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Parkinson, Ben

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Mindfulness-based interventions for care partnerships experiencing anxiety and depression symptoms after stroke: a mixed methods study

Ben Parkinson

A thesis submitted in partial fulfilment of the requirements of Glasgow Caledonian University for the degree of Doctor of Philosophy (PhD)

November 2021
Abstract

Introduction Mindfulness can improve anxiety and depression symptoms, but few studies evaluate mindfulness-based interventions (MBIs) with care partnerships affected by stroke. Care partnership involves someone with a chronic condition and their partner (e.g. spouse, caregiver) working together in a partnership.

Aim Study the experiences and outcomes for care partnerships using MBIs together after stroke.

Methods Systematic mixed studies review and mixed methods case study research. The thesis was ethically approved and completed 2016-2021. The systematic review examined change to stress, anxiety symptoms, depression symptoms, mindfulness, and relationships after using MBI. Mixed methods case study research recruited care partnerships experiencing anxiety symptoms and/or depression symptoms after stroke. Participants received an online MBI called Be Mindful and data was collected weeks 0, 4, and 8. Data collection involved the Hospital Anxiety Depression Scale, the Mutuality Scale, the Mindful Attention Awareness Scale, and post-intervention interviews. Potential for effectiveness was evaluated with effect direction and minimal clinically important difference (MCID). Interpretative Phenomenological Analysis (IPA) explains the findings.

Results The systematic review included 10 studies and found MBIs improve mindfulness, stress, anxiety symptoms, and depression symptoms. Qualitative synthesis produced the mindfulness with care partnerships themes. The mixed methods case study research recruited 5 care partnerships (10 participants). Most care partnerships were white, living together, and spouses. Be Mindful adherence was between 0%-100%. Participants improved mindfulness (n=8, 80%), anxiety symptoms (n=7, 70%), depression symptoms (n=4, 40%), and mutuality (n=3, 30%). MCID was achieved for anxiety symptoms (n=5, 50%) and depression symptoms (n=2, 20%). IPA found evidence of conflicting and contradictory experiences so dialectical tension was used to articulate the continuum of perspectives and themes produced in the analysis.

Conclusion Care partnerships using MBIs can experience improvements in mindfulness, anxiety symptoms, and depression symptoms. This thesis makes an original contribution to knowledge by exploring the experience and outcomes for care partnerships using MBIs together. This thesis highlights the value of MBIs for care partnerships, but the findings are preliminary and more research is needed before making firm recommendations.
Plain language summary

A plain language summary (or lay summary) is used to share information with the public. A plain language summary is for a wide audience and needs to be easy to understand. This plain language summary will share information about a study using online mindfulness with people who are anxious or depressed after a stroke.

Mindfulness is a form of meditation that is used widely and can help people after a stroke. Mindfulness is normally learnt by attending weekly group sessions with a mindfulness teacher. Online mindfulness offers an alternative way of learning mindfulness and is preferable and more accessible for some people. Learning with a partner can help people engage with mindfulness and can have additional benefits. Little is known about what it is like for stroke survivors to learn mindfulness with a partner using an online course. This prompted Ben Parkinson, a student from Glasgow Caledonian University to complete a study in 2019 to find out more about online mindfulness for people affected by stroke. The study was delivered under guidance of an experienced team of academics and in partnership with an advisory group. The advisory group consisted of people with lived experience of stroke who helped with the design and implementation of the study.

The study recruited five stroke survivors and their care partners together in a partnership. All participants lived in Scotland or northern England and were white. Most stroke survivors were male and aged 48-60. Most care partners were female and aged 40-65. All stroke survivors had problems with their mood and physical health. The study lasted eight weeks and offered participants a popular online mindfulness course called Be Mindful. Information was collected from each participant using questionnaires and interviews. The information about the experience of using online mindfulness was gathered before, during, and after participants used online mindfulness.

Stroke survivors used online mindfulness more than care partners. Four stroke survivors completed the whole course. None of the care partners completed the online mindfulness course. Online mindfulness appears safe. Four stroke survivors and four care partners increased their mindfulness using online
mindfulness. The relationship between stroke survivor and care partner improved for two stroke survivors and one care partner. Online mindfulness helped anxiety symptoms or depression symptoms for some people. During the study three stroke survivors and two care partners’ anxiety symptoms improved. Two stroke survivors’ depression symptoms improved.

Findings were mixed. Some participants were interested in online mindfulness and some people were not. Some participants used online mindfulness and some did not. Some participants worked together and some did not. Some people experienced improvements and some did not. Speaking to the participants highlighted the different experiences for each person. Variation of experience was one of the main findings in this study and shows stroke is different for everyone.

It is possible online mindfulness can help stroke survivors and their care partners. Online mindfulness can increase mindfulness and relationship quality. Anxiety symptoms and depression symptoms can get better with online mindfulness. Partners can support stroke survivors and help them reflect when using mindfulness.

This study shows online mindfulness can help people after a stroke. The study has shown partners might be able to help the stroke survivor use online mindfulness. Learning mindfulness with a partner can help stroke survivors reflect on the experience of learning mindfulness. The findings are mixed, so we have to be cautious when thinking about what they mean. This study has informed research into using mindfulness for people affected by stroke. More good quality research is required before recommending online mindfulness for stroke survivors and their care partners.

Findings from the study will be shared using publications and conferences. The results will also be shared with voluntary sector organisations and on social media.
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List of abbreviations

ACT: Acceptance and Commitment Therapy

AE: Adverse event

AMSTAR 2: A critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions

CARE: Case reporting guidelines

CBT: Cognitive Behavioural Therapy

DALY: Disability-adjusted life-years

GAD7: Generalised anxiety disorder assessment

GCU: Glasgow Caledonian University

GRIPP2: Tool to improve reporting of patient and public involvement

HADS: Hospital Anxiety Depression Scale

IPA: Interpretative phenomenological analysis

MAAS: Mindful Attention Awareness Scale

MAT: Monitor and Acceptance Theory

MBCT: Mindfulness-based cognitive therapy

MBI: Mindfulness-based intervention

MBSR: Mindfulness-based stress reduction

MCID: Minimal clinically important difference

MMAT: Mixed methods appraisal tool

MS: Mutuality Scale

N/A: Not applicable
NHS: National Health Service

N/R: Not reported

NVivo: Qualitative data analysis software

PHQ9: Patient health questionnaire

PPI: Patient and public involvement

PRISMA: Preferred reporting items for systematic review and meta-analysis

PSS: Perceived stress scale

PwD: People with dementia

SAE: Serious adverse event

SPIO: Study, participant, intervention, and outcome

SPS: Statistical Analysis Software

TIA: Transient ischaemic attack

TIDieR: Better reporting of interventions template for intervention description and replication checklist
List of items to be removed

These items were removed before the thesis was added to the University repository.

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Preface

The thesis is submitted in partial completion of a Doctorate of Philosophy (PhD) at Glasgow Caledonian University. The PhD was completed part-time between 2016-2021 and was funded by Glasgow Caledonian University.

Thesis aims

The overall aims of the thesis were:

- To explore the experience and outcomes for care partnerships using mindfulness-based interventions (MBIs) together.
- To systematically review research using MBIs with people living with chronic conditions and their care partners (Chapter 4 on page 65).
- To research the use of online MBI with stroke survivors and their care partners (Chapter 5 on page 132).

Thesis author

Ben graduated as a registered mental health nurse from Glasgow Caledonian University in 2005 and completed an MSc (with distinction) in psychosocial interventions at the University of the West of Scotland in 2015. Ben’s nursing career has involved working in addiction services, primary care mental health, and higher education. He has been employed full-time as a lecturer of nursing at Glasgow Caledonian University since 2015 and became a senior fellow with the Higher Education Academy in 2020. Ben has a keen interest in psychological approaches and trained as a cognitive behavioural therapist and clinical supervisor. Ben's interest in research comes from using evidenced-based psychological interventions in clinical practice, teaching evidence-based practice, his work with research ethics committees, and supervision of dissertation students. The decision to complete a PhD came from wanting to develop as a researcher and become more involved in research activity at the University. The choice of topic for the PhD came from wanting to incorporate psychological interventions and mental health with one of the established research teams at Glasgow Caledonian University. At the time of applying for the PhD, a research team was exploring the use of mindfulness with people
affected by stroke and the group were advertising for a PhD student. This thesis reports on the work completed during the PhD and was supported by Glasgow Caledonian University and a team of academic supervisors (Professor Maggie Lawrence, Dr. Evelyn McElhinney, and Professor Jo Booth).

Acknowledgements

This thesis has been supported by a number of key people and organisations. My academic supervisors have been a constant source of support, guidance, and encouragement throughout the PhD and I would like to offer special thanks to Professor Maggie Lawrence, Dr. Evelyn McElhinney, and Professor Jo Booth. I would also like to thank Dr. Grace Poulter for her endless enthusiasm for academic writing and support with publication. Professor Jon Godwin was also a huge asset during the PhD and provided guidance and support with the statistical elements of the thesis. The thesis also required second reviewers during the systematic reviews and I appreciate the assistance of Loukia Gkanasouli, Sean Carrol, Dr. Ukachukwu Abaraogu, and Naomi Clark.

The thesis would also not have been possible if it were not for the contribution made by the advisory group and participants. I am hugely grateful to the advisory group and participants who were an essential ingredient in the thesis and offered their time and expertise for the benefit of the research and my development. A number of key organisations also provided encouragement and support during the study and a special mention is required for the Stroke Association and Chest Heart Stroke Scotland who provided much needed assistance with the recruitment of participants. I am also hugely grateful to Wellmind Media for letting me use their Be Mindful course during the study and the help and assistance they provided.

Glasgow Caledonian University deserve a special mention because they encouraged my academic development and supported the PhD throughout. My colleagues have also been hugely supportive and understanding towards my studies and I very much appreciate the support offered by Glasgow Caledonian University.
The final thanks must go to my wife who has supported me the most and been with me through the highs and lows of PhD study. This thesis would not have been possible without the support of my wife and I am eternally grateful.

Declaration

I hereby declare that this thesis is my own compositions and that I have conducted the research on which it reports. Due acknowledgements are given to the people who assisted with this work, with details of their contributions.
Chapter 1. Introduction

The first chapter provides an introduction to the thesis and will outline the nature and extent of stroke. The chapter will consider the impact of living with stroke from the perspective of stroke survivors (Section 1.2 on page 27) and their care partners (Section 1.4 on page 32). The introduction will also provide a rationale for supporting stroke survivors and their care partners together in care partnerships (Section 1.5 on page 34). The introduction will consider post-stroke anxiety symptoms and/or depression symptoms (Section 1.3 on page 29) and highlight the importance of supported self-management (Section 1.6 on page 34).

1.1 Stroke

A stroke occurs when the blood vessels supplying oxygen to the brain are disrupted. Ischaemic strokes occur when there is a vascular blockage in the brain and are often caused by athrothrombosis or embolism. The vascular blockage reduces or stops the supply of oxygen and nutrients to brain tissues and causes them to become damaged (Lee and Lee, 2020). Haemorrhagic strokes involve a ruptured blood vessel or bleeding in the brain, which damages brain tissue and can cause a wide variety of stroke related difficulties. Haemorrhagic strokes can be further divided into subarachnoid or intracerebral depending on the depth of the bleed and area affected (Gomes and Wachsmann, 2013). Transient ischaemic attacks (TIAs) are a temporary disruptions of oxygenated blood to the brain, which does not cause cerebral infarctions and usually resolves in less than 24 hours (Bose, Wilson and Mistri, 2017). People who have experienced having a stroke are sometimes called stroke survivors (Section 1.2 on page 27) and they can experience a wide variety of bio-psychosocial consequences (Langhorne, Bernhardt and Kwakkel, 2011).

Stroke is the second leading cause of death worldwide and a major cause of disability (Katan and Luft, 2018; Soto et al., 2020). The negative impact of stroke include a wide number of medical and social difficulties (Langhorne, Bernhardt and Kwakkel, 2011a). Statistics indicate 13.7 (95% CI, 12.7, 14.7) million strokes, 5.5 (95% CI, 5.3, 5.7) million deaths, and 116.4 (95% CI, 111.4,
121.4) million disability-adjusted life-years (DALY) were attributable to stroke in 2016 (Johnson et al., 2019). DALYs combine morbidity and mortality data to give an indication of disease burden, but measuring disease burden using DALYs has been criticised for devaluing the lives of people living with disabilities (Arnesen and Nord, 1999). Despite concerns about the best way of measuring disease burden for stroke, recent figures suggest global incidence of stroke, mortality, DALYs reduced between 1990 and 2016 by 8.1% (n=13676761, 95% CI, -10.7, -5.5), 36.2% (n=5528232, 95% CI, -39.3, -33.6), and 34.2 (n=116445136, 95% CI, -37.2, 31.5) respectively (Johnson et al., 2019).

In Scotland Data and Intelligence (previously ISD Scotland) indicate the incidence of stroke was 9159 (175 per 100,000) in 2018, which is a 12% decrease from 2009 (Data and Intelligence, 2020). The incidence rate was 20% higher for males (n=4575, 196.7 per 100,000) than females (n=4584, 153.4 per 100,000) in Scotland in 2018. The death rate for stroke in Scotland was 3835 (76.4 per 100,000) deaths in 2018, which is a decrease of 34% since 2009. The morality rate for stroke was higher for males (n=1622, 79.7 per 100,000) than females (n=2213, 73 per 100,000) in Scotland in 2016 (Data and Intelligence, 2020).

Improvements in public health, acute stroke care, and better access to specialist units appear to be having a positive impact on the incidence and mortality rates associated with stroke (Soto et al., 2020). However, the global burden of stroke appears to be rising as the population grows and more people live longer, which increases the numbers of people living with stroke and the amount of DALYs (Feigin et al., 2019). In 2018 approximately 86.2% (n=6681) of people living in Scotland survived 30 days or more following stroke, which is an improvement from 82.8% (n=5569) in 2009 (Data and Intelligence, 2020).

The improved survival rates for stroke have increased the number of people living with stroke in the community and the need for community-based stroke rehabilitation and longer-term support/self-management (Langhorne, Bernhardt and Kwakkel, 2011a; Soto et al., 2020).

Stroke survivors often experience difficulties after hospital discharge and living with stroke can have a huge impact on peoples’ lives. A systematic mixed
studies review examined 78 studies (n=68 quantitative, n=9 qualitative, n=1 mixed methods) to identify the social consequences of stroke for working age adults (Daniel et al., 2009). The review revealed social consequences with employment, relationships, sexual activity, money concerns, and reduced leisure activities were most common following stroke. Although, methodological and reporting variation made it difficult to compare results and find precise estimates of the extent to which these areas were affected (Daniel et al., 2009). Moreover, the systematic review was published over ten years ago, which makes it possible the findings will be out of date (Shojania et al., 2007). A more recent meta-analysis provides estimates for the number of stroke survivors returning to work after stroke and suggest 55.7% (95% CI, 51.3,60) and 67.4% (95% CI, 60.4,74.4) are back to work by years one and two respectively (Duong et al., 2019). The impact on social relationships was examined in a systematic review of 70 studies, which found post-stroke relationships can become strained and non-family networks are particularly vulnerable (Northcott et al., 2016).

Whilst a systematic review of qualitative studies (n=43) found stroke can have a negative impact of sexual activity and sexuality for both stroke survivor and their intimate partner(s) (McGrath et al., 2019).

Stroke survivors can also experience continued medical difficulties after discharge from hospital. A narrative review provides a summary of common medical difficulties experienced by people following stroke (Lui and Nguyen, 2018). The review states stroke survivors can experience a wide variety of medical difficulties and the complications may have a negative impact on stroke rehabilitation. Possible difficulties experienced following stroke include: motor impairment (e.g. mobility, falls), cognitive impairment, incontinence, frequent infections, and pain (Lui and Nguyen, 2018). A different study examined the medical consequences of stroke for people (n=81) and found the five most common medical consequences were: urine infections (48%), shoulder pain (37%), insomnia (37%), depression (32%), and pain not related to their shoulder (32%) (Civelek, Atalay and Turhan, 2016). A similar cross-sectional survey (n=161 participants) suggested fatigue (59.6%, 95% CI, 51.5, 67.7); pain (56.5%, 95% CI, 48.7, 64.3); post-stroke anxiety (24%, 95% CI, 17.1, 30.9); and post-stroke depression (25.3, 95% CI, 18.3, 32.4) were common at one-year post stroke (Broussy et al., 2019).
Cognitive impairment following stroke is common and can affect the stroke survivor's attention, concentration, memory, language ability, and orientation (Al-Qazzaz et al., 2014). A systematic review and meta-analysis of studies published between 1995-2017 (n=23) found the prevalence of cognitive impairment in the first year following stroke was 38% [95% CI=32-43%] ($I^2=92.5\%$, $p<0.01$) (Sexton et al., 2019). Whilst results from a longitudinal cohort study (Mahon et al., 2017) recruited first incidence stroke survivors’ (n=257) and measured participant cognition using the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005). The MoCA was completed at regular intervals over a four-year period and showed a significant number of stroke survivors (MoCA <26; n=217; 84%, m=19.5) had global cognitive impairment by year four. This study suggests 84% (n=217) of participants may have had cognition levels similar to those seen with people living with post-stroke dementia. The longitudinal data also revealed a significant decline in MoCA scores (MoCA 2.8; $p <0.0001$) over the study period, which suggests cognition levels continue to deteriorate over the first four years post-stroke (Mahon et al., 2017).

Qualitative evidence suggests stroke survivors can experience difficulties with language, communication, memory, comprehension, visual-spatial processing, and mood (e.g. depression, anxiety) (Pappadis et al., 2019). Long-term consequences of stroke have also been studied and revealed 21% (n=262) of stroke survivors lived for 15 years after their first stroke and level of disability varied from mild (33.8% 95% CI, 26.2, 42.4), moderate (14.3%, 95% CI, 9.2, 21.4), to severe disability (15%, 95% CI, 9.9, 22.3) (Crichton, Bray and Mckevitt, 2016). By year 15 of the study participants reported a number of difficulties and post-stroke anxiety (34.9%, 95% CI, 27, 43.8) and depression (39.1 %, 95 CI, 30.9, 47.9) were common.

1.2 Stroke survivors

The terminology used to describe people is important and many terms have been used to describe someone who has had a stroke (e.g. stroke patient, stroke victim) (Zrelak, 2021). This thesis takes an inclusive approach and uses the term 'stroke survivor' to describe someone who has experienced a stroke (e.g. ischaemic or haemorrhagic) and regardless of the aetiology or severity.
Collins-Burke and Cronkwright (2020) explain ‘stroke survivor’ terminology is preferable to other terms and can play an important role in self-identity. Victim terminology suggests helplessness and passivity, whilst survivor terminology implies overcoming adversity and resilience (Zrelak, 2021). Using appropriate ‘survivor’ language when talking about people who have experienced a stroke can be empowering for some people and was the preferred option for this thesis (Collins-Burke and Cronkwright, 2020).

A qualitative study interviewed ten people about the meaning and experience of being a stroke survivor (Murray and Harrison, 2004). The study used interpretative phenomenological analysis (Smith, Flowers and Larkin, 2009) and produced four themes: disrupted embodiment and loss of self; invisibility of emotional difficulties; gender, romance, and sexuality; and social interactions (Murray and Harrison, 2004). The research highlights the multiple ways stroke can impact of peoples’ lives and recommends people be supported to accept their physical limitations following stroke. It was also suggested that family members and care partners have an important role in helping people adjust to life after stroke (Section 1.4 on page 32). The study provides insight into the experience of being a stroke survivor, but participants were mainly working age and the length of time since stroke varied between 4-20 years (mean 9, SD 5.5). The age of participants and length of time following stroke are important considerations because stroke survivors self-identity changes over time (Pallesen, 2014) and the results may not reflect everyone’s experience of living with stroke.

A more recent qualitative study interviewed people with post-stroke aphasia (n=9) and found their self-identity presented several dilemmas for them (Taubner, Hallén and Wengelin, 2020). The stroke survivors described being the same (i.e. pre-stroke) and different (i.e. post-stroke) following their stroke and described their self-identify as fluctuating between being ‘disabled’ and being ‘normal’ (Taubner, Hallén and Wengelin, 2020). This research highlights the variable duality experienced by some stroke survivors, however, the findings may not apply to all stroke survivors because the study focused on people with post-stroke aphasia. Long-term self-identity of stroke survivors was examined in a small qualitative study (n=15), which interviewed people five years after having had a stroke (Pallesen, 2014). The study found stroke survivors’
continued to experience difficulties after the stroke, but had greater level of acceptance of their circumstances. The study also found stroke survivors were living more isolated lives and were less engaged with the community, which was thought to be a possible risk factor for developing anxiety and/or depression symptoms (Pallesen, 2014).

### 1.3 Post-stroke anxiety and depression symptoms

The International Classification of Diseases (ICD-10) provides a comprehensive manual for diagnosing mental health difficulties and is used to determine the type (e.g. generalised anxiety disorder and depression disorder) and severity (e.g. moderate, severe) of mental health difficulty (World Health Organisation, 2019). Diagnostic manuals are useful for diagnosing clinical mental health difficulties, but have been criticised for lacking validity and reliability (Johnstone, 2017). It is also possible for people to experience mental health symptoms (e.g. low mood, anxiety) without reaching diagnostic threshold for ICD-10 (World Health Organisation, 2019). Sub-threshold mental health symptoms are clinically relevant and can be a risk factor for developing more severe mental health difficulties (Pocklington, 2017). A large cross-sectional study (n=4316) found low level depression symptoms (i.e. sub-threshold) can have a significant ($p < 0.001$) negative impact on quality of life (Chachamovich et al., 2008). Furthermore, a systematic review examined longitudinal cohort studies (n=16) and discovered people with sub-threshold depression were more likely to develop clinical depression (incidence rate ratio $=1.95$, 95% CI 1.28-2.97) (Lee et al., 2018). This thesis takes an inclusive approach and uses the terms anxiety symptoms and depression symptoms to describe self-reported anxiety and depression related mental health difficulties, which may not meet diagnostic threshold.

Post-stroke affective disorders are common, and comorbid anxiety and depression symptoms can occur frequently after stroke (Schöttke and Giabbiconi, 2015; Stein et al., 2018). Anxiety is an umbrella term used to describe a group of stress-related mental health difficulties, which can occur following stroke (e.g. phobia, generalised anxiety disorder, panic) (Knapp et al., 2020). The nature of anxiety will vary depending on sub-type and severity (Chun et al., 2018), but people with anxiety often experience intense fear/worry,
autonomic arousal, and engage in safety seeking behaviours (e.g. avoidance) (Wells, 2013; Berle et al., 2016). Depression occurs when someone experiences a low mood, loss of interest/enjoyment, reduced energy/activity, and a number of other possible symptoms. Depression is often described as mild, moderate, or severe depending on the number and severity of symptoms (World Health Organisation, 2019).

A recent large-scale systematic review and meta-analysis collected results from 97 observational studies (22,262 participants; 34 countries) to investigate the frequency of post-stroke anxiety (Knapp et al., 2020). The results indicate post-stroke anxiety rates of 18.7% (95% CI, 12.5, 24.9) when assessed using clinical interview and 24.2% (95% CI, 21.5, 26.9) when assessed using a rating scale. The review also found the prevalence and sub-type of anxiety can vary after stroke: agoraphobia 8.4% (95% CI, 6.5, 10.4), social anxiety 2.3% (95% CI, 0.9, 3.7), simple phobia 2.1% (95% CI, 1.5, 4.3), obsessive-compulsive disorder 2% (95% CI, 0.8, 3.2), and panic disorder 3.7% (95% CI, 2.4, 5) (Knapp et al., 2020). A meta-analysis of observation studies (n=61) examined results from 25,488 participants to estimate the prevalence of post-stroke depression. The results of the review showed the prevalence of post-stroke depression to be approximately 31% (95% CI, 28%, 35%) and the figures remain at 23% (95% CI, 14%,31%) five years after stroke (Hackett and Pickles, 2014). Similarly, a more recent narrative review examined 124 studies to assess the prevalence of post-stroke depression. The review discovered the prevalence of post-stroke depression was between 18-33%, but suggest the rate may be higher because post-stroke depression is often underdiagnosed (Medeiros et al., 2020).

Narrative reviews are sometimes criticised for not being systematic and lacking transparency (Green, Johnson and Adams, 2006). This narrative review did take a semi-systematic approach (e.g. search methods), but the lack of transparency with screening does raise concerns about possible bias (Moher et al., 2009; Medeiros et al., 2020).

The main risk factors for post-stroke anxiety include having a pre-stroke history of anxiety and/or the presence of post-stroke depression (Schöttke and Giabbiconi, 2015). Whilst the risk factors associated with post-stroke depression include having a history of mental health difficulties, lower age (<70 yrs.), severity of stroke, and level of disability may also increase the risk of developing
post-stroke depression (Shi et al., 2017). Experiencing post-stroke anxiety/depression symptoms can increase mortality rates, worsen levels of disability, negatively affect quality of life, impact on personal relationships, and impede stroke rehabilitation (Ayerbe, 2015).

A meta-analysis examined results of 15 observational studies (n=250; 294 participants) to assess the association between post-stroke depression and risk of stroke reoccurrence and mortality. The analysis revealed a hazard ratio for post-stroke depression and all-cause mortality of 1.59 (95% CI, 1.30,1.96), but did not find any clear links with stroke reoccurrence (Cai et al., 2019). Despite inconclusive evidence for a link between post-stroke depression stroke reoccurrence (Cai et al., 2019), a meta-analysis of 14 studies suggests perceived psychosocial stress can be a factor in stroke reoccurrence and increased overall risk of stroke by 1.33 (95% CI, 1.17,1.50; p<0.00001) (Booth et al., 2015). Data from a prospective cohort study of stroke survivors (n=201) found participants with anxiety were more dependent (p <0.0005) and had lower quality of life (p <0.001) compared to those without anxiety (Chun et al., 2018). Whilst data from a retrospective case-control study found people with post-stroke depression (n=280) experienced higher levels of disability, lower effectiveness of treatment, and often required longer stays in hospital (Paolucci et al., 2019).

