether carers saw themselves as going through a process of personal recovery for themselves. The findings from a qualitative research study (See Chapter 4) concluded that carers do not relate to the term 'recovery' for themselves and found this to be misleading. As a result, the focus of developing the CARS shifted to assessing carers adaptation, resilience, and posttraumatic growth as a result. This study gained ethical approval from the NHS (REC reference: 21/SC/008, dated: 01/03/2021). See Appendix K.

Phase 1: Item generation and development of the draft CARS

Item generation was informed by the initial Hilton et al. (2022) systematic review using the COSMIN checklist (Mokkink et al., 2010) of all outcome measures that assess different aspects of personal recovery for carers of those with psychosis and schizophrenia. The data from a qualitative study with 17 carers around the topic of personal recovery was then used to inform the item generation (see Chapter 4). The key themes highlighted by this qualitative study explored how carers build resilience by putting in place coping strategies to assist them with their caring responsibilities. This then leads to more ingrained positive adaptations, leading to personal growth.

A pool of 85 items was generated and discussed by the research team, and a final draft questionnaire consisting of 39 items was then presented to 10 carers for discussion during a set of cognitive interviews. A full description of the development stage of the questionnaire can be found in a separate paper (see Chapter 5).

FIGURE 4: *Flow diagram showing the stages of development of the Carers Adaptation and Resilience Scale (CARS)*



Phase 2: Cognitive Interviews

To confirm the content validity of the items with the target population, 10 cognitive interviews were conducted with carers. These were one-to-one interviews conducted by remote means remotely using Microsoft Teams due to COVID-19 restrictions in the United Kingdom at the time of the interviews (July/August 2021). The sample size was selected based on guidance by Willis (2008) who explains that samples are generally small (between 8 – 12 participants) due to the need for efficient and timely development and evaluation of the survey items. Convenience sampling was used, and participants were recruited through NHS services, third sector charities, word of mouth and social media. Participants were all carers of someone who had experienced at least one psychotic episode in their lifetime.

Cognitive Interviewing Procedure

A semi-structured topic guide was used with open ended questions and probes to guide the interview. A combination of the think aloud technique (Tourangeau et al., 2000) and verbal probing (Blair & Presser, 1993) was used. This hybrid model is recommended as a good method to elicit a detailed exploration of each questionnaire item (Beatty & Willis, 2007; Blair & Brick, 2009) that is open ended yet also allows the researcher to ask more focused questions if needed. Participants were presented with an online survey that included demographic questions and the draft CARS with 39 items. Interviews were audio recorded so that further analysis could be completed from transcripts of the data.

Interview data analysis

An initial item matrix was created that included the main recommendations made by participants for each questionnaire item and the demographic questions. These recommendations were discussed within the research team and final decisions were made on which items to drop and any wording changes required. A final draft questionnaire of 37 items was then used in the final survey for validation. The CARS (see Appendix E) is scored based on the 5 item response options 1 (Not at all), 2 (A little), 3 (Moderately), 4 (Quite a bit), 5 (A lot) providing a total score across all 29 items of 145. Three items (22, 23 and 24) in the domain 'Mental Health Concerns' need to be reversed scored before summing the items.

Phase 3: Questionnaire validation

Participants and sampling

Any carer, relative or friend who provided care for a loved one who had experience of psychosis was eligible to take part in the final validation study. The service user being cared for was required to have had a least one episode of psychosis in their lifetime. All recruitment took place across England and was supported by the NHS as an NIHR portfolio adopted study. Most participants were recruited via the NHS through mental health services such as: Early Intervention Services, Community Mental Health Teams, In-patient units, and carer support groups. A total of 16 NHS Trusts from across England supported recruitment for this study. The NHS Trusts were: Birmingham & Solihull Mental Health NHS Foundation Trust; Camden and Islington NHS Foundation Trust; Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust; Gloucestershire Health and Care NHS Foundation Trust; Greater Manchester Mental Health NHS Foundation Trust; Lancashire and South Cumbria NHS Foundation Trust; Leeds & York Partnership NHS Foundation Trust; Mersey Care NHS Foundation Trust; Midlands Partnership NHS Foundation Trust; Oxford Health NHS Foundation Trust; Oxleas NHS Foundation Trust; Southern Health NHS Foundation Trust; South West Yorkshire Partnership NHS Foundation Trust; South West London and St. Georges Mental health NHS Trust; Sussex Partnership NHS Foundation Trust;

and Tees, Esk and Wear Valley's NHS Foundation Trust. Recruitment also occurred through charities, social media, and word of mouth.

Procedure

Any carer interested in the study was either given a recruitment flyer or a link to the survey pack was provided. See Appendix S for study advertising materials, and Appendix V for a screenshot of the study blog. The CARS online survey pack was created using Qualtrics software (Qualtrics, 2021) and included all the required documents for the study: participant information sheet, consent form (see Appendices T and U) and the set of measures being tested. See Appendix W for a screenshot of the Qualtrics survey pack. The survey pack was completed as a one off for most carers, however, a subset of 33 carers repeated the survey pack 2 weeks later to assess test-retest reliability. This subset of carers was self-selected as they opted in based on a question at the end of the original survey pack.

Assessments

Carers were asked about their sociodemographic information and their caring responsibilities before completing a battery of three measures alongside the draft CARS. The secondary measures included the Carer Wellbeing and Support Scale (CWS) (Quirk et al., 2012) which is a well validated self-report measure comprised of 49 items across two subscales (A – Wellbeing, B – Support) assessing the experiences of mental health carers. For this study subscale A (32 items) of the CWS was used to assess carer wellbeing, exploring carers thoughts on their caring role, interpersonal relationships, financial situation, physical health, emotional health, stigma, and personal safety. The response options on the CWS are a 5-point Likert scale ranging from 1 'not at all' to 5 'a lot'. This measure was selected as it scored well on the COSMIN checklist as a well validated measure. It also assessed carer wellbeing which was an important outcome of comparison for the CARS validation.

The Posttraumatic Growth Inventory – Short Form (PTGI-SF) (Cann et al., 2010) is a 10 item questionnaire assessing aspects of posttraumatic growth in various areas of an individual's life and is scored on a scale of 1 – 5 with each response option providing a phrase about the extent to which the individual has experienced that change in their lives (e.g. 0 = I did not experience this change as a result of my crisis to 5 = I experienced this change to a very great degree as a result of my crisis). The PTGI-SF was found to capture much of the variance found in the original PTGI (Tedeschi & Calhoun, 1996) and has been recommend as a good alternative when a shorter questionnaire is required (Cann et al., 2010). This measure was selected to assess whether the theory of Posttraumatic Growth showed comparable scores to the CARS as this was a concept that emerged from the qualitative interview study (Chapter 4). The short form was selected to reduce burden on participants when completing the survey pack.

The final measure used for this study was the WHOQOL-BREF (WhoQol Group, 1998), a 28-item questionnaire assessing general quality of life including: physical health, psychological health, social relationships, and environmental factors which provides a well validated and reliable brief version to the WHOQOL-100. This measure was selected as it provides a good overview the global health status of carers and covers a wider array of domains compared to the CWS. It is a well validated measure that is commonly used in health research. The shorter version was selected to reduce burden on participants when completing the survey pack.

Analysis

An Exploratory Factor Analysis (EFA) using a Promax oblique rotation was used to explore the factor loadings and remove redundant items from the draft CARS using SPSS (IBM Corp, 2020). Analysis of KMO (Kaiser-Meyer-Olkin) test was conducted to assess the adequacy of sampling level. Further analysis included an assessment of

Barlett's test of sphericity and the determinant score of the correlation matrix to see if EFA was an appropriate analysis. Eigenvalues with a cut off based on Kaiser's criterion of 1 were used to measure the variance accounted for by the EFA.

Reliability of the CARS was assessed looking at Cronbach's alpha values, item-total correlations of each item, split-half Spearman Browns correlations, and finally test-retest reliability measured approximately two weeks after the initial completion of the CARS.   The validity of CARS was measured using a variety of assessments. The acceptability and ecological validity were tested during the development phase of the CARS through Cognitive Interviews (see Chapter 5). Convergent validity of the CARS was assessed by comparing results with the secondary measures: CWS (Subscale A), PTGI-SF and the WhoQol-Bref. The expected relationship between the CARS and secondary measures was that a moderate correlation would be found suggesting a level of convergent validity was present. Completed surveys were required to be completed to a minimum level of 90% to be included in the analysis.

Results

The CARS online survey pack was accessed 381 times during the 7-month testing period (September 2021 to May 2022) and a total of 138 surveys were completed.

Demographic characteristics of the sample

138 carers from the UK took part with females representing 78% of the sample. Most carers (80%) were aged between 45 and 74 years and were predominantly from a white British ethnic background (86%). Over half of the sample (59%) had completed an undergraduate or postgraduate qualification at college or university. The carers' employment status was mixed, with 20% of the sample employed full-time, 19%

employed part-time and 39% retired. Just over half the sample (58%) were married or in a civil partnership. See Table 9 for demographic characteristics of the sample.

TABLE 9: *Sociodemographic characteristics of participants for the CARS validation study*

Sample Characteristic	*n*	%
Gender		
Male	27	19.6
Female	108	78.3
Not defined	3	2.1
Age category		
18-24	1	0.7
25-34	9	6.5
35-44	8	5.8
45-54	22	15.9
55-64	48	34.8
65-74	41	29.7
75-84	7	5.1
85 and above	2	1.4
Ethnicity		
White British	118	85.5
Other White background	8	5.8
Black or Black British	2	1.4
Mixed background	2	1.4
Asian or Asian British	6	4.3
East Asian background	2	1.4
Highest level of education		
Completed secondary school	28	20.3
Completed some college/university	29	21
Completed undergraduate degree	38	27.5

Completed a postgraduate qualification	43	31.2
Employment status		
Full-time	27	19.6
Part-time	26	18.8
Self-employed	13	9.4
Unemployed	8	5.8
Retired	54	39.1
Student	2	1.4
Unable to work (caring responsibilities/illness)	18	13.0
Other (voluntary, semi-retirement)	3	2.2
Marital status		
Single	24	17.4
Married/Civil partnership	80	58.0
Widowed	7	5.1
Separated/Divorced	27	19.6

*Note. N = 138, *due to caring responsibilities/illness*

Caring characteristics of the sample

Carers had on average been caring for their family member or friend for 14.5 years (M = 14.5, SD = 12.3). Carers reported spending an average of 33 hours a week caring for friend of family member (M = 32.5, SD = 43.5) with a range of between 0 – 168 hours. Where carers declared zero hours of care this related to the service user being in-patient at a hospital, however, the carer still felt they had a caring responsibility for that person. About half the sample (54%) co-resided with the person they were caring for, and a large proportion of carers (65%) were caring for their adult son or daughter, while 14% were caring for a partner or spouse. Thirty three percent of those being cared for had a diagnosis of some form of schizophrenia, 29% had a diagnosis of psychosis, while 20% had a diagnosis of bipolar disorder with psychosis. Most of those being cared for (94%) had had some contact with mental health services in the past. See Table 10 for further caring characteristics of the sample.

TABLE 10: *Caring characteristics of participants for the CARS validation study*

Sample characteristic	*n*	%	M	Range	SD
Duration of care responsibilities (years)			14.5	1 - 66	12.3
Care provided each week (hours)			32.5	0* - 168	43.5
Co-residence with service user	74	53.6			
Person cared for:					
Son/daughter	90	65.2			
Partner/spouse	19	13.8			
Sibling	10	7.2			
Parent	9	6.5			
Friend	1	0.7			
Other	9	6.5			
Diagnosis of person cared for:					
Psychosis	40	29.0			
Schizophrenia (all types)	46	33.3			
Schizoaffective disorder	14	10.1			
Bipolar disorder with psychosis	28	20.3			
Other	10	7.2			
Symptomatic at time of completing survey	64	46.4			
Mental Health Service use of person cared for					
Early Intervention Service (EIS)	28	20.3			
Community MH Service (CMHT)	74	53.6			
Hospital in-patient	15	10.9			
Discharged from a service	13	9.4			
Never used MH services	3	2.2			

Unsure	5	3.6

*Note. N = 138 *Some participants declared that they did not provide care as the service user was in-patient, however they still felt they had a caring responsibility.*

Impact of COVID-19

All carers were asked whether the COVID-19 pandemic had affected their caring responsibilities, with 63% of carers reporting 'yes' and provided a short free text summary of how they had been affected. The most frequent comment was that there had been a disruption to the usual contact with the service user, generally that they were not able to see each other face to face unless they lived together. Another common problem related to the disruption to support provided by the mental health services, which ranged from appointments moving online to being stopped altogether. A few carers reported serious failings in case management that had led to suicide attempts and in one instance death. Many carers described bringing service users to live with them, which increased their stress and caring load but for some this had a positive outcome as it improved communication with the service user. Carers struggled with the social isolation of lockdown, found they had less time for self-care and could not get respite for themselves. Many carers reported a negative effect on the service user's mental health, with increased anxiety, increased delusional beliefs, disruptions to routines which destabilised the service user, and for some the pandemic triggered a psychotic relapse. Carers also reported how the pandemic had disrupted the service user's personal recovery as they were delayed in leaving in-patient units or supported housing or struggled with social isolation.

Validation of the CARS

Exploratory Factor Analysis

An initial exploratory factor analysis (EFA) of the 37-item CARS provided a 9-factor model, and steps were taken to reduce the number of items to provide a clearer factor model. Item reduction was done in two ways, by looking at the Item-total correlations and factor loadings. Three iterations of Item-total correlations were conducted until no further items needed to be removed as it would not improve the alpha score. The factor loadings were also inspected and any factor that was not grouping together was either dropped or merged into another factor based on the conceptual basis of that item. Overall, a total of 8 items were removed.

The final EFA was conducted using a Promax oblique rotation on the 29 items of the draft CARS. The KMO (Kaiser-Meyer-Olkin) test showed an adequate level of sampling adequacy for the analysis, KMO = .888. Barlett's test of sphericity (p < .001) and the determinant score (5.323) of the correlation matrix showed that an EFA was an appropriate analysis. The initial analysis assessed the Eigenvalues with a cut off based on Kaiser's criterion of 1. Six factors had eigenvalues over 1, which explained 67.46% of the variance (see Table 14 of this publication). Factor 1 accounted for 36.46% of the variance, while factor 2 accounted for 10.77% of the variance. Factors 3,4 5 and 6 were all below an eigenvalue of 2 and explained the remaining 20.23% of the variance. Inspection of the scree plot (Appendix F) confirmed this 6-factor model. Table 11 shows the factor loadings after rotation.

Generating domains

The item clustering was reviewed by the research team. The clustering indicated that factor 1 related to personal growth, factor 2 related to adaptation and resilience, factor 3 related to personal recovery, factor 4 related to carers concerns about their mental health, and factors 5 and 6 were merged based on the conceptual meaning of the items and related to understanding and empathy of others. See Table 13 of this publication for item clustering correlations. This produced the final 29 item CARS with 5 domains: Personal Growth (10 items); Adaptation and Resilience (6 items); Personal Recovery (5 items); Mental Health Concerns (3 items); and Understanding and Empathy (5 items). Readability results of the CARS show it is fairly easy to read as it equates to a school reading age of between 12 and 13 years (Felsch reading ease = 63.9, Flesch-Kincaid grade = 7.7). A final assessment of the psychometric properties of the final CARS was then conducted.