1.3.1 Management of anxiety and depression symptoms after stroke

Management of anxiety and depression symptoms after stroke is complex and should begin with a holistic assessment of the development and maintenance of the difficulties (Ayerbe, 2015). Assessing post-post anxiety/depression symptoms usually involves using a validated assessment tool and a clinical interview (Knapp et al., 2020). A systematic review and meta-analysis explored the validity of assessment tools for post-stroke depression symptoms (Meader et al., 2014). The meta-analysis included 24 studies (n=2907 participants) and six widely used assessment tools: Patient Health Questionnaire (PHQ)-2 (Löwe, Kroenke and Gräfe, 2005); Patient Health Questionnaire (PHQ)-9 (Kroenke, Spitzer and Williams, 2001); Hospital Anxiety and Depression Scale total score and depression sub-scale (Zigmond and Snaith, 1983); Beck’s Depression
Inventory (Beck, Steer and Carbin, 1988); Hamilton Depression Rating Scale (HDRS) (Williams, 2001). The review concluded no tool could accurately make a diagnosis of depression (without false positives), but the tools could be used to confirm stroke survivors do not have depression (with few false negatives). This analysis highlights the need for better assessment and screening of post-stroke depression and reinforces the need to use these tools in conjunction with a clinical interview (Meader et al., 2014). Another challenge associated with supporting people with post-stroke anxiety/depression is the high level of co-occurrence whereas the literature/guidance focuses on post-stroke anxiety and depression separately (Stein et al., 2018). Recommended treatment for post-stroke anxiety/depression usually involves some form of antidepressant (e.g. paroxetine) and/or a psychosocial intervention (e.g. cognitive behavioural therapy) (Ayerbe, 2015; Starkstein and Hayhow, 2019; Medeiros et al., 2020).

Despite progress with stroke prevention and stroke care, post-stroke anxiety/depression is often undiagnosed, inadequately treated, and clinical outcomes can be poor (Hackett and Pickles, 2014; Ayerbe, 2015; Dar et al., 2017; Ladwig et al., 2018).

1.4 Care partners

A key feature of this thesis is the involvement of care partners. A range of terms are used to describe someone who provides unpaid support and/or care to a stroke survivor (e.g. family caregiver, informal caregiver) (Denham et al., 2018). Initially this study used the term family caregiver, but this was changed to care partner and care partnership. In this thesis a care partner is defined as someone (e.g. friend, relative, neighbour) who supports (e.g. emotional, physical, domestic) a person living with stroke. Care partnership refers to both the stroke survivor and their care partner working together in a pair or dyad (Bennett et al., 2017). The terms ‘care partner’ and ‘care partnership’ are used because the terminology reflects the shared nature of living with stroke and moves away from stroke survivors being seen as passive recipients of care (Bennett et al., 2017).

Care partners have an important role in stroke rehabilitation with qualitative data showing care partners (n=71) make a large and impactful contribution to the care and support of stroke survivors (Haley et al., 2019). The focus on early
discharge from hospital and the long-term consequences associated with stroke result in a large amount of care and rehabilitation being delivered in the community (Langhorne, Bernhardt and Kwakkel, 2011a). However, the acute nature of stroke and focus on early discharge from hospital does not give much time to adjust to becoming a care partner and can leave people feeling underprepared for the role (Lutz et al., 2017).

Care partners are often spouses or adult children who may provide 30 plus hours care per week (Wolff et al., 2018). A qualitative meta-synthesis (n=39 studies) examined the experience of being a stroke care partner and identified several themes. The main theme highlights the commitment required to be a care partner and describes the role as a full-time job. The sub-themes refer to restructuring of life, altered relationships, and physical and psychosocial challenges (Kokorelias et al., 2020). The challenges faced by care partnerships include interpersonal problems, difficulties supporting the family, and concern about wellbeing of the stroke survivor (Camak, 2015; McCarthy et al., 2020). These challenges can result in care partners experiencing psychological symptoms themselves (Greenwood and Mackenzie, 2010; Rajan et al., 2016).

A meta-analysis with 12 studies (n=1756 participants) calculated the global prevalence of depression and anxiety among stroke care partners. The review indicated the prevalence of depression and anxiety for stroke care partner was 40.2% (95% CI, 30.1, 51.1) and 21.4% (95% CI, 11.6, 35.9) respectively (Loh et al., 2017). A recent small-scale survey of stroke care partners (n=117) reported participants experienced anxiety (43.9%), mild-moderate depression (26.5%), and severe depression (27.4%) (Hu et al., 2018). These studies present slightly different results, which raises doubt about the true prevalence of anxiety/depression among stroke care partners and concerns about the generalisability of the findings. A recent review of the methodology used in systematic reviews of prevalence (n=235) found wide variation in how they are completed and raised concerns about the lack of methodological consensus in prevalence reviews (Borges Migliavaca et al., 2020).
1.5 Care partnerships

Together stroke survivors and their care partners experience issues related to the stroke, adjusting to new roles, and coping with any pre-existing relationship difficulties (McCarthy et al., 2020). It is also common for stroke survivors and their care partners to experience anxiety and/or depression (Hackett and Pickles, 2014; Loh et al., 2017; Hu et al., 2018; Knapp et al., 2020). There is growing recognition of the need to promote the mental health of stroke survivors and their care partners (Greenwood et al., 2008; Ekstam et al., 2015; Bakas, McCarthy and Miller, 2017). There is also evidence that suggests the mental health of stroke survivors and their care partner might be interconnected (Klinedinst et al., 2009). A recent critical review explored whether there is a relationship between stroke survivor and care partner mental health (Hultman et al., 2019). The review included studies that compared levels of anxiety (n=2) and depression (n=10) between stroke survivors and their care partners. The review found a statistically significant relationship in anxiety (n=2, 100%) and depression (n=7, 70%), which suggests the mental health of stroke survivors and their care partners is interconnected (Hultman et al., 2019). These findings reinforced the need to screen both stroke survivors and their care partners for depression symptoms and to support stroke survivors and their care partners together in care partnerships (Badr and Acitelli, 2017; Bakas, McCarthy and Miller, 2017).

1.6 Supported self-management

Supported self-management is recommended for people affected by stroke living in the community (Kidd et al., 2020). Supported self-management is a complex process and closely related to self-care, symptom management, and self-efficacy (Richmond and Connolly, 2020). The thesis will use the following definition for supported self-management:

“the ability of the individual, in conjunction with family, community, and health care professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions” (Richmond and Connolly, 2020, p. 261).
Supported self-management is important for stroke survivors, but some find it difficult. A review suggests stroke survivors can experience personal barriers (e.g. lack of confidence), psychological barriers (e.g. cognitive impairment), and environmental barriers (e.g. lack of resources) when accessing supported self-help (Babkair and Dickson, 2017). Another review highlights the problems with using a “one-size-fits-all” approach and the importance of tailoring supported self-management to people and their particular circumstances (Kidd et al., 2020, p. 985). A qualitative study collected data from stroke survivors (n=16) and discovered participants wanted supported self-management to start as soon as possible, continue in the community, and to involve relatives/care partners (Satink et al., 2015).

A recent systematic review investigated the potential benefit of supported self-management and family involvement (Deek et al., 2016). The review discovered supported self-management and family involvement reduced hospital readmission rates, accident and emergency attendance, and anxiety levels. However, the evidence needs to be used with caution because some of the data came from participants with other chronic conditions (e.g. heart failure, diabetes). Despite concerns about the heterogeneity of participants, the review suggests combining family involvement and supported self-management strategies could reduce use of hospital-based services and might improve psychological wellbeing for people affected by stroke (Deek et al., 2016). More research is needed to understand the best use of self-management and how to help care partnerships reduce anxiety and depression symptoms after stroke (Rowat et al., 2016).

1.7 Summary

The chapter introduced the area of study and outlined the nature and extent of stroke. Stroke is a major global health challenge with significant biopsychosocial implications for stroke survivors and their families (Langhorne, Bernhardt and Kwakkel, 2011a; Feigin et al., 2019). Post stroke anxiety and depression symptoms are common and can negatively affect clinical outcomes and quality of life for stroke survivors and their care partners (Wan-Fei et al., 2017; Quattropani and Geraci, 2018). A large proportion of stroke care is provided in the community and care partners have an important role to play in
supporting stroke survivors after leaving hospital (Langhorne, Bernhardt and Kwakkel, 2011a).

This chapter considered life after stroke from a stroke survivors and care partner perspective and introduces the concept of stroke care partnerships (Section 1.5 on page 34). It is important to support stroke survivors and their care partners together because their mental health is interconnected (Hultman et al., 2019). Supported self-management strategies may help stroke care partnerships, but research is needed to understand the best way of providing supported self-management for care partnerships experiencing anxiety and depression symptoms after stroke. The following background chapter provides a critical review of mindfulness and provides a justification for researching online mindfulness-based intervention with care partners experiencing anxiety and depression symptoms following stroke.
Chapter 2. Background

The previous chapter introduced the thesis and highlighted the challenges faced by people experiencing anxiety and depression symptoms after stroke. Stroke survivors and their care partners often experience difficulties with anxiety and depression symptoms, and it is helpful to support both as a stroke care partnership (Bakas, McCarthy and Miller, 2017). Helping stroke care partnerships develop supported self-management strategies for anxiety and depression symptoms following stroke is an important, but under researched area (Wang et al., 2019). Mindfulness is a popular self-management strategy, which could help people affected by stroke (Lawrence et al., 2013). This background chapter provides a critical review of the literature on mindfulness and presents a rationale for studying online mindfulness with care partners experiencing anxiety and depression symptoms following stroke.

2.1 Mindfulness

Mindfulness is a specific type of attentional state, which underpins Buddhist meditation (Kabat-Zinn, 2003). Part of Buddha’s teachings included a system of training to increase insight and to overcome suffering. An important part of this system is mindfulness meditation (Bodhi, 2011). Mindfulness meditation is a technique used to self-induce a state of relaxation, which can involve focused attention and open-monitoring (Britton et al., 2018). Mindfulness meditation may also be embedded within a spiritual or religious context (Bond et al., 2009). However, mindfulness involves more than meditation and is better thought of as a way of being that is open and accepting to day-to-day experiences (Shapiro, Thakur and De Sousa, 2015).

The development of mindfulness has occurred over thousands of years and through distinct phases (Bodhi, 2011). Early mindfulness was embedded within the Buddhist traditions and rooted in a religious context. Buddhist mindfulness covers a wide number of traditional approaches: Theravada tradition, Mahayana, and Vajrayana (Tibetan). These distinct approaches to Buddhism consist of several different sub-categories and are all governed by a set of ethical principles (Kabat-Zinn, 2003). More recently secular forms of mindfulness were developed and the use of mindfulness was adapted for
clinical situations (Kabat-Zinn, 2011). The move toward using secular mindfulness in clinical environments did cause concerns for traditional mindfulness scholars who believe a reductionist approach to mindfulness might detract from the full potential of the approach (Bodhi, 2011; de Zoysa, 2016). Palitsky and Kaplan (2019) share these concerns and state the current dichotomy between religious and secular mindfulness does not capture the spiritual nuance and ethical practice associated with traditional mindfulness. However, some scholars do believe it is justifiable to use secular mindfulness within a clinical context due to the clinical value it may have for people living with chronic health difficulties (Bodhi, 2011).

2.1.1 Mindfulness definitions

Defining mindfulness is an important step when researching and implementing mindfulness in clinical settings (Anālayo, 2019). There is limited consensus about how to define mindfulness, with various definitions being used in the literature (Chiesa, 2013; de Zoysa, 2016; Palitsky and Kaplan, 2019). A review examined different definitions for mindfulness and discovered Buddhist (n=8) and Western (n=9) examples, which highlights the different perspectives and interpretations of mindfulness (Khoury et al., 2017).

Buddhism defines mindfulness as a mental faculty, which is related to memory and/or attending to the present moment (Anālayo, 2019). This understanding of mindfulness originates from the term Sati, which is sometimes translated to mean “memory and lucid awareness of present happenings” (Bodhi, 2011, p. 25). Other Buddhist definitions highlight the role of embodiment and ethics and define mindfulness as “embodied and ethically sensitive practice of present moment recollection” (Stanley, 2013, p. 65). Buddhist mindfulness is also seen as an “active, engaged and not a detached, non-reactive process” (Rapgay and Bystrisky, 2009, p. 151).

The expansion of mindfulness into Western society and use in clinical environments has produced a number of Western definitions of mindfulness (Chiesa, 2013). The original definition of Western mindfulness provided by Kabat-Zinn (2004, p.4) described mindfulness as “paying attention in a particular way, on purpose, in the present moment, and non-judgementally”. An alternative definition describes mindfulness as “the awareness that emerges
through paying attention on purpose, in the present moment, and non-
judgementally to the unfolding of experience moment to moment” (Kabat-Zinn,
2003, p. 145). The Western definitions are similar to traditional definitions, but
Buddhist scholars caution against using simplified interpretations of mindfulness
and believe secular versions do not truly reflect Buddhist mindfulness (Anālayo,
2019). Many different definitions of mindfulness exist, but they all share some
commonality and focus on directing attention to the present moment (Khoury et
al., 2017). Mindfulness definitions rarely incorporate a social or interpersonal
element and have mainly focused on the intrapersonal experience of
mindfulness (Khoury et al., 2017).

The various definitions of mindfulness help reveal how mindfulness can be
broken down into three interwoven components: attention, intention, and
attitude (Shapiro, Thakur and De Sousa, 2015). Using these components
illustrates how paying attention (attention), on purpose (intention), and in a
particular way (attitude) is characteristic of mindfulness practice (Shapiro et al.,
2006). Bishop et al. (2004) proposes a similar two-part operational definition for
mindfulness: self-regulation of attention (awareness) and openness to the
present moment (acceptance), which highlights the different and interwoven
interpretations of mindfulness. Having a conceptualisation of mindfulness is
necessary when conducting research and/or using mindfulness in clinical
settings (Bishop et al., 2004). However, there does not appear to be a singular
definition of mindfulness and instead there are several different interpretations
and conceptualisations (Brown and Ryan, 2006; Cullen, 2011). Despite some
uncertainty about the best definition for mindfulness, there is growing
consensus about the core components of ‘mindfulness’ and how these can be
used in different situations or context (Cullen, 2011).

2.1.2 Measuring mindfulness

An area where it is important to have a definition for mindfulness is in clinical
research and practice (Bishop et al., 2004). One of the challenges with using
mindfulness in clinical research and practice is how to measure mindfulness
and evaluate whether interventions influence mindfulness and/or clinical
difficulties (Baer, 2011). Developing instruments to measure mindfulness for
clinical research and practice is challenging because they have to be both valid
and reliable (Bishop et al., 2004). Currently the main approach for measuring mindfulness is to use self-report mindfulness questionnaires (e.g. Mindful Attention Awareness Scale, Brown and Ryan, 2003), which are widely used in clinical research and practice (Qu, Dasborough and Todorova, 2015). Bergomi, Tschacher and Kupper (2013) completed an overview of validated self-report mindfulness questionnaires (n=8) available for adults. The overview examined the strengths and weaknesses of each self-report mindfulness questionnaire and concluded that none of the selected questionnaires were fully capable of measuring mindfulness. Qu et al. (2015) also provided a summary of self-report mindfulness questionnaires (n=11) and concluded the complex ontology and epistemology of mindfulness make accurate measurement difficult.

The main concern with self-report mindfulness questionnaires is whether they are measuring the same thing or something slightly different (Bergomi, Tschacher and Kupper, 2013). A study examined commonly used self-report mindfulness questionnaires (n=8) against nine different aspects of mindfulness (observing experience, acting with awareness, acceptance, non-judgement, non-avoidance, non-reactivity, non-identification, insight, describing) to discover what each questionnaire was measuring. The study found none of the selected self-report mindfulness questionnaires measured every aspect of mindfulness and some of the questionnaires were assessing completely different aspects of mindfulness (Bergomi, Tschacher and Kupper, 2013). The variation in what is being measured in self-report mindfulness questionnaires makes it difficult to compare findings from different questionnaires and poses a challenge for researchers and clinicians wanting to accurately measure mindfulness (Bergomi, Tschacher and Kupper, 2013).

### 2.2 Use of mindfulness

The use and popularity of mindfulness has grown rapidly in recent years (Chiesa et al., 2017). A National Health Interview Survey (n=34,525) conducting in the United States in 2012 indicated 6.6% (n=2279) of participants practiced some form of meditation (e.g. spiritual meditation, mantra meditation) in the previous twelve months and 1.9% (n=656) of those practiced mindfulness (Burke et al., 2017). A secondary analysis of the same data showed people were more likely to use meditation (including mindfulness) if they were white,
female, college educated, and between 40-64 years of age. The analysis also revealed anxiety (29.2%, n=10081), stress (21.6%, n=7457), and depression (17.8%, n=6145) were the most common health reasons for meditating (Cramer et al., 2016).

A similar analysis was completed on data from the 2017 National Health Survey (n=26,742) and estimated 46 million Americans practice some form of meditation (e.g. mindfulness, yoga, mantra) (Macinko and Upchurch, 2019). The figure of 46 million people practicing some form of meditation in the last twelve months equates to approximately 19% (n=5081) (Macinko and Upchurch, 2019) of all adults in the United States and represents a large increase from the figure of 6.6% (n=2279) in 2014 (Burke et al., 2017). Looking at data for mindfulness specifically, it appears 5% (n=1337) of adults in the United States used mindfulness in 2017, which again is a large increase from 1.9% (n=656) in 2012 (Simonsson, Martin and Fisher, 2020).

The most recent analysis of mindfulness use in the United States suggests it is more common among females, sexual minorities, young/middle aged people, white, employed, and those experiencing mental health or physical pain (Simonsson, Martin and Fisher, 2020). These findings suggest mindfulness is becoming more common in the United States, but it appears to be the same type of people using mindfulness in greater numbers and the lack of diversity is a concern (Burke et al., 2017; Simonsson, Martin and Fisher, 2020). Waldron et al. (2018) share concerns about a lack of diversity in mindfulness and stress the importance of being inclusive and engaging more minority groups and/or people from disadvantaged backgrounds.

The National Health Survey provides useful data on mindfulness use in the United States (Simonsson, Martin and Fisher, 2020), but there is not comparable data available for the United Kingdom. The Mental Health Foundation commissioned a survey on 2009 and asked members of the public (n=2007) about mindfulness. The survey found 26% (n=522) of participants practiced meditation, but 12% (n=241) said they practiced rarely (Halliwell, 2010). This survey gives an indication of mindfulness use in the United Kingdom, but the evidence is dated and could underestimate use because it was gathered before the recent growth in mindfulness apps and other modes of
delivery (Plaza et al., 2013). Similarly, the survey was published in a report and did not provide full details of the methods used or indicate whether it had been peer-reviewed. The incomplete reporting raises questions about the validity of the survey (Simera et al., 2010) and uncertainty about peer-review casts doubt about quality of the work (Rowley and Sbaffi, 2018).

2.3 Mindfulness-based interventions (MBIs)

Mindfulness-based intervention (MBI) is an umbrella term used to describe structured mindfulness courses that have developed from traditional Buddhist meditation (Lee and Young, 2018). The first structured MBI course was developed in the early 1980s to help people experiencing chronic pain (Kabat-Zinn, 1982). This initial course evolved into what is now known as mindfulness-based stress reduction (MBSR) (Kabat-Zinn, 2013). MBSR is widely used in clinical and non-clinical settings and is accompanied by a detailed protocol (Santorelli et al., 2017).

The original MBSR course (Kabat-Zinn, 2004) consists of eight-weekly group sessions (2.5-3.5 hours) and a day retreat (7.5 hours). The MBSR course content covers several formal mindfulness practices: body scan, gentle yoga, sitting meditation, and walking meditation. The curriculum also includes a number of informal practices: awareness of pleasant/unpleasant events, awareness of breath, and paying attention to routine activities. Each group session includes mindfulness practice with group dialogue and inquiry about the experience of mindfulness and integrating mindfulness into daily life. The MBSR course incorporates home practice and encourages participants to practice formal (45 minutes 6/week) and informal (15 minutes 6/week) mindfulness between sessions and for the duration of the course (Santorelli et al., 2017).

Since MBSR (Kabat-Zinn, 2004) was introduced, a number of similar mindfulness courses have been developed. The different MBIs share many similarities with the original MBSR course and include mindfulness-based cognitive therapy (MBCT) (Teasdale et al., 2000), mindfulness-based relapse prevention (MBRP) (Bowen et al., 2009), mindfulness-based childbirth and parenting (MBCP) (Duncan and Bardacke, 2009), and mindfulness-based eating awareness training (MB-EAT) (Kristeller and Wolever, 2011). There are
also MBIs developed for couples wanting to enhance their romantic relationship with each other. The couple-oriented MBI is called Mindfulness-Based Relationship Enhancement (MBRE) (Carson et al., 2004) and includes additional paired mindfulness activities for couples to undertake together (e.g. dyadic eye gazing, couple yoga). There are no MBIs designed for care partnerships and research involving people with chronic conditions and their care partners together normally use MBIs designed for people to use by themselves and without a partner (Parkinson et al., 2019)

There have also been a number of other therapeutic approaches developed, which use aspects of mindfulness as part of a broader therapy. These broader approaches using mindfulness include acceptance and commitment therapy (ACT) (Hayes et al., 2004) and compassionate mind training (CMT) (Gilbert and Procter, 2006). Despite some variation between different MBIs, most courses involve learning mindfulness meditation and establishing a daily practice (Kabat-Zinn, 2013). Mindfulness teaching and practice contains three core elements: development of awareness through mindfulness practices (e.g. meditations), a particular attitude (e.g. kindness, curiosity), and an embodied understanding of human vulnerability (e.g. by exploring experiences of distress) (Crane, 2017).

Crane et al. (2017) have produced a framework to help establish the necessary elements for all MBIs. This framework states MBIs should develop present moment awareness through contemplation and mindfulness meditation. All MBIs should incorporate psychological/educational principles, be informed by a model of human distress, and improve self-regulation (Crane et al., 2017). Crane and Hecht (2018) support this framework by stating MBIs should only be branded MBSR or MBCT if the course closely aligns with the specific protocol and do not deviate away from the core methods of the course. This is an important quality control requirement and reduces the risk of courses being labelled MBSR when they do not follow the protocol (Cullen, 2011).

An important element of MBIs, is the mindfulness teacher who has an essential role in initiating and encouraging mindfulness practice (McCown, 2016). Recent growth of mindfulness has created huge demand for mindfulness teachers, so teacher training pathways have been established to maintain quality and
consistency of MBI teaching (Marx, 2019). Mindfulness teachers now have minimum training requirements and expectation for continuous professional development (McCown, 2016). Mindfulness teacher preparation involves foundation training (e.g. attend MBI and start personal practice), basic teacher training (e.g. attend MBI teaching course and co-facilitate MBI), and advanced training (e.g. supervise others) (Crane et al., 2010). Mindfulness teacher preparation involves a long-term commitment to mindfulness, which is demonstrated through the teacher’s own personal practice and their embodiment of mindfulness (Cullen, 2011). There are also competence scales (e.g. mindfulness-based interventions: teaching assessment criteria) used to evaluate mindfulness teaching and can be used to help support and develop teachers (Crane and Kuyken, 2019). Robust development of mindfulness teaching is necessary because the existing mindfulness evidence-base was produced with highly competent mindfulness teachers and it is important to maintain the same standards as the number of mindfulness teachers grow (Piet, Fjorback and Santorelli, 2016). However, the governance and support structures (e.g. training, supervision) required for teachers have not been properly established for the wide variety of MBIs, which could result in some forms of MBI being poorly taught and/or disseminated (Marx, 2019). It is also unlikely busy public services will be able to replicate the high level of training/supervision provided in clinical trials when disseminating MBIs in clinical services, so there could be tension between best practice and clinical reality (Rycroft-Malone et al., 2019). It is important the quality of MBIs is maintained as MBIs become more popular and/or are disseminated in clinical settings, otherwise the therapeutic potential for MBI might be reduced (Piet, Fjorback and Santorelli, 2016).

Interest in mindfulness continues to grow (Chiesa et al., 2017) and some critics suggest it has become overly commercialised, but it is also possible it is just evolving due to success (Walsh, 2016). Recent developments in the field of MBI include the adaptation and implementation of established MBIs in new environments or with different groups of individuals (Crane et al., 2017). An example of MBSR being adapted for a specific population is the HEADS: UP course, which was developed in conjunction with people affected by stroke and tailored specifically for their needs (Lawrence, 2019b). The current work
reported in this thesis builds on previous developments and will use an established online MBI (i.e. Be Mindful) (Section 7.4 on page 161) with a specific group of people (i.e. people affected by stroke) and in a new context (i.e. care partnerships).

2.4 Online MBI

There has been growing interest in online and/or technology assisted MBIs in recent years (Creswell, 2017). Online MBIs are a relatively new phenomena and there is little consensus about the best terminology and/or definitions to describe MBIs delivered primarily via the internet. The term online MBIs is used in this context to describe a web-based therapeutic intervention, which is a:

“Self-guided intervention program that is executed by means of a prescriptive online program operated through a website and used by consumers seeking health and mental health related assistance. The intervention programme itself attempts to create positive change and/or improve knowledge, awareness, and understanding via the provision of sound health–related material and use of interactive web-based components” (Barak, Klein and Proudfoot, 2009, p. 5).

Online MBIs are thought to have several advantages over non-online delivery: anonymity, accessibility, scalability, and cost effectiveness (Spijkerman, Pots and Bohlmeijer, 2016). The limited number of mindfulness teachers can make it difficult to access face-to-face group MBI (Rycroft-Malone et al., 2019) and online MBI can offer a scalable solution to increase supply (Spijkerman, Pots and Bohlmeijer, 2016). Online MBI may also offer easier access for some hard to reach populations (e.g. rural communities), who otherwise may not have access to a qualified mindfulness teacher (Creswell, 2017). People can also find the flexibility and convenience of online MBI a positive factor (Stjernswärd and Hansson, 2020). Whilst survey evidence (n=500 participants) shows most people would have online MBI as their first choice when choosing between online MBI (n=212, 43%), individual MBI (n=187, 38%), and non-online group MBI (n=97, 20%). However, some people still selected non-online group MBI, so it is important people are given the choice and allowed to select their preferred option (Wahbeh, Svalina and Oken, 2016).
2.4.1 Barriers to using online MBI

Online digital technology has produced huge societal advances in recent years, but there are concerns some people are being left behind and that digital inequity is creating a more uneven society (Zheng and Walsham, 2021). Not everyone can access or use online digital technology (Mitchell et al., 2019) and poor communities can have difficulty accessing the internet and securing a reliable connection (McCloud et al., 2016). So despite the internet being widely available, there remains sections of society who may struggle to access online technology and this can create digital inequity and become a barrier to using online MBI (McCloud et al., 2016; Mitchell et al., 2019).

Another barrier for using online MBI might be health literacy, which is defined as “the ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and system contexts” (Liu et al., 2020, p. 1). A recent systematic review examined the impact of low health literacy on peoples’ ability to access and use online health interventions (Kim and Xie, 2017). The review included research published since 2010 (n=74) and found barriers to accessing online interventions included both readability and usability. The review concluded by highlighting the need for educational support and more accessible online interventions for people with low health literacy (Kim and Xie, 2017). However, the review did not include any studies looking at online MBI specifically and the findings need to be interpreted cautiously when being applied to online MBIs. It is also important to remember online MBI will not meet everyone’s needs/preferences and should be viewed as an alternative option for people willing and able to use online technology (Wahbeh, Svalina and Oken, 2016).

Cognitive impairment may be another barrier for stroke survivors using online MBI (Cohen, Mitzner and Griffiths, 2020). Although, expert opinion suggests access to MBI can be improved for people with cognitive impairment by having shorter sessions, using memory aids, increased repetition, simplified language, and by removing the day retreat (Chan et al., 2020). Online MBIs are usually shorter in duration, can often be used repeatedly, sometimes use simplified content, and rarely include a day retreat (Spijkerman, Pots and Bohlmeijer, 2016). Given the characteristic of many online MBI, it is possible online MBI
may offer some advantages over traditional face-to-face group MBI for people with cognitive impairment, although more research is required investigating online MBI for people with cognitive impairment following stroke.

Post-stroke fatigue may be another barrier for people accessing online MBI. Fatigue is a common physical complication following stroke with results from a systematic review suggesting between 25% and 85% of stroke survivors experience post-stroke fatigue (Cumming et al., 2016). Post-stroke fatigue can make rehabilitation more difficult and limit recovery for stroke survivors (Su, Yuki and Otsuki, 2020). However, research has been completed using online MBI with people experiencing fatigue following brain injury (including stroke) and found online MBI was acceptable and may improve mental fatigue (Johansson and Bjuhr, 2016). Another physical limitation that can occur following stroke and may make using online MBI challenging is mobility difficulties and/or pain (Lui and Nguyen, 2018). Mobility difficulties and/or pain may limit the stroke survivors ability to complete some of the MBI practices (e.g. mindful movement, yoga), but MBIs usually encourage people to work within their limitations and to not push beyond their capabilities (Santorelli et al., 2017). Completing mindful movement seated and/or adapting certain practices can help people with cognitive and/or physical limitations engage with MBI practices (Simpson et al., 2017; Douglas et al., 2021)

Age is another factor to consider when thinking about possible barriers to online MBI. Variation exists among older adults internet use, with people age 65-74 years being more likely to use the internet compared to people aged 75 years and older (Hunsaker and Hargittai, 2018). Research evidence suggests age may be a factor for some people, but it appears older adults are using the internet more than previously and this pattern is likely to continue in years to come (König, Seifert and Doh, 2018). Race and ethnicity may also be a factor, with older adults from black and minority ethnic groups, being less likely to use technology assisted health interventions compared to their similarly aged white peers (Mitchell et al., 2019). These issues highlight the potential inequity of internet use within society and demonstrate the challenges associated with using online technology to deliver MBI to people affected by stroke. It is also worth remembering other factors (e.g. income, education, personal autonomy, computer skills) influence internet use and strategies to increase access have to
take an holistic approach and consider multiple barriers (Hargittai, Piper and Morris, 2019). It is also important to remember stroke survivors (Clark et al., 2018) and stroke nurses (Kidd et al., 2020) do not want a one-size-fits all approach to stroke self-management. People affected by stroke should be able to choose between online MBI and other modes of delivery (e.g. non-online) depending on their preferences and circumstances (Wahbeh, Svalina and Oken, 2016).

2.4.2 Adherence with online MBI

Online MBI is a possible alternative to non-online MBI, however, there are several concerns with the use of online MBIs. The primary concerns include adherence and dropout rates with online MBI (Fish, Brimson and Lynch, 2016; Langé, 2019). Poor adherence and high dropout rates are a concern because people who complete and engage better with MBIs are more likely to achieve better clinical outcomes (Carmody and Baer, 2008; Spijkerman, Pots and Bohlmeijer, 2016). Determining adherence in online mindfulness research is difficult and there is no consensus about what constitutes adherence. Spijkerman, Pots and Bohlmeijer (2016) completed a systematic review of online MBIs and found only a third of studies (n=10) evaluated adherence and the definitions varied. Five studies (50%) defined online MBI adherence as 100% completion of all sessions and reported adherence rates between 39.5% and 92% (Spijkerman, Pots and Bohlmeijer, 2016).

Another systematic review of online MBIs (n=10) found early dropout was common, highly variable (between 7.7% and 52.3%), and had no clear pattern (Fish, Brimson and Lynch, 2016). The rates of dropout seen with online MBI appear slightly higher than what has been documented with non-online MBI. A systematic review investigating the safety of non-online MBI examined results from RCTs (n=36) and found dropout rates were highly variable (between 0% and 36.8%) (Wong et al., 2018). One study has compared online MBI (n=20) with non-online MBI (n=12) and measured dropout rates for people experiencing mental fatigue following stroke or traumatic brain injury (Johansson and Bjuhr, 2016). The study reported zero dropout for non-online MBI and three dropouts for online MBI, but this was a small-scale study and
research is needed to better understand MBI dropout rates for people affected by stroke.

2.4.3 Group support with online MBI

Another concern with online MBI relates to the potential influence of learning MBI in a group environment. Much of the existing MBI research has focused on people attending MBI classes and learning mindfulness with a group of individuals (Gambrel and Keeling, 2010). Learning MBI methods (e.g. regular meditation and home practice) is usually seen as the ‘active ingredient’ and the group delivery a convenient method of teaching large numbers of people (Bishop, 2002). Although, the group environment of MBIs is now seen as an important element and possible mechanism for change (Section 2.5 on page 51) (Imel et al., 2008; Cormack, Jones and Maltby, 2018). Likewise, stroke survivors and their care partners have suggested learning in a group might offer motivation and support (Jani et al., 2018). Although, it would appear possible to incorporate group elements into online mindfulness. A proof of concept analysis investigated whether combining online MBI with peer support would make it easier for people to access mindfulness and whether they would experience improvements in stress and mindfulness. This study showed the potential of combining online MBI with peer support, but was conducted with collegiate support and in a non-clinical population. The study concluded online MBI with peer support was feasible and might provide benefits to participants, but suggested further research is required before firm conclusions can be drawn (Kemper and Yun, 2015). This thesis aims to address some of these concerns by using online MBI with care partnership affected by stroke.

2.4.4 Clinical outcomes and suitability of online MBI

It is also important to consider the clinical outcomes and the suitability of online MBI for stroke survivors. A recent systematic review including 15 RCTs investigated the effects of online MBIs for people with mental health difficulties (Spijkerman, Pots and Bohlmeijer, 2016). Spijkerman, Pots and Bohlmeijer (2016) systematic review and meta-analysis discovered online MBI has a small to medium effect on stress (g=0.51, 95% CI: 0.26 to 0.75, p <0.001), anxiety (g=0.22, 95% CI: 0.05 to 0.39, p=0.010), depression (g=0.29, 95% CI: 0.13 to 0.46, p <0.001), and mindfulness (g=0.32, 95% CI: 0.23 to 0.42, p <0.001).
Another systematic review (n=16 studies) investigated online MBI for people with physical health difficulties and found positive outcomes for pain, coping, and depression (Toivonen et al., 2017). Although, the review did not find online MBI was superior to other active treatments (e.g. cognitive behavioural therapy). Finding different therapies (e.g. MBI and cognitive behavioural therapy) are equally effective to each other is common and thought to be related to common factors (e.g. expectancy) in each therapy (Wampold, 2015). The phenomenon is called the “dodo bird verdict” and suggests all psychotherapies are equally effective when compare to each other and not just a waiting list control (Rosenzweig, 1936, p. 415). The systematic review also compared different ways of delivering online MBI and found no difference between synchronously, asynchronously, or live teacher facilitated MBI (Toivonen et al., 2017). Whilst this finding could suggest it is unnecessary to have a teacher facilitating online MBI, it is also possible the dodo verdict applies (Rosenzweig, 1936) and worth remembering stroke survivors and stroke nurses want different options for self-management (Clark et al., 2018; Kidd et al., 2020).

One of the studies in Toivonen et al.’s (2017) review recruited people following acquired brain injury (n=16) and/or stroke (n=18) and reported reductions in mental fatigue (p <0.001), depression (p=0.015), and anxiety (p=0.011) across both groups (Johansson, Bjuhr and Rönnbäck, 2015). Singh (2018) completed a Doctoral thesis examining the acceptability and feasibility of online MBI for stroke survivors. This RCT recruited people from the NHS and randomised participants to either online MBI course or a waiting list control. The study screened 54 participants, but most were either ineligible (n=18) or declined to take part (n=34). Two stroke survivors were enrolled into the study, completed the course, and provided follow-up data (Singh, 2018). Outcome measures showed reliable and clinically significant change (Jacobson and Truax, 1991) in depression for one participant and a reliable deterioration in anxiety for the other. Reliable and clinically significant change are methods used to evaluate participant change on an individual basis and can be applied to most continuous scales used in clinical setting/research (Evans, Margison and Barkham, 1998). Reliable change is said to have occurred if the scale indicates change which is greater than what might be attributed to measurement error.
Whilst clinically significant change compares the final participant measure with a meaningful comparison group, or normative data, to see whether the participants is within a clinical or non-clinical range (Evans, Margison and Barkham, 1998). Reliable and clinically significant change are widely used, but there is debate about whether it should be used when collecting ordinal data (e.g. Hospital Anxiety and Depression Scale, Zigmond and Snaith, 1983). The concern with using reliable and clinically significant change with ordinal data is because it is a parametric test using mean and standard deviation, which may not be appropriate for non-parametric ordinal data (Perdices, 2015).

Singh (2018) highlighted the challenges of recruiting stroke survivors into a study using online MBI and raised questions about feasibility of achieving adequate participants for a large study. Another Doctoral thesis (Langé, 2019) reported a randomised study comparing a four-week online MBI with waiting list control (Langé, 2019). Fifteen stroke care partners were recruited, but this reduced to nine by post-intervention and to five at follow-up. Participants found online MBI acceptable, but results for stress, anxiety, depression and mindfulness were mixed (Langé, 2019). One participant reported a reliable and clinically significant change (Jacobson and Truax, 1991) for stress, anxiety, and mindfulness. Whilst another participant reported a reliable deterioration for stress and mindfulness (Langé, 2019). Again it is uncertain whether using reliable and clinically significant change with ordinal data was appropriate (Perdices, 2015), but the findings give an indication of the mixed results produced in the study. The study also highlights the challenges of recruiting and retaining stroke care partners in sufficient numbers and raised questions about feasibility of MBI research with this population (Langé, 2019).

2.5 Mechanism of change within MBI

The mechanism for change is the process which produces therapeutic benefit in an intervention (Kazdin, 2007). The mechanism for change should provide an explanation of how an MBI works and identify active ingredients in the intervention (Alsubaie et al., 2017). Identifying the mechanism for change is an important step whether a new MBI is being developed or an existing MBI is being evaluated in a new context (Craig et al., 2008). The mechanism may also consider contributing factors for change (e.g. mediators) and/or characteristic
that may influence outcomes (e.g. moderators) (Kazdin, 2007). Investigating the mechanisms of change often involves examining the key construct (e.g. mindfulness) and/or dismantling studies (Stein and Witkiewitz, 2020), to determine whether the hypothesised active ingredient is involved with therapeutic change (Shapiro et al., 2006). Knowing exactly what mechanism is involved with change helps maximise the therapeutic potential and ensures the active ingredients are retained when the intervention is disseminated into clinical practice (Kazdin, 2007).

MBI theory suggests regular mindfulness practice increases mindfulness and the increased mindfulness helps reduce psychological distress (Kiken et al., 2015). Baer, Carmody and Hunsinger (2012) examined mindfulness changes during MBSR using the Five Facet Mindfulness Questionnaire (Baer et al., 2006) on a weekly basis with each participant (n=87) and found a significant increase in mindfulness at week two and a reduction in stress at week four of the course. The authors did not claim causation, because other factors may have contributed to the change, but did suggest increased mindfulness may mediate improvements in mental health after mindfulness training (Baer, Carmody and Hunsinger, 2012). However, the research did not examine specific elements of MBIs and dismantling studies are needed to find the active ingredient (Stein and Witkiewitz, 2020).

The different interconnected components make MBIs complex interventions (Clark, 2013; Demarzo, Cebolla and Garcia-Campayo, 2015). A complex intervention is a health intervention consisting of several different components, which interact with each and may contribute to the effectiveness of the intervention (Kühne et al., 2015). MBI curricula prioritise three core practices: sitting meditation, mindful movement, and body scan (Crane et al., 2017). Research has been completed to see what impact each individual MBI practice has on participants. Sauer-Zavala et al. (2013) evaluated and compared the effects of sitting meditation, body scan, and mindful yoga in a non-clinical population. The study found mindful yoga improves psychological wellbeing; mindful yoga and sitting meditation improve emotional regulation; and sitting meditation helps reduce unhelpful evaluation of observed stimulus during practices. Although, the amount of mindfulness practice used within the study (3 hours) was minimal, which raises questions about whether these findings can
be applied to MBIs that use more mindfulness practice. It is also uncertain whether a clinical population would experience the same level and type of impact experienced by the non-clinical participants used in the study (Sauer-Zavala et al., 2013).

A recent systematic review examined dismantling studies to identify the active component within MBIs. The review retrieved eight studies (n=2 MBSR, n=3 MBCT, n=3 MBI) and found acceptance and mindfulness were important mechanisms (Stein and Witkiewitz, 2020). Acceptance and increased mindfulness are likely important mechanism in MBIs (Gu et al., 2016; Alsubaie et al., 2017), but methodological weaknesses (e.g. small sample) and uncertainty about the best way of measuring mindfulness and acceptance make it difficult to draw any firm conclusions (Stein and Witkiewitz, 2020). For example, the measurement of acceptance and mindfulness varied in the studies, so it is possible they were measuring slightly different constructs (Bergomi, Tschacher and Kupper, 2013b; Stein and Witkiewitz, 2020).

A meta-synthesis explored how MBCT (Teasdale et al., 2000) produced therapeutic change and identified five themes: “taking control through understanding, awareness and acceptance; the impact of the group; taking skills into everyday life; feelings towards self; the role of expectation” (Cairns and Murray, 2015, p. 342). These themes capture the varied and interacting mechanisms within MBCT and include both specific (e.g. awareness) and non-specific (e.g. expectation) mechanisms. However, the review was unable to ascertain what mechanisms were most powerful or produced the most therapeutic benefit.

MBIs involve participants learning different mindfulness practices (e.g. sitting meditation, mindful movement, and body scan) and development of a personal practice is encouraged during the course (Crane et al., 2017). The personal practice element involves participants committing to MBI practice during sessions, between sessions, and after the sessions have finished (Santorelli et al., 2017). Maintaining a regular home practice can be challenging, with many people stating it can be difficult to find the time to practice regularly (Birtwell et al., 2019). A systematic review of mindfulness randomised/non-randomised controlled studies (n=14) measuring the utility of home practice found the
guidance given on home practice varied and was not consistent with recommended protocols (Lloyd et al., 2018). Seven studies examined the impact of home practice on clinical outcomes, but only four studies showed home practice was linked to better outcomes (Lloyd et al., 2018). These papers highlight the importance of home practice in MBIs, but the use of home practice in research and evidence of effectiveness is inconsistent.

The original MBSR course and many other MBIs have been developed for use in face-to-face group settings (Kabat-Zinn, 2011; Santorelli et al., 2017). The face-to-face sessions and interactions with fellow participants and the teacher is a non-specific aspect, which can be an active component of MBIs (Imel et al., 2008; Cairns and Murray, 2015). Imel et al. (2008) examined data from 59 different face-to-face groups (n=606 participants) to find out whether attending MBI in a face-to-face group had an effect on participant outcomes. The researchers collected pre/post-intervention data on psychological symptoms using the Global Severity Index (GSI) of the Symptom Checklist-90-Revised (Derogatis and Unger, 2010) and physical symptoms using the Medical Symptom Checklist (MSC) (Lesserman and Dorrington, 1989). The results showed a significant group effect on psychological symptoms ($p < 0.001$) (GSI), but no group effect with physical symptoms (MSC) ($p > 0.5$). Although, a serious limitation in this study was the lack of attention given to group processes and the absence of any formal measure of group cohesion (Imel et al. 2008).

The group processes involved with learning MBI in a face-to-face group has been explored using qualitative methods. A qualitative study interviewed 12 participants (students, teachers, trainers) and developed a Grounded Theory to explain how participants experienced the face-to-face group MBI as a “vessel on a communal journey” and as an opportunity to learn and practice together (Cormack, Jones and Maltby, 2018, p. 6). This study provides insight into the experience of people attending face-to-face group MBI, but the study involved non-clinical participants and the findings may not be relevant when being applied to a clinical setting.

A meta-synthesis of qualitative studies (n=7) examining how different features of MBCT (Teasdale et al., 2000) contribute to therapeutic outcomes discovered face-to-face group MBI helped participants develop “a shared sense of distress,
provided a validating and normalising experience … and also appeared to increase levels of motivation” (Cairns and Murray, 2015, p. 351). The meta-synthesis did not include anyone affected by stroke and included studies were of variable quality, so the findings have to be interpreted cautiously within the context of people affected by stroke. McCown (2016) believes future research should focus more on the interpersonal dimensions of MBIs and establish what processes occur when people learn MBI together.

Psychological mechanisms have been an important focus of MBI research, but neurobiological research is also providing useful insights into possible mechanisms (Creswell, 2017). A review of clinical and non-clinical populations examined studies (n=13) using MRI (magnetic resonance imaging) data to see whether structural and/or functional neurobiological changes occur following MBI (Hatchard et al., 2017). This review included seven studies using clinical populations and found MBI may produce changes in neural activity in certain areas and can affect brain function (e.g. visual attention, memory, emotion), although, the research is limited to certain conditions and did not include people affected by stroke (Hatchard et al., 2017).

The multifaceted nature of MBIs makes it difficult to determine the exact mechanism of change (Bishop, 2002). The difficulty of establishing the mechanism of change with MBIs is magnified by having different definitions of mindfulness (Chiesa, 2013), multiple MBI curricula (Teasdale et al., 2000; Santorelli et al., 2017), and each MBI curriculum being made up of several different interconnected components (Kühne et al., 2015). It is also important to consider the non-specific factors associated within attending an MBI (e.g. the group), which may also play an important role in producing therapeutic change (Imel et al., 2008; Cairns and Murray, 2015). Determining the mechanism of change is further complicated by the limited MBI research involving people affected by stroke, so it is difficult to know what mechanisms are involved when people affected by stroke use MBIs. Acceptance and increases in mindfulness appear to be the most likely mechanisms for change in MBIs, but more research is required to properly measure these constructs (Bergomi, Tschacher and Kupper, 2013) and to establish the exact mechanisms involved (Gu et al., 2015; Alsubaie et al., 2017; Stein and Witkiewitz, 2020).
2.6 MBIs for people affected by stroke

MBIs can alleviate various health related difficulties (Ludwig and Kabat-Zinn, 2008). Gotink et al. (2015) completed an overview of systematic reviews and meta-analyses of MBIs in healthcare. Their review included results from 115 RCTs (n=8683 participants) and indicated a small to medium effect size for depression (d=0.37; 95% CI 0.28 to 0.45), anxiety (d=0.49; 95% CI 0.37 to 0.61), stress (d=0.51; 95% CI 0.36 to 0.67), quality of life (d=0.39; 95% CI 0.08 to 0.70), and physical functioning (d=0.27; 95% CI 0.12 to 0.42) (Gotink et al., 2015). Another review of systematic reviews (n=26) evaluated the effectiveness of MBIs with a number of different physical and/or mental health difficulties (Long, Briggs and Astin, 2017). The review concluded MBIs will likely benefit people with most chronic conditions and especially those people struggling emotionally and/or experiencing depression (Long, Briggs and Astin, 2017).

Both reviews of systematic reviews (Gotink et al., 2015; Long, Briggs and Astin, 2017) examined the use of MBIs with people living with chronic health conditions, but only two of the included systematic reviews explored MBIs with people affected by stroke (Lawrence et al., 2013; Lazaridou, Philbrook and Tzika, 2013).

Lawrence et al. (2013) completed one of the systematic reviews examining MBIs for stroke survivors and included four studies (n=160 participants). The second systematic review by Lazaridou, Philbrook and Aria A Tzika (2013) examined MBIs with people affected by stroke, but also included studies using yoga. This systematic review captured 10 studies, but nine of those were yoga studies and were not relevant to MBI. The only MBI (Johansson, Bjuhr and Rönnbäck, 2012) study (n=1) in the review was also included in the Lawrence et al. (2013) review and added little value to what was already published in terms of MBI use with people affected by stroke.

Lawrence et al. (2013) examined a range of outcomes in their systematic review: stress, anxiety, depression, blood pressure, social participation, and quality of life (Lawrence et al., 2013). The systematic review found stroke survivors might gain bio-psychosocial benefit from MBIs, although, heterogeneity of studies prevented meta-analysis from being completed. Lawrence et al. (2013) suggests MBIs might have therapeutic benefits for stroke.
survivors, however, the systematic review was published several years ago and may be outdated. Shojania et al. (2007) researched how quickly systematic reviews become outdated and suggests systematic reviews be updated every five and a half years. The Lawrence et al. (2013) systematic review search was last repeated in 2018 (unpublished) and no new research was discovered; it is likely the original paper remains reflective of the current evidence-base. However, the review conclusions remain tentative because the included papers had methodological weaknesses. More robust MBI research is required before being able to make any firm conclusions about the value of MBI for people affected by stroke (Lawrence et al., 2013).

Another systematic review and meta-analysis has been completed to investigate the efficacy of MBI for treating fatigue following stroke, traumatic brain injury, and/or multiple sclerosis (Ulrichsen et al., 2016). The review included four studies (n=257 participants), but only two studies included people affected by stroke and those studies included mixed samples of people affected by stroke and people with traumatic brain injury (Johansson et al., 2015; Johansson, Bjuhr and Rönnbäck, 2015). Despite the low number of people affected by stroke (n=30, 11.7%) and the heterogeneity of the sample the meta-analysis showed an estimated moderate effect size of -0.37 (95% CI: -0.58, -0.17, p <0.01) for fatigue reduction in the whole sample (Ulrichsen et al., 2016). However, these results will also need to be interpreted cautiously in the context of stroke.

Other studies have also investigated the use of MBI with people affected by stroke. A two-stage mixed methods study examined the preferences, feasibility, and acceptability of seven mindfulness/relaxation strategies for people affected by stroke (Wang et al., 2019). Stage one involved people affected by stroke (n=13) watching mindfulness/relaxation practices and advising how they could be adapted for the needs of people affected by stroke. Stage two involved four of the adapted mindfulness/relaxation practices being used by participants (n=38) twice weekly for four weeks. A focus group was completed after using the mindfulness/relaxation practices and found adapted mindfulness/relaxation practices were acceptable for participants (Wang et al., 2019). However, the study used self-selected participants, so it is possible only people who were expecting to like mindfulness/relaxation practices would apply (Hicks, Hanes...
and Wahbeh, 2016). The study also used mindfulness and relaxation practices alongside each other, so it is difficult to know whether participants found the relaxation and/or mindfulness practice most helpful. This is important because mindfulness and relaxation are not the same and produce their outcomes via different mechanisms. The most distinct difference between mindfulness and relaxation is whether the intention is to change (i.e. relaxation) or notice/accept (i.e. mindfulness) unpleasant experiences (Luberto et al., 2020). A randomised controlled trial examined the effect of one-month mindfulness practice versus one-month relaxation training with distressed students (n=83). The study found both mindfulness and relaxation decrease distress and increased positive mood compared to control conditions (p <0.05), although, mindfulness appears to have a specific beneficial impact on unhelpful thoughts and rumination (Jain et al., 2007).