Reliability

The CARS has excellent internal consistency with a Cronbach's alpha score of .93. Split-half reliability was estimated using the Spearman-Brown coefficient for unequal length based on the 29 items. Items were split based on alternative items (odd numbers compared to even numbers). The Cronbach's alpha was .89 part 1 (odd numbered items), with part 2 (even numbers) showing an alpha score of .87. The Spearman-Brown coefficient was .93, indicating a very high split-half reliability.

To check the test re-test reliability of the CARS, the questionnaire was administered to a subset of 33 participants approximately two weeks after completing the measure. The total scores at both timepoints were significantly correlated (r (32) = .836, p < .001). A paired-samples t-test showed the mean difference between both timepoints (M = 1.364, SD = 11.163) was not statistically significant t (32) = .702, p = .488. These results show that the CARS demonstrates good test re-test reliability.

Validity

Content validity

The results from the cognitive interviews on the initial 37 item CARS showed that carers found the questionnaire acceptable in terms of content and ecological validity.

Convergent validity

Further tests of validly were conducted accounting for missing data. Six participants did not complete all items on the comparator measures which represents 4.34% missing data. All partial data were removed from the analysis leaving data from 132 participants for the final analysis of convergent validity. To assess the convergent validity of the CARS a series of Pearson's correlations were run exploring associations between the new measure and the CWS, PTGI and WhoQol-Bref. See Table 14 of this publication. The CARS demonstrated significant correlations with all three other measures with a medium effect. The CARS was moderately correlated to the CWS *r* (130) = .416, *p* < .001. The CARS showed the strongest correlation with the PTGI *r* (130) = .480, *p* < .001. The CARS showed the lowest (but moderate) correlation with the WhoQol-Bref (*r* (130) = .334, *p* < .001).

Discussion

The original aim in developing the CARS was to create a new measure of personal recovery for carers of those with psychosis and schizophrenia. Through qualitative interviews with carers, it became apparent that the term 'personal recovery' was perhaps not the right concept to be assessing. The findings from the qualitative interviews highlighted that there are more factors involved in how carers adapt to their caring role. For example, the notion of posttraumatic growth (Tedeschi & Calhoun, 2004) which relates to how there can be positive gains because of the struggle with trauma and loss. This can lead a person to 'restructure their life narrative' (Calhoun & Tedeschi, 2014b) and this connects to the concept of what carers discussed in the qualitative study (Chapter 4), that they find ways to "rebuild their lives" (Q009). These concepts are inherent in the personal recovery approach, and this study shows there also seems to a more nuanced and complex connection to other factors such as personal growth, resilience, adaptation, and increased empathy and understanding of others, which is reflected in studies focussing on the positive aspects of caregiving (Chen & Greenberg, 2004; Kate et al., 2013; Shiraishi & Reilly, 2019)

The five domains of the CARS (Personal Growth; Adaptation and Resilience; Personal Recovery; Mental Health Concerns; and Understanding and Empathy) are all conceptually related to the subcomponents of personal recovery, as understood by the CHIME framework (Leamy et al., 2011) and the factors related to the positive aspects of caregiving discussed above. This confirms the findings of the qualitative data (Chapter 4) and shows that personal recovery is a part of the adaptation process for carers. The results from the CARS EFA show that posttraumatic growth may be a more relevant construct for carers as this was the first factor and had the most items (10). Not only did the CARS show excellent reliability in terms of internal consistency and test re-test reliability but it also demonstrated good convergent validity as it showed a medium correlation to other measures of carer wellbeing. This concurrent validity assessment showed the strongest correlation with the PTGI-SF measure, a 10-item measure looking at posttraumatic growth and how carers life priorities, strength and resilience may have changed since a traumatic event (Tedeschi & Calhoun, 2004). This confirms the EFA of the CARS as the strongest and largest loading factor related to elements of posttraumatic growth for carers, suggesting that this may be a more useful construct to consider when looking at carer adaption and personal recovery. The CARS also correlated with the CWS which asked about the carer's role, their relationships with the person they care for and other family and friends, the carers financial situation, their physical health, and their emotional wellbeing. This confirms that the CARS is also a solid measure for assessing carer aspects of psychological wellbeing. The WhoQol-Bref showed the weakest correlation with the CARS, however, this was still classed as a significant moderate correlation ($r = .35$, $p < 0.001$). This may have been because the WhoQol-Bref askes more about the carer's physical health and environmental situation and less about their psychological wellbeing and the impact on their relationships. Again, this indicates that the CARS is mainly assessing aspects of carers psychological wellbeing, personal recovery, and adaption.

Strengths

The CARS is a well validated measure with sound psychometric properties. The final 29-item measure is relatively short so is not too burdensome for participants. This study also shows that the CARS can be successfully given as an online measure, as this was the primary means by which carers completed the survey pack despite being offered a paper version. The CARS has also been developed with strong input from carers themselves, which follows the current research agenda of having strong personal and public involvement (PPI) (DeVellis, 2012; Mes et al., 2019). The most important strength of the CARS is that it provides the first freely available measure assessing the concepts of personal recovery, adaptation, posttraumatic growth, and resilience for carers of those with psychosis. It also indicates that the model of ‘personal recovery’ is not seen as appropriate by many carers, however, there are still aspects of personal recovery evident from the data.

Limitations

Despite the KMO statistic indicating that the CARS has an adequate sample size to conduct an EFA, the sample size is less than the recommended heuristic of 200 participants for questionnaire validation (De Vet et al., 2011; DeVellis, 2012; Mokkink et al., 2010). Recruitment for this study was particularly difficult as it was conducted through the COVID-19 pandemic that affected carers significantly, so completing a survey for research purposes was not a priority for them. It also became apparent that many of the third sector charities had reduced their meetings and moved them online, and many were not running groups, meaning that this potential recruitment route was not fruitful. The best recruitment came from the 16 NHS trusts that agreed to advertise the study, and after extending the recruitment window by two months we were able to use the survey data from 138 participants.

A further limitation of the CARS related to the demographic characteristics, as the data gathered came mainly from females from a white British background with a relatively high level of education. For example, nearly 60% of the sample had completed a university degree or postgraduate qualification. This does link to the literature showing that most care for those with psychosis and schizophrenia is provided by mothers (Caqueo-Urízar et al., 2014). It does however highlight that the CARS may not be generalisable to carers from ethnic minority populations as only 12 participants out of the sample of 138 came from an ethnicity other than ‘White’ which represents 7.11% of the sample. Issues around homogeneity of carer samples have been commented on in other research studies so does seem to be a frequent problem with this population (Gallagher & Wetherell, 2020; Hazell et al., 2020; Smith et al., 2014) . Many of the carer’s groups were closed due to COVID-19 so even if the researcher had targeted recruitment at different carers groups in more ethnically diverse geographic locations this would have proved very difficult. This study did aim to recruit from NHS trusts in more multicultural cites however these trusts did not manage to recruit many participants unfortunately. This would be a key focus in a larger validation study of the CARS, where a stratified sampling strategy could be used.

Future research

A further larger validation study with a larger sample size would enable a confirmatory factor analysis to be conducted, where it would also be possible to assess the predictive validity of the CARS. For example, investigating whether newer carers who may not have adapted to their caring role would not score as highly on the CARS as more long-term carers. Another aspect that would strengthen the psychometric evaluation of the CARS would be to assess the discriminant validity against other questionnaires that measure the opposite of personal growth and recovery. This was not assessed in this study due to the complex nature of what is understood of personal recovery for carers. This study looked more at exploring the concept and hence it was impossible to assess what was divergent from a concept little understood.

Using the CARS in applied settings

The CARS could be used in both clinical and research settings. Used alongside other measures of wellbeing and quality of life, the CARS could be used at several timepoints to show what improvements may have been made for carers. It may also be possible to calculate the total scores per domain, highlighting which areas carers may need more support with. Completing the CARS may also illustrate to carers that others progressed using some of the strategies, providing a positive message of hope to carers which is a vital element to personal recovery (Neil et al., 2009). The CARS could also be a valuable addition in research settings, for studies assessing the effectiveness of new interventions for carers and families as there is currently no other measure available, assessing aspects of personal recovery and this would strengthen the evidence base of novel interventions.

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Appendix

Appendix E: *Final validated version of the Carer Adaption and Resilience Scale (CARS) – with domain names*

Carer Adaptation and Resilience Scale (CARS)

This questionnaire is all about you as someone who supports a family member or close friend with psychosis and/or schizophrenia. It is about **YOUR** mental and emotional wellness. We do understand that how you feel is often closely linked with how the person you care for is feeling, but for this scale we are interested in **YOUR** wellbeing and not that of the person you care for.

Please try to answer every question. Every answer is valuable and there is no right or wrong answer. If you are unsure of an answer, choose the one that seems the most appropriate which can often be your first response to the question.

Thinking about **how things have been for you** since your family member or close friend was in crisis and they needed extra support from you:

Personal Growth

1. Since becoming a carer, I have learned more about myself.
2. Being a carer has helped me to become wiser.
3. Being a carer has given me a greater sense of purpose in life.
4. My outlook on life has become more positive as a result of being a carer.
5. I have grown as a result of the traumatic experience of my family member or close friend's mental health crisis.
6. I am more hopeful about my future as a carer.
7. I feel grateful because things could have been worse for me as a carer.
8. Since becoming a carer, I am better at communicating with my close family and friends.
9. Since becoming a carer I have stronger relationships with my close family and friends.

10. I have a stronger relationship with my loved one because I have become their carer.

Adaptation and Resilience

11. Since becoming a carer I feel more confident that I can handle things if the person I care for becomes unwell again.
12. I feel more able to stand up for myself and the person that I care for.
13. Since becoming a carer, I have learned to manage my stress levels better.
14. Since becoming a carer, I have realised that I am emotionally stronger than I thought I was.
15. Being a carer has helped me learn how to deal with difficult situations.
16. Because of my caring experiences, I feel more resilient.

Personal Recovery

17. I have managed to pursue my own interests alongside being a carer.
18. Since becoming a carer, I have learned to take time for myself.
19. I have managed to maintain or regain my social life despite my caring responsibilities.
20. I have found engaging hobbies and activities that help me switch off from my caring responsibilities.
21. I have managed to re-establish my life since the person I care for had their mental health crisis.

Carer mental health concerns

22. I feel anxious about my caring responsibilities.*
23. I feel depressed about my caring responsibilities.*
24. I feel overwhelmed by my caring responsibilities.*

Understanding and empathy of others

25. Since becoming a carer, I have become more understanding of others.
26. Since becoming a carer, I have more empathy for others.

27. Since becoming a carer, I am more patient.
28. I am able to make deeper personal connections with other carers.
29. As a carer, I try to use my knowledge and experience to help others.

End of Questionnaire. Thank you for your responses.

Response options

5-point Likert scale

Not at all [1] A little [2] Moderately [3] Quite a bit [4] A lot [5]

Scoring notes:

*Items 22, 23 and 24 (carer mental health concerns) are negatively scored. They will need to be reversed scored. The total of each item is summed to give a final score out of a possible 145. The greater the score shows a positive outcome.

APPENDIX F: *Scree plot showing the factor loadings of the Carer Adaptation and Resilience Scale (CARS)*

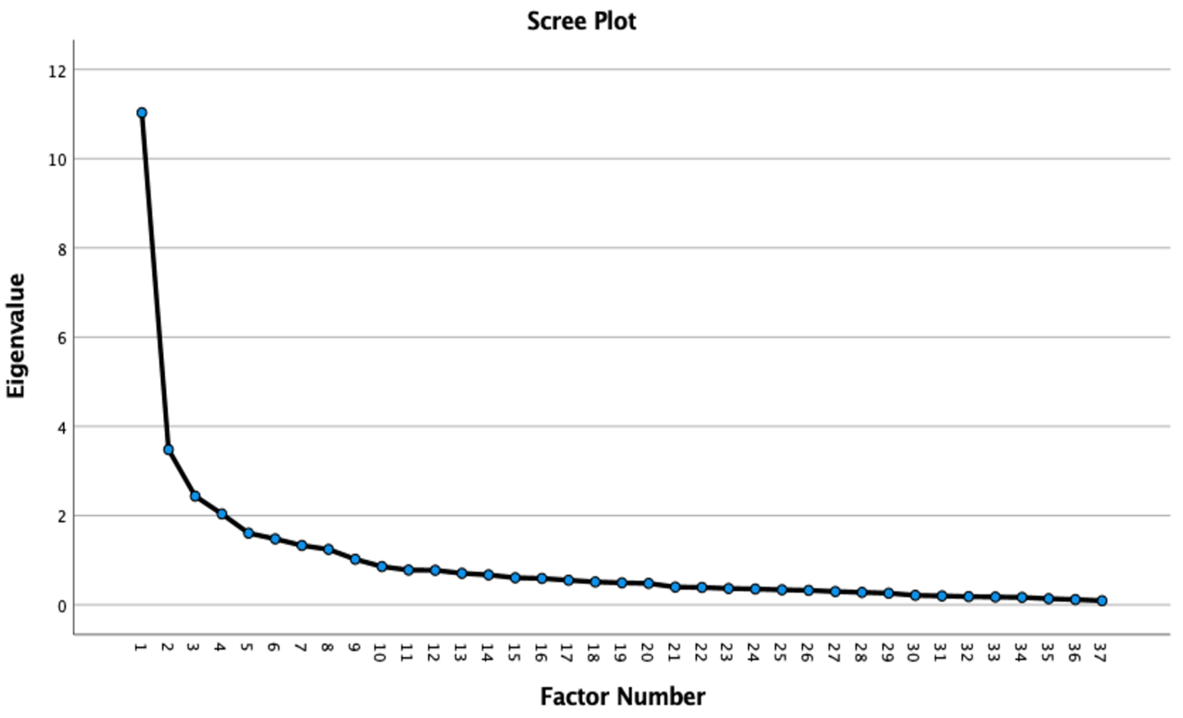


TABLE 11: *Factor Loadings and Communalities for Promax Oblique Rotated 6-Factor Solution for 37 CARS Items (N = 138)*

	Factor loading						
	1	2	3	4	5	6	Communality
Since becoming a carer, I have stronger relationships with my close family and friends.	**0.810**	0.031	-0.079	0.127	0.028	-0.139	0.648
Being a carer has given me a greater sense of purpose in life.	**0.770**	-0.002	-0.242	0.076	-0.016	0.018	0.528
I have a stronger relationship with my loved one because I have become their carer.	**0.713**	-0.013	-0.015	0.051	-0.123	-0.051	0.400
I am more hopeful about my future as a carer.	**0.705**	-0.035	0.036	0.220	-0.087	0.095	0.654
Being a carer has helped me to become wiser.	**0.704**	0.257	0.043	-0.250	0.050	-0.092	0.695
Since becoming a carer, I am better at communicating with my close family and friends.	**0.682**	0.081	0.080	-0.035	0.101	-0.067	0.625