A different qualitative study also explored the acceptability of MBI from the perspective of stroke survivors (n=21) and care partners (n=7) and discovered MBI was feasible and acceptable for people affected by stroke (Jani et al., 2018). However, the study results were based on participants attending a two-hour mindfulness taster session, so it is unclear how participants would feel after attending a full MBI. Despite the short duration of the mindfulness practice Jani et al. (2018) highlighted the potential value of MBI for people affected by stroke and took the novel approach of including stroke survivors and care partners together.

### 2.7 MBIs for care partners

MBIs have shown potential for alleviating the stress experienced by some care partners when caring for people with chronic conditions (Hou et al., 2013; Whitebird et al., 2013). One systematic review examined 14 studies (n=849 participants) and found improvements in stress, anxiety, depression, and mindfulness for care partners following MBI (Li, Yuan and Zhang, 2016). Similarly, Jaffray et al. (2016) completed a systematic review of 10 studies (n=432 participants) and found MBIs improved depressive symptoms, reduced care burden, and increased quality of life for care partners. Neither systematic review (Jaffray et al., 2016; Li, Yuan and Zhang, 2016) was able to perform
meta-analysis and both struggled making firm conclusions because of the methodological weaknesses present in the studies being reviewed.

Qualitative research also shows care partners can experience beneficial effects from online MBIs (Stjernswärd and Hansson, 2020). The study asked care partners (n=10) to use an online MBI for 20 minutes per day over eight weeks, which is far less practice than recommended with MBSR (Santorelli et al., 2017). Content analysis produced four main themes: a timely and untimely intervention; mainly positive effects; relationship to the patient; creating a routine and maintaining motivation. These findings highlight the subjective experience for care partners using online MBI and indicate online MBIs may be a flexible and acceptable tool for care partners. However, the majority (n=9, 90%) of this small sample were female, which does reduce the transferability of the findings to more diverse populations (Stjernswärd and Hansson, 2020).

2.8 Critical perspectives of mindfulness and MBIs

Interest in mindfulness and MBIs has grown exponentially in recent years (Chiesa et al., 2017; Goldberg et al., 2017), but some people are concerned it is being sold as a panacea for all human problems (Van Dam et al., 2018). Evidence suggests more people are using mindfulness, but it appears to be the same type of people using mindfulness in greater numbers (Burke et al., 2017; Simonsson, Martin and Fisher, 2020). There are concerns about the lack of diversity among people using mindfulness and whether samples are representative in mindfulness research (Section 2.2 on page 40). A recent systematic review examined the sociodemographic profile of participants in mindfulness research in the United States and found the majority (n=3571, 78%) were Caucasian, likely to be employed, and likely to be college graduates (Waldron et al., 2018). It could be argued the lack of diversity in MBI research reflects the characteristics of the people using mindfulness (Section 2.2 on page 40). However, this interpretation does not consider the ethical principle of justice and fairness of distribution within society. Ethical research should ensure the benefits and burdens of research are shared equally in society and no groups of people should be privileged or disadvantaged through research activity (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979). It is necessary for us all to
acknowledge and rectify inherent structural inequality and how this can manifest within mindfulness when diversity issues are not addressed (Anālayo, 2020). The lack of diversity in MBI research also occurs in stroke research with many samples being predominantly white/Caucasian (Wang et al., 2019). The lack of diversity in some research affects representativeness of samples and makes it harder to generalise findings to the wider society (Waldron et al., 2018).

The proliferation of MBIs has also created concern that some interventions claiming to be MBIs are offering little more than relaxation (Cullen, 2011). As mentioned previously, mindfulness and relaxation are very different and produce different outcomes (Luberto et al., 2020). Traditional mindfulness practitioners also believe secular MBI protocols can be too technique driven (Monteiro, Musten and Compson, 2014) and may reduce the effectiveness of traditional Buddhist mindfulness (Marx, 2015).

The nature of MBI research creates some methodological challenges for researchers. A systematic review (Goldberg et al., 2017) examined MBI studies (n=142) to establish whether research methodology was improving and whether researchers were addressing some of the limitations commonly associated with mindfulness research. This review discovered limited improvement in mindfulness research quality between 2000-2016, with many studies continuing to use short follow-up periods, no fidelity measures, not evaluating therapist competence, and/or not using control groups (Goldberg et al., 2017). Davidson and Kaszniak (2015) state MBI researchers have difficulty clearly defining mindfulness, accurately measuring change, and creating appropriate control groups. The lack of an active control condition in many MBI studies is a long standing issue and does not appear to be improving (Goldberg et al., 2017). The persistent lack of appropriate active control in MBI research is a cause for concern because it does not consider the potential for non-specific factors (e.g. placebo) to influence outcomes (Baer, 2003). All these methodological issues could lead to the therapeutic potential of MBIs to be exaggerated and/or people to be misled about the effectiveness of MBIs (Van Dam et al., 2018).

Most MBI research has focused on the beneficial effects and less attention has been given to potential risks and/or unwanted effects (Schlosser Id et al., 2019). Reporting adverse events (AE) and serious adverse events (SAE) is important
for transparency and to ensure MBIs are not wrongly assumed to be risk free (Van Dam et al., 2018). AEs occur when participants experience an unexpected medical occurrence and SAEs involve death, life threatening issues, or hospitalisation (International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use, 1996). Unwanted effects in MBI can be caused by issues related to the MBI, the participant, and/or the teacher (Baer et al., 2019). Reporting of AE/SAE in MBI research is improving, but still variable and often missing from research reports (Van Dam et al., 2018). Baer et al. (2019) produced a summary of findings from four reviews (n=299 studies) investigating AE/SAE in MBI research, which showed 0-10.6% of participants involved in MBI research experience a AE/SAE. The rate of AE/SAE seen in this review is similar to what you would expect with control conditions, although, the limited reporting of AE/SAE in MBI research raises questions about the accuracy of the findings (Baer et al., 2019).

2.9 Summary and rationale for study

Stroke is a chronic health condition with serious consequences for the people affected and their family (Langhorne, Bernhardt and Kwakkel, 2011a). Research shows there is a high prevalence of anxiety and/or depression symptoms in stroke survivors (Broomfield et al., 2014) and stroke care partners (Loh et al., 2017). Experiencing anxiety and/or depression symptoms after stroke can negatively affect quality of life (Wan-Fei et al., 2017) and rehabilitation outcomes (Quattropani and Geraci, 2018). MBIs are effective self-management strategies for reducing anxiety and depression symptoms (Gotink et al., 2015; Spijkerman, Pots and Bohlmeijer, 2016) and might help people affected by stroke (Lawrence et al., 2013). People affected by stroke sometimes prefer having access to flexible MBI and learning with the support of a care partner (Jani et al., 2018). Online MBI provides a flexible and convenient way of accessing MBI and may be suitable for people affected by stroke (Johansson et al., 2015; Singh, 2018; Langé, 2019; Stjernswärd and Hansson, 2020). Using online MBI in a care partnership is a novel approach (Price-Blackshear et al., 2020), which might offer several advantages for people affected by stroke who are unable to leave the home and/or attend non-online mindfulness (Li, Yuan and Zhang, 2016; Stjernswärd and Hansson, 2020). A review of online MBIs

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concluded future research should investigate the value of online MBIs for different clinical populations and consider people using online MBIs in groups (Fish, Brimson and Lynch, 2016). Learning mindfulness in a stroke care partnership might offer additional benefits to learning mindfulness in a group setting (Smith et al., 2015; Jani et al., 2018), but this has not been researched previously (Parkinson et al., 2019). This study builds on existing research in the field of MBIs for people affected by stroke and is the first study to examine online mindfulness with care partnerships experiencing anxiety and depression symptoms following stroke.

This chapter provides a critical review of mindfulness literature and provides a rationale for the study of online mindfulness for care partnerships experiencing anxiety and depression symptoms following stroke. The next chapter presents the overall thesis aims and specific research questions answered during the thesis.
Chapter 3. Thesis aims

- To explore the experience and outcomes for care partnerships using mindfulness-based interventions (MBIs) together.
- To systematically review research using MBIs with people living with chronic conditions and their care partners (Chapter 4 on page 65).
- To research the use of online MBI with stroke survivors and their care partners (Chapter 5 on page 132).

3.1 Systematic review questions

- Do people living with chronic conditions and their care partners experience interpersonal changes when using MBI together (Section 4.5.5 on page 93)?
- Do people living with chronic conditions and their care partners experience changes in mindfulness after using MBI together (Section 4.5.6 on page 95)?
- Do people living with chronic conditions and their care partners experience changes in stress after using MBI together (Section 4.5.7 on page 97)?
- Do people living with chronic conditions and their care partners experience changes in anxiety symptoms after using MBI together (Section 4.5.8 on page 99)?
- Do people living with chronic conditions and their care partners experience changes in depression symptoms after using MBI together (Section 4.5.9 on page 102)?

3.2 Study questions

- Is it feasible to study online mindfulness with stroke survivors and their care partners together in a care partnership (Section 8.1 on page 225)?
- Do stroke survivors and their care partners find it appropriate to use online MBI together (Section 8.2 on page 232)?
- Do stroke survivors and their care partners experience changes in mindfulness after using MBI together (Section 8.3 on page 233)?
- Do stroke survivors and their care partners experience interpersonal changes after using MBI together (Section 8.4 on page 235)?
- Does online MBI have the potential to reduce anxiety symptoms for stroke survivors and their care partners (Section 8.5 on page 238)?
• Does online MBI have the potential to reduce depression symptoms for stroke survivors and their care partners (Section 8.6 on page 240)?
Chapter 4. Mindfulness for care partnerships living with chronic conditions and experiencing mental health difficulties: a systematic mixed studies review

4.1 Introduction

The previous chapters have introduced the experience of living with stroke and the importance of care partnerships. The chapters have explained how people affected by stroke can experience difficulties with anxiety and depression symptoms and how supported self-management strategies help care partnerships cope better with life after stroke. The background chapter critically discussed the use of mindfulness-based interventions (MBIs) and considered the potential value for care partnerships experiencing anxiety and depression symptoms after stroke.

A peer-reviewed systematic review was published by the author during this PhD and explored the use of MBIs with care partnerships (Parkinson et al., 2019). A copy of the published systematic review is available in the appendix (Appendix 1 on page 307). The published systematic review included qualitative, quantitative, and mixed methods studies (n=9) and found attending MBIs in a care partnership can improve psychological wellbeing, increase coping, and promote engagement. The systematic review was the first review to explore this topic, but conclusions should be interpreted cautiously because of weaknesses in the included studies and lack of transparency in the review synthesis (Parkinson et al., 2019). Another limitation of the original published review was the inclusion of studies using mixed samples. Some included studies had samples with care partnerships and people attending by themselves, which made it difficult to distinguish between individual and care partnership data.

The original systematic review included evidence published between 1980-2017 and is now several years old. Research investigating when systematic reviews become outdated suggests a median survival of five years, but significant new evidence can be found in less than two years (Shojania et al. 2007). MBI research is a rapidly evolving field of study (Chiesa et al., 2017), so it was necessary to update the review and report the latest available evidence on the
subject. The update also provided opportunity to enhance the quality of the
review and address some of the weaknesses in the published version. The
updated systematic mixed studies review will be reported in this chapter.

4.2 Systematic review aim

To systematically review research using MBIs with people living with chronic
conditions and their care partners.

4.3 Systematic review questions

The systematic mixed studies review will answer the following questions:

- Do people living with chronic conditions and their care partners experience
  interpersonal changes when using MBI together (Section 4.5.5 on page 93)?
- Do people living with chronic conditions and their care partners experience
  changes in mindfulness after using MBI together (Section 4.5.6 on page 95)?
- Do people living with chronic conditions and their care partners experience
  changes in stress after using MBI together (Section 4.5.7 on page 97)?
- Do people living with chronic conditions and their care partners experience
  changes in anxiety symptoms after using MBI together (Section 4.5.8 on
  page 99)?
- Do people living with chronic conditions and their care partners experience
  changes in depression symptoms after using MBI together (Section 4.5.9 on
  page 102)?

4.4 Methods

A systematic review should have clear reviews questions, a comprehensive
search strategy, explicit eligibility criteria, appraise the literature, synthesise
findings, and transparently report the methods and results (Aromataris and
Pearson, 2014). Systematic reviews have traditionally kept qualitative and
quantitative research separate, but systematic mixed studies reviews
synthesize evidence from qualitative, quantitative, and mixed methods studies
(Sandelowski, Voils and Barroso, 2006; Cerigo and Quesnel-Vallée, 2020). This
review uses a systematic mixed studies approach and incorporates a variety of
different study designs (Pluye and Hong, 2014). The rationale for using a systematic mixed studies approach is that combining qualitative, quantitative, and mixed methods perspectives helps increase the richness of a review and gives greater insight into the topic (Heyvaert, Hannes and Onghena, 2017). Although, systematic mixed studies reviews do pose some challenges and careful consideration is needed before deciding to use the approach. The main challenge with systematic mixed studies reviews is combining different research designs and using different synthesis methods, which can involve multiple stages and be very labour intensive (Cerigo and Quesnel-Vallée, 2020). There is also the possibility of methodological weakness because systematic mixed studies reviews often retrieve highly variable research designs, which increases heterogeneity within the review (Cerigo and Quesnel-Vallée, 2020). Including studies with high heterogeneity makes precise statistical analysis difficult and can limit the usefulness of findings for practice and policy makers (Achana et al., 2014). Although, using a systematic mixed studies approach on this occasion allowed for a more comprehensive understanding of the multiple complex questions posed by the review (Cerigo and Quesnel-Vallée, 2020).

4.4.1 Design

Systematic mixed studies reviews synthesise evidence from different types of research and use the principles of mixed methods research to develop new insight or understanding (Heyvaert, Maes and Onghena, 2013). Systematic review design is influenced by the reviewers’ philosophical perspective and are often grounded between realist and idealist perspectives (Gough, Oliver and Thomas, 2017). Realists believe reality is external and concrete, whilst idealists believe reality is subjective and open to interpretation. The opposing perspectives of realism and idealism exist at either ends of a continuum with most reviewers positioning themselves somewhere between the two extremes (Heyvaert, Hannes and Onghena, 2017). This mixed studies synthesis takes a pragmatic approach and is also ontologically and epistemologically situated between realist and idealist perspectives (Section 6.3 on page 139 for discussion on pragmatism).

Systematic mixed studies review design can be either segregated, integrated, or contingent (Sandelowski, Voils and Barroso, 2006). These designs have
different perspectives about whether qualitative and quantitative data are interchangeable or distinct from each other. This review uses a segregated design because qualitative and quantitative approaches are different and require distinct synthesis methods (Heyvaert, Hannes and Onghena, 2017). The segregated design uses qualitative and quantitative synthesis methods to complement each other and to configure evidence in this review (Sandelowski, Voils and Barroso, 2006). A segregated design was used because it retains the integrity of different research approaches and mitigates some of the concerns about synthesising different perspectives in systematic mixed studies reviews (Harden and Thomas, 2005) (Section 4.4 on page 66).

Systematic mixed studies reviews use different designs depending on the review questions, the sequencing of the synthesis, and the importance given to the quantitative and qualitative components (Pluye and Hong, 2014). This review used an explanatory sequential design and involved an initial quantitative synthesis (e.g. direction of effect) followed by a qualitative synthesis (e.g. thematic synthesis) (Ferguson, Kerrigan and Hovey, 2020). Priority was given to the initial quantitative stage because the original review retrieved mostly quantitative studies (n=6) and it was anticipated that the update would also retrieve mainly quantitative studies (Parkinson et al., 2019).

4.4.2 Prospective registration

Prospective registration involves publishing a systematic review protocol and is thought to improve transparency, reduce selective reporting, and minimise possible bias in a review (Stewart, Moher and Shekelle, 2012). Prospective registration is also a key strategy for avoiding duplication of work and reducing research waste (Cristea and Naudet, 2019). A cross-sectional survey emailed authors (n=6650) of systematic reviews published between 2010-2016 to establish the awareness and opinion of prospective registration (Tawfik et al., 2020). The survey found almost half of authors (n=122, 44.2%) did not register their systematic review and only a small minority (n= 28, 10.1%) said they registered all their reviews. The limited use of prospective registration is a concern because a recent study evaluated orthodontic systematic reviews (n= 182) and found review quality was better when it was prospectively registered (Sideri, Papageorgiou and Eliades, 2018). The survey shows prospective
registration is not always completed, but the low response rate (n= 275, 4.14%) makes it difficult to gauge the true level of prospective registration amongst reviewers (Tawfik et al., 2020).

The original systematic mixed studies review protocol was prospectively registered using PROSPERO (CRD42016042113) (Parkinson et al., 2016). PROSPERO is a popular prospective register for health and social care systematic reviews, which publishes review protocols online and maintains an audit trail of amendments made to the protocol (Tawfik et al., 2020). The prospective register was amended for the updated review in 2020. The main amendments made to the review protocol for the updated review were changes to terminology (e.g. care partnership), phrasing of the review questions, and greater clarity about the approach to data synthesis (Parkinson et al., 2020).

4.4.3 Search methods

The search methods involved developing practice-based review questions (Section 4.3 on page 66) and using the study design, population, intervention, outcome (SPIO) structure to search and screen the literature (Section 4.4.5 on page 72) (Lawrence et al., 2013). This systematic approach to question development and literature searching helps improve transparency and quality of systematic reviews (Cooke, Smith and Booth, 2012; Shea et al., 2017). A recent systematic review examined whether using a search strategy (e.g. SPIO) improved the quality of the search (Eriksen and Frandsen, 2018). The systematic review was unable to find strong evidence supporting the use of search strategies (e.g. SPIO), but the systematic review only included a small number of studies (n=3) and more research is needed before making firm conclusions (Eriksen and Frandsen, 2018).

This review completed a systematic search using keywords, truncation, subject headings, Boolean operators, and limiters (including search fields) (Table 1 on page 71). The search was the same for both reviews, but the initial review searched between 1980-2017 and the updated review retrieved literature published 1980-2020. The main limitation of the search was having the electronic database search limited to title/abstract and English language. A prospective exploratory study examined search methods in systematic reviews (n=73) and discovered limiting searches by title/abstract was a common (n=24,
33%) pragmatic strategy, but could reduce the search yield by 5% (Bramer et al., 2018). Reducing the search yield might prevent relevant studies from being discovered (Lin, 2009), but reviewers have to balance the desire to maximise search yield with the amount of resources and time needed to search a large number of potentially irrelevant results (Bramer et al., 2018). The need to balance the demands of the review with the resources available was particularly important because the update was completed during pandemic lockdown restrictions and required second reviewers to contribute their time and screen bibliographic records. A survey of UK-based academics (n=143) investigated the impact of pandemic lockdown restrictions on academic life and discovered work-life balance was adversely affected (i.e. got worse) for the majority (n=85, 59.4%) of participants (Ashencaen Crabtree, Esteves and Hemingway, 2020). The survey provides insight into the challenges of academic life during a pandemic lockdown, but needs to be viewed cautiously because of the small non-representative sample (Ashencaen Crabtree, Esteves and Hemingway, 2020).

Restricting the search to papers published in English was done on basis of feasibility and within the context of an unfunded PhD, however, limiting the search to 'English language' could have caused some research to be missed (Morrison et al., 2012). A systematic review investigating the impact of using English language limiters found little evidence of bias, but the review did acknowledge the impact may vary depending on the clinical field (Morrison et al., 2012). The Buddhist origin of mindfulness does cause concern about possible English language bias, but the costs associated with translating papers prevented the review from including research published in other languages (e.g. Thai).
Table 1: Electronic Search of CINAHL (EBSCO)

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<tr>
<td>S2</td>
<td>(MH “mindfulness”)</td>
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<tr>
<td>S3</td>
<td>AB MBSR</td>
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<td>S4</td>
<td>AB MBCT</td>
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<tr>
<td>S5</td>
<td>AB Breath*</td>
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<tr>
<td>S6</td>
<td>AB Meditat*</td>
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<tr>
<td>S7</td>
<td>(MH “meditation”)</td>
</tr>
<tr>
<td>S8</td>
<td>AB Relax*</td>
</tr>
<tr>
<td>S9</td>
<td>(MH “relaxation”)</td>
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<td>S10</td>
<td>S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9</td>
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<tr>
<td>S11</td>
<td>AB Dyad*</td>
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<tr>
<td>S12</td>
<td>AB couple*</td>
</tr>
<tr>
<td>S13</td>
<td>(MH “couple’s therapy”)</td>
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<tr>
<td>S14</td>
<td>AB spous*</td>
</tr>
<tr>
<td>S15</td>
<td>(MH “spouses”)</td>
</tr>
<tr>
<td>S16</td>
<td>AB Partner*</td>
</tr>
<tr>
<td>S17</td>
<td>AB Famil*</td>
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<tr>
<td>S18</td>
<td>(MH “Family Therapy”)</td>
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<tr>
<td>S19</td>
<td>AB carer*</td>
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<td>S20</td>
<td>AB Caregiver*</td>
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<td>S21</td>
<td>(MH “Caregivers”)</td>
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<td>S22</td>
<td>S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21</td>
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<td>S23</td>
<td>S10 AND S22</td>
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(limiters: published since 1980; English language; all adults).

4.4.4 Information sources

The information sources used for a search will influence the completeness and size of yield produced (Harari et al., 2020). It is estimated 60% of published systematic reviews fail to retrieve an adequate amount of relevant literature (i.e. >95%), which results in many systematic reviews reporting on incomplete and potentially bias search results (Bramer et al., 2017). Reporting on incomplete or bias search results can lead to inaccurate conclusions and recommendations from a systematic review (Harari et al., 2020).

It is important for systematic reviews to search a wide range of information sources to increase the search yield and reduce the chances of important studies being missed (Bramer et al., 2017). This review searched databases: AMED (EBSCOhost); CINAHL (EBSCOhost); Medline (ProQuest); Nursing and Allied Health Database (ProQuest); Psychology Database (ProQuest); PsycINFO (ProQuest). It also searched clinical trial registers: The Cochrane Central Register of Controlled Trials (CENTRAL). Other sources searched included: relevant websites, Google Scholar, and the reference lists of included papers.
4.4.5 Eligibility criteria

Inclusion and exclusion criteria were established to determine whether studies were eligible for the systematic review on page 73). An inclusive approach was taken to eligibility because systematic mixed studies reviews (i.e. qualitative, quantitative, and mixed methods) are open to different perspectives and supposed to include different study designs (Heyvaert, Hannes and Onghena, 2017; Jordan et al., 2018). Limiting the systematic review by study design (e.g. RCTs) would have prevented small-scale pilot and feasibility studies from being included and would have limited the scope of the review. The review included all peer-reviewed primary research where attending as a care partnership was a requirement for enrolment (i.e. people with chronic conditions not allowed to attend by themselves). The original review included some studies with mixed samples and had people by themselves and people in care partnership together in the same study. However, it was decided the update should exclude studies with mixed samples because having a mixed sample could create bias in the results. The published review also included an academic thesis (n=1) (Hankin, 2009; Parkinson et al., 2019), but the updated review excluded unpublished academic theses for pragmatic reasons and to reduce the data extraction burden on second reviewers. Excluding unpublished literature is common, with evidence suggesting less than a quarter of systematic reviews (n=78, 22%) include unpublished data/studies (Golder et al., 2016). Similarly, a cross-sectional study for systematic review (n=129) found very few (n=15, 1.9%) included unpublished academic theses and excluding unpublished academic theses had little impact on results (Hartling et al., 2017). However, excluding unpublished academic theses may prevent important work from being included and could cause data on adverse events to be lost (Golder et al., 2016).

Although, it could be argued thesis authors have a responsibility to ensure their results are disseminated properly through peer-reviewed journal publication. However, research investigating publication rates for psychology thesis found roughly a quarter (25.6%, 95% CI 23.0, 28.4) become published and a large majority remain unpublished (Evans et al., 2018).

The focus of the review was care partnerships living with chronic conditions. There is no singular definition of a chronic condition, but the term is being used to describe any health condition that is chronic in nature, has a significant
impact on health, and requires long-term (self) management (Goodman et al., 2013). The term chronic condition applies to a range of clinical presentations, so eligibility criteria was inclusive enough to accept participants with various diagnoses or self-reported difficulties.

Intervention eligibility included mindfulness-based stress reduction (MBSR) (Kabat-Zinn, 2013), mindfulness–based cognitive therapy (MBCT) (Segal et al., 2018), or other closely related mindfulness-based interventions (MBIs). If the intervention was not clearly branded (e.g. MBSR, MBCT) then the content of the intervention would have to closely follow the MBSR curriculum (e.g. body scan, gentle yoga, sitting meditation, and walking meditation) (Santorelli et al., 2017). The review did not include interventions where mindfulness is part of a broader approach (e.g. Tai Chi, Qigong or Yoga) or used with other ‘active ingredients’ (e.g. Acceptance and Commitment Therapy and Compassion Focussed Therapy). The review also excluded studies focusing on parenting or romantic relationships. During the review update the eligibility was amended to allow inclusion of MBIs delivered remotely (e.g. telephone, online). The amendment to eligibility was made because of the focus on online MBIs in the thesis and importance of online approaches during the COVID-19 pandemic (Holmes et al., 2020).