My outlook on life has become more positive as a result of being a carer.	**0.661**	0.082	0.039	0.167	-0.093	0.037	0.607
Since becoming a carer, I have learned more about myself.	**0.515**	0.181	0.038	-0.185	0.044	0.138	0.536
I have grown as a result of the traumatic experience of my family member or close friend's mental health crisis.	**0.378**	0.296	0.185	-0.185	0.032	0.097	0.536
I feel grateful because things could have been worse for me as a carer.	**0.226**	-0.089	0.143	0.184	0.156	0.199	0.348
Since becoming a carer I feel more confident that I can handle things if the person I care for becomes unwell again.	0.057	**0.658**	-0.085	0.161	-0.056	0.009	0.498
Because of my caring experiences, I feel more resilient.	0.015	**0.654**	0.001	0.211	0.100	0.047	0.681
Since becoming a carer, I have learned to manage my stress levels better.	-0.043	**0.636**	0.105	0.291	0.090	-0.046	0.662

Since becoming a carer, I have realised that I am emotionally stronger than I thought I was.	0.053	**0.628**	-0.074	0.108	0.035	0.214	0.670
Being a carer has helped me learn how to deal with difficult situations.	0.312	**0.552**	-0.011	-0.152	-0.033	-0.134	0.453
I feel more able to stand up for myself and the person that I care for.	0.259	**0.386**	0.062	-0.130	-0.013	0.136	0.431
I have managed to pursue my own interests alongside being a carer.	-0.043	-0.138	**0.807**	0.187	0.090	-0.088	0.747
Since becoming a carer, I have learned to take time for myself.	-0.120	0.274	**0.793**	-0.098	-0.114	-0.098	0.580
I have managed to maintain or regain my social life despite my caring responsibilities.	0.103	-0.367	**0.740**	-0.028	0.144	0.111	0.621

I have found engaging hobbies and activities that help me switch off from my caring responsibilities.	-0.121	0.225	**0.721**	-0.038	-0.201	-0.021	0.481
I have managed to re-establish my life since the person I care for had their mental health crisis.	0.081	-0.058	**0.648**	0.099	0.009	0.062	0.546
I feel anxious about my caring responsibilities.	-0.006	0.085	0.008	**0.803**	-0.039	0.071	0.702
I feel overwhelmed by my caring responsibilities.	0.043	0.006	0.025	**0.789**	0.032	-0.077	0.665
I feel depressed about my caring responsibilities.	0.045	0.200	0.030	**0.691**	-0.046	-0.074	0.608
Since becoming a carer, I have become more understanding of others.	-0.118	0.076	-0.037	-0.023	**0.980**	-0.018	0.865
Since becoming a carer, I have more empathy for others.	0.034	-0.002	-0.051	-0.005	**0.902**	-0.034	0.793
Since becoming a carer, I am more patient.	0.076	0.394	0.012	-0.035	**0.437**	-0.006	0.586

As a carer, I try to use my knowledge and experience to help others.	-0.186	0.159	-0.025	-0.060	-0.046	**0.889**	0.728
I am able to make deeper personal connections with other carers.	0.187	-0.078	-0.029	-0.005	-0.011	**0.594**	0.427

TABLE 12: *Eigenvalues, Percentages of Variance and Cumulative Percentages for Factors for 29 item CARS*

Factor	Eigenvalue	% of variance	Cumulative %
1	10.57	36.46%	36.46%
2	3.12	10.77%	47.23%
3	1.92	6.63%	53.87%
4	1.41	4.85%	58.71%
5	1.31	4.50%	63.21%
6	1.23	4.25%	67.46%

TABLE 13: *Correlations of Extracted Factors after Promax Rotation*

Factor	1	2	3	4	5	6
Factor 1	-					
Factor 2	0.64	-				
Factor 3	0.41	0.32	-			
Factor 4	0.35	0.26	0.44	-		
Factor 5	0.59	0.49	0.34	0.15	-	
Factor 6	0.52	0.47	0.27	0.13	0.45	-

TABLE 14: *A correlation matrix of all the measures used in the validity analysis of the 29-item CARS*

	CARS	CWS-A	PTGI-SF	WhoQol-Bref	M	SD
CARS	-				80.89	19.84
CWS-A	.416*	-			101.57	25.93
PTGI-SF	.480*	0.111	-		2.81	0.97
WhoQol-Bref	.334*	.472*	0.52	-	12.09	3.54

**Correlation is significant at the 0.001 level (2-tailed).*

Chapter 7: Discussion

Overview of chapter

This chapter will outline the aims and key findings of this PhD and discuss these in relation to relevant literature on personal recovery and carers. The main focus is to discuss whether the concept of personal recovery can be successfully applied to a carer population, and if not, what other concepts might be more relevant and valid for carers. Following this, I will discuss the rationale for creating a new outcome measure for carers and briefly summarise the key issues that arose in the development of the Carer Adaptation and Resilience Scale (CARS). The methodological considerations for this PhD will also be reviewed and I will consider the importance of reflexivity and researcher bias in psychological research and how these were dealt with in this study. The strengths and limitations of this PhD will also be explored before a discussion about future clinical and research implications of the findings from this thesis and use of the CARS.

Rationale for this PhD

Personal recovery has been a useful concept to understand more about how service users experience and manage their mental health difficulties. It has provided a positive framework that has guided mental health service provision in most English-speaking countries around the globe (Price-Robertson, Obradovic, et al., 2017). It has also influenced wider mental health discourse, promoting empowerment and the idea of learning to live your best life despite still experiencing symptoms of mental illness. Personal recovery outcomes are seen as an important assessment point in both clinical practice and research. For example, the Questionnaire about the Process of Recovery (QPR, Neil et al., 2009) is commonly used in mental health research studies (Varese et al., 2021). The rationale behind this PhD was to explore whether the concept of personal recovery could also be applied to carers of those with psychosis and schizophrenia. By understanding carers' personal recovery experiences, it may be possible to foster and promote this for carers. Also, being able to assess carers personal recovery, could provide better insight into their mental health and assist clinicians and researchers to provide tailored support to them. Carers clearly need more support to enable them to look after themselves and to provide good care to their loved ones, which was highlighted in the introduction to this thesis. Investigating personal recovery for carers also provides a more holistic view of their caring experience. As the introduction to this thesis outlined, the bulk of past research about carers has focused on the negative aspects of caring, such as the physical and emotional burden of care (Awad & Voruganti, 2008; Nordstroem et al., 2017; Poon et al., 2017) with limited research on the positive aspects of caring. It has been noted that the experience of caring is multidimensional, with carers experiencing both negative and positive aspects (Estradé et al., 2023). Looking at the positive aspects to caring and how this can bolster adaptive coping strategies has been seen as an important research priority (Chen & Greenberg, 2004; Estradé et al., 2023; Onwumere et al., 2018; Shiraishi & Reilly, 2019). It would seem that because of the importance of personal recovery in service user research literature and clinical services, this would be an important area to investigate for carers. It is also important to be able to measure this concept quantitatively, to allow outcomes to be assed in carer interventions.

Aims of this PhD

Three aims were outlined for this PhD. The first was to understand the nature and experience of personal recovery for carers. The second aim was to develop a new outcome measure to assess personal recovery for carers. The final aim was to validate the new outcome measure using psychometric testing. The following discussion expands on how these aims were achieved.

Conceptualising personal recovery for a carer population

One of the main challenges of this PhD was to apply the concept of personal recovery to a new population. There have been calls for more research on family and carer recovery (Deane et al., 2015; Lovelock, 2016; Marshall et al., 2013; Norton & Cuskelly, 2021; Wyder & Bland, 2014) as was highlighted in the introduction to this thesis; however, there is very limited literature looking specifically at personal recovery for carers. A recent systematic review by Vera San Juan et al. (2021) found that carers' perspectives of recovery have been lacking and that their views are typically not taken into account in recovery definitions. This has meant that their key role in the service users recovery journey has not been recognised. Much of the research related to carer recovery has focused on carers views of service user recovery (Jacob et al., 2015; Mak et al., 2018; Vera San Juan et al., 2021). The first step in this PhD was to review the current literature and frameworks describing personal recovery, such as the Leamy et al. (2011) CHIME Framework, the Anthony (1993) definition, the work of Slade et al. (2009, 2010), Resnick et al. (2005), and the Substance Abuse and Mental Health Services Administration (SAMHSA) (2012) in the USA. One of the most useful summaries of the various definitions of personal recovery was outlined by Wyder and Bland (2014) who provided an overview of the principles of personal recovery for carers such as: connectedness, hope and optimism about the future, identity, meaning in life and empowerment. This work is very closely aligned with the CHIME framework used to understand service user recovery. This concept was then operationalised for this PhD by extracting the key words used when describing personal recovery, which were then categorised into: hope, goals, relationships, support, meaning, identity, and adaptation. A full summary of this was included in the systemic review as supplementary material (see Appendix B). This summary of key terms formed the basis of the search strategy for the systematic review (see Chapter 3) looking for outcome measures assessing personal recovery for carers. Creating a key words checklist seemed to be the most comprehensive and transparent way to conceptualise personal recovery for carers as it unpicked key concepts, revealing the sub-components of these concepts and helped to identify how this can be related to carers.

The findings of the systematic review are summarised in Table 15 of this thesis. The key findings of this stage of the research showed that there is no single self-report measure that assesses personal recovery for carers but that certain well validated measures could be used in conjunction to assess some aspects of personal recovery. This however would be burdensome for carers to complete, so the review called for a new outcome measure to be developed looking specifically at personal recovery. Another key finding of the review was the importance of having a high level of participant involvement in the development of any new measure. The systematic review (Chapter 3) found that of the ten measures identified for further assessment using the COSMIN checklist (Mokkink et al., 2010), only half of these had been specifically developed for carers of those with psychosis, and only five out of the ten measures showed ‘good’ to ‘excellent’ level of public involvement in the development of the measure. The quality appraisal used in the systemic review (De Vet et al., 2011; Terwee et al., 2007) provided a map of good practice and how best to develop a new outcome measure which guided the remainder of this PhD.

TABLE 15: *Summary of aims, key findings, and outputs from this PhD*

Chapter	Aims	Key findings	Output
Chapter 3 **Self-Report Measures Assessing Aspects Of Personal Recovery In Relatives And Other Informal Carers Of Those With Psychosis: A Systematic Review**	1. To identify all self-report measures developed for carers of those with psychosis that assess aspects of personal recovery.	95 potentially relevant self-report measures were identified but most of these were not targeting for carers of those with psychosis or schizophrenia. Of the ten measures considered relevant for review, only 50% them were developed specifically for carers of those with psychosis and schizophrenia. More self-report measures should be developed for specific patient populations to make them relevant and valid for the specific population being measured.	Published paper providing a summary and quality appraisal of relevant outcome measures for carers that assess aspects of Personal Recovery.

Chapter	Aims	Key findings	Output
	2. To quality appraise the psychometric properties of the self-report measures identified, using the COSMIN checklist.	A quality appraisal of the ten self-report measures using the COSMIN checklist showed highly variable methodological quality of the measures. Recommendations for instrument selection were made. The measures that showed the strongest psychometric properties were the Carer Wellbeing and Support Scale (CWS), Experience of Caregiving Inventory (ECI) and the Schizophrenia Caregiving Questionnaire (SCQ).	
	3. To investigate the level of public involvement in the development of each self-report measure.	50% (n = 5) of the self-report measures assessed showed ‘good’ to ‘excellent’ levels of public involvement in the development of the measure.	

Chapter	Aims	Key findings	Output
		More self-report measures should be developed with a high level of public involvement to improve the validity of the measure for that population.	
	4. To explore how well the self-report measures identified fit within the personal recovery framework.	No single self-report measure assessed most or all aspects of personal recovery. The CWS and SCQ were recommended as the best measures to use to assess personal recovery for carers.	
<u>Chapter 4</u> **"You've Got To Put Your Own Oxygen Mask On First" – A Qualitative Study Looking At Personal Growth, Recovery, And Resilience For Carers Of Those With Psychosis And Schizophrenia.**	1. To qualitatively explore whether carers experience personal recovery as is outlined by the 'Recovery Approach'	Three main themes were found: **1. Carer's Personal Recovery:** Whether carers recognise that they are on a journey of personal recovery for themselves or not. Often carer recovery is dependant of the recovery of the service user in parallel. The terminology of 'recovery' is problematic for carers to identify with.	A publishable qualitative journal article exploring a new psychological concept for a novel population.

Chapter	Aims	Key findings	Output
		2. Building Resilience: Carers finding ways to cope better with their caring responsibilities by making adaptations, getting support and improving their self-care. **3. Personal Growth:** Changes to carers' cognitive processes, behaviour, and outlook on life. Shows how the negative aspects of providing long term care can lead to positive personal transformation. Links to theory of Post-Traumatic Growth (Tedeschi & Calhoun, 2004).	
	2. Data to inform item generation for the new questionnaire	The term 'Personal Recovery' was not seen as appropriate or valid for most carers interviewed.	The basis for the development of a new outcome measure.

Chapter	Aims	Key findings	Output
		Some of the processes behind the concept of 'Personal Recovery' were evident. Carers do go through a process of change related to building resilience, adapting to their caring role. Some carers experience personal growth which was linked to the concept of posttraumatic growth.	
Chapter 5: **Carer Adaptation And Resilience Scale (CARS): Development Of A New Measure For Carers Of Those With Psychosis And Schizophrenia Using Cognitive Interviews**	1. To assess the draft CARS to measure: - Content Validity - Item wording - Response options	Comments were pooled and showed three main problem categories: **1. Specificity:** Item wording was not specific enough to carers experiences. **2. Semantic:**	Draft 37-item version of the CARS ready for psychometric validation.

Chapter	Aims	Key findings	Output
		The meaning of items were unclear due to the wording used. **3. Conceptual:** Problems understanding the underlying concept/approach of the content of the item. Changes were made to item wording; some items were dropped and the instructions to the questionnaire were improved. Participants were happy with the format of the response options. Cognitive Interviewing (Willis & Artino Jr, 2013; Wright et al., 2021) proved to be a very successful approach for gaining detailed feedback on the draft questionnaire.	

Chapter	Aims	Key findings	Output
Chapter 6: **Carer Adaptation And Resilience Scale (CARS): Development And Validation Of A New Measure For Carers Of Those With Psychosis And Schizophrenia**	1. To validate the CARS using the following psychometric methods: - Exploratory Factor Analysis (EFA) - Reliability tests: Cronbach's alpha scores, item-total correlations, split-half Spearman Brown correlations, test re-test reliability. - Validity tests: ecological validity, convergent validity compared to other secondary measures.	Data from 138 completed online survey packs was used to assess the 37-item draft CARS 8 items were removed due to poor item performance. The final 29-item CARS is based on a 6-factor model. The 5 domains of the CARS relate to: - Personal Growth - Adaptation and Resilience - Personal Recovery - Mental Health Concerns - Understanding and Empathy.	A fully validated new measure to assess aspects of psychological wellbeing for carers of those with psychosis and schizophrenia: Carer Adaptation and Resilience Scale (CARS).

Chapter	Aims	Key findings	Output
		CARS found to have strong psychometric properties: good reliability, a significant correlation to the secondary measures showing good validity, excellent ecological validity due to the high level of input from carers in the development of the measure.	

Exploration of personal recovery for carers

It was apparent that having a high level of carer involvement in the development of the new measure is instrumental for creating a valid measure. The next step was to explore the concept of personal recovery directly with carers and this was done through qualitative interviews. I was very aware that I did not want to 'prime' the carers interviewed with the concept of personal recovery. Therefore, an inductive ontological approach was taken to look at the 'bottom up' information. For this, the study needed a high level of reflexivity and consideration to not discuss the actual term of personal recovery until the end of the interview. The qualitative interview topic guide (see Appendix A) was developed carefully to try to avoid direct reference to personal recovery. Rather the key terms outlined in the operationalised list of personal recovery terms was used to inform the topic guide questions. I felt this worked well to provide a more accurate and unbiased view of carers experiences, while the triangulation interviews that were conducted after the main qualitative interviews provided a dedicated space to discuss the concept of personal recovery in more depth.

The key finding from the qualitative interviews was that carers did not find the term 'personal recovery' valid or acceptable to explain their experiences. The terminology was seen as problematic as most carers understood 'recovery' in terms of clinical or even economic recovery. This fits with the findings of the Vera San Juan et al. (2021) systematic review that found that carers mainly understood recovery in clinical terms, while service users understood recovery more in terms of social or personal recovery. Additionally, Jacob et al. (2015) found that carers' main divergence away from service users views in terms of understanding mental health recovery was because their views aligned with the traditional clinical view of remission of symptoms. This meant that carers would think of personal recovery as impossible because they could not see the possibility of symptom remission and a return to pre-illness life for their loved one. These findings mirror the results of the qualitative study. In that some carers found the term personal recovery potentially damaging as it held connotations that things could return to pre-illness status and that their loved one should be better now. This then adds to their sense of grief and loss at a life that could have been for their loved one and themselves. One of the reasons why carers could not connect with the term ‘personal recovery’ may relate to the term’s development out of the consumer and survivor movement of the 1980’s and 1990’s that was based on service user empowerment, advocacy and self-help (Shepherd et al., 2008) and very much linked to their experiences of mental health services. Carers stated that they often did not feel they needed to experience ‘recovery’ because they had not been unwell themselves, this links to the idea that their perception of recovery was mainly based on clinical outcomes. This is encapsulated the following quote from the qualitative paper (see Chapter 4):

> *“So, I think this recovery idea is the problem? I dealt with somebody with psychosis. And I don't feel I had to be looked upon afterwards as somebody who needed to recover.” T003.*

This finding from the qualitative study of Chapter 4 provided insight into the findings of the systematic review (Chapter 3) as it partly explains why it was difficult to find an outcome measure to assess personal recovery for carers. This is mainly because it has not been a term linked commonly to carers in the past, either by clinicians, researchers, or carers themselves. So, this finding proved to be a great challenge as well as an interesting result. It did mean that the direction and aims of the PhD needed to be reconsidered.

It's not about recovery it’s about “rebuilding your life” (Q015, Chapter 4)

The qualitative findings provided rich insight into other concepts that are more helpful in understanding the process that carers go through. The three main themes identified from the thematic analysis of the qualitative data were: Carer’s Personal Recovery, Building Resilience, and Personal Growth. See Table 3 in Chapter 4.

Clearly carers did not see themselves as being on a recovery journey, but they did acknowledge that things for them improved if the service user was more stable, which links to the idea of ‘parallel recovery’ (Lovelock, 2016). This does seem like a rather tautological argument, which is the idea that recovery occurs in parallel and that the two ‘journeys’ are linked. It seems common sense that if the service user is well then, the carer is well, however, it puts the carer’s own wellbeing in a precarious position, if their happiness and emotional stability is so closely linked to the person they care for. The qualitative data highlighted the importance of carers being able to look after themselves and keep themselves in a stable equilibrium so that they could have the strength and resilience to continue to care for their loved ones when things declined again. As this quote suggests “You’ve got to put your own oxygen mask on first” Q013; this links to the theory of resilience.

Resilience

The theme ‘Building Resilience’ identified in the qualitative data provided a useful alternate understanding of the process that carers go through. This theme explored how carers were able to find better ways of coping with their caring responsibilities, how they make positive adaptations to assist themselves, such as getting support from family and friends and improving their self-care. As was discussed in Chapter 4, these findings link to the theory of resilience, which has been defined as a “dynamic process encompassing positive adaption within the context of significant adversity” (Luthar et al., 2000). Resilience for carers specifically relates to overcoming adversity, to not only survive the day-to-day burden of care, but to thrive and grow stronger to become a more emotionally flexible and a healthier person (Van Breda, 2001; Zauszniewski et al., 2015). Echezarraga et al. (2019) proposed that ‘resilience’ and ‘personal recovery’ are two separate constructs that have several overlapping factors and converge along the ‘journey’ of recovery. These common factors include experiencing adversity or trauma, the use of internal strengths and using external environmental resources to achieve greater subject wellbeing. From the description provided by Echezarraga et al. (2019) it would seem that the theory of resilience is potentially more useful when thinking of carer experiences rather that the concept of personal recovery. In fact, Mountain and Shah (2008) argued that service users who narrated the skills and strengths they had used on the ‘road to recovery’ were in fact naming resilience factors. Echezarraga et al. (2019) concluded that resilience is an integral part and an asset to the recovery process that facilitates personal recovery by counterbalancing the impact of potential risk factors.

Mannion (1996) supports this hypothesis as they found personal resilience was a major factor in the positive changes made by carers and related this to a process of adaption and recovery. The findings from the qualitative study outlined in Chapter 4 showed that carers used several coping tools such as: trying to stay positive, being emotionally flexible, openness, honesty about their loved one’s mental health, getting support from external and internal sources, and self-care. Taken together, these enabled carers to build resilience and ‘rebuild their lives’.

These findings mirror those found by Zauszniewski et al. (2015) who carried out an integrative review of the indicators of resilience in carers. They found resilience was linked to factors such as: acceptance, hardiness, mastery, hope, self-efficacy, sense of coherence, and resourcefulness. The outcomes of resilience link with reduced perceived burden, decreased emotional distress, reduced burnout, better morale and sense of satisfaction, greater psychological wellbeing, better quality of life, and an improved knowledge and understanding of the service user’s diagnosis and symptom management (Amagai et al., 2016; Behrouian et al., 2021; Zauszniewski et al., 2015). The theme ‘Building Resilience’ identified in Chapter 4 is supported by the findings of a recent qualitative study by Estradé et al. (2023) who describe from their data a theme called ‘Learning from mistakes and building resilience and hope’. Estradé et al. (2023) found that carers felt they could become more resilient, accepting, and understanding even if they still hold a sense of loss and grief. Carers were also seen to adapt and adjust their expectations, enabling them to take on a realistic sense of hope, which was a key element to moving forward with their lives (Estradé et al., 2023). The findings from Chapter 4 provided insight into the different elements of how carers can build up their resilience, but there was also evidence that for some this can lead to personal growth, more specifically posttraumatic growth.

Personal Growth

The third main theme identified in the qualitative work of this thesis was ‘Personal Growth’ which related to adaptive changes to carers’ cognitive processes, behaviours, and outlook on life. Carers who manage to make positive adaptations in light of their caring responsibilities and were able to build resilience showed evidence of personal growth. This related to carers gaining a new perspective on life, finding greater meaning and purpose, becoming more patient and understanding of others, having more empathy for others especially those with a mental health diagnosis, improved interpersonal connections, and being able to make deeper personal connections with others. These findings link very well with those found by Estradé et al. (2023) who found that carers were able to find a sense of meaning from the experience of the illness itself, they demonstrated a newfound perspective and purpose in life and that their relationship with their loved one was strengthened. The findings from this PhD are also consistent with research showing that caring can be a source of positive transformation that can provide a sense of inner strength and satisfaction (Chen & Greenberg, 2004; Pickett et al., 1997; Shiraishi & Reilly, 2019).

It is important to note that the 'Personal Growth' described by carers was a change that occurred over a longer term for some carers and was something born out of a traumatic situation that was thrust upon them. This links well with similar literature that notes how carers go through a traumatic experience as their loved one is experiencing their psychotic crisis (Shiraishi & Reilly, 2019). Carers are shocked and completely unprepared often with a distinct lack of understanding about the symptoms they are witnessing (Estradé et al., 2023). As the introduction outlined, carers show symptoms of posttraumatic stress (PTSS) due to the exposure to difficult patient behaviours like verbal and physical aggression (Darmi et al., 2017; Hanzawa et al., 2013; Kingston et al., 2016). For many carers this traumatic experience starts even before the onset of the illness and returns in a cyclical nature if the person they care for relapses (Shiraishi & Reilly, 2019). This can lead to the carer to be consumed by the illness in a "perpetual embodied vigilance" (Lavis et al., 2015) watching out for the first warning signs of relapse. Lavis et al. (2015) found similar findings arguing that carers are in a continual process of adjustment, finding their lives and themselves have, bit-by-bit, been cumulatively and hugely reshaped. This reshaping lasts well beyond the service user's 'recovery' journey.

The findings also show that carers go through a traumatic process which can then lead to personal growth. The concept of posttraumatic growth (PTG) as outlined by Calhoun and Tedeschi (Calhoun & Tedeschi, 2001; Calhoun & Tedeschi, 2014a; Tedeschi & Calhoun, 1996, 2004) can be seen as useful to apply to the experience of carers, more so than the concept of 'personal recovery'. As this quote from Chapter 4 suggests:

> *"That is a perfect description posttraumatic growth! Because it is traumatic…it's actually describing what happened, the trauma to the carer, and the growth post the trauma…that's a clearer description, than recovery." T003.*

PTG has been defined as the experience of positive change that occurs as a result of the struggle with highly challenging life experiences (Tedeschi & Calhoun, 2004). It is manifested in several ways, such as increased appreciation for life, more meaningful interpersonal relationships, increased sense of personal strength, changed life priorities, and a richer existential and spiritual life (Tedeschi & Calhoun, 2004). The qualitative data overwhelmingly showed how traumatic it was to care for a loved one with a serious mental illness as all carers described extremely upsetting situations that they had to deal with, often with little understanding or support from health professionals, wider family or friends. Despite this, carers described positive personal transformation, discussing strength, empowerment, increased confidence (often to fight for better service provision for their loved one), having a greater sense of meaning and purpose in the lives, strengthened relationships with deeper personal connections and improved communication skills. These qualitative findings can be directly translated to the framework of PTG. For example, the three general domains of PTG have been outlined as: changes in the perception of self, changes in the experience of relationships with others, and finally changes in one's general philosophy of life (Calhoun & Tedeschi, 2006). PTG has been argued to be a way to "restructure the life narrative" (Calhoun & Tedeschi, 2006) which allows the individual a way to learn to accommodate the unanticipated events around the traumatic experience. Calhoun and Tedeschi (2006) postulate that in order to achieve a sense of PTG the individual needs to go through a period of 'reflective rumination’ to repair, restructure and rebuild the individual’s way of understanding the world. There is often a time lag in this process, and this was mirrored in the results of this thesis, in that carers that had only recently taken on a caring role were less likely to describe elements of PTG. Calhoun and Tedeschi (2006) also note the importance of understanding the ‘meaningfulness’ of the experience, which would happen once the initial aftermath of the trauma has occurred, and the individual is coping successfully so that the person is not preoccupied with mere survival. This is an important consideration for assisting carers to reach a level of PTG themselves. A key stage is to help them cope with the basics of day to day caring as the first steppingstone before they are able to reach PTG.

Links have been made between PTG and the theory of resilience, and this is reflected in the findings of this thesis. Janoff-Bulman (2014) proposed that an aspect of PTG is an element of ‘psychological preparedness’ for future traumatic events that is similar to the concept of resilience: “these stronger and wiser people embody resilience” (Calhoun and Tedeschi, 2006 pg. 11). Rutten et al. (2013) linked the theory of PTG to resilience by arguing that individuals that have the resilience to adapt and recover quickly after experiencing life adversities may be able to surpass their previous levels of mental health by adapting to obtain a better understanding of life, new perspectives and be able to respond better to similar challenges in the future. It is important to note however, that there should be a clear delineation between the two theories, as Calhoun and Tedeschi (2006) state that resilience was never defined as a ‘transformation or reformulation’, rather the ‘ability to recover readily from illness, depression or adversity’. It would seem that PTG relates more to a permanent change to an individual’s core personality, while resilience is the ability to bounce back to a pre-existing state. An important element to PTG is that it is a complex phenomenon that often surprises people as it is not a conscious goal (Tedeschi & Calhoun, 2004), and this is something that was echoed in the qualitative data, that any growth was a by-product of an unwanted hardship as this quote demonstrates:

> *“You probably will end up stronger and more knowledgeable as a person as a result of this. It isn't a strength and a knowledge that you would actually seek out*

> *to be honest with you. You wouldn’t wish it, it's not ‘well I’m really glad I went through that trauma’, no.” T001 (Chapter 4)*

As the PhD progressed it became clear that PTG was an important theory to assess for carers and this was the rationale behind the selection of the Posttraumatic Growth Inventory Short Form (PTGI-SF) (Cann et al., 2010) as a secondary measure for the psychometric evaluation of the new measure.

Justification of the need to create a new quantitative measure

Despite the qualitative data showing that the concept of personal recovery was not appropriate to apply to carers, some valuable insight was gained in the process that carers do go through. The results from the systematic review (Chapter 3) showed that there was no single measure to assess personal recovery for carers, but it also showed that there was no measure to assess adaptation, resilience, or personal growth for carers either. The initial aim to create a new measure of personal recovery for carers therefore had to change as there was still a gap present. Creating a new measure for carers was seen as valuable to provide quantifiable and generalisable data so that we can understand a more holistic picture of carers’ experiences and support their wellbeing. Chapter 3 (the systematic review) showed the importance of creating outcome measures specifically for the population being assessed (Boyer et al., 2016; Harvey et al., 2005; Rat et al., 2007) as this allows for more valid results to be gained from a particular population. Creating a new outcome measure for carers could also have valuable clinical and research applications. An obvious application would be to assess carers’ wellbeing and support needs. It could also be used to assess the efficacy of new interventions for carers, and it could provide insight into specific mechanisms of action behind the adaptation to caring and how carers may become more resilient and what facilitates personal growth for them. A new measure may also be helpful on an individual level for carers as it could show them how far they have come on their journey by highlighting some of the positive aspects to caring that they may have experienced. Thus, the Carer Adaptation and Resilience Scale (CARS) was developed.