Primary outcomes for the review were changes in stress, anxiety, and depression symptoms. Secondary outcomes included changes to mindfulness and interpersonal changes in the care partnership (Table 2 on page 74).
Table 2: SPIO (study designs, participants, interventions, outcomes)

<table>
<thead>
<tr>
<th></th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study designs</strong></td>
<td>Peer-reviewed primary research using any study design.</td>
<td>Studies where care partnership data is unavailable.</td>
</tr>
<tr>
<td></td>
<td>Studies where attending in a care partnership was a requirement for enrolment.</td>
<td>Discussion papers, editorials, non-intervention studies, and academic thesis/dissertation.</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>Adult with chronic condition(s) and their care partners living in the community.</td>
<td>Adults with chronic condition(s) and their care partners attending by themselves. Under 18s.</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td>MBI delivered to a care partnership.</td>
<td>Mindfulness used as part of an intervention (e.g. ACT or yoga) or used in conjunction with other approaches. People/couples attending MBI to improve parenting or romantic relationships.</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>Interpersonal changes in the care partnership.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Changes to mindfulness.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Changes to stress, anxiety symptoms, and depression symptoms.</td>
<td></td>
</tr>
</tbody>
</table>

4.4.6 Study selection

RefWorks was used for storing bibliographic records, removal of duplicates, and to share bibliographic records with other reviewers (Ivey and Crum, 2018).

Study selection used a double screening approach (Waffenschmidt et al., 2019). The first step of screening involved reading the titles/abstracts of all the retrieved records and using inclusion/exclusion criteria to code them: ‘include’, ‘undecided’ or ‘exclude’. The second stage involved reading full-text versions of all bibliographic records coded ‘undecided’ or ‘include’ to determine whether they meet inclusion/exclusion criteria. Both stages of the double screen were completed by two reviewers and disagreements were resolved through discussion between reviewers (Waffenschmidt et al., 2019).

The biggest challenge with study selection was when to include/exclude MBIs that were part of a broader intervention. Many studies were excluded because the MBI had been combined with another active ingredient (e.g. care planning), which may have contributed to the therapeutic effect and become of confounder
in the review (Parahoo, 2014). Another challenge was the amount of studies that recruited care partnerships (i.e. person with a chronic condition and their care partner) and people by themselves (i.e. person with chronic condition and no care partner). Recruitment of people by themselves and care partnerships (Section 4.4.7 on page 76) into the same study created mixed samples and made it difficult to extract data specifically on care partnerships. The inclusion and exclusion criteria was adapted for the systematic review update to ensure only care partnership data was included in the synthesis. The process of screening and selection is illustrated using a PRISMA diagram (Moher et al., 2009) (Figure 1 on page 75).

**Figure 1: PRISMA**

![PRISMA Diagram](Moher et al., 2009)
4.4.7 Data extraction

Data extraction is an important stage of the review process, but extraction errors are common and can produce bias (Mathes, Klaßen and Pieper, 2017). A data collection tool was developed and piloted by two reviewers. The data extraction tool collected data related to study design, participants, interventions, outcomes (e.g. stress, anxiety symptoms, depression symptoms, mindfulness, and interpersonal) (Lawrence et al., 2013). Data was extracted separately by two reviewers and inconsistencies were discussed by reviewers. Missing data was requested via email from authors or recorded as ‘not reported’ (NR).

Data extraction was complicated by some studies recruiting both care partnerships and people by themselves. The issue of mixed samples was resolved by contacting the lead authors of the studies using mixed samples and requesting data for care partnerships only. Not all studies with mixed samples provided care partnership data and some studies had to be excluded on the basis of having mixed samples. Paller, et al. (2015) and Kubo et al., (2018, 2019, 2020) provided anonymous care partnership data for the review, which allowed for participants attending by themselves to be removed from the published findings. The mean, standard deviation, and \( p \) value for people with chronic conditions and their care partners were obtained directly from the author or by using a Wilcoxon signed-rank test and Statistical Package for Social Science (SPSS version 22).

4.4.8 Quality appraisal

The original review (Parkinson et al., 2019) completed quality appraisal using the Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012), but this tool was recently updated (Nha Hong et al., 2018). The latest version of the MMAT was developed to improve content validity and was produced using a literature review and two-stage e-Delphi methods (Hong et al., 2019). An international panel of methodologists was involved in both stages of the e-Delphi (\( n=74 \) and 56) and made 11 enhancements to the MMAT (Pace et al., 2012). The MMAT includes two screening questions and up to 15 further questions depending on the research design. The MMAT should not be used to provide an overall quality score and excluding studies on the basis of a low MMAT score is discouraged (Nha Hong et al., 2018). This review aligns with these
recommendations by using the MMAT with all included studies and not using the quality appraisal to exclude studies (Nha Hong et al., 2018).

Two reviewers used the latest version of the MMAT (Nha Hong et al., 2018) to separately quality appraise the studies. This included repeating quality appraisal on the papers included in the original review with the latest version of the MMAT (Nha Hong et al., 2018). Any disagreement about the quality appraisal was discussed and resolved by the reviewers. The quality appraisal process involved evaluating individual studies and also considering strengths and weaknesses across studies (Moher et al., 2009).

4.4.9 Mixed research synthesis

The review used a segregated explanatory sequential design, so the quantitative synthesis occurred prior to the qualitative synthesis (Ferguson, Kerrigan and Hovey, 2020). The main outcomes examined in the synthesis were interpersonal factors, mindfulness, stress, anxiety symptoms, and depression symptoms. Heterogeneity of data/studies made meta-analysis unfeasible, so data was synthesised using alternative methods (Campbell et al., 2020). The Cochrane Handbook of Systematic Reviews recommends effect direction and vote counting for situations where meta-analysis is not possible (McKenzie and Brennan, 2020). The main limitation of vote counting is that it does not take into account study quality and can provide a misleading result when there are a large number of low quality studies (Heyvaert, Hannes and Onghena, 2017). The Cochrane Handbook of Systematic Reviews also suggests vote counting can be used with the Sign Test to calculate statistical significance (McKenzie and Brennan, 2020). Calculating statistical significance using the Sign Test provides additional data on the direction of effect, but the binary assumptions (i.e. positive vs negative effect) are inappropriate when using direction of effect because some studies produce mixed results or no effect (Nikolakopoulos, 2020). The synthesis took a pragmatic approach to resolve the issues of using the Sign Test with vote counting and excluded studies with mixed results or no effect (Boon and Thomson, 2020).

This review compared mean scores of validated measures before and after intervention/control. Assessing pre/post mean scores helped determine whether change occurred and the effect direction. Vote counting and effect direction
were used to establish when change was positive (improved), negative (worse), or unclear (same) (Campbell et al., 2020). Studies showing positive and negative results were used with hypothesis testing (Section 7.7.1.3 on page 187) and inferential statistics to calculate statistical significance and the probability of finding the results, if the null hypothesis were true (Boon and Thomson, 2020). The Sign Test was used to calculate a two-tailed \( p \) value using GraphPad (GraphPad, 2020). The \( p \) value of \( \leq 0.05 \) was used to indicate statistical significance and whether the null hypothesis can be rejected (Chavalarias et al., 2016).

Thematic synthesis (Thomas and Harden, 2008) was completed with all studies containing a qualitative component and reporting relevant outcomes (e.g. stress, anxiety symptoms, depression symptoms, mindfulness, and interpersonal). All qualitative data (e.g. participant quotes and text) pertaining to relevant outcomes was extracted by independent reviewers and included in the thematic synthesis. Thematic synthesis involved three stages: coding the qualitative data, development of descriptive themes, and generation of analytical themes (Thomas and Harden, 2008). Prior to thematic synthesis all the extracted qualitative data was placed into one qualitative data set and uploaded to NVivo 12 (QSR International). All stages of the thematic synthesis were completed using NVivo 12 (QSR International). The synthesis was completed by one reviewer and reviewed by academic supervisors.

The first stage of thematic synthesis involved coding the qualitative data set (Thomas and Harden, 2008). The data was coded line-by-line and every sentence had at least one initial code (Figure 2 on page 79).
The second stage of thematic synthesis was to develop descriptive themes (Thomas and Harden, 2008). Developing descriptive themes involved using the initial codes and looking for similarities and differences between codes. The initial codes were then grouped together into larger descriptive themes (Figure 3 on page 79).

The final stage of the thematic synthesis involved using the descriptive themes to generate analytical themes and produce new insight into the area of study (Thomas and Harden, 2008). Generating analytical themes involved synthesizing the descriptive themes into more abstract and conceptual themes (Thomas and Harden, 2008) (Figure 4 on page 80). A common debate with
thematic synthesis is the level of interpretation used and how closely the final synthesis should reflect the original data (Dixon-Woods et al., 2005). A key feature of thematic synthesis is that it should go beyond the original studies and provide a new interpretation of the phenomenon (Barnett-Page and Thomas, 2009). Otherwise thematic synthesis would offer little more than what was original data presented in the primary research (Dixon-Woods et al., 2005).

Figure 4: Analytical themes

The final stage of a segregated mixed studies synthesis is to synthesise the quantitative and qualitative components (Sandelowski, Voils and Barroso, 2006). Synthesis of the separate quantitative and qualitative components of the mixed studies review occurred during the discussion section (Heyvaert, Hannes and Onghena, 2017). The discussion section of the systematic review provided opportunity to integrate the distinct quantitative and qualitative synthesis and provide new insight into the use of MBIs by care partnerships. The focus of the final stage was to configure the quantitative synthesis and qualitative synthesis and use the distinct evidence syntheses to complement each other and provide a new perspective on the phenomenon (Sandelowski, Voils and Barroso, 2006).

4.4.10 Strengths and limitations

The updated systematic mixed studies review was self-evaluated using the assessment of multiple systematic reviews (AMSTAR 2) (Shea et al., 2017). AMSTAR 2 contains 16 criteria and was developed to evaluate systematic reviews of randomised and non-randomised studies. The AMSTAR 2 was used to identify strengths and limitations in the systematic review (Table 14 on page 129). Using AMSTAR 2 (Shea et al., 2017) helped highlight strengths/limitations, but the critical appraisal needs to be viewed cautiously because the AMSTAR 2 was not designed for use with mixed studies reviews (Shea et al., 2017).
4.4.11 Reporting

Accurate and detailed reporting is an important aspect of the research process (Shanahan, Lopes de Sousa and Marshall, 2017). The systematic review is reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Moher et al., 2009) (Appendix on page 310). Since writing this systematic review, an updated version of the PRISMA has been published (Page et al., 2021). The updated PRISMA includes a number of changes to the way systematic reviews should be reported and future systematic reviews will likely have to align with the latest version of the PRISMA.

The quantitative data for people with chronic conditions and care partners is presented using tables, whole numbers (n), means (M), standard deviation (SD), p values ≤0.05 (*), percentages (%), and effect sizes (d or g) (Parahoo, 2014). Effect size will be interpreted using the following levels: very small (0.1), small (0.2), medium (0.5), large (0.8), very large (1.2), and huge (2.0) (Sawilowsky, 2009). The quantitative synthesis is reported using an effect direction plot (Thomson and Thomas, 2013) (Table 12 on page 108). Qualitative synthesis is presented as a thematic synthesis (Thomas and Harden, 2008) and reports the mindfulness with care partnerships themes (Figure 5 on page 109). A visual diagram and excerpts from selected papers are used to report the mindfulness with care partnerships themes.

4.5 Findings

4.5.1 Search outcomes

The initial search retrieved 4977 bibliographic records, which reduced to 3630 after duplicates were removed. Double screening identified 10 studies for inclusion (Figure 1 on page 75).

4.5.2 Study characteristics

The 10 included studies were all based in North America or Europe and had been published 2010-2020 (Kubo et al., 2018, 2019, 2020; Price-Blackshear et al., 2020; Birnie, Garland and Carlson, 2010; Lengacher et al., 2012; Paller et al., 2015; Smith et al., 2015; Berk et al., 2019; McDonnell et al., 2020). The
updated review added six new studies to the synthesis (Kubo et al., 2018, 2019, 2020; Berk et al., 2019; McDonnell et al., 2020; Price-Blackshear et al., 2020) and changes to the eligibility criteria for the update (Section 4.4.5 on page 72) removed five studies (Hankin, 2009; Van Den Hurk et al., 2015; Marconi et al., 2016; Cash et al., 2016; Schellekens et al., 2017) included in the published systematic review (Appendix 1: Journal publication from the thesis 2019 on page 307). Sample size varied between 14-154 (mean 52.7, SD 44.5). Cancer was the most common chronic condition being studied (n=7, 70%), but other chronic conditions were also included. Other chronic conditions included were cognitive decline (n=1, 10%) (Paller, et al., 2015); dementia (n=1, 10%) (Berk et al., 2019); and depression (n=1, 10%) (Smith et al., 2015) (Table 3 on page 83).

Seven quantitative (Kubo et al., 2018, 2019, 2020; Price-Blackshear et al., 2020; Birnie, Garland and Carlson, 2010; Lengacher et al., 2012; Paller, et al., 2015), one qualitative (Smith et al., 2015), and two mixed methods (Berk et al., 2019; McDonnell et al., 2020) studies were included. Four quantitative studies were pilot pre/post-test design (Kubo et al., 2018; Birnie, Garland and Carlson, 2010; Lengacher et al., 2012; Paller et al., 2015) and three studies were RCTs (Kubo et al., 2019, 2020; Price-Blackshear et al., 2020). The quantitative components in the two mixed methods studies were pilot pre/post-test design (Berk et al., 2019; McDonnell et al., 2020). Only three studies included a control group (Kubo et al., 2019, 2020; Price-Blackshear et al., 2020) and one study collected follow-up data (Kubo et al., 2020). The qualitative study used Grounded Theory (Smith et al., 2015) and the two mixed methods studies with a qualitative component used either content analysis or thematic analysis (Berk et al., 2019; McDonnell et al., 2020) (Table 3 on page 83).
<table>
<thead>
<tr>
<th>Authors &amp; Country</th>
<th>Number enrolled</th>
<th>Diagnosis</th>
<th>Approach</th>
<th>Intervention (delivery)</th>
<th>Control</th>
<th>Follow-up</th>
<th>Funding (code)</th>
<th>Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berk et al. (2019); Netherlands</td>
<td>14</td>
<td>Dementia</td>
<td>Mixed methods (pilot study)</td>
<td>MBSR (group)</td>
<td>No</td>
<td>No</td>
<td>Alzheimer Nederland and the Fred Foundation (WE.09-2016-4)</td>
<td>Weeks 0 and 8 (+/- 2) PSWQ DASS MHC-SF FFMQ Post-intervention interview</td>
</tr>
<tr>
<td>Birnie et al. (2010); Canada</td>
<td>42</td>
<td>Cancer</td>
<td>Quantitative (pre/post-test)</td>
<td>MBSR (group)</td>
<td>No</td>
<td>No</td>
<td>Social Sciences and Humanities Research Council (NR)</td>
<td>Week 0 and 8-10 POMS C-SOSI MAAS</td>
</tr>
<tr>
<td>Kubo et al. (2018): US</td>
<td>26</td>
<td>Cancer</td>
<td>Quantitative (pilot study)</td>
<td>Headspace™ (mobile application)</td>
<td>No</td>
<td>No</td>
<td>National Institutes of Health (grant KL2TR000143, K07CA166143) and Kaiser Permanente Planned Giving Fund</td>
<td>Week 0 and 8 Distress Thermometer HADS PROMIS</td>
</tr>
<tr>
<td>Kubo et al. (2019): US</td>
<td>46</td>
<td>Cancer</td>
<td>Quantitative (RCT)</td>
<td>Headspace™ (mobile application)</td>
<td>TAU</td>
<td>No</td>
<td>American Cancer Society (128952-PEP-16-056-01-PCSM)</td>
<td>Weeks 0 and 8 Distress Thermometer HADS FFMQ</td>
</tr>
<tr>
<td>Kubo et al. (2020): US</td>
<td>60</td>
<td>Cancer</td>
<td>Quantitative (RCT)</td>
<td>Headspace™ (mobile application)</td>
<td>TAU</td>
<td>Yes</td>
<td>The Permanente Medical Group (TPMG) Delivery Science Research Program</td>
<td>Weeks 0, 6, and 12 Distress Thermometer HADS FFMQ</td>
</tr>
<tr>
<td>Lengacher et al. (2012); US</td>
<td>52</td>
<td>Cancer</td>
<td>Quantitative (pilot study)</td>
<td>MBCR (group)</td>
<td>No</td>
<td>No</td>
<td>Cancer Center Integrative Medicine Pilot Research Grant Program (15259)</td>
<td>Weeks 0 and 6 PSS CES-D scale STAI</td>
</tr>
<tr>
<td>McDonnell et al. (2020); US</td>
<td>62</td>
<td>Cancer</td>
<td>Mixed methods (pilot study)</td>
<td>Breathe Easier (group)</td>
<td>No</td>
<td>No</td>
<td>Bristol Myers Squibb Foundation and American Cancer Society (MRSG-17-152-01)</td>
<td>Weeks 0 and 8 PSS HADS Post-intervention interview</td>
</tr>
<tr>
<td>Authors &amp; Country</td>
<td>Number enrolled</td>
<td>Diagnosis</td>
<td>Approach</td>
<td>Intervention (delivery)</td>
<td>Control</td>
<td>Follow-up</td>
<td>Funding (code)</td>
<td>Data Collection</td>
</tr>
<tr>
<td>-------------------</td>
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<td>----------------</td>
</tr>
<tr>
<td>Paller <em>et al.</em> (2015); US</td>
<td>29</td>
<td>Cognitive decline (various)</td>
<td>Quantitative (pilot study)</td>
<td>MBSR (group)</td>
<td>No</td>
<td>No</td>
<td>Cognitive Neurology and Alzheimer's Disease Center at Northwestern University and the North Shore Senior Center. (NIH P30 AG13854)</td>
<td>Weeks 0 and 8 (+/- 2) BAII GDS</td>
</tr>
<tr>
<td>Price-Blackshear <em>et al.</em> (2020); US</td>
<td>154</td>
<td>Cancer</td>
<td>Quantitative (RCT)</td>
<td>MBRE (online)</td>
<td>MBI (online)</td>
<td>No</td>
<td>University of Missouri Systems (NR)</td>
<td>Weeks 0 and 8 PSS PROMIS MAAS DAS QMI IMS</td>
</tr>
<tr>
<td>Smith <em>et al.</em> (2015); UK</td>
<td>16</td>
<td>Depression</td>
<td>Qualitative (grounded theory)</td>
<td>MBCT (group)</td>
<td>No</td>
<td>No</td>
<td>NR</td>
<td>Post-intervention interview</td>
</tr>
</tbody>
</table>

Key
BAI= Beck Anxiety Inventory; CES-D scale= Centre for Epidemiological Studies Depression Scale; C-MBI= Couples Mindfulness Based Intervention; CSOS-I= Calgary Symptoms of Stress Inventory; DASS= Depression Anxiety Stress Scale; DAS= Dyadic Adjustment scale; FFMQ= Five Facet Mindfulness Questionnaire; GDS= Geriatric Depression Scale; HADS= Hospital Anxiety and Depression Scale; IMS= Interpersonal Mindfulness Scale; MAAS= Mindful Attention Awareness Scale; MBCT= Mindfulness Based Cognitive Therapy; MBI= Mindfulness Based Intervention; MBSR= Mindfulness Based Stress Reduction; MBCR= Mindfulness Based Cancer Recovery; MBRE= Mindfulness Based Relationship Enhancement; Mental Health Continuum Short Form= MCH-SF; NR= Not reported; POMS= Profile of Mood States; PROMIS= Patient-Reported Outcomes Measurement Information System; PSS= Perceived Stress Scale; PSWQ= Penn State Worry Questionnaire; QMI= Quality of marriage Index; STAI= State-Trait Anxiety Inventory; TAU= Treatment as usual
4.5.3 Participant characteristics

The review includes people with chronic conditions (n=250) and care partners (n=249). All people with chronic conditions attended MBI with a care partner, but some people with chronic conditions attended with more than one care partner and some care partners did not provide data (Section 4.5.3 on page 85). The mean sample size for people with chronic conditions and caregivers was 21 (SD 18.3) and 21.1 (SD 17.7) respectively. The mean age was 60 (SD 10.4) for people with chronic conditions and 56.3 (SD 8.27) for care partners. The review included a variety of different care partnerships including caregivers (n=5), couples (n=1), partners (n=3), and/or a combination (n=1) (Table 4 on page 86).
Table 4: Participant characteristics

<table>
<thead>
<tr>
<th>Study</th>
<th>People with chronic conditions</th>
<th>Care partners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sample, n</td>
<td>Age, mean (SD)</td>
</tr>
<tr>
<td>Berk et al. (2019)</td>
<td>7</td>
<td>71.46 (7.41)</td>
</tr>
<tr>
<td>Birnie, Garland and Carlson (2010)</td>
<td>21</td>
<td>62.9 (7.37)</td>
</tr>
<tr>
<td>Kubo et al. (2018)</td>
<td>13</td>
<td>66.4 (9.6)</td>
</tr>
<tr>
<td>Kubo et al. (2019) Intervention</td>
<td>14</td>
<td>61.4 (14.2)</td>
</tr>
<tr>
<td>Control</td>
<td>8</td>
<td>63.8 (12.1)</td>
</tr>
<tr>
<td>Kubo et al. (2020) Intervention</td>
<td>16</td>
<td>64.5 (9.2)</td>
</tr>
<tr>
<td>Control</td>
<td>14</td>
<td>67.5 (9.4)</td>
</tr>
<tr>
<td>Lengacher et al. (2012)</td>
<td>26</td>
<td>53.5 (10.4)</td>
</tr>
<tr>
<td>McDonnell et al. (2020)</td>
<td>32</td>
<td>66.5 (5.5)</td>
</tr>
<tr>
<td>Paller et al. (2015)</td>
<td>13</td>
<td>72 (range 55-81)</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>Intervention</td>
<td>36</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>41</td>
</tr>
<tr>
<td>Smith et al. (2015)</td>
<td>9</td>
<td>58 (NR)</td>
</tr>
</tbody>
</table>

Key
ALS= Amyotrophic lateral sclerosis; MS= Multiple sclerosis; NR= Not reported; SD= Standard deviation
4.5.4 Intervention

The included studies used a variety of different MBIs (Table 5 on page 89). Three studies used Mindfulness-Based Stress Reduction (MBSR) (Birnie, Garland and Carlson, 2010; Paller et al., 2015; Berk et al., 2019). Three studies used a commercially available MBI app called Headspace™ (Kubo et al., 2018, 2019, 2020). Two studies used Mindfulness Based Cancer Recovery (MBCR) (Carlson and Speca, 2010) for people with cancer (Lengacher et al., 2012; McDonnell et al., 2020). One of the studies using MBCR offered participants the choice between two different levels of MBI (McDonnell et al., 2020). Level 1 involved sitting meditation only and level 2 involved sitting meditation combined with other practices (e.g. standing meditation, floor meditation) (McDonnell et al., 2020). One study used Mindfulness-Based Cognitive Therapy (MBCT) (Teasdale et al., 2000) for people recovering from depression (Smith et al., 2015). One study used Mindfulness-Based Relationship Enhancement (MBRE) (Carson et al., 2004), which is an MBI designed for couples and adds additional couple-oriented mindfulness practices (e.g. dyadic eye gazing, partnered yoga) into the original MBSR protocol (Price-Blackshear et al., 2020). The three studies with a control group used either treatment as usual (Kubo et al., 2019, 2020) or compared couple-orientated online MBRE (Carson et al., 2004) with an online MBI delivered to individuals (Price-Blackshear et al., 2020).

Studies delivered MBIs using face-to-face groups (n= 5, 50%), app delivery (n=3, 30%), online methods (n=1, 10%), or by combining face-to-face groups with self-help methods (n=1, 10%). Most MBIs were delivered over eight weeks duration (n=6, 60%), but one study reduced the duration to six weeks (Lengacher et al., 2012). The studies using app delivered MBI (Kubo et al., 2018, 2019, 2020) were self-paced, so participants could decide how quickly they wanted to complete the MBI. Although, the study design asked participants to use the MBI app for eight weeks’ duration. Studies reporting information about contact time per week provided participants with either 1 (n=1, 10%), 1.5 (n=2, 20%), 2 (n=2, 20%), or 2.5 (n=1, 10%) hours of MBI teaching per week. Studies using app delivered MBI (n=3, 30%) did not specify session duration and another study (n=1, 10%) did not report the length of weekly contact.
Three studies included a retreat in their MBIs and these varied in length between 3-4 hours. Six studies gave participants recommended home practice targets and these varied between 10-90 minutes per day. Some studies (n=6, 60%) provided participants with different resources. The resources provided to participants included pre-recorded meditation, instructional manuals, practice logs, and email reminders. Most studies included common MBI practices (e.g. body scan, yoga, sitting meditation) (Baer, 2014), but studies used a varied number of different MBI practices. MBI reporting was inconsistent and sometimes incomplete, which makes it difficult to know exactly what was delivered and how closely studies aligned with MBI protocols (Table 5 on page 89).
Table 5: Mindfulness based interventions

<table>
<thead>
<tr>
<th>MBI name (protocol)</th>
<th>Delivery (method)</th>
<th>Duration (weeks)</th>
<th>Class length (hours)</th>
<th>MBI teacher</th>
<th>Retreat (hours)</th>
<th>Home practice (minutes)</th>
<th>Resources provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berk et al. (2019)</td>
<td>TANDEM (MBSR)</td>
<td>Group class</td>
<td>8</td>
<td>2.5</td>
<td>Mindfulness trainers</td>
<td>4</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practices</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Body scan; movement and awareness; sitting meditation; yoga; walking meditation; 3-minutes breathing space; sitting meditation; partner yoga; 3-minutes breathing space coping; sitting meditation with a difficult situation; compassionate touch meditation; varying meditation exercises; silent lunch; raisin exercise; seven pillars of mindfulness; visualization to demonstrate link between thoughts and feelings; exploring boundaries and dealing with limitation; psychoeducation; exploring connection between thoughts, feeling, and body; thoughts aren’t facts exercise; mindful communication; nourishing and depleting activities; vicious flower; reflections on training; how to home practice; eating with awareness; routine activity with mindfulness; planning homework; (un)pleasant events monitoring; awareness of communication difficulties; mindfulness reminders; letter to self.</td>
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<tr>
<td>Birnie, Garland and Carlson (2010)</td>
<td>MBSR (MBSR)</td>
<td>Group class</td>
<td>8</td>
<td>1.5</td>
<td>NR</td>
<td>3-6</td>
<td>NR</td>
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<td>Practices</td>
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<tr>
<td>Psychoeducation about MBI and stress; full and relaxed breathing; guided awareness of the body; visualization to show link between mind and body; yoga; body scan; problem solving; awareness of breath; walking mindfulness; link between thoughts and mood explored; awareness of thought processes; self-monitoring cognitions; challenging thoughts; visualization in meditation; relapse prevention.</td>
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<tr>
<td>Kubo et al., (2018, 2019, 2020)</td>
<td>Headspace™ (NR)</td>
<td>Online/app</td>
<td>Self-paced</td>
<td>Variable</td>
<td>N/A</td>
<td>N/A</td>
<td>10-20</td>
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</tbody>
</table>

Practices

(Mandatory) 30-day foundation course and the cancer pack; (optional) 10-30 day condition specific modules on anxiety, depression, acceptance, sleep, or relationships; guided meditation; breathing exercises; body scan, being aware of emotions; visualization; 1-2 minutes lectures; awareness of mindfulness; integration of mindfulness into daily life; reminder emails.

<table>
<thead>
<tr>
<th>MBI name (protocol)</th>
<th>Delivery (method)</th>
<th>Duration (weeks)</th>
<th>Class length (hours)</th>
<th>MBI teacher</th>
<th>Retreat (hours)</th>
<th>Home practice (minutes)</th>
<th>Resources provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>MBCR (MBCR)</td>
<td>Group class</td>
<td>6</td>
<td>2</td>
<td>Psychologist</td>
<td>N/A</td>
<td>30-90</td>
<td>Recorded meditation (CDs) and manual</td>
</tr>
<tr>
<td>McDonnell et al. (2020)</td>
<td></td>
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<tr>
<td>MBI name (protocol)</td>
<td>Delivery (method)</td>
<td>Duration (weeks)</td>
<td>Class length (hours)</td>
<td>MBI teacher</td>
<td>Retreat (hours)</td>
<td>Home practice (minutes)</td>
<td>Resources provided</td>
</tr>
<tr>
<td>Breathe Easier (MBSR &amp; MBCR)</td>
<td>Group class</td>
<td>8</td>
<td>2</td>
<td>Nurse and Psychiatrist</td>
<td>4</td>
<td>NR</td>
<td>Recorded meditation (CDs), practice log, and manual</td>
</tr>
<tr>
<td>McDonnell et al. (2020)</td>
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<td>Practices</td>
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<tr>
<td>Exploring emotional/psychological responses and physical symptoms; sitting meditation; walking meditation; body scan; yoga; nutrition.</td>
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<table>
<thead>
<tr>
<th>MBI name (protocol)</th>
<th>Delivery (method)</th>
<th>Duration (weeks)</th>
<th>Class length (hours)</th>
<th>MBI teacher</th>
<th>Retreat (hours)</th>
<th>Home practice (minutes)</th>
<th>Resources provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>MBSR (MBSR)</td>
<td>Group class</td>
<td>8</td>
<td>1.5</td>
<td>NR</td>
<td>No retreat</td>
<td>30-60</td>
<td>Recorded meditation (CDs)</td>
</tr>
<tr>
<td>Paller et al. (2015)</td>
<td></td>
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<tr>
<td>Practices</td>
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<tr>
<td>Mindfulness; mindful eating; learning to breathe easier; body scan; reacting and responding to stress; mindful coping; stressful communication; sitting yoga; mountain meditation; stand and stretch; loving-kindness meditation; silent meal; integrating mindfulness into daily life; relapse prevention; educational content (e.g. dyspnea, physical activity, fatigue, body balance, stress, communication, and mindfulness).</td>
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<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>Mindfulness of breath; mindfulness of body; mindful check-in; standing/floor yoga; mindfulness of (un)pleasant events; mindfulness of thoughts; loving-kindness practice; mindful awareness; walking meditation.</td>
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<tr>
<td>MBI name (protocol)</td>
<td>Delivery (method)</td>
<td>Duration (weeks)</td>
<td>Class length (hours)</td>
<td>MBI teacher</td>
<td>Retreat (hours)</td>
<td>Home practice (minutes)</td>
<td>Resources provided</td>
</tr>
<tr>
<td>C-MBI (MBRE) or I-MBI (MBSR)</td>
<td>Online</td>
<td>8</td>
<td>1</td>
<td>Pre-recorded sessions with MBSR teacher</td>
<td>No retreat</td>
<td>NR</td>
<td>Pre-recorded videos, email reminders, guided audio meditation, and manual</td>
</tr>
<tr>
<td>Practices</td>
<td>C-MBI involved the participant with a chronic condition practicing MBI with their care partner. Introduction to mindfulness; mindful eating; 9-dot exercise; mindfulness of everyday activities; body scan; triangle of awareness (thoughts, bodily sensations, and feelings); formal sitting meditation; breath meditation; (un)pleasant events monitoring; sitting meditation; mindful yoga; dealing with difficult thoughts; three-minute breathing space; stressful communications calendar; loving-kindness meditation; mindful listening and communication; mindfulness of technology usage; dimension of wellness; and strategies for continuing meditation.</td>
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<td></td>
<td>I-MBI involved the person with a chronic condition practicing by themselves. Introduction to mindfulness; benefits of mindfulness; 9-dot exercise; mindfulness of everyday activities; body scan; body scan with partner; triangle of awareness (thoughts, bodily sensations, and feelings); formal sitting meditation; breath meditation; (un)pleasant events monitoring; sitting meditation; (un)pleasant events calendar; mindful yoga with a partner; dyadic eye gazing exercise with partner; loving-kindness meditation; stressful communication calendar; interpersonal mindfulness; mindful responses to daily stressors; reacting vs responding to stress; developing self-compassion; and mindful touching/massage exercises.</td>
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</tr>
<tr>
<td>Smith et al. (2015)</td>
<td>MBI name (protocol)</td>
<td>Delivery (method)</td>
<td>Duration (weeks)</td>
<td>Class length (hours)</td>
<td>MBI teacher</td>
<td>Retreat (hours)</td>
<td>Home practice (minutes)</td>
</tr>
<tr>
<td>MBCT (MBCT)</td>
<td>Group class</td>
<td>8</td>
<td>NR</td>
<td>Psychologist and family therapist</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
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<tr>
<td>Practices</td>
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<tr>
<td>Specific practices not reported. Study states MBI was delivered as per MBCT protocol.</td>
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</tbody>
</table>

**Key**
- MBCR = Mindfulness Based Cancer Recovery (Carlson and Speca, 2010)
- MBCT = Mindfulness Based Cognitive Therapy (Segal, Williams and Teasdale, 2002)
- MBI = Mindfulness Based Intervention
- MBRE = Mindfulness Based Relationship Enhancement (Carson *et al.*, 2004)
- MBSR = Mindfulness Based Stress Reduction (Santorelli *et al.*, 2017)
- N/A = Not applicable
- NR = Not reported
- TANDEM = a Dutch acronym for ‘attention training for people with dementia and their caregivers’
4.5.5 Interpersonal

The interpersonal experience of care partnerships using a MBI together was evaluated with validated measures by one study (n=1, 10%) (Price-Blackshear et al., 2020). Price-Blackshear et al. (2020) used the Quality Marriage Index (QMI) (Norton, 1983) and the Dyadic Adjustment Scale (DAS) (Spanier, 1976). Price-Blackshear et al. (2020) reported a statistically significant ($p < 0.05$) decrease and very small/small effect size (Sawilowsky, 2009) in relationship quality for people with chronic conditions and care partners using the QMI (Norton, 1983) and people with chronic conditions with the DAS (Spanier, 1976). People with chronic conditions experienced significantly worse dyadic coping and relationship quality after receiving couples’ MBI. Care partners reported a non-significant improvement in dyadic adjustment and a significant worsening in quality of marriage after couples’ MBI (Price-Blackshear et al., 2020) (Table 6 on page 94).
<table>
<thead>
<tr>
<th>Study</th>
<th>Measure</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
</tr>
<tr>
<td><strong>People with chronic conditions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>DAS</td>
<td>98.54 (NR)</td>
<td>95.5* (NR)</td>
</tr>
<tr>
<td></td>
<td>QMI</td>
<td>35.26 (NR)</td>
<td>34.12* (NR)</td>
</tr>
<tr>
<td><strong>Care partners</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>DAS</td>
<td>100.78 (NR)</td>
<td>101.71 (NR)</td>
</tr>
<tr>
<td></td>
<td>QMI</td>
<td>37.04 (NR)</td>
<td>35.67* (NR)</td>
</tr>
</tbody>
</table>

*Key*
* * p <0.05; DAS= Dyadic Adjustment Scale; g= Hedges g effect size; N/A= Not applicable; QMI= Quality of Marriage Index; SD= Standard deviation
4.5.6 Mindfulness

Five studies (n=5, 50%) evaluated change in mindfulness using validated self-report questionnaires (Price-Blackshear et al., 2020; Birnie, Garland and Carlson, 2010; Kubo et al., 2019, 2020; Berk et al., 2019). Two studies used the full Five Facet Mindfulness Questionnaire (FFMQ) (Carmody and Baer, 2008) and one study used the Five Facet Mindfulness Questionnaire: short form (FFMQ-SF) (Bohlmeijer et al., 2011). Two other studies evaluated mindfulness using the Mindful Attention Awareness Scale (MAAS) (Brown and Ryan, 2003). Four studies reported improved mindfulness for people with chronic conditions and all five studies reported improved mindfulness for care partners. Two studies achieved a statistically significant (p <0.05) improvement for people with chronic conditions, which occurred either immediately post-intervention (Birnie, Garland and Carlson, 2010) or by follow-up (Kubo et al., 2020). Two studies achieved a statistically significant improvement for care partners (Birnie, Garland and Carlson, 2010; Kubo et al., 2020). The one study gathering follow-up data showed mindfulness levels continued to increase after completing the MBI and that statistically significant improvements were maintained 12 weeks from baseline (Kubo et al., 2020). One control group of care partners receiving treatment as usual also showed a statistically significant improvement during the study (Kubo et al., 2019). Studies (Birnie, Garland and Carlson, 2010; Kubo et al., 2020) with statistically significant results reported small effect sizes for people with chronic conditions and medium effects sizes for their care partners (Sawilowsky, 2009) (Table 7 on page 96).
### Table 7: Changes in mindfulness

<table>
<thead>
<tr>
<th>People with chronic conditions</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
<td>Follow-up mean (SD)</td>
</tr>
<tr>
<td>Berk et al. (2019)</td>
<td>FFMQ-SF 83.0 (6.32)</td>
<td>82.17 (7.25)</td>
</tr>
<tr>
<td>Birnie, et al. (2010)</td>
<td>MAAS 4.22 (0.71)</td>
<td>4.36* (0.65)</td>
</tr>
<tr>
<td>Kubo et al. (2019)</td>
<td>FFMQ 78.636 (7.865)</td>
<td>82.364 (6.772)</td>
</tr>
<tr>
<td>Kubo et al. (2020)</td>
<td>FFMQ 88.636 (10.661)</td>
<td>90.167 (8.156)</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>MAAS 2.89 (NR)</td>
<td>3.47 (NR)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care partners</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
<td>Follow-up mean (SD)</td>
</tr>
<tr>
<td>Berk et al. (2019)</td>
<td>FFMQ-SF 81.0 (7.44)</td>
<td>85.29 (7.20)</td>
</tr>
<tr>
<td>Birnie, et al. (2010)</td>
<td>MAAS 4.18 (0.74)</td>
<td>4.53* (0.60)</td>
</tr>
<tr>
<td>Kubo et al. (2019)</td>
<td>FFMQ 81.250 (9.117)</td>
<td>82.462 (9.033)</td>
</tr>
<tr>
<td>Kubo et al. (2020)</td>
<td>FFMQ 75.500 (9.253)</td>
<td>80.182 (10.362)*</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>MAAS 2.91 (NR)</td>
<td>3.45 (NR)</td>
</tr>
</tbody>
</table>

Key
- *p* <0.05
- d=Cohen’s *d* effect size
- FFMQ=Five facet Mindfulness Questionnaire
- FFMQ-SF=Five facet Mindfulness Questionnaire: short form
- MAAS=Mindful Attention Awareness Scale
- N/A=Not applicable
- NR=Not reported
- SD=Standard deviation
4.5.7 Stress

Four studies (n=4, 40%) gathered data on stress using validated self-report questionnaires (Price-Blackshear *et al.*, 2020; Birnie, Garland and Carlson, 2010; Lengacher *et al.*, 2012; McDonnell *et al.*, 2020), but one study offered two levels of MBI practice (Section 4.5.4 on page 87) and reported changes to stress for each level (McDonnell *et al.*, 2020). Three studies evaluated stress using the Perceived Stress Scale (Cohen *et al.*, 1983) and one study used the Calgary Symptom of Stress Inventory (C-SOSI) (Carlson and Thomas, 2007).

All four studies reported improved stress levels for people with chronic conditions and care partners, but the study using two levels of MBI found stress levels did not change for care partners using level 2 MBI (i.e. sitting, lying and standing meditation) (McDonnell *et al.*, 2020). Statistically significant ($p < 0.05$) improvements and small effect sizes (Sawilowsky, 2009) were reported for people with chronic conditions in two studies (Lengacher *et al.*, 2012; Price-Blackshear *et al.*, 2020). One study found a statistically significant improvement and very small effect size (Sawilowsky, 2009) for care partners (Price-Blackshear *et al.*, 2020). Price-Blackshear *et al.* (2020) produced a statistically significant reduction in stress for people with chronic conditions and care partners in both the intervention (i.e. couple MBI) and control conditions (i.e. individual MBI) of the study (Table 8 on page 98).
<table>
<thead>
<tr>
<th>People with chronic conditions</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
</tr>
<tr>
<td><strong>Birnie, Garland and Carlson (2010)</strong></td>
<td>C-SOSI</td>
<td>49.45 (35.40)</td>
</tr>
<tr>
<td><strong>Lengacher et al. (2012)</strong></td>
<td>PSS</td>
<td>19.5 (7.1)</td>
</tr>
<tr>
<td><strong>McDonnell et al. (2020)</strong></td>
<td>Level 1</td>
<td>PSS</td>
</tr>
<tr>
<td></td>
<td>Level 2</td>
<td></td>
</tr>
<tr>
<td><strong>Price-Blackshear et al. (2020)</strong></td>
<td>PSS</td>
<td>2.99 (NR)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care partners</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
</tr>
<tr>
<td><strong>Birnie, Garland and Carlson (2010)</strong></td>
<td>C-SOSI</td>
<td>38.80 (29.27)</td>
</tr>
<tr>
<td><strong>Lengacher et al. (2012)</strong></td>
<td>PSS</td>
<td>18.1 (6.6)</td>
</tr>
<tr>
<td><strong>McDonnell et al. (2020)</strong></td>
<td>Level 1</td>
<td>PSS</td>
</tr>
<tr>
<td></td>
<td>Level 2</td>
<td></td>
</tr>
<tr>
<td><strong>Price-Blackshear et al. (2020)</strong></td>
<td>PSS</td>
<td>2.69 (NR)</td>
</tr>
</tbody>
</table>

Key
* p <0.05; C-SOSI=Calgary Symptoms of Stress Inventory; d= Cohen's d effect size; g= Hedges g effects size; N/A=Not applicable; NR=Not reported; PSS=Perceived Stress Scale; SD=Standard deviation
4.5.8 Anxiety symptoms

Eight studies (n=8, 80%) measured anxiety symptoms using validated self-report questionnaires (Lengacher et al., 2012; Paller et al., 2015; Kubo et al., 2018, 2019, 2020; Berk et al., 2019; McDonnell et al., 2020; Price-Blackshear et al., 2020) (Table 9 on page 100), but one study offered two levels of MBI (Section 4.5.4 on page 87) and reported changes to anxiety symptoms for each level (McDonnell et al., 2020). Change in anxiety symptoms was evaluated using five different validated self-report questionnaires. Selected questionnaires were the Patient Reported Outcomes Measurements Information System (PROMIS) (Reeve et al., 2007); the Penn State Worry Questionnaire (PSWQ) (Meyer et al., 1990); the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983); the Beck’s Anxiety Inventory (BAI) (Beck et al., 1988), and the State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch and Lushene, 1970).

People with chronic conditions reported improved anxiety symptoms in six studies and care partners reported improved anxiety symptoms in seven studies. Improvements in anxiety symptoms were statistically significant ($p < 0.05$) for patient in three studies (Lengacher et al., 2012; Kubo et al., 2018, 2020). Two of these studies produced small effect sizes (Lengacher et al., 2012; Kubo et al., 2020) and one study (Kubo et al., 2018) produced a very large effect size (Sawilowsky, 2009). The one study gathering follow-up data found people with chronic conditions maintained a statistically significant ($p < 0.05$) improvement in anxiety symptoms at 12 weeks from baseline (Kubo et al., 2020). No studies found statistically significant changes for care partners (Table 9 on page 100).
Table 9: Anxiety symptom scores

<table>
<thead>
<tr>
<th>People with chronic conditions</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
</tr>
<tr>
<td>Berk et al. (2019)</td>
<td>PSWQ</td>
<td>42.43 (11.76)</td>
</tr>
<tr>
<td>Kubo et al. (2018)</td>
<td>HADS-A</td>
<td>7.900 (4.228)</td>
</tr>
<tr>
<td>Kubo et al. (2019)</td>
<td>HADS-A</td>
<td>8.083 (4.502)</td>
</tr>
<tr>
<td>Kubo et al. (2020)</td>
<td>HADS-A</td>
<td>6.462 (2.402)</td>
</tr>
<tr>
<td>Lengacher et al. (2012)</td>
<td>STAI: Trait</td>
<td>42.7 (12.6)</td>
</tr>
<tr>
<td></td>
<td>STAI: State</td>
<td>41.2 (13.3)</td>
</tr>
<tr>
<td>McDonnell et al. (2020)</td>
<td>HADS-A</td>
<td>7.16 (NR)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7.16 (NR)</td>
</tr>
<tr>
<td>Paller et al. (2015)</td>
<td>BAI</td>
<td>6.43 (7.94)</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>PROMIS</td>
<td>56.02 (NR)</td>
</tr>
</tbody>
</table>

<p>| Care partners                 |              |         |         | Effect size |              |         |         | Effect size |
| Berk et al. (2019)            | PSWQ         | 55.0 (6.35) | 52.29 (13.73) | N/A         | 0.25 d | N/A          | N/A          | N/A         |
| Kubo et al. (2018)            | HADS-A       | 11.444 (3.358) | 9.333 (3.240) | N/A         | 0.64 d | N/A          | N/A          | N/A         |
| Kubo et al. (2019)            | HADS-A       | 8.083 (2.937) | 8.154 (3.288) | N/A         | 0.023 d | 7.429 (2.760) | 7.625 (3.777) | N/A         | 0.059 d |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Measure</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kubo et al. (2020)</td>
<td>HADS-A</td>
<td>Baseline: 8.091 (4.134)</td>
<td>Post: 8.000 (4.090)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Baseline: 5.923 (2.362)</td>
<td>Post: 4.923 (2.565)</td>
</tr>
<tr>
<td>Lengacher et al. (2012)</td>
<td>STAI: Trait</td>
<td>Baseline: 38.5 (12.5)</td>
<td>Post: 37.8 (11.9)</td>
</tr>
<tr>
<td></td>
<td>STAI: State</td>
<td>Baseline: 36.5 (13.4)</td>
<td>Post: 35.4 (14.8)</td>
</tr>
<tr>
<td>McDonnell et al. (2020)</td>
<td>HADS-A</td>
<td>Level 1: Baseline: 7.5 (NR)</td>
<td>Post: 6.39 (NR)</td>
</tr>
<tr>
<td>Paller et al. (2015)</td>
<td>BAI</td>
<td>Baseline: 9.27 (9.37)</td>
<td>Post: 6.33 (5.84)</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>PROMIS</td>
<td>Baseline: 53.68 (NR)</td>
<td>Post: 51.19 (NR)</td>
</tr>
</tbody>
</table>

Key:
* p < 0.05; BAI = Beck’s Anxiety Inventory; d = Cohen’s d effect size; g = Hedges g effect size; HADS-A = Hospital Anxiety and Depression Scale: anxiety sub-scale; N/A = Not applicable; NR = Not reported; PROMIS = National Institute of Health; Patient Reported Outcomes Measurements Information System; PSWQ = Penn State Worry Questionnaire; STAI = State-Trait Anxiety Inventory
4.5.9 Depression symptoms

Seven studies (n=7, 70%) measured depression symptoms using validated self-report questionnaires (Lengacher et al., 2012; Paller, et al., 2015; Kubo et al., 2018, 2019, 2020; McDonnell et al., 2020; Price-Blackshear et al., 2020), but one study offered two levels of MBI practice (Section 4.5.4 on page 87) and reported changes to depression symptoms for each level (McDonnell et al., 2020) (Table 10 on page 103). Changes in depression symptoms were evaluated using four different validated measures. The different validated measures were the Patient Reported Outcomes Measurements Information System (PROMIS) (Reeve et al., 2007), Centre for Epidemiological Studies Depressive Scale (CES-D) (Radloff, 1977), Geriatric Depression Scale (GDS) (Yesavage et al., 1983), and Hospital Anxiety and Depression scale (HADS) (Zigmond and Snaith, 1983).

Improved depression symptoms were reported in all seven studies for people with chronic conditions (Lengacher et al., 2012; Paller, et al., 2015; Kubo et al., 2018, 2019, 2020; McDonnell et al., 2020; Price-Blackshear et al., 2020) and in six studies for care partners (Lengacher et al., 2012; Paller, et al., 2015; Kubo et al., 2018, 2019, 2020; Price-Blackshear et al., 2020). The study offering level 1 and level 2 MBI (Section 4.5.4 on page 87) found no change for people with chronic conditions and a worsening of depression symptoms for care partners when using level 2 (McDonnell et al., 2020). Statistically significant (p <0.05) improvements in depression symptoms were reported in one study for people with chronic conditions (Kubo et al., 2018) and two studies for care partners (Paller, et al., 2015; Kubo et al., 2018). The study showing statistically significant results for people with chronic conditions had a medium effects size (Kubo et al., 2018). Whilst the studies showing statistically significant results for care partners had small effect sizes (Paller, et al., 2015; Kubo et al., 2018) (Table 10 on page 103).
Table 10: Depression scores

<table>
<thead>
<tr>
<th>People with chronic conditions</th>
<th>Intervention</th>
<th></th>
<th>Control</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
<td>Follow-up mean (SD)</td>
<td>Effect size</td>
</tr>
<tr>
<td><strong>Kubo et al. (2018)</strong></td>
<td>HADS-D</td>
<td>6.800 (3.425)</td>
<td><strong>3.900 (2.961)</strong>*</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Kubo et al. (2019)</strong></td>
<td>HADS-D</td>
<td>5.083 (3.204)</td>
<td>4.455 (3.328)</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Kubo et al. (2020)</strong></td>
<td>HADS-D</td>
<td>4.917 (3.965)</td>
<td>3.538 (4.013)</td>
<td>3.385 (3.686)</td>
</tr>
<tr>
<td><strong>Lengacher et al. (2012)</strong></td>
<td>CES-D</td>
<td>20.4 (11.7)</td>
<td>16.5 (11.4)</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>McDonnell et al. (2020)</strong></td>
<td>HADS-D</td>
<td>5.47 (NR)</td>
<td>4.58 (NR)</td>
<td>4.14 (NR)</td>
</tr>
<tr>
<td>Level 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Paller et al. (2015)</strong></td>
<td>GDS</td>
<td>8.00 (4.23)</td>
<td>7.00 (4.04)</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Price-Blackshear et al. (2020)</strong></td>
<td>PROMIS</td>
<td>59.41 (NR)</td>
<td>59.37 (NR)</td>
<td>N/A</td>
</tr>
<tr>
<td>Care partners</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Kubo et al. (2018)</strong></td>
<td>HADS-D</td>
<td>5.667 (3.905)</td>
<td><strong>3.889 (3.180)</strong>*</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Kubo et al. (2019)</strong></td>
<td>HADS-D</td>
<td>5.083 (3.397)</td>
<td>4.231 (2.555)</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Kubo et al. (2020)</strong></td>
<td>HADS-D</td>
<td>4.583 (3.118)</td>
<td>4.273 (2.901)</td>
<td>4.900 (3.035)</td>
</tr>
<tr>
<td>Intervention</td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
<td>Follow-up mean (SD)</td>
<td>Effect size</td>
</tr>
<tr>
<td>-------------</td>
<td>-------------------</td>
<td>----------------</td>
<td>---------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Lengacher et al. (2012)</td>
<td>CES-D</td>
<td>13.3 (9.1)</td>
<td>11.4 (9.3)</td>
<td>N/A</td>
</tr>
<tr>
<td>McDonnell et al. (2020)</td>
<td>HADS-D</td>
<td>4.11 (NR)</td>
<td>4.61 (NR)</td>
<td>N/A</td>
</tr>
<tr>
<td>Paller et al. (2015)</td>
<td>GDS</td>
<td>8.44 (8.57)</td>
<td>6.5 (7.78)*</td>
<td>N/A</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>PROMIS</td>
<td>59.26 (NR)</td>
<td>57.96 (NR)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Key
* p <0.05; CES-D=Centre for Epidemiologic Studies Depression Scale; d= Cohen’s d effect size; g= Hedges g effects size; GDS=Geriatric Depression Scale; HADS-D=Hospital Anxiety and Depression Scale: depression sub-scale; PROMIS=National Institute of Health Patient Reported Outcomes Measurements Information System; N/A=Not applicable; NR=Not reported
4.5.10 Psychological distress

Five studies evaluated global psychological distress using validated self-report methods and one of those studies used two different methods to measure psychological distress (Birnie, Garland and Carlson, 2010; Berk et al., 2019) (Table 11 on page 106). Changes in psychological distress were measured using the Depression Anxiety Scale (DASS-21) (Henry and Crawford, 2005); Distress Thermometer (National Comprehensive Cancer Network, 2020); Mental Health Continuum Short Form (MHC-SF) (Lamers et al., 2011); and the Profile of Mood States (POMS) (McNair, Lorr and Droppleman, 1971).