The CARS 'journey'

The CARS was developed following guidance on good questionnaire development (Creswell & Plano Clark, 2011; DeVellis, 1991, 2012; Streiner et al., 2015). Following an exploratory sequential research design (Creswell & Plano Clark, 2011), outlined in Chapter 2, it was clear how the exploratory phase of the systematic review and qualitative interviews then led onto the next phase of measure development (see Figure 2 in Chapter 2). To ensure good ecological validity and acceptability to carers, the concept of 'personal recovery' became less of a focus in the development of the questionnaire items. Instead, much of the wording of the items was taken directly from the qualitative interview data, thus following an inductive 'bottom up' approach. It became clear that the measure should assess the sub-components of personal recovery such as: adaptation, adjustment to caring, resilience, acceptance, self-care, personal growth, posttraumatic growth, empowerment, support, and interpersonal relationships, and that this should be done without imposing the phrase of 'personal recovery'. Therefore, the name of the measure was changed from the Relatives Recovery Questionnaire (CRQ) to the Carer Adaptation and Resilience Scale (CARS).

Developing the draft outcome measure

Chapter 5 of this thesis described in detail the development of the CARS, from the initial 85 item pool to the final 37-item scale. The main aims of this phase were to assess the content validity of items, assess the clarity of item wording and to see if the response options were acceptable to carers. The use of the cognitive interviewing technique (Willis, 2004; Willis, 2008; Willis & Artino Jr, 2013; Wright et al., 2021) proved to be an unexpected benefit at this stage. The original research proposal had stipulated two focus groups would be used to discuss the draft questionnaire, however, COVID-19 restrictions at the time meant that any kind of fact to face group focus group was not possible. A viable alternative was individual online cognitive interviews with carers where we could work through the draft questionnaire ‘live’. In practice, I felt that this provided far richer data than a focus group as it felt like a very intimate experience between myself and the carer. We were able to spend on average an hour together talking through their responses and how the question items made them feel or think about their situation. Some of the carers themselves valued the experience, with one carer sharing that it had ‘really brought things home’ for them. The results from the cognitive interviews highlighted problems with some items in terms of the ‘specificity’ of the wording for carers experiences, the ‘semantic’ meaning of items and whether the wording was confusing, and the ‘conceptual’ nature of some items and if this was too complex. These findings lead to 3 items being dropped, 2 items being merged and the re-wording of 22 items. Carers also provided feedback on the questionnaire instructions and recommended some changes; however, they were happy with the original 5-point Likert scale response options initially proposed.

Validating the CARS

The next step on the CARS journey was to validate the measure using a large sample of carers. This represented the main quantitative component of the PhD and is outlined in full in Chapter 6. Data from 138 survey packs were analysed and a final six factor model was found based on an Exploratory Factor Analysis. A total of eight items were dropped from the CARS due to poor factor loadings. The final 29-item CARS is divided into five domains based on the results from the EFA (two factors were merged into one domain as we felt the two factors addressed the same topic area). The final five domains were: Personal Growth, Adaptation and Resilience, Personal Recovery, Mental Health Concerns, and finally Understanding and Empathy. These domains match to the previous theoretical literature discussed in this chapter, for example, the theory of resilience, posttraumatic growth and to an extent personal recovery.

The subsequent psychometric evaluation demonstrated that the CARS has strong psychometric properties, good reliability, good convergent validity, and excellent ecological validity due to the high level of input from carers in the development to the measure. It is interesting to note that out of all the secondary measures used to assess convergent validity, the Posttraumatic Growth Inventory – Short Form (PTGI-SF) (Cann et al., 2010) showed the strongest correlation with the CARS, r (130) = .480, $p < .001$. This represents clear evidence signalling that the theory of PTG is a relevant concept to consider for carers.

Did the methodological choices and methods work for this PhD?

The short answer is yes! The pragmatic approach taken for this PhD meant that the most useful methods could be used at each stage. Choosing a mixed methods approach fitted well with this pragmatic approach and following an exploratory sequential research design (Creswell & Plano Clark, 2011) provided a clearly structured framework that directed the development of the measure. Using a mixed methods approach, allowed the use of an interpretivist ontology to explore the concept of personal recovery in depth through the qualitative interviews. The subsequent thematic analysis presented an unexpected outcome that carers do not ‘recover’ but this provided valuable insight and without this inductive exploratory phase the resulting questionnaire would not have been at particularly valid for carers. The final quantitative phase of the research allowed for the empirical testing of the new questionnaire in a formal, objective and systematic way – thus following more a positivist ontology.

There are two important points to note about the methods chosen. The first one relates to the use of the COSMIN checklist for the systematic review in Chapter 3. There were both positive and negative aspects to using the COSMIN checklist. The COSMIN has several strengths as a robust and rigorous assessment tool that was developed by an international team of experts (Mokkink et al., 2010). The COSMIN also provides a very useful taxonomy of definitions of measurement properties, which has been helpful considering the wide array of inconsistent definitions currently in use (Rosenkoetter & Tate, 2018). The COSMIN checklist is becoming recognised as the ‘gold standard’ and is a popular tool for many health-related systematic reviews (Rosenkoetter & Tate, 2018). Because the COSMIN checklist assesses all available studies that have validated outcome measures, it also provides an excellent overview of all the research on the particular outcome measure to date. There are however limitations to the COSMIN checklist. The

COSMIN 4-point checklist works on a rule where the ‘lowest score wins’ and because of this the overall score is often much lower than the ‘average’ score for that property. For example, the checklist heavily weights the reporting and handling of missing items, which it has been argued underrepresents the overall quality of the studies (Park et al., 2013). The COSMIN checklist highlights what should be considered good practice in measure development. For example: to achieve high scores on the COSMIN checklist researchers should provide detailed reporting of missing items and imputation methods. Sample sizes should be adequately large with recommended calculations based on seven times the number of items on the measure or being greater than or equal to 100 to achieve an ‘excellent’ score on checklist. This represents quite an arbitrary cut off criterion in terms of sample sizes, and would suggest that the CARS would not perform very well based on the COSMIN checklist because the sample size of 138 would be considered low.

The second important methodological note relates to the robustness of the qualitative phase of this research. Two concepts central to judging the robustness of findings are reliability and validity. Reliability is the extent to which the research data measures what it initially set out to measure, and it also relates to whether that data can be replicated, and this is contested in qualitative research. Constructivists argue that no single reality exists in the first place, so any sort of replication of findings is pointless (Marshall & Rossman, 2010). Lewis et al. (2013) do see reliability as important; however, the concept needs to be modified to look at collective findings and overarching meanings generated which requires transparency showing consistent and rigorous data analysis and interpretation. The qualitative work in this thesis aimed to be rigorous in the data analysis and interpretation and thus followed the clear steps outlined by Braun & Clarke (2006 & 2019) and demonstrated a clear epistemological and ontological stance as is outlined in Chapter 2. Validity is understood as the correctness and precision of research, and how well the findings accurately represent the phenomena being studied. Again, there is debate among researchers about whether this concept is valid for qualitative research. Guba and Lincoln (1994) argue that qualitative research should be judged on other criteria such as authenticity, whether the research has brought about greater understanding and prompted action by empowering people to change their social situation. Lewis et al. (2013) and Silverman (2013a) argue that the term validity should be used in a modified manner because this will ensure that qualitative research is taken seriously by policy makers.

To ensure robustness of validity, qualitative researchers can include certain techniques in their analysis. Triangulation is where different sources can be used to confirm findings, with sources including: others research, using different methods of data collection, gaining multiple analyses from others (researchers and respondents) and by looking at the data from different theoretical perspectives (Patton, 2002). Mays and Pope (2000) suggest other methods to ensure robustness such as: respondent validation (checking the results are accurate with participants), providing a clear explanation of the methods of data collection and analysis (being transparent), being reflexive, paying attention to negative and deviant cases that do not fit with the researchers theory which prompts theory refinement or the use of an alternative theory, and ensuring the research is relevant and adds to scientific knowledge. The qualitative study of this thesis included many of Mays and Pope's (2000) recommendations, for example respondent validation was achieved by conducting the additional triangulation interviews. Additionally, a transparent account of the methods of data collection and analysis was presented, and reflexivity was an important component to the study and is evidenced in the qualitative outcome paper. The recommendation by Mays and Pope (2000) to pay attention to the negative or deviant cases actually became a central finding to this thesis as it became apparent through the qualitative interviews that the central concept being investigated, personal recovery, needed further respondent validation and this is what promoted a further set of follow-up or 'triangulation' interviews.

Importance of having carer involvement in the study

The value of research is that it is acceptable, valid and useful for the population being studied. This is why PPI (Patient and Public Involvement) is so important in research and has become a recent research priority, for example, the INVOLVE framework (INVOLVE, 2012) outlined by the National Institute of Health Research (NIHR) in the UK. The systematic review highlighted the importance of having a good level of PPI (Patient and Public Involvement) in questionnaire design and is it seen as good practice in measure development (Streiner et al., 2015). PPI refers to the active partnership between the public and health researchers, meaning that the public work alongside the research team as advisors or co-researchers as they have direct insight into what it is like to live with a particular insight, leading to research that is more relevant to the needs of patients, carers and service users (INVOLVE, 2012). This PhD has shown a good level of PPI. Study material like information sheets and consent forms were shown to carers who provided feedback on the clarity and readability of the work. The qualitative interview topic guide was reviewed by carers before ethical approval was sought. I also received feedback from some carers on the draft online survey pack before commencing the measure development phase of the research. Without the direct feedback from carers, I would have created a measure based on a concept that carers did not relate to and that some even felt was potentially detrimental. Carer involvement was a core component in the success of this work and is very much appreciated.

Reflexivity and researcher bias

It has been argued that all research is subject to researcher bias (Morrow, 2005) and both quantitative and qualitative research perspectives have different ways of approaching subjectivity and this is very much impacted by the paradigm guiding the research. For example, interpretivists/constructivists are more likely to embrace the researcher as being a co-constructor of the meaning and interpretation of the data. One way to address this source of bias is for the researcher to make their implicit assumptions and biases overtly clear to themselves and other researchers (Morrow, 2005). This process is known as reflexivity and is mainly a tradition within qualitative research. One of the most valuable methods for reflexivity is by keeping a self-reflective journal throughout the research study as a place where the researcher can keep a record of their experiences, reactions, assumptions, or biases (King, 2004; Ritchie et al., 2013). Ormston et al. (2013) suggest a solution of ‘emphatic neutrality’, where because the research cannot be value free, that the researcher should be fully transparent by stipulating their assumptions and biases through reflexive accounts. Morrow (2005) makes the recommendation that academic writing should include a ‘researcher-as-instrument’ statement that outlines the researchers past experience, training, assumptions, expectations and biases that might have been brought to the research, and how these were managed. Providing reflective accounts in qualitative research promotes transparency and is an indicator of quality in research (Sirris, 2022; Yardley, 2000).

Because of the qualitative component of this PhD, it was important to provide a reflective account to explain my position as a researcher and any biases that may have been present in this research. My choice of research topic was very much influenced by my experience of two acute psychotic breaks in my 20's where my family became my carers. I saw the immense effect this had on my family and wanted to do something to help other carers. This experience I feel was a great positive for this PhD as I had lived experience of psychosis and a deep understanding of what other service users and families have gone through. I did not share my personal experience of psychosis with the carers interviewed for the study unless they asked me, and this would only ever be at the end of the interview. I did not want my experience to influence their decision to take part or the information they shared with me. Surprisingly my experience of becoming a parent had a big impact in how I related to the carers I worked with. I suddenly understood the strong impetus a parent has to help and protect their child. I kept a reflective journal throughout the qualitative phases of this PhD so I could track how my prior experience and assumptions may have influenced the data collection or analysis. My position as a female from a middle-class background with white British ancestry should also be considered here. I do not have lived experience as a person from an ethnic minority background or from those of another gender or class. This means that the lens through which I devised this study, the topic guide, the questionnaire items and the interpretation of the qualitative data will have been biased to my understanding of the world and I may not have captured the views of others in a generalisable sense. It must also be noted that I have emigrated to England as an adult, having grown up in South Africa. Therefore, I have had a different experience as a white person living towards the end of apartheid. I have had to learn about British culture, the different ethnic minority groups that make up the population, and the class system. It could be considered that this has given me 'fresh eyes' on a culture that I did not grow up in. Because of this I like to think that I may view cultural differences in the UK more objectively. I was also aware that my past experience as a researcher was a factor to consider. My own position as a qualitative researcher is very much aligned with the interpretivist/constructionist paradigm due to my past work using discourse analysis (Potter & Wetherell, 1987) for my undergraduate dissertation and working as a qualitative researcher prior to starting my postgraduate studies. I value the subjective nature of experience and see that individuals all have experiences that are unique to them that are built up from their personal histories, interpersonal relationships, political milieu of the time, power dynamics with others, and influenced by their perception of themselves and society. The type of qualitative analysis required for this PhD was far more pragmatic and did not require this level of analysis, so it was something that I was aware of and journaled about. This may have biased my interpretation of the qualitative data looking at things from an interpretivist lens rather than a more pragmatic lens. I can see that there is great value in working as a team on research studies particularly for qualitative research as it can be very easy for a researcher to get subsumed into their own worldviews when carrying out the analysis.

A further potential point of researcher bias present in this PhD relates to the view of one supervisor (WS) who was sceptical about applying the concept of personal recovery to carers. Professor Sellwood has worked directly with carers in the past in his capacity as a clinical psychologist and felt that carers would mainly understand recovery from a clinical perspective. Professor Sellwood felt that carers experienced a process of adaptation or adjustment rather, but was open to the research study and made his views explicit from the beginning. This helped me to understand his potential bias when it came to the qualitative data analysis team meetings. I tried to remain open to the idea of personal recovery for carers as far as possible.

Strengths of this PhD

This PhD has several strengths. It has provided a thorough investigation of the concept of personal recovery for a new population. The concept of personal recovery is influential to service user literature and has made a real impact on mental health service provision, so it appeared to be an important concept to consider for carers. This PhD therefore filled the gap in current literature on this topic and answered the calls for more a greater focus on recovery for carers and families (Deane et al., 2015; Lovelock, 2016; Marshall et al., 2013; Norton & Cuskelly, 2021; Price-Robertson, Manderson, et al., 2017; Price-Robertson, Obradovic, et al., 2017; Wyder & Bland, 2014). This PhD demonstrates that the perspectives of carers were truly considered as it did not simply take a deductive approach to confirm personal recovery, but rather took an inductive approach to explore what might be going on instead, and letting the data 'speak for themselves'. The findings from this PhD do provide an exploration of the more positive aspects of caring which tends to be under researched. This has provided a more holistic view of carer experience, something that has been called for previously (Onwumere et al., 2018). This PhD also supports the call for greater support for carers and provides a new measure that can assist in understanding carer experience and how to promote greater wellbeing.

A further strength of this PhD was the good level of PPI involvement as carers were consulted at all phases of the research, and because of this the CARS can be seen as being valid and meaningful to the population being assessed. This PhD has also produced a useful output in the form of a validated new measure that will be very beneficial for future research and in clinical settings. This work has also provided a snapshot of carer experience through the COVID-19 pandemic, as data were collected during the final quantitative phase (see Chapter 6). This was primarily to provide insight into the population characteristics but also gives some insight into the challenges that carers faced during the pandemic. This finding supports other similar research that also revealed the impact that the COVID-19 pandemic had on carers (Onwumere et al., 2021; Mork et al., 2022). Another strength of this PhD is the finding that the cognitive interviewing method is a highly effective technique in questionnaire design and is recommended for use in further measure development studies.