Four studies reported improved psychological distress for people with chronic conditions and care partners (Birnie, Garland and Carlson, 2010; Kubo et al., 2018, 2019). One study used two similar measures for psychological distress and produced contradictory results. One measure showed improvement in psychological distress and the other measures showed deterioration in psychological distress (Berk et al., 2019). Statistically significant improvements ($p < 0.05$) were reported in two studies for people with chronic conditions (Birnie, Garland and Carlson, 2010; Kubo et al., 2018). The studies showing statistically significant results for people with chronic conditions produced a small effect size (Birnie, Garland and Carlson, 2010) and a very large effect size (Kubo et al., 2018) (Sawilowsky, 2009). Three studies produced statistically significant results for care partners (Birnie, Garland and Carlson, 2010; Kubo et al., 2018, 2020). The studies with statistically significant results for care partners found small effect sizes (Birnie, Garland and Carlson, 2010; Kubo et al., 2020) and large effect sizes (Kubo et al., 2018) (Table 11 on page 106).
Table 11: Psychological distress

<table>
<thead>
<tr>
<th>People with chronic conditions</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berk et al. (2019) DASS-21 MHC-SF</td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
</tr>
<tr>
<td>6.0 (5.05)</td>
<td>3.85 (0.47)</td>
<td>6.29 (5.77)</td>
</tr>
<tr>
<td>Birnie et al. (2010) POMS</td>
<td>12.24 (31.03)</td>
<td>2.33 (23.42)*</td>
</tr>
<tr>
<td>Kubo et al. (2018) Distress thermometer</td>
<td>5.600 (2.459)</td>
<td>2.500 (1.650)*</td>
</tr>
<tr>
<td>Kubo et al. (2019) Distress thermometer</td>
<td>4.667 (1.875)</td>
<td>3.417 (2.234)</td>
</tr>
<tr>
<td>Kubo et al. (2020) Distress thermometer</td>
<td>4.538 (2.602)</td>
<td>3.615 (3.254)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care partners</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berk et al. (2019) DASS-21 MHC-SF</td>
<td>Baseline mean (SD)</td>
<td>Post mean (SD)</td>
</tr>
<tr>
<td>10.95 (8.51)</td>
<td>3.44 (1.42)</td>
<td>10.0 (9.91)</td>
</tr>
<tr>
<td>Birnie et al. (2010) POMS</td>
<td>6.71 (30.46)</td>
<td>-2.76 (19.61)*</td>
</tr>
<tr>
<td>Kubo et al. (2018) Distress thermometer</td>
<td>6.444 (1.667)</td>
<td>4.556 (2.128)*</td>
</tr>
<tr>
<td>Kubo et al. (2019) Distress thermometer</td>
<td>4.692 (2.097)</td>
<td>4.000 (2.121)</td>
</tr>
<tr>
<td>Kubo et al. (2020) Distress thermometer</td>
<td>4.667 (1.875)</td>
<td>3.417 (2.193)*</td>
</tr>
</tbody>
</table>

Key:
* p <0.05; DASS-21=Depression Anxiety Stress Scale; d=Cohen’s d effect size; g=Hedges g effects size; MHC-SF=Mental Health Continuum Short Form; N/A=Not applicable; POMS=Profile of Mood States; SD=Standard deviation
4.5.11 Quantitative synthesis

All nine studies (Price-Blackshear et al., 2020; Birnie, Garland and Carlson, 2010; Lengacher et al., 2012; Paller et al., 2015; Kubo et al., 2018, 2019, 2020; Berk et al., 2019; McDonnell et al., 2020) with a quantitative component, using validated measures, and collecting pre/post-intervention data were included in the quantitative synthesis (Table 12 on page 108).

The only study collecting data on interpersonal change found a deterioration in interpersonal factors of people with chronic condition and mixed effects for care partners. The limited studies gathering relevant data and contradictory findings made it impossible to synthesise data on interpersonal change. Mindfulness levels improved in most studies for people with chronic conditions (n=4, 8%) and all studies for care partners (n=5, 100%), but the change was not statistically significant (p >0.05). All studies found people with chronic conditions (n=4, 100%) and care partners (n=5, 100%) improved their stress levels following MBI. Although, the change in stress was not statistically significant (p >0.05) for either patient or care partners. Anxiety symptoms reduced in most studies for people with chronic conditions (n=6, 75%) and care partners (n=7, 87.5%), but the change was not statistically significant (p >0.05). The majority of studies found MBI reduced depression symptoms for people with chronic conditions (n=7, 100%) and care partners (n=6, 85.7%). The change in depression symptoms was statistically significant for people with chronic conditions (p=0.0156) and care partners (p=0.0313). Psychological distress reduced in most studies for people with chronic conditions (n=4, 80%) and care partners (n=4, 80%), although, the change was not statistically significant (p >0.05). The quantitative synthesis found people with chronic conditions and care partners improved in mindfulness, stress, anxiety, and depression symptoms, but the difference was only statistically significant (p <0.05) for depression symptoms.
Table 12: Effect direction plot

<table>
<thead>
<tr>
<th>Study</th>
<th>Interpersonal</th>
<th>Mindfulness</th>
<th>Stress symptoms</th>
<th>Anxiety symptoms</th>
<th>Depression symptoms</th>
<th>Distress symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People with chronic conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Berk et al. (2019)</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Birnie, Garland and Carlson (2010)</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
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<tr>
<td>Kubo et al. (2018)</td>
<td>▲</td>
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<td>Kubo et al. (2019)</td>
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<td>Kubo et al. (2020)</td>
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<td>Lengacher et al. (2012)</td>
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<tr>
<td>McDonnell et al. (2020)</td>
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<td>Paller et al. (2015)</td>
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<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>▼</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td><strong>P value</strong></td>
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<td>0.3750</td>
<td>0.1250</td>
<td>0.2891</td>
<td>0.0156*</td>
<td>0.1250</td>
</tr>
<tr>
<td><strong>Care partners</strong></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Berk et al. (2019)</td>
<td>▲</td>
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<td>▲</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Birnie, Garland and Carlson (2010)</td>
<td>▲</td>
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<tr>
<td>Kubo et al. (2018)</td>
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<td>Kubo et al. (2019)</td>
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<td>Kubo et al. (2020)</td>
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<td>Lengacher et al. (2012)</td>
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<td>▲</td>
</tr>
<tr>
<td>McDonnell et al. (2020)</td>
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<td>▲</td>
</tr>
<tr>
<td>Paller et al. (2015)</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td>Price-Blackshear et al. (2020)</td>
<td>□</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td><strong>P value</strong></td>
<td>N/A</td>
<td>0.0625</td>
<td>0.1250</td>
<td>0.0703</td>
<td>0.0313*</td>
<td>0.1250</td>
</tr>
</tbody>
</table>

Key
* \( p < 0.05 \); ▲ improved effect; ▼ worse effect; □ unclear effect/mixed effect; N/A not applicable
4.5.12 Qualitative synthesis

All three studies containing qualitative data were included in the qualitative synthesis (Smith et al., 2015; Berk et al., 2019; McDonnell et al., 2020). Thematic synthesis (Thomas and Harden, 2008) of the qualitative data produced three interconnected and overlapping themes. The three themes developed through thematic synthesis were: togetherness, becoming mindful, and wellness (Figure 5 on page 109). Full details of how thematic synthesis was used to develop the three themes is provided in the methods section (Section 4.4.9 on page 77). These themes give insight into how people with chronic conditions and their care partners experience using MBIs together (Figure 5 on page 109). Each theme will be explored separately and excerpts used to maintain transparency and to promote rigour (Pietkiewicz and Smith, 2014).

Figure 5: Mindfulness with care partnerships themes

![Diagram](image)

4.5.12.1 Togetherness

The thematic synthesis (Thomas and Harden, 2008) highlights the importance of interpersonal aspects when people with chronic conditions and their care partners use MBIs together. Togetherness is the first mindfulness with care partnerships theme (Figure 5 on page 109) and illuminates important interpersonal aspects experienced when care partnerships use MBIs together. Togetherness was evident in the data at both a group and partnership level. Togetherness as a group was experienced as being connected to others and appeared to help people normalise their experiences and offered support to care partnerships.
“All participants felt positive about participating in a group, which was a safe place where one could be oneself and share one’s experiences. The group was considered a very valuable aspect of the training; participants felt connected to the group members and felt less alone because of them. Some participants shared more in the group than others. A few participants noticed differences when comparing themselves to the group. One person with dementia noticed that other people with dementia were worse off than he was. One caregiver noticed that everyone was dealing with the diagnosis in their own way” (Berk et al., 2019, p. 5).

Togetherness was also experienced within care partnerships and highlights interpersonal aspects of living with chronic conditions and the importance of working together and supporting each other.

“It appeared that engaging in the course together often facilitated increased ‘commitment’ to the ‘joint project’ (Sam) of learning new skills and feelings of mutual or ‘collegiate support’ (Sam). In turn, engaging together appeared to lead to positive shifts in the partnership” (Smith et al., 2015, p. 460).

Benefits thought to occur because of togetherness include increased attendance and encouragement to engage in the process of using MBIs. The possible benefits highlight how togetherness could help care partnerships participate fully and may help adherence with MBIs.

“Participants reported ‘we enjoyed coming together’ and felt this facilitated attendance, which could be difficult when depressed and anxious, ‘I don’t know that she would’ve gone to … every meeting if she had been on her own’. These data were supported by eight participants’ interviews and validated by the MBCT course facilitator who compared attendance records and noted that partnership groups were better attended than individuals’ groups” (Smith et al., 2015, p. 460).

Other positive aspects of using MBI in a care partnership include having a greater understanding of each other and improved communication. These
perceived interpersonal benefits appeared consistently and produce one of the main aspects of the synthesis.

“Doing the course together seemed to facilitate increased understanding of how they each ‘suffer’ (Bill), ‘I’ve gained from the course, a little bit of understanding and a little bit of somewhere I can come to listen to what has been going on’ (Jane) and a more ‘sympathetic attitude’ (Sam) towards suffering. Six participants referred to increased empathy, and the data suggested that these effects were not solely due to learning mindfulness skills but through the interaction of learning mindfulness skills together” (Smith et al., 2015, p. 461).

The togetherness experienced by care partnerships learning MBI together appears to have a positive impact on the relationship and brings them closer together.

“Some participants reported that the training had influenced their relationship as a couple. Caregivers were better able to prevent or deal with quarrels. They felt more connected. One caregiver mentioned that they had more physical contact. Several participants mentioned that the communication between them had improved” (Berk et al., 2019, p. 6).

The theme togetherness also contained concerns held by some care partnerships about learning MBI with their partner. The synthesis did not identify any evidence of major relationship difficulties, but some care partnerships had concerns about learning MBI with someone they already know.

“Well, what went through my mind [before the training started] was, ‘She’s not going to say unpleasant things about me, is she?’ That wasn’t the case (Berk et al., 2019, p. 5).

The synthesis highlights the central role of togetherness for care partnerships using MBI together. This synthesis suggests togetherness may be an important element for care partnerships using MBIs and could facilitate engagement with MBIs, provide mutual support, and improve interpersonal functioning.
4.5.12.2 Becoming mindful

Becoming mindful is the second mindfulness with care partnerships theme (Figure 5 on page 109). Becoming mindful occurs in the context of togetherness and involves the care partnership learning and using MBIs. The becoming mindful theme also gives insight into the mechanisms of change involved with care partnerships learning MBI together. Several mechanisms were identified in the synthesis and highlight the multiple components involved with becoming mindful.

“… ‘talking about thoughts not being facts that really opened my mind’ (Rose); MBCT appeared to help people to step back from thoughts to ‘see the wood for the trees’ (Bill). This was important for half of the participants” (Smith et al., 2015, p. 459).

“There appeared to be a positive cycle of feeling better and doing more, reported by six participants … This appeared to be connected to learning mindfulness skills, for example, having the breathing space to draw upon, and also feeling less alone in depression” (Smith et al., 2015, p. 461).

A key feature of becoming mindful is how learning MBI together helps care partnerships become more aware and accepting of themselves and their situation.

“At night, sometimes I wake up in a panic, and I used to stay up all night … awake with palpitations and feeling miserable. But now I know I can’t change it. There’s nothing that I can do about the situation. It is how it is and it will follow its course. And then I just focus on my breath. And I know I can’t do anything to change this. This doesn’t make it painless, but it helps me to keep going.” (Berk et al., 2019, p. 6).

The increased awareness and acceptance associated with becoming mindful appears to influence how people with chronic conditions and their care partners interact with each other in the care partnership. The interpersonal components evident in the becoming mindful theme highlight how the different themes overlap and interact with each other.
“Doing the course together seemed to facilitate increased understanding of how they each ‘suffer’ (Bill), ‘I’ve gained from the course, a little bit of understanding and a little bit of somewhere I can come to listen to what has been going on’ (Jane) and a more ‘sympathetic attitude’ (Sam) towards suffering. Six participants referred to increased empathy, and the data suggested that these effects were not solely due to learning mindfulness skills but through the interaction of learning mindfulness skills together” (Smith et al., 2015, p. 461).

Some care partnerships also appear to use their newly acquired MBI skills to help enhance their relationship, which suggests a close link between becoming mindful and interpersonal processes.

“This skill was often applied to difficulties within the relationship and pertaining to the interpersonal strain of depression, highlighting the perceived bidirectional relationship between mindfulness and partnership processes” (Smith et al., 2015, p. 459).

Most care partnerships experienced becoming mindful positively, but some did report difficulties on occasions. The synthesis did include several minor difficulties with people using MBI, but no major adverse events were identified.

“Participants experienced relaxation, falling asleep during practice, and having difficulties doing the exercises at home. The longer exercises (45 min) were more difficult to plan but were recognized as beneficial” (Berk et al., 2019, p. 5).

Becoming mindful appears to involve being more aware and accepting, and is also closely linked with togetherness. Achieving higher levels of awareness and acceptance appears to be linked to the improved wellness reported by some care partnerships.

4.5.12.3 Wellness

Wellness is the third mindfulness with care partnerships theme (Figure 5 on page 109). Wellness appears to occur in the context of togetherness, becoming mindful, and is associated with relaxation and calmness.
“Participants reported several skills learned through the MBCT course, which interacted with partnership processes and were linked to positive changes. The majority of participants described using the breathing space as a new way of coping with stress, ‘If these thoughts come into my mind of a night time, I think breathing exercises […] whereas before I’d be awake half the night.” (Smith et al., 2015, p. 459).

The wellness experienced by some care partnerships appears to be linked with improved awareness and acceptance. Changes to awareness and acceptance appears to be linked with using MBI together and helped increase level of relaxation and calmness.

“Participants mostly report increased calmness and relaxation. The training helped both caregivers and PwD [people with dementia] to cope with and accept the diagnosis. They reported an increased awareness and spending less time on automatic pilot and instead being in the moment. Some participants reported increased self-care. Moreover, participants learned new ways to deal with difficulties” (Berk et al., 2019, p. 6).

The improvements experienced by some care partnerships when learning MBI together were not experienced by everyone. Some participants experienced either no change or difficult emotions when learning MBI.

“The training brought beneficial changes to all participants, with the exception of one PwD [people with dementia] who said that nothing had changed” (Berk et al., 2019, p. 6).

“One participant frequently experienced sadness while practicing. Although she appreciated a new-found connection with her emotions, she also struggled with how to deal with this” (Berk et al., 2019, p. 5).

The wellness reported by some care partnerships appears interconnected with togetherness and becoming mindful. Viewing wellness in the context of togetherness and becoming mindful provides a new interpretation of the experience for care partnerships using MBI together.
4.5.13 Quality appraisal within studies

All included studies (n=10) were evaluated for strengths and weaknesses using the mixed methods appraisal tool (MMAT) (Nha Hong et al., 2018) (Table 13 on page 116). All studies had clear research questions and gathered appropriate data to answer the research questions. All quality criteria was achieved in the one qualitative study (Smith et al., 2015) and the two mixed methods studies (Berk et al., 2019; McDonnell et al., 2020). Meeting all the qualitative criteria suggests the qualitative components of the included studies are high quality. The three RCTs (Kubo et al., 2019, 2020; Price-Blackshear et al., 2020) achieved some, but not all quality criteria. Kubo et al. (2019) achieved the most quality criteria and Price-Blackshear et al. (2020) achieved the least. The main weaknesses identified by the MMAT (Nha Hong et al., 2018) were completeness of the data (Kubo et al., 2020; Price-Blackshear et al., 2020), whether assessors were blinded to test allocation (Kubo et al., 2019; Price-Blackshear et al., 2020), and uncertainty about treatment adherence (Kubo et al., 2020; Price-Blackshear et al., 2020).

The four quantitative studies (Birnie, Garland and Carlson, 2010; Lengacher et al., 2012; Paller, et al., 2015; Kubo et al., 2018) and two mixed methods studies (Berk et al., 2019; McDonnell et al., 2020) using non-randomised designs were variable quality. Berk et al. (2019) achieved the most quality criteria, whilst McDonnell et al. (2020) and Kubo et al. (2018) achieved the least. The most obvious weakness in all six studies was the lack of control group and the limited attention given to possible confounders. The two studies (Berk et al., 2019; McDonnell et al., 2020) using mixed methods demonstrated methodological weaknesses by lacking adequate integration, interpretation, and exploration of the combined qualitative and quantitative components. Weaknesses not identified by the MMAT (Nha Hong et al., 2018) include the lack of follow-up. Only one study (Kubo et al., 2020) used a follow-up period and the follow-up was for 12 weeks after baseline.
Table 13: Mixed methods appraisal tool (MMAT)

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<td>Qualitative data collection methods adequate for research question?</td>
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<td>Interpretation of results substantiated by data?</td>
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<td>Coherence between qualitative data, analysis and interpretation?</td>
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<td>Outcome assessors blinded to the intervention?</td>
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<td>Integration of components interpreted?</td>
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<td>Divergences/inconsistencies addressed?</td>
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<td>Do components adhere to their quality criteria?</td>
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(Nha Hong et al., 2018)
4.5.14 Quality appraisal across studies

The included studies are collectively vulnerable to different forms of bias. Publication bias is a possibility because the review only included published studies, which tend to be those studies showing statistically significant results (i.e. \( p < 0.05 \)). Publication bias produces a skewed impression because only a sub-set of research is published and many non-significant (i.e. \( p > 0.05 \)) studies fail to become published (Rosenthal, 1979). Language bias is another factor that may have skewed the included studies. Language bias occurs when a systematic review only searches for studies in a particular language (e.g. English) which may prevent potentially relevant studies published in a different language from be included (Stern and Kleijnen, 2020). This review is vulnerable to both publication bias and language bias because the search only included published studies written in English (Section 4.4.5 on page 72).

4.6 Discussion

This systematic mixed studies review updated a review published (Appendix 1: Journal publication from the thesis 2019 on page 307) in the early stages of the PhD and produced a new synthesis of research using MBIs with care partnerships. The review asked whether people living with chronic conditions and their care partners experience interpersonal changes or changes in mindfulness when using MBI together? The review also asked whether people living with chronic conditions and their care partners experience changes in stress, anxiety symptoms, or depression symptoms after using MBI together (Section 3.1 on page 63)? The systematic mixed studies review used a segregated explanatory sequential design, which involved an initial quantitative synthesis followed by a qualitative synthesis (Ferguson, Kerrigan and Hovey, 2020) (Section 4.4 on page 66).

Studies came from North America or Europe and were published since 2010, which suggests research using MBIs with care partnerships is fairly new and limited to certain countries (Section 4.5.2 on page 81). The publication pattern in this review mirrors the wider literature, with evidence from a recent review of published papers in the Mindfulness journal suggesting North America (50.8%) and Europe (30.9%) were the largest producers of mindfulness research since
2010 (Toniolo–Barrios, Brasil and Pitt, 2020). The studies in the review focused on a range of chronic conditions, but none included people affected by stroke and their care partners. Two studies involving people affected by stroke and their care partners were identified in the search. One of the identified studies was excluded because it used a mixed sample and had some people attending with a care partner and some people attending by themselves (Jani et al., 2018). The other study was excluded because a full-text version was not available from either library services or the author (Henderson et al., 2017). The original systematic review did include studies with mixed samples (Parkinson et al., 2019), but the update wanted to reduce possible bias by removing those studies using mixed samples or where partnership data could not be extracted (Section 4.4.5 on page 72).

Publication trends show mindfulness research methods have become more diverse between 2010-2019 and researchers are using a wider range of study designs (Toniolo–Barrios, Brasil and Pitt, 2020). This review took an inclusive approach and included studies using various study designs and using different validated measures. This decision was necessary because the limited research in the area (Parkinson et al., 2019), but the heterogeneity made meta-analysis unfeasible and alternative synthesis methods were necessary (Campbell et al., 2020). Common weaknesses in the studies include small sample sizes, limited use of control conditions, and lack of follow-up (Section 4.5.13 on page 115). The weaknesses in study design found in this review are consistent with many other MBI studies, which have traditionally been criticised for lacking methodological rigour (Davidson et al., 2015). However, more recent research suggests the quality of mindfulness research has improved considerably between 2010-2019 and researchers are now more likely to use robust designs and have larger samples (Toniolo–Barrios, Brasil and Pitt, 2020). It is thought the poor study design evident in this review may reflect the preliminary/pilot nature of many of the studies using MBIs with care partnerships and does not necessarily reflect the wider mindfulness literature. The weaknesses evident in the included studies is a concern because the quality of the findings produced by a systematic review is closely linked to the quality of the studies included in the synthesis (Roberts and Ker, 2015).
The new synthesis showed the majority of studies were reporting improved mindfulness, stress, anxiety symptoms, depression symptoms, and psychological distress for people with chronic conditions and care partners. The thematic synthesis (Thomas and Harden, 2008) produced the mindfulness with care partnerships themes (Figure 5 on page 109) and showed how togetherness, becoming mindful, and wellness interconnect when care partnerships use MBI together. The separate synthesis was integrated to provide insight into the experience and outcomes for care partnerships using MBIs together.

4.6.1 Interpersonal

Exploring interpersonal changes for care partnerships learning MBI together was an important aspect of the review. Only one included study gathered interpersonal data so quantitative synthesis was not possible. The quantitative results revealed a worsening of interpersonal factors for people with chronic conditions and a mixed effect for care partners (Section 4.5.5 on page 93). The one study gathering quantitative interpersonal data concluded individual MBI may be preferable to using MBIs with care partnership, although, they acknowledge a number of methodological factors (e.g. different MBI instructors) that may have contributed to the findings (Price-Blackshear et al., 2020).

The current synthesis differs from the previous published version (Parkinson et al., 2019) because it used narrower eligibility criteria and excluded studies with mixed samples and/or unpublished academic thesis (Section 4.4.5 on page 72). One of the excluded thesis investigated group MBI with 25 couples affected by multiple sclerosis (MS) (Hankin, 2009). The thesis used a single group design and gathered pre/post-intervention interpersonal data using the dyadic adjustment scale (DAS) (Spanier, 1976). The thesis used a single-group design and found a non-significant (p >0.05) improvement in dyadic satisfaction (Hankin, 2009). The thesis had several limitation including using a convenience sample and incomplete reporting, which makes it difficult to be certain about the validity of the findings (Parahoo, 2014).

The limited and sometimes contradictory quantitative evidence makes drawing conclusions difficult, but the qualitative synthesis provides additional insight into care partnerships’ interpersonal experience of using MBI together. The
mindfulness with care partnership themes highlight three interconnected themes, which show how togetherness and becoming mindful can impact on interpersonal factors when using MBI in a care partnership (Section 4.5.12 on page 109). The mindfulness with care partnerships themes (Figure 5 on page 109) shares similarity with the grounded theory: learning new mindfulness skills together (Smith et al., 2015). The learning new mindfulness skills together theory (Smith et al., 2015) was reported in one of the included studies and shows how mindfulness (specific factors), group processes (non-specific factors), and interpersonal processes (partnership factors) influence outcomes for care partnerships using MBIs. This grounded theory highlights the value of learning MBIs in a care partnership and suggests the approach may produce benefits for participants (Smith et al., 2015). The benefits thought to occur when learning MBI in a partnership include improved dyadic coping and better engagement with MBI (Smith et al., 2015). The learning new mindfulness skills together theory (Smith et al., 2015) provides an initial understanding of the potential value of using MBI with care partnership, but was developed with people affected by depression symptoms and attending face-to-face group MBI. More research is needed to see whether the learning new mindfulness skills together theory (Smith et al., 2015) applies to other clinical area (e.g. stroke) and with different modes of delivery (e.g. online).