Limitations of this PhD

The main limitation of this PhD is the sample size in the quantitative phase. The target sample size was 200 participants which was based on recommendations by DeVellis (2012) and Comrey (1988) to have a sample that is appropriately large and representative enough to carry out an EFA. Recruitment for the quantitative study proved to be slow and difficult, due to data collection occurring through the COVID-19 pandemic, meaning that many carer support groups had closed down because they were not able to successfully transfer across to running online groups. I found recruitment through 3rd sector charities particularly difficult and even experienced animosity from some support group leaders as they felt this study was an unnecessary demand on carers who were already overwhelmed and struggling. Therefore, the bulk of recruitment occurred through the 14 different NHS trusts that were supporting the study, which also proved slow, as the trusts did not offer any kind of patient identification meaning that carers could not be approached directly. NHS trusts did advertise the study through different mental health services and through their own social media and newsletters.

A further limitation related to the homogenous sample which was predominantly made up of white British females. For example, the development of the CARS is based primarily on the interview data collected from participants from a white British background. This means that issues relevant to ethnic minority carers were not captured in the development stage of this new measure and thus the measure cannot be generalised across all carer groups. A small percentage of participants from minority ethnic groups did take part in the larger validation study but this only made up 7.11% of the whole sample. This lack of heterogeneity in sample make up is consistent with other carer literature (Gallagher & Wetherell, 2020; Hazell et al., 2020; Smith et al., 2014), so is a common concern across research with this population.

Another limitation of this PhD also relates to the quantitative stage and relates to the assessment of the CARS validity, in particular divergent validity. The aim of assessing divergent validity is to measure how far a new measure does not correlate with a measure of the ‘opposite’ construct. This proved to be a great challenge as it was not clear what would be an ‘opposite’ construct for the concepts assessed in the CARS. The topics assessed in the CARS seemed quite a complex mix of adaptation, resilience and posttraumatic growth and there was no clear-cut measure that could be seen to be the opposite of these constructs. The measure of convergent validity did show correlation to similar measures, which is a good indicator of the validity of the CARS.

The CARS may be seen to be culturally specific as it was developed using a sample from an individualistic and secular country – the UK. An example of this relates to the items on the CARS that asked about spirituality or religion as a potential coping mechanism for carers. This was an item on the Posttraumatic Growth Inventory – Short Form (PTGI-SF) (Cann et al., 2010) that was developed in the USA, and appeared to be a key element in PTG, however, this item was dropped from the CARS as it did not load with any other factor for the EFA and appeared to be a weak item from the item-total correlations, possibly because the UK is a far more secular nation compared to the USA.

Implications

The theoretical implications of this PhD show that the concept of 'personal recovery' is not relevant to carers and can in fact be seen as damaging in reminding carers that the person they care for should be able to 'recover' to premorbid levels. This was mainly because carers had a different understanding of the term 'personal recovery' basing the word 'recovery' more along the lines of a clinical or economic recovery where things return to the way they were before. The theory of Posttraumatic Growth was found to be more relevant to carers as it appeared to capture the notion of a change in carers outlook on life but through a traumatic experience. This aligns more with the themes from the qualitative interviews such as 'rebuilding lives' and becoming more resilient. This PhD provides greater theoretical understanding about the experiences of carers and offers a more holistic view of the carer experience but looking at some of the positive aspects to caring. Clinical implications of this PhD relate to the 'end product' of the CARS measure than could be used by Family and Systemic Therapists to measure outcomes for carers over the course of therapeutic work. This could provide valuable insight into the wellbeing of carers and whether they are making progress in adapting to their caring role. It also provides a measure that looks at some of the positive outcomes from caring and is not focused on carer burden. The CARS may also act as a therapeutic tool as it may show carers how far they have come on their caring 'journey'.

Future directions

There are several future directions for this research. One of the most obvious next steps would be to run a larger validation study of the CARS with a bigger sample, ideally over 200 participants. With a larger data set a principal components analysis could be run, which could confirm the six-factor model found from EFA in the quantitative phase of this PhD. Conducting a larger validation study would also allow for a purposive sampling strategy to be adopted, where a deliberate attempt can be made to sample participants with particular characteristics or from a wider variety of cultural backgrounds (Flick, 2008; Ritchie et al., 2003). To create a truly generalisable measure, input from those from minority backgrounds would need to be sought. One way to do this could be to run focus groups or cognitive interviews with those from minority backgrounds to get an understanding of the questionnaire and if it captures their caring experiences accurately. An updated version of the CARS that considers these views could then go through a larger validation study with a stratified sample to make sure that individuals from different ethnic background are captured in the sample. This would allow researchers to see if the CARS was generalisable to all carers of those with psychosis. A further consideration would need to be made as to or whether it may be more appropriate to create a culturally adapted version of the CARS. It may also be possible to adapt the CARS for carers of those with other serious mental ill health, such as bipolar disorder, personality disorder or posttraumatic stress disorder. Ideally the CARS will be used in an applied settings to support carers. This may be in clinical settings to assess whether therapeutic interventions have a positive outcome for carers. For example, it may be a good measure to use during family therapy as a counterpart measure to the Questionnaire about the Process of Recovery (QPR) (Neil et al., 2009). The CARS could also be used in clinical research settings to assess whether new interventions work well for carers, or to explore the mechanisms of change that take place for carers as they travel along their caring journey.

Conclusions

This PhD has answered all the aims outlined at the proposal stage. The first aim was to understand the nature and experience of personal recovery for carers. This was clearly answered, and I found that carers experience of personal recovery is present; however, it takes a different form to that which is understood for service users. Additionally, the semantic 'wording' of the term personal recovery is not acceptable to carers and may in fact be detrimental to use. This PhD did find that other theories may be more relevant and helpful in understanding carers' experiences, such as the concepts of resilience and posttraumatic growth. The second aim of this work was to develop a new outcome measure to assess personal recovery for carers. This was met; however, the new measure does not overtly assess personal recovery, rather the subcomponents of recovery. Finally, this work has managed to validate the new measure, with the CARS being found to demonstrate good reliability and excellent validity due to the high level of input from carers themselves in the development stage, however the measure cannot be generalised to capture the experiences of carers from a minority ethnic background. Overall, this work provides greater insight into the carer 'journey' and maps out some of the positive adaptations that carers can make to become stronger, wiser, more resilient, empowered, and nurturing to themselves.

Appendices

Appendix G: *Inclusion and exclusion criteria for title and abstract screening of systematic review*

Criteria	Inclusion	Exclusion
Duplicate	Not a duplicate	A duplicate
Abstract/ Language	Abstract and paper title provided in the English Language.	Abstract or title either not in English, or non-existent.
	Paper appears to have been published in English language, in an English language journal.	Paper appears to be published in a language other than English.
Publication type	Primary research studies, measure validation papers, measure development papers, systematic review, meta-analysis, conference proceedings, grey literature, peer reviewed papers.	Opinion/discussion piece, book review, a noting of a correction to a study, study protocol, unpublished dissertations, and theses.
		Papers using a qualitative approach as their primary research methodology.
	Papers using a quantitative approach or mixed methods as their primary methodology.	
Date of publication	Any	None
Population	Adult carers/relatives/friends – may include: parents, spouses, partners,	Paid carers, in-patient care staff, young carers, relatives under the age of 18 years old. Young carers (below age 18)

	grandparents, siblings, extended family, close friends in a caring role.	were excluded as they have a different and more complex care experience to adult carers that may include more input from external agencies.
Clinical group (service user)	The service user of the relative/carer must have a diagnosis of a psychosis related serious mental health problem and must be an adult over the age of 16 years. Includes: Schizophrenia (all types), acute and chronic psychosis, first episode psychosis, psychotic episodes. Psychotic features of other serious mental illness, such as bipolar disorder and personality disorder, where this is the main focus of the paper.	All forms of dementia. Any form of learning disability. Any form of developmental disorder such as: language disorders, learning disorders, motor disorders, autistic spectrum disorders and ADHD. Any physical health problems such as cancer, stroke, head injury etc. Those under the age of 16 years.
Outcome measures	Any formal set of questions that have been designed and tested for use with relatives and carers. Includes self-report measures such as: questionnaires, surveys, outcome assessments, instruments and rating scales.	Measures designed for populations other than relatives, even if those measures are commonly used in research studies with relatives, for example: The General Health Questionnaire (GHQ).

	Also includes measures completed by a health professional through verbal questioning of the relative, such as in a structured interview.	Any measures assessing the service user. Measures that include a section with open ended questions or semi-structured interviews. Measures developed or translated into another language. It will be assumed that measures that have been used in foreign language research studies will have been translated into a foreign language, unless it is stipulated in the methods sections that English language measures were used.
Concepts being assessed in the outcome measures	Relatives' own personal recovery as relates to the 'recovery approach' and 'mental health recovery'. Aspects of recovery such as: Hope, optimism, goals, relationships, identity, meaning, personal responsibility, 'full engagement with life', empowerment, knowledge, 'life satisfaction', self-direction, 'full potential', person-driven, 'peer support', 'support groups', community, strengths, respect, 'motivation to	Physical health, general health, carer burden, family burden, negative aspects of caregiving, caregiving hassles, stress scales, strain scales, caregiver distress, depression, anxiety, personality inventories, medical outcomes.

change', 'positive thinking', 'valuing success', aspirations, 'positive sense of identity', 'quality of life', 'meaningful life', 'meaningful social roles', 'rebuilding life', employment, self-efficacy, coping, adaptability

Other aspects relating to the positive aspects of caregiving: social support, interpersonal support, family satisfaction, family adaptability and cohesion, spirituality and personal growth.

APPENDIX H: *Example search strategy for systematic review*

Search strategy: PsychINFO (EBSCOHost)

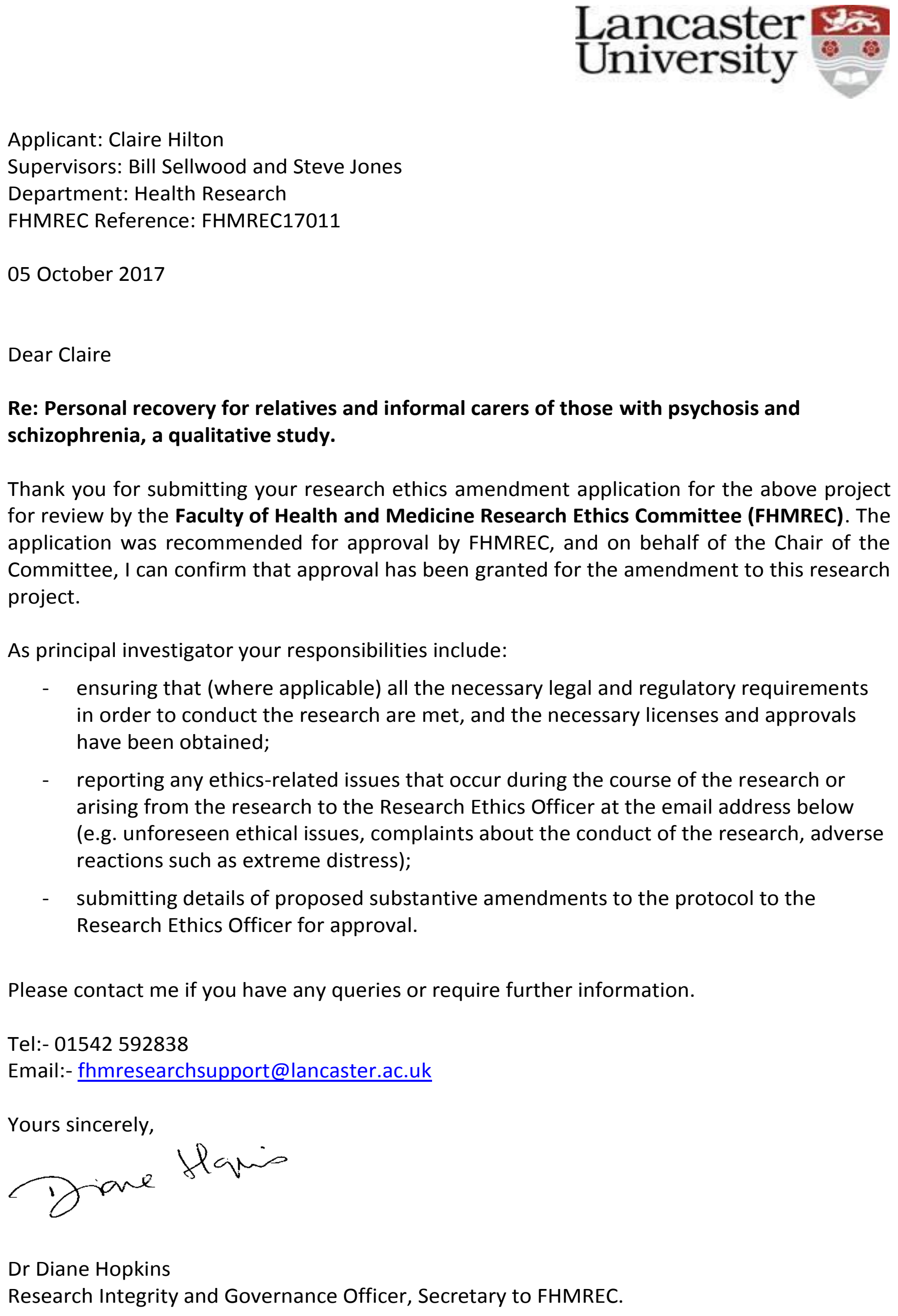
1. [POPULATION] (Using thesaurus subject terms) DE "Caregivers” OR DE "Family" OR DE "Extended Family" OR DE "Family Members" OR DE "Adult Offspring" OR DE "Biological Family" OR DE "Daughters" OR DE "Sons" OR DE "Parents" OR DE "Fathers" OR DE "Mothers" OR DE "Siblings" OR DE "Brothers" OR DE "Sisters" OR DE "Spouses" OR DE "Husbands" OR DE "Wives" OR DE "Significant Others"
2. [POPULATION] (Using key words) carer* OR relative* OR families OR 'family caregiver*'
3. Thesaurus subject terms OR key words
4. [POPULATION] (Using thesaurus subject terms) DE "Psychosis" OR DE "Acute Psychosis" OR DE "Affective Psychosis" OR DE "Chronic Psychosis" OR DE "Postpartum Psychosis" OR DE "Reactive Psychosis" OR DE "Schizophrenia" OR DE "Acute Schizophrenia" OR DE "Paranoid Schizophrenia" OR DE "Mental Disorders" OR DE "Bipolar Disorder" OR DE "Schizoaffective Disorder" OR DE "Chronic Mental Illness" OR DE "Personality Disorders"
5. [POPULATION] (Using key words) psychosis OR psychoses OR psychotic OR 'psychotic disorder' OR schizophren*
6. Thesaurus subject terms OR key words
7. [TYPE OF INSTRUMENT] (using thesaurus subject terms) DE "Measurement" OR DE "Psychological Assessment" OR DE "Behavioral Assessment" OR DE "Cognitive Assessment" OR DE "Emotional Assessment" OR DE "Motivation Measures" OR DE "Stress and Coping Measures" OR DE "Questionnaires" OR DE "Surveys" OR DE "Data Collection"
8. [TYPE OF INSTRUMENT] (using key words) "outcome measure*" OR "instrument* and assessment*" OR "measurement scale*" OR "rating scale*" OR "survey*" OR "questionnaire*" OR "patient reported outcome measure" OR "patient reported outcome" OR "self-report measure"
9. Thesaurus subject terms OR key words
10. [CONSTRUCT] (key words only) recovery OR "recovery in mental health" OR "recovery model mental health" OR "mental health recovery" OR hope OR optimism OR meaning OR purpose OR empowerment OR "life satisfaction" OR "positive thinking" OR "valuing success" OR aspirations OR "positive sense of identity" OR "quality of life" OR "meaningful life" OR "rebuilding life" OR self-efficacy OR coping OR adaptability OR adjustment
11. Final Search using searches 3 AND 6 AND 9 AND 10
12. Limit to Age 18+ (Adulthood), English Language, Human Participants

Appendix I: *Quality criteria for good measurement properties modified from Terwee et al. (2007) and DeVet et al. (2011) used in systematic review*

Measurement property	Rating*	Criteriaª
Content validity (including face validity)	+	All items refer to relevant aspects of the construct to be measured AND are relevant for the target population AND are relevant for the purpose of the measurement instrument AND together comprehensively reflect the construct to be measured
	?	Not all information for '+' reported
	-	Criteria for '+' not met
Structural validity	+	*Factors should explain at least 50% of the variance or adequate or good fit by goodness-of-fit criteria for a confirmatory factor analysis (CFA) or exploratory factor analysis (EFA).*
	?	Not all information for '+' reported
	-	Criteria for '+' not met
Internal consistency	+	At least limited evidence for unidimensionality or positive structural validity AND Cronbach's alpha(s) ≥0.70 and ≤0.95

	?	Not all information for ‘+’ reported OR conflicting evidence for unidimensionality or structural validity OR evidence for lack of unidimensionality or negative structural validity
	-	Criteria for ‘+’ not met
Reliability	+	ICC or weighted Kappa ≥0.70
	?	ICC or weighted Kappa not reported
	-	Criteria for ‘+’ not met
Construct validity *(Hypothesis testing)*	+	*Convergent or divergent validity tested AND good correlations reported*
	?	No correlations with instrument(s) measuring related construct(s) AND no differences between relevant groups reported
	-	Criteria for ‘+’ not met

APPENDIX J: *Letter of favourable opinion from Lancaster University FHM Ethics committee*



Applicant: Claire Hilton
Supervisors: Bill Sellwood and Steve Jones
Department: Health Research
FHMREC Reference: FHMREC17011

05 October 2017

Dear Claire

Re: Personal recovery for relatives and informal carers of those with psychosis and schizophrenia, a qualitative study.

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

APPENDIX K: *HRA Letter of favourable opinion for NHS ethical approval for the CARS study*

NHS
Health Research
Authority

South Central - Oxford B Research Ethics Committee
Whitefriars
Level 3, Block B
Lewin's Mead
Bristol
BS1 2NT

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

24 February 2021

Prof William Sellwood
Director of Clinical Psychology
Lancaster University
Division of Health Research
Health Innovation One
Lancaster University
LA1 4AT

Dear Prof Sellwood

Study title:	**Development and validation of the Carer Recovery Questionnaire (CRQ).**
REC reference:	**21/SC/0008**
Protocol number:	**N/A**
IRAS project ID:	**219438**

Thank you for your letter of 17th February 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Good practice principles and responsibilities

Appendix L: *Qualitative study recruitment poster*

Do you care or support someone with psychosis or schizophrenia?

Are you aged over 18 years?

I would like to talk to you about your experiences of providing care and how this may have affected your health and wellbeing.

If you would like to take part in this study as part a PhD research project, then please contact Claire Hilton.

Tel: 01524 593555
Mob: 07393 874814
email: c.a.hilton@lancaster.ac.uk
twitter: @clairehilton7
website: https://recoveryforrelatives.wordpress.com

THE SPECTRUM CENTRE

E·S·R·C
ECONOMIC
& SOCIAL
RESEARCH
COUNCIL

Health & Medicine | Lancaster University

APPENDIX M: *Qualitative study participant information sheet*

Participant Information Sheet

Investigating the personal experiences of relatives and informal carers of those with psychosis and schizophrenia, a qualitative study

My name is Claire Hilton and I am conducting this research as a student in the Research PhD programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore your experience of caring for someone with psychosis and schizophrenia and how you have adjusted your life because of you caring role. Through these interviews, I am particularly interested to find out how your sense of identity may have changed, about any changes to your social roles, and whether your caring role has had an impact on how you think about your future. I would also like to ask you about whether you have developed a new understanding of meaning and purpose in life despite the ongoing challenges of your caring role, and whether you feel this has helped you move forward with your life.

Why have I been approached?

You have been approached because the study requires information from people who have experience in caring for a relatives or friend with psychosis or schizophrenia.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Not taking part in this study will not affect any other treatments or interventions you are receiving on other Lancaster University studies or from the NHS.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to be interviewed by myself (Claire Hilton) about your thoughts, feelings and experiences of your caring role. The interview will last around one hour, however, we don't have to talk for that long if you don't want to.

Will my data be Identifiable?

The demographic information you provide is confidential. The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication/examined.
- Hard copies of demographic questionnaires and consent forms will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected. The anonymised transcripts will be kept for 10 years on the secure university servers, after which they will be destroyed.
- At the end of the study, hard copies of questionnaires and consent forms will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal. The results will also be used to develop a new questionnaire, which is the second phase of my PhD.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Claire Hilton, Tel: (01524) 593555 Email: c.a.hilton@lancaster.ac.uk

My supervisors are:
Professor Bill Sellwood, Tel: (01524) 593998 Email: b.sellwood@lancaster.ac.uk

Professor Steven Jones, Tel: (01524) 593382 Email: s.jones7@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Catherine Walshe Tel: (01524) 510124
Deputy Director of Research, Email: c.walshe@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Health Research)
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Research Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

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

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Samaritans	Carers UK
Tel: 116 123	Tel: 0808 808 7777
Email: jo@samaritans.org	Email: info@carersuk.org
www.samaritans.org	www.carersuk.org

APPENDIX N: *Qualitative study participant consent form*

THE SPECTRUM CENTRE

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Economic and Social Research Council
Shaping Society

Health Research

Lancaster University

Consent Form

Study Title: Investigating the personal experiences of relatives' and informal carers of those with psychosis and schizophrenia, a qualitative study.

We are asking if you would like to take part in a research project that looks to explore your experiences of caring for a relative or close friend with psychosis or schizophrenia.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Claire Hilton.

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study. ☐

2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐

4. I understand that audio recordings will be kept until the research project has been examined. ☐

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

6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐

7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐

8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐

9. I understand that the researcher will discuss data with their supervisor as needed. ☐

10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor. ☐

11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

12. I consent to my data being made available to other researchers at Lancaster University for future research projects. ☐

13. I consent to take part in the above study. ☐

Name of Participant______________ Signature___________Date _______

Name of Researcher _____________Signature _______________Date ___________

APPENDIX O: *Qualitative study participant debrief sheet*

Investigating the personal experiences of relatives' and informal carers of those with psychosis and schizophrenia, a qualitative study

Thank you for taking part in this study. The main aim of this study was to look at how your life is affected by taking on a caring role for a person with psychosis or schizophrenia.

In particular, I was interested to find out about your own personal recovery journey that you have been on from the start of your caring role. ‘Recovery’ is understood as a personal journey, where a person can find meaning and purpose in life, rebuilt their sense of self, and find hope for a better future, even if they are still having clinical symptoms. There is currently very little research looking what recovery means for relatives and informal carers of those with psychosis and schizophrenia. Most research about recovery has focused on the person with the diagnosis and not the relatives or carers that look after them. It has been argued that relatives are on a parallel journey of recovery, and understanding more about what recovery means for relatives and carers can give insight into their wellbeing and inform better support in the future.

The findings from these interviews will be written up as a journal article, and will also inform the development of a new questionnaire I am developing for my PhD, which will look at measure recovery for relatives and carers.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Samaritans	Carers UK
Tel: 116 123	Tel: 0808 808 7777
Email: jo@samaritans.org	Email: info@carersuk.org
www.samaritans.org	www.carersuk.org

APPENDIX P: *CARS Development study recruitment poster*

Would you like to help to develop a new questionnaire looking at carer recovery?

www.recoveryforrelatives.wordpress.com

Carer recovery

To support carers it is important to understand their wellbeing. One way is to look at whether they are on a recovery journey despite still caring for someone with psychosis. Many carers have adapted to their caring role and found ways to rebuild their lives. Understanding carer recovery would help us see how well carers are coping and then the right support can be put in place. This study is looking for help to develop a new questionnaire: **Carer Recovery Questionnaire (CRQ).**

[INSERT NHS TRUST LOGO HERE]

Health Research | Lancaster University

THE SPECTRUM CENTRE

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Economic and Social Research Council
Shaping Society

Are you eligible?

- 18 years or older?
- Care for someone with psychosis or schizophrenia?
- Have a phone line or stable internet connection?

What's involved?

- One-off individual chat about the new questionnaire
- Chats will take place online
- We will offer you a £10 Amazon voucher as a 'thank you'

Contact

Claire Hilton
c.a.hilton@lancaster.ac.uk
Mobile: 07743 599589
twitter: @CarerRecovery
www.recoveryforrelatives.wordpress.com

APPENDIX Q: *CARS development study participant information sheet*

Participant Information Sheet

Development of the Carer Recovery Questionnaire (CRQ)

My name is Claire Hilton and I am conducting this research as part of my PhD in Health Research at Lancaster University.

What is the study about?

The purpose of this study is to develop a new questionnaire that looks at the wellbeing of carers of those with psychosis and schizophrenia.

When a service user/patient receives a diagnosis of psychosis or schizophrenia, this has a big impact on the service user and also their family and friends. Family members often take on the responsibility of caring for their relative and can find the role demanding both physically and mentally. Understanding carer wellbeing is important to make sure carers receive good support. There is new research suggesting that carers go through a journey of recovery and adaption to their role as carer. This study hopes to get feedback from carers on a new questionnaire called the Carer Recovery Questionnaire.

Why have I been approached?

You have been approached because the study requires information from people who have experience in caring for a relative or friend with psychosis or schizophrenia.

Do I have to take part?

No. It's completely up to you whether or not you take part. If you do not wish to take part in this study, this will not affect the clinical services that you or the person you care for receive.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to read this information sheet and complete an online consent form. A copy of the information sheet and consent form can be emailed to you on request. You will then be asked to attend an online feedback session to discuss your thoughts about the new questionnaire. The feedback session will be one to one and last around 30 minutes.

Will my data be Identifiable?

The demographic information you provide is confidential. The researcher will make an audio recording of the session and will be taking some notes about what is discussed. Any notes the researcher makes will be confidential.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will not be transcribed.
- Audio recordings will be destroyed and/or deleted one the researcher's thesis has been examined.
- Demographic questionnaires and consent forms will be kept digitally on a secure university server.

There are some limits to confidentiality: if what is said in the feedback session makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

If you feel you would like to withdraw your interview data from the study this can be done up to two weeks after the interview has taken place.

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study. For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

What will happen to the results?

The feedback will be used to make changes to the new questionnaire being developed. You may also be asked to complete a pilot of the questionnaire (so we can check it works well online and is easy to complete). The researcher will approach you during the feedback session to see if you would be happy to do this. The data collected for this study may be used for other research projects in the future. The data would be anonymised and only used in ethically approved research.

Are there any risks?

There is a risk that you may become distressed following the interviews due to the sensitive nature of the topic. If you experience any distress following participation you are encouraged to inform the researcher and contact the charities listed at the end of this sheet.

Are there any benefits to taking part?

To thank you for your time in taking part in this study, the researcher will send you a £10 Amazon voucher. Please note that there will not be any therapeutic benefit in taking part in this study. If you have comments or complaints about the health services relating to you or the person you care for then please approach the services directly.

Who has reviewed the project?

This study has been reviewed and approved by the NHS Research Ethics Committee and has received Health Research Authority approval.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Claire Hilton, Tel: (01524) 593555 Email: c.a.hilton@lancaster.ac.uk

My supervisors are:
Professor Bill Sellwood, Tel: (01524) 593998 Email: b.sellwood@lancaster.ac.uk
Professor Steven Jones, Tel: (01524) 593382 Email: s.jones7@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Prof Bruce Hollingsworth, Email: b.hollingsworth@lancaster.ac.uk
Director of Postgraduate Studies
Faculty of Health and Medicine
(Division of Health Research)
Lancaster University
Lancaster
LA1 4AT

If you wish to speak to someone outside of the Research Doctorate Programme, you may also contact:

Dr Jennifer Logue, Email: j.logue1@lancaster.ac.uk
Associate Dean for Research
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4AT

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

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Samaritans Tel: 116 123 Email: jo@samaritans.org www.samaritans.org	Carers UK Tel: 0808 808 7777 Email: advice@carersuk.org www.carersuk.org	I will include the relevant NHS PALS service details here.

Appendix R: *CARS development study consent form*

Consent Form

Study Title: Development the Carer Recovery Questionnaire (CRQ)

Before you consent to participating in this study, please could you read the participant information sheet. If you have any questions or queries before signing the consent form please speak to the principal investigator, Claire Hilton.

14. I confirm that I have read the information sheet and fully understand what is expected of me within this study. ☐

15. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

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

17. I understand that the online interview will be audio recorded and the data will be protected on encrypted devices and kept secure. ☐

18. I understand that once my data has been incorporated into the main data set it might not be possible for it to be withdrawn. ☐

19. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher/s, but my personal information will not be included, and I will not be identifiable. ☐

20. I understand that my name will not appear in any reports, articles or presentation without my consent. ☐

21. I understand that any information I give will remain confidential unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor. ☐

22. I consent to my data being made available to other researchers at Lancaster University for future research projects. ☐

23. I am happy to be contacted about further research opportunities (optional). ☐

24. I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study. ☐

25. I consent to take part in the above study. ☐

Name of Participant______________ Signature_____________ Date _______

Name of Researcher ______________Signature _________________Date ___________

Appendix S: *CARS Validation study recruitment poster*

Would you like to test a new questionnaire looking at carer recovery?

www.carerrecovery.wordpress.com

Carer recovery

To support carers it is important to understand their wellbeing. One way is to look at whether they are on a recovery journey despite still caring for someone with psychosis. Many carers have adapted to their caring role and found ways to rebuild their lives. Understanding carer recovery would help us see how well carers are coping and then the right support can be put in place. This study is looking for help to test a new questionnaire: **Carer Recovery Questionnaire (CRQ).**

Health Research | Lancaster University

THE SPECTRUM CENTRE

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL
Economic and Social Research Council
Shaping Society

NHS
Lancashire & South Cumbria
NHS Foundation Trust

25 Aug 2021 V 1.3

Are you eligible?

- 18 years or older?
- Care for someone with psychosis or schizophrenia?
- Have an internet connection?
- Live in the United Kingdom

What's involved?

- Reading the study information sheet
- Completing the online consent form
- Completing a one-off online questionnaire pack

Contact

Claire Hilton
c.a.hilton@lancaster.ac.uk
Mobile: 07743 599589
twitter: @CarerRecovery
www.carerrecovery.wordpress.com

APPENDIX T: *CARS Validation study participant information sheet*

THE SPECTRUM CENTRE
E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL
Economic and Social Research Council
Shaping Society
Health Research
Lancaster University

Participant Information Sheet

Carer Recovery Questionnaire (CRQ) testing study

My name is Claire Hilton and I am conducting this research as part of my PhD in Health Research at Lancaster University.

What is the study about?

The purpose of this study is to carry out full testing of a new questionnaire that looks at the wellbeing of carers of those with psychosis and schizophrenia.

When a service user or patient receives a diagnosis of psychosis or schizophrenia, this has a big impact on the service user and also their family and friends. Family members often take on the responsibility of caring for their relative and can find the role demanding both physically and mentally. Understanding carer wellbeing is important to make sure carers receive good support. There is new research suggesting that carers go through a journey of recovery and adaption to their role as carer. A new questionnaire called the Carer Recovery Questionnaire (CRQ) looks at how well carers have adjusted to their new caring role and whether they have found new purpose and meaning from their caring role.

The new questionnaire has been developed with the help of carers. The questions were developed based on information from in-depth interviews with carers. The draft questionnaire was then discussed with carers to make sure the questions made sense.

In order for a questionnaire to be proved useful and valid for carers, larger testing needs to take place, and this is what this study is for.

Why have I been approached?

You have been approached because the study requires information from people who have experience in caring for a relative or friend with psychosis or schizophrenia.

Do I have to take part?

No. It's completely up to you whether or not you take part. If you do not wish to take part in this study, this will not affect the clinical services that you or the person you care for receive.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to read through this information sheet and complete an online consent form. A copy of the information sheet and consent form can be emailed to you on request. You will then be asked to complete an online questionnaire pack made up of 5 questionnaires that should take approximately 30 minutes to complete. You will only be required to complete the questionnaire pack once, however, we will be asking a small sample of carers to complete the questionnaire pack a second time approximately two weeks later.

Will my data be Identifiable?

The demographic information and answers to the questionnaires you provide is confidential. The data will be pooled with other participants data for statistical analysis.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Electronic versions of the demographic questionnaire, consent form and questionnaire responses will be kept on secure Lancaster University servers.
- All your personal data will be confidential and follow GDPR rules.
- The data files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- Research data will be kept securely for up to 10 years.

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study. For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

What will happen to the results?

The results will be summarised and reported in a PhD thesis and may be submitted for publication in an academic or professional journal. The final version of the questionnaire will be made freely available to academic health researchers and health care professionals. The data collected for this study may be used for other research projects in the future. The data would be anonymised and only used in ethically approved research.

Are there any risks?

There is a risk that you may become distressed while completing the questionnaire pack. If you do experience any distress following participation you are encouraged to inform the researcher and contact the charities listed at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. If this study goes well, then there will be a benefit to carers in the future. If you have comments or complaints about the health services relating to you or the person you care for then please approach the services directly rather than adding your concerns on the study questionnaires.

Who has reviewed the project?

This study has been reviewed and approved by the NHS Research Ethics Committee and has received Health Research Authority approval.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Claire Hilton, Tel: (01524) 593555 Email: c.a.hilton@lancaster.ac.uk

My supervisors are:
Professor Bill Sellwood, Tel: (01524) 593998 Email: b.sellwood@lancaster.ac.uk
Professor Steven Jones, Tel: (01524) 593382 Email: s.jones7@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Prof Bruce Hollingsworth, Email: b.hollingsworth@lancaster.ac.uk
Director of Postgraduate Studies
Faculty of Health and Medicine
(Division of Health Research)
Lancaster University
Lancaster
LA1 4AT

If you wish to speak to someone outside of the Research Doctorate Programme, you may also contact:

Dr Jennifer Logue, Email: j.logue1@lancaster.ac.uk
Associate Dean for Research
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4AT

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

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Samaritans

Tel: 116 123

Email: jo@samaritans.org

www.samaritans.org

Carers UK

Tel: 0808 808 7777

Email: advice@carersuk.org

www.carersuk.org

APPENDIX U: *CARS validation study consent form*

Consent Form

Study Title: Carer Recovery Questionnaire (CRQ) testing study

Before you consent to participating in this study, please could you read the participant information sheet. If you have any questions or queries before signing the consent form please speak to the principal investigator, Claire Hilton.

26. I confirm that I have read the information sheet and fully understand what is expected of me within this study. ☐

27. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

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

29. I understand that once my data has been incorporated into the main data set it might not be possible for it to be withdrawn. ☐

30. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher/s, but my personal information will not be included, and I will not be identifiable. ☐

31. I understand that my name will not appear in any reports, articles or presentation without my consent. ☐

32. I understand that any information I give will remain confidential unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor. ☐

33. I consent to my data being made available to other researchers at Lancaster University for future research projects. (Optional) ☐

34. I am happy to be contacted about future research opportunities. (Optional) ☐

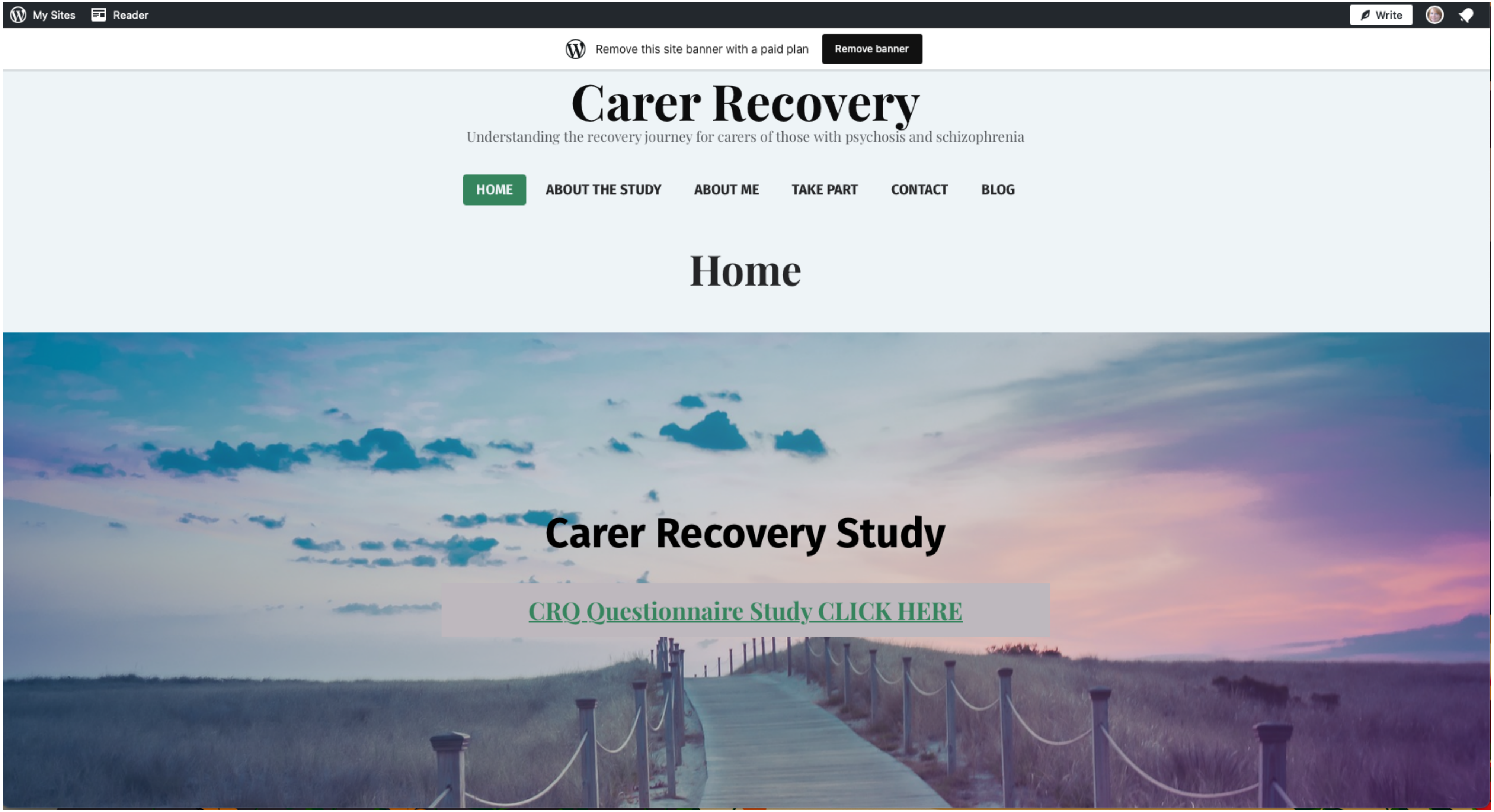
35. I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study. ☐

36. I consent to take part in the above study. ☐

Name of Participant______________ Signature____________ Date ____________

Name of Researcher _______________Signature _________________Date ____________

Appendix V: *Screenshot of CARS study blog*



Carer Recovery

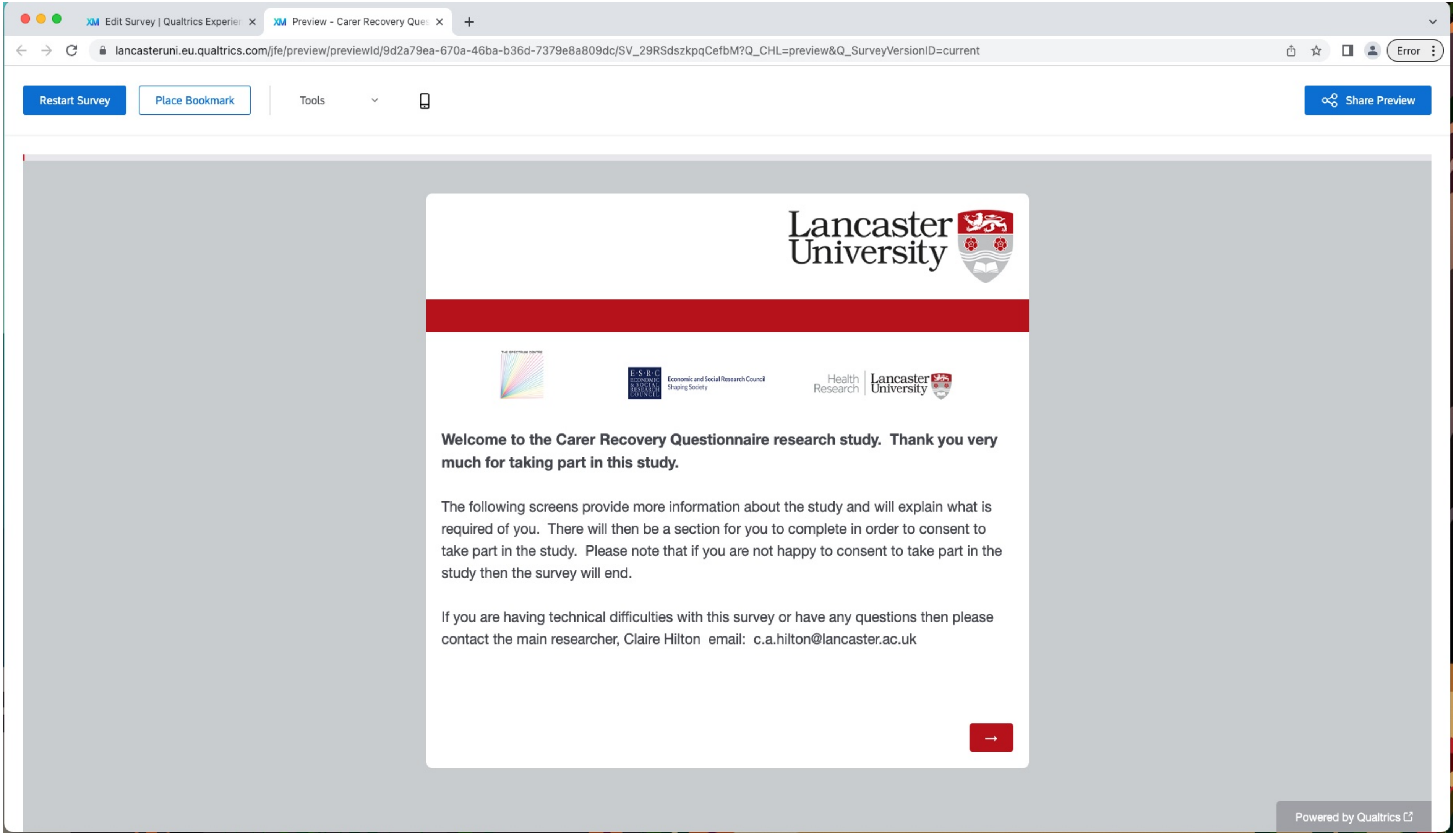
Understanding the recovery journey for carers of those with psychosis and schizophrenia

Home

Carer Recovery Study

CRQ Questionnaire Study CLICK HERE

APPENDIX W: *Qualtrics screen shot showing the landing page of the online questionnaire pack form the CARS validation study*



Welcome to the Carer Recovery Questionnaire research study. Thank you very much for taking part in this study.

The following screens provide more information about the study and will explain what is required of you. There will then be a section for you to complete in order to consent to take part in the study. Please note that if you are not happy to consent to take part in the study then the survey will end.

If you are having technical difficulties with this survey or have any questions then please contact the main researcher, Claire Hilton email: c.a.hilton@lancaster.ac.uk

List of Abbreviations

CARS: Carer Adaptation and Resilience Scale

CHIME Framework of personal recovery: Connectedness, Hope and Optimism, Identity, Meaning, Empowerment

CIRF: Cognitive Interviewing Reporting Framework

COSMIN: COnsensus-based Standards for the selection of health Measurement Instruments

COVID-19: Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)

CRQ: Carer Recovery Questionnaire (original title of the CARS)

CWS: Carer Wellbeing and Support Scale

DSM-5: The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

EFA: Exploratory Factor Analysis

EIS: Early Intervention Services

FEP: First Episode Psychosis

HEE: Health Education England

KMO: Kaiser-Meyer-Olkin test of sampling adequacy

MMR: Mixed methods research

NHS: National Health Service

NICE: National Institute of Clinical Excellence

NIHR: National Institute for Health Research

PTGI-SF: Posttraumatic Growth Inventory - Short Form

PPI: Patient and Public Involvement

PTG: Posttraumatic Growth

PTSD: Posttraumatic stress disorder

PTSS: Posttraumatic stress symptoms

QPR: Questionnaire about the Process of Recovery

REC: Research Ethics Committee

WHOQOL-BREF: World Health Organisation Quality of Life measure - Brief version

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