The combined quantitative and qualitative mixed studies synthesis suggests care partnerships can experience an enhanced relationship when using MBI together and highlights several positive interpersonal features (e.g. communication). However, not everyone will benefit from using MBIs in a care partnership and it is possible some people may experience a worsening in their relationship (Section 4.5.5 on page 93). Using MBIs with care partnerships involves several interconnected components and is highly complex. The complexity exists because MBIs are complex interventions and can be deconstructed into the whole interventions (e.g. MBSR), component parts (e.g. sitting meditation), and powers (e.g. mechanisms) (Clark, 2013). The complexity associated with MBIs is increased further when they are used by care partnerships. The complexity in increased when care partnerships use MBIs because the interpersonal dimensions become another component to consider
and adds to the complexity. This complex picture needs to be explored further before the effects of MBIs on care partnerships are properly understood.

### 4.6.2 Mindfulness

Change in mindfulness is thought to be a key mechanism for MBIs (Alsubaie et al., 2017), but the original review (Parkinson et al., 2019) did not report whether care partnerships experience changes in mindfulness after using MBI together. It is important to know whether care partnerships experience changes in mindfulness, so this review provides an original synthesis on the mindfulness changes experienced by care partnership using MBI together (Section 4.5.11 on page 107).

Changes to mindfulness are important for MBI research, but only half the included studies measured change in mindfulness (Section 4.5.6 on page 95). The limited attention given to measuring changes in mindfulness seen in this review is consistent with publications in the Mindfulness journal (Toniolo–Barrios, Brasil and Pitt, 2020). Examination of publications in the Mindfulness journal between 2010-2019 shows changes in mindfulness were thought to be a predictor variable in about half of published papers (n= 451, 52.5%). However, change in mindfulness was only measured as a primary outcome in a small minority of studies (n= 24, 1.7%). This data suggests very few studies are measuring mindfulness as a primary outcome, despite it being considered an important predictor variable (Toniolo–Barrios, Brasil and Pitt, 2020). Although, the data only refers to studies published in the Mindfulness journal and other journals may have a different experience and publish more (or less) studies measuring mindfulness as a primary outcome. The limited attention given to changes in mindfulness by research is confounded because all included studies used self-report measures, which can be inaccurate and create methodological weaknesses in MBI research (Davidson et al., 2015). One of the main weaknesses in self-report mindfulness measurement is social desirability, which can cause bias in the results (Wong et al., 2018). Combining self-report measurement with an objective behavioural measurement (e.g. breath counting) of mindfulness would have helped reduced the potential for bias and increase validity of the results (Levinson et al., 2014).
The quantitative synthesis showed the majority of studies found increased mindfulness for people with chronic conditions and all studies found increased mindfulness for care partners. The change in mindfulness was not statistically significant for either people with chronic conditions or their care partners ($p > 0.05$), which increases the risk of making a type 1 error. Although, the $p$ value for change in mindfulness for care partners was close to statistical significance ($p = 0.0625$) and highlights the arbitrary nature of using statistical significance level of $p \leq 0.05$ as a threshold in research (Aguinis, Vassar and Wayant, 2019).

The qualitative synthesis revealed people with chronic conditions and their care partners experienced increased mindfulness after using MBI together (4.5.12.2 on page 112). Increased mindfulness was most evident in the becoming mindful theme and was associated with increased awareness and acceptance. The increased mindfulness evident in the synthesis may improve interpersonal relationships and highlights the interconnected nature of mindfulness and interpersonal factors. Research investigating mindfulness in the context of romantic relationships suggests increased mindfulness can improve romantic relationships (Kappen et al., 2018). The aspect of mindfulness thought to be most closely linked to improved romantic relationship is partner acceptance. However, the research investigating the links between mindfulness and romantic relationship needs to be interpreted cautiously because it was completed in non-clinical participants and may not apply to people with chronic conditions (Kappen et al., 2018).

The mixed studies synthesis shows people living with chronic conditions and their care partners can become more mindful and achieve greater awareness and acceptance using MBI together (Section 4.5.12.2 on page 112). Achieving greater awareness and acceptance is an important element of care partnerships using MBI together and may have an impact on outcomes (Alsubaie et al., 2017). The Monitor and Acceptance Theory (MAT) suggests MBIs achieve positive outcomes by helping people monitor (awareness) and accept (acceptance) their present moment experiences (Lindsay and Creswell, 2017). Developing awareness through active monitoring helps promote cognitive function, but can cause affective reactivity. Developing greater acceptance with MBIs helps reduce affective reactivity caused by increased awareness and promotes positive mental health (Lindsay and Creswell, 2017).
The mindfulness with care partnerships themes (Figure 5 on page 109) are compatible with MAT (Lindsay and Creswell, 2017) because both highlight the role of awareness and acceptance in achieving with improved outcomes. The difference between the mindfulness with care partnerships themes and the MAT (Lindsay and Creswell, 2017) is the focus on interpersonal elements (e.g. togetherness) in the mindfulness with care partnerships themes (Section 4.5.12 on page 109).

4.6.3 Stress, anxiety symptoms, and depression symptoms

The included studies produced statistical significant improvement for some people with chronic conditions and their care partners (Section 4.5 on page 81). Although, the results were mixed and not all studies achieved statistically significant improvements for stress, anxiety symptoms, and depression symptoms. An interesting result from one of the included studies was the statistically significant improvement in stress for participants in the control arm (Price-Blackshear et al., 2020). The unexpected results with the control group could reflect regression to the mean (Marsden and Torgerson, 2012), but both arms of the study used MBI and the variable being examined was having a partner. Both conditions received an active treatment and the positive outcomes show MBIs can be effective for reducing stress with or without a partner (Price-Blackshear et al., 2020) (Table 8 on page 98).

The quantitative synthesis showed improvement in stress, anxiety symptoms, depression symptoms, and generic psychological distress for the majority of studies, but the difference was only statistically significant ($p <0.05$) for depression symptoms (Section 4.5.11 on page 107). Having a statistically significant result for depression symptoms reduces the chances of making a type 1 error and suggests the null hypothesis can be rejected. However, the lack of statistically significant results for stress, anxiety symptoms, and generic psychological distress raises doubt about whether the results occurred by chance for those outcomes. Boon and Thomson (2020) caution against using statistical significance with effect direction and stress a statistically significant change ($p <0.05$), does not indicate effectiveness of an intervention. The limitations associated with effect direction and the poor quality of some included
studies means the results of the quantitative synthesis should be interpreted cautiously (Section 4.4.9 on page 77).

The minimal improvement in some cases raises questions about the potential effectiveness of MBI for care partnerships and appears to differ from published literature on the topic. Bohlmeijer et al. (2010) conducted a systematic review to investigate the effectiveness of MBIs on anxiety, depression, and psychological distress for people with chronic conditions. The review included eight RCTs of variable quality and found a small effect size for anxiety, depression, and psychological distress (Bohlmeijer et al., 2010). A more recent systematic review of RCTs (n=115) also indicated a small to medium effect size for stress, anxiety, and depression after using MBI (Gotink et al., 2015). However, the quantitative data and statistical analysis does not give a full picture and it is necessary to consider context and the subjective experience of using MBIs in care partnerships (Balkin and Lenz, 2021).

The qualitative synthesis included the theme wellness, which reflects the increased levels of relaxation and calmness experienced by care partnerships using MBI together (Section 4.5.12 on page 109). The wellness theme is articulated in terms of increased relaxation and calmness, because this reflects the participants' perspective and experience of using MBI together. It is important to emphasise the wellness theme is not articulated in terms of improved stress, anxiety symptoms, and/or depression symptoms. The focus on developing positive health states, rather than amelioration of psychological distress, was evident in the wellness theme and is consistent with the salutogenic model of health (Mittelmark and Bull, 2013). Antonovsky (1979) seminal work on the salutogenic model of health advocates for a paradigm shift away from condition orientated models of pathogenesis and towards more health promoting models of salutogenesis. The wellness theme produced in the qualitative synthesis highlights the importance of considering change from multiple perspectives and not just condition focused outcomes (Mittelmark and Bull, 2013). Despite the limitations of using conditions focused outcomes, mindfulness research does appear to still prioritise stress, anxiety symptoms, and depression symptoms over other outcomes. Research investigating publication patterns in the Mindfulness journal showed stress, anxiety, and depression were consistently the three top outcomes between 2010-2019.
(Toniolo–Barrios, Brasil and Pitt, 2020). Future MBI research would benefit from evaluating change from both condition (i.e. improved anxiety) and wellbeing perspectives (i.e. life satisfaction) (Lomas et al., 2019).

The quantitative and qualitative synthesis complement each other by suggesting care partnership experience positive changes after using MBIs. Improvements in stress, anxiety symptoms, and depression symptoms were sometimes small, not always statistically significant, and/or experienced by everyone. Positive change was not always condition specific and participants sometimes reported improvement in relaxation and calmness. These findings highlight tension between whether MBIs are supposed to reduce distress or help people become better at managing stress (Sauer et al., 2011).

### 4.6.4 Strength and limitations

The assessment of multiple systematic reviews (AMSTAR 2) (Shea et al., 2017) highlighted many strengths (n=11, 69%), but also some weaknesses (n=5, 31%) in the systematic review (Section 4.4.10 on page 80). Strengths in the review include using a structured search framework (i.e. SPIO), although, the review did not use the recommended PICO framework (Eriksen and Frandsen, 2018). There was also evidence of strength in the systematic search, independent screening/selection, data extraction, mixed studies synthesis, and reporting of the review (Shea et al., 2017).

The main weaknesses were the level of detail provided in the prospective registration, which did not include a plan for investigating heterogeneity (Parkinson et al., 2020). The review could also have provided more detail about the interventions/ comparators provided, although, this was not a focus of the review. Another weakness came from using the Mixed Method Appraisal Tool (MMAT) (Nha Hong et al., 2018), which does not cover all aspects necessary for AMSTAR 2 (Shea et al., 2017). However, the MMAT was used because it could critically appraise the wide variety of study designs used in the review (Nha Hong et al., 2018).

This updated review included several enhancement on the published version (Parkinson et al., 2019). The main enhancement to the published review was excluding studies with mixed samples and only including studies where care
partnership data was reported or could be extracted (Section 4.4.5 on page 72). This change ensured only data from care partnership was included in the systematic review and reduced possible bias caused by having mixed samples in the systematic review. Other enhancements include having a new question about changes to mindfulness, which is an important mechanism in MBIs (Alsubaie et al., 2017). The updated review also includes greater transparency about the mixed studies design (i.e. segregated explanatory sequential) (Heyvaert, Hannes and Onghena, 2017) and included new quantitative and qualitative synthesis methods. Weaknesses not captured using AMSTAR 2 (Shea et al., 2017) include using English language and abstract limiters during the search, which risks missing important studies (Morrison et al., 2012; Bramer et al., 2018). Another weakness includes using effect direction for quantitative synthesis, which does not take into account the quality of studies or the amount of change that occurred (Thomson and Thomas, 2013).

Enhancements could have been made to the review by considering adherence and whether participants completed the MBIs as intended. Adherence was not a focus of this review, but is important because it helps determine the extent that change can be attributed to the intervention (Parahoo, 2014). Although, establishing adherence to MBI is challenging because of the use of home practice and the problems associated with measuring the quality of mindfulness practice (Parsons et al., 2017). In the review six studies (n=6, 60%) reported adherence to MBI (Lengacher et al., 2012; Kubo et al., 2018, 2019, 2020; McDonnell et al., 2020; Price-Blackshear et al., 2020) and four studies (n=4, 40%) did not report adherence to MBI in their study (Birnie, Garland and Carlson, 2010; Paller, et al., 2015; Smith et al., 2015; Berk et al., 2019). Studies reporting adherence measure the number of sessions attended, amount of home practice, and/or the time spent using online MBI. These measures of adherence focus entirely on the amount of time the person used MBI, but do not take into consideration whether the person was using mindfulness correctly (Parsons et al., 2017). This is an important distinction because time spent practising mindfulness, does not always translate into better outcomes and practice quality may also need to be considered when thinking about adherence (Ribeiro, Atchley and Oken, 2017). Measuring adherence with online MBI is further complicated because all three studies used automated systems for...
monitoring screen time, which will not capture informal practices (e.g. mindful meal) and/or practices completed offline (Kubo et al., 2018, 2019, 2020; Price-Blackshear et al., 2020).
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(Shea et al., 2017)
4.6.5 Implication for practice

This review provides tentative evidence to support the use of MBI with care partnerships and suggests care partnerships may experience improvements in mindfulness, stress, anxiety symptoms, and depression symptoms. It is also thought using MBI in a care partnership may promote wellbeing through enhanced relaxation and calmness. Clinical services could use this evidence to support the use of MBIs with care partnerships. Additional benefits of care partnerships using MBI together may include increased togetherness and extra mutual support for each other (Section 4.5.12.1 on page 109). The review also highlights the need for caution when using MBIs with care partnerships and highlights the potential for relationships to worsen. It would be important to advise care partnerships using MBI together that there is a possibility it might worsen their relationship.

The current literature review builds on the previously published version (Parkinson et al., 2019) and adds to the literature on using MBIs with care partnerships. The review generated knowledge about the use of MBIs with care partnerships and produced an original synthesis of evidence, which will help future researchers using MBIs with care partnerships. The knowledge generated in this review will help provide a justification for researchers to use MBIs with care partnerships. Although, the low quality of many of the included studies means the findings of the review need to be interpreted cautiously and indicate the need for more robust research. Future iterations of the systematic review should consider whether participants fully engaged with the MBI and whether adherence is linked to outcomes.

Future primary research should use robust study designs and improve internal validity by incorporating active control conditions and follow-up (Parahoo, 2014). One challenge faced by this systematic review was the amount of research recruiting care partnerships and participants by themselves in mixed samples. It is recommended future research involving care partnerships should not use mixed samples and/or be able to extract data for those people attending in a partnership. This would help establish the role of care partnership using MBI together and avoid possible bias associated with using mixed samples.
Research should use high quality mixed methods designs, so the breadth and depth of understanding can be increased (Johnson, Onwuegbuzie and Turner, 2007). Future research should also consider wellbeing outcomes (e.g. satisfaction) alongside more condition focused outcomes (e.g. anxiety) (Lomas et al., 2019). It is also important for research to investigate the use of MBI with care partners in other clinical settings (e.g. stroke). The recent COVID-19 pandemic has also highlighted the importance of delivering interventions remotely and future research will need to place greater importance on using online/remote delivery (Holmes et al., 2020). This systematic review highlights the urgent need to study online MBIs with care partnerships affected by stoke.

4.7 Conclusions

The systematic mixed studies review found care partnerships can experience changes to mindfulness, anxiety symptoms, and depression symptoms when using MBI together. The systematic review also found care partnerships can experience improved relaxation and calmness after using MBI together. The evidence was less clear about interpersonal changes and the review found care partnerships may experience a worsening in relationship after using MBI. This review adds to the MBI literature and generates knowledge about the use of MBI with care partnerships. The review demonstrates originality by presenting a new mixed studies synthesis and through the development of the mindfulness with care partnerships themes. The review also highlights several weaknesses in the current literature and stresses the tentative nature of the findings. This review identified a lack of research using online MBI with care partnerships affected by stroke and calls for future research to include online MBI and care partnership affected by stroke. The next chapters of the thesis will report on a study using online MBI with care partners affected by stroke.
Chapter 5. Online mindfulness for care partnerships living with anxiety and depression symptoms after stroke.

5.1 Introduction

Stroke is a common chronic health condition with serious consequences for stroke survivors and their care partners (Langhorne, Bernhardt and Kwakkel, 2011). There is a high prevalence of anxiety and/or depression symptoms among stroke survivors (Broomfield et al., 2014) and their care partners (Loh et al., 2017). Experiencing anxiety and/or depression symptoms after stroke can negatively affect quality of life (Wan-Fei et al., 2017) and rehabilitation outcomes (Quattropani and Geraci, 2018). Mindfulness-based interventions (MBIs) are effective strategies for reducing anxiety symptoms and depression symptoms (Gotink et al., 2015; Spijkerman, Pots and Bohlmeijer, 2016) and can help people affected by stroke (Lawrence et al., 2013).

The initial focus of this PhD was MBIs delivered face-to-face in groups and the first iteration of the systematic review completed in 2017 did not include online MBIs (Parkinson et al., 2019). Research evidence suggests the provision of MBIs is inadequate and demand often exceeds supply, which raises questions about the sustainability of face-to-face group MBIs (Rycroft-Malone et al., 2019). Concern about the sustainability of face-to-face group MBI prompted the decision to change the focus of the PhD to online MBIs. There is growing scientific evidence supporting the use of online MBIs and they are increasingly seen as a viable alternative to face-to-face group MBI (Section 2.4 on page 45).

The main reasons for choosing online MBI was evidence suggesting online MBI can provide an accessible, low cost, and convenient option for participants (Spijkerman, Pots and Bohlmeijer, 2016). There is also evidence to suggest online MBI is clinically effective and might be as effective as face-to-face group MBI (Spijkerman, Pots and Bohlmeijer, 2016; Toivonen et al., 2017). An asynchronous (i.e. pre-recorded) online MBI was selected so it could be delivered without needing large numbers of MBI teachers and would be more scalable in practice (Creswell, 2017). Using online MBI was low cost (Appendix...
19: Study expenses on page 338) and allowed for care partnerships to commence online MBI immediately after giving consent, instead of having to wait for sufficient numbers for a face-to-face-group to be financially viable. Online MBI also made it feasible to recruit care partnerships from a wider geographical catchment area and removed the need for participants to travel to the face-to-face group sessions. Research into online MBI and practical factors associated with delivering the study made using online MBI an ideal choice for this study.

Having decided to use online MBI, it was important to update the systematic review and include online MBIs (Section 4.5 on page 81). The updated systematic review was completed in 2020 and found care partnerships can experience changes to mindfulness, stress, anxiety symptoms, and depression symptoms when using MBI together. The updated systematic review recommended future research should use mixed methods and examine the use of online MBI with care partnership affected by stroke. Chapters four to eight of this thesis seeks to address this need by exploring the use of online MBI with care partnerships experiencing anxiety and depression symptoms after stroke.

5.2 Study aim

The primary aims of this study is to research the use of online MBI with stroke survivors and their care partners.

5.3 Study questions

- Is it feasible to study online mindfulness with stroke survivors and their care partners together in a care partnership (Section 8.1 on page 225)?
- Do stroke survivors and their care partners find it appropriate to use online MBI together (Section 8.2 on page 232)?
- Do stroke survivors and their care partners experience changes in mindfulness after using MBI together (Section 8.3 on page 233)?
- Do stroke survivors and their care partners experience interpersonal changes after using MBI together (Section 8.4 on page 235)?
- Does online MBI have the potential to reduce anxiety symptoms for stroke survivors and their care partners (Section 8.5 on page 238)?
• Does online MBI have the potential to reduce depression symptoms for stroke survivors and their care partners (Section 8.6 on page 240)?
Chapter 6. Methodology

Methodology is the study of research methods and helps determine the most appropriate way of answering research questions (Parahoo, 2014). Methodological considerations involve choosing the best philosophical foundations for the project and the best strategies to answer the research questions (Dillon and Wals, 2006). This study explored the experience of stroke survivors and their care partners learning mindfulness together using an online MBI. The research involved several interconnected components (e.g. people affected by stroke; learning mindfulness; online interventions, partnership factors) and much complexity. Redfern, McKeVitt and Wolfe (2006) states stroke care and management is a complex clinical area. MBIs are complex interventions with several interacting components (e.g. body scan, sitting meditation, mindful movement) (Demarzo, Cebolla and Garcia-Campayo, 2015). There is also uncertainty about what elements within MBIs produce therapeutic change, although, increased mindfulness following MBIs is thought to be an important mechanism (Alsubaie et al., 2017). Complexity also exists with online interventions (Murray, 2012) and interpersonal partnerships (Robinson et al., 2005). The multifaceted nature of stroke survivors and their care partners using online MBI together means this project is best defined as complex health intervention research (Pearson et al., 2005; Craig et al., 2008).

6.1 Complex health intervention research

Complex health intervention research is an evolving aspect of research, which is guided by several different methodology frameworks (Pinto, Caldeira and Martins, 2018). These methodology frameworks provide researchers with structure and help to guide decision-making (Corry et al., 2013). Bradley et al. (1999) produced an early guide for researchers, which suggested complex interventions should be developed and evaluated using three stages: 1) understand the evidence and theory behind the intervention; 2) develop the components involved with the intervention; 3) consider the people and context involved with implementing the intervention. The Joanna Briggs Institute (JBI) also produced a model for evidence-based health care, which covered both development and effective use of complex health interventions (Pearson et al., 2005; Craig et al., 2008).
A key element of the JBI model is the importance placed on the feasibility, appropriateness, meaningfulness, and effectiveness of complex health interventions. The JBI framework uses the mnemonic FAME (i.e. feasibility, appropriateness, meaningfulness, and effectiveness) to highlight the importance of these elements in their model (Jordan et al., 2018). The Medical Research Council (MRC) (2000) has also produced guidance for developing and evaluating complex interventions. The MRC framework breaks down the process into four stages: 1) development, 2) feasibility, 3) evaluation, and 4) implementation (Craig et al., 2008). Recent developments in the field of complex health intervention guidance include placing greater emphasis on how contextual factors might influence the success (or otherwise) of an intervention (Craig et al., 2018). The MRC (2000) guidance is popular with researchers (Robinson et al., 2005; Lakshman et al., 2012), but there is no consensus on the best framework to use and many researchers omit using a framework altogether (Redfern, McKeivitt and Wolfe, 2006; Corry et al., 2013).

For this study the lack of existing literature exploring the outcomes and experience of stroke survivors and their care partners using MBI together suggests this is an exploratory/developmental area of study. This study is informed by complex health intervention guidance, but the guidance is used flexibly. The decision to use the complex health intervention guidance flexibly is influenced by limited resources available and an understanding that full alignment with complex health intervention guidance is resource intensive (Pinto, Caldeira and Martins, 2018). The study aligns with early phases of complex intervention guidance (i.e. understanding and development), by using mixed methods (Bradley et al., 1999; Pearson et al., 2005; Craig et al., 2008) and focusing on feasibility, appropriateness, and effectiveness (Pearson et al., 2005; Jordan et al., 2018).

### 6.2 Mixed methods research

Mixed methods research is a relatively new concept, which has evolved through various stages of development. In the past few decades mixed methods research has become a distinct methodology with its own worldview, historical context, and terminology (Tashakkori and Teddlie, 2010). There are several different definitions for mixed methods research and much debate about the
best way of articulating the approach (Creswell and Plano Clark, 2017).

Johnson et al. (2007, p. 123) believe mixed methods research “combines
elements of qualitative and quantitative research approaches for the broad
purposes of breadth and depth of understanding and corroboration”. Creswell
and Plano Clark (2017) extend this definition by stating mixed methods
research should be guided by an appropriate philosophical underpinning;
integrate qualitative and quantitative perspectives; and use established mixed
methods research designs. Whilst Morse (2009) suggests the term mixed
methods research can be used to describe situations where two or more forms
of qualitative (or quantitative) research are used in the same study. These
definitions allow for much variation to exist within mixed methods research and
for different approaches to have evolved over time. However, all mixed methods
research should articulate the mixed methods questions, the mixed methods
design, the weighting to each segment of the design, and cite relevant literature
(Creswell and Clark, 2018).

The development of mixed methods research has evolved through various
stages and faced many challenges. Early formative work (pre 1980) focused on
triangulation of quantitative and qualitative data to improve scientific quality
(Campbell, Fiske and Helson, 1959). This was followed by a period (1970-
1990s) of heated debate over whether differing paradigms were compatible with
each other, and whether it was possible to combine different research
paradigms in the same study (Johnson and Onwuegbuzie, 2004). Rossman and
Wilson (1985) acknowledge this tension and separated perspectives into those
who believe paradigms are incompatible with each other; those who think
paradigms are of equal importance, but separate; and those who believe
paradigms can be successfully integrated. Later (1980-2000) attention moved
to establishing early procedures for carrying out mixed methods research
(Creswell and Plano Clark, 2017). This work included developing conceptual
frameworks (Greene, Caracelli and Graham, 1989) and practical strategies for
combining different approaches (Morgan, 1998). More recently (since 2000)
mixed methods research has continued to evolve and become increasingly
sophisticated. The theory and practice of mixed methods research is
comprehensively documented in text books (e.g Creswell and Plano Clark,
and is now considered a third methodological perspective, alongside qualitative and quantitative methodologies (Doyle and Brady, 2009).

Contemporary issues in mixed methods research include concerns that qualitative approaches are underrepresented within mixed methods research and that quantitative approaches dominate (Howe, 2004). Although, Giddings and Grant (2006) suggest thinking of mixed methods research in a binary qualitative-quantitative system does not fully reflect the diversity within either perspective and mixed methods research more generally. Growing concern about qualitative research becoming overshadowed by quantitative research promoted researchers to reassert qualitative approaches in their mixed methods research (Howe, 2004). This phase has seen greater emphasis being put on qualitative methods and new qualitative-orientated mixed methods conceptualisations being developed (Mayoh and Onwuegbuzie, 2015).

Examples of qualitative dominant mixed methods designs include Mixed Methods Grounded Theory (MM-GT), which combines a strong grounded theory element with a mixed methods design (Johnson, McGowan and Turner, 2010). Mixed Methods Phenomenological Research (MMPR) aligns with phenomenology and puts greater emphasis on the qualitative element with the mixed methods design (Mayoh and Onwuegbuzie, 2015). This explicit and transparent use of qualitative approaches in mixed methods research has become more common in recent years, as researchers try to move away from the traditional dichotomy associated with qualitative and quantitative research (Parahoo, 2014). This shift in perspective has generated much debate about whether different methodologies are compatible and the risk associated with using different methodologies in combination with each other (Creswell and Plano Clark, 2017).

It is also worth considering the possible negatives or limitations associated with mixed methods research. Halcomb (2019) states researchers should not use mixed methods all the time and need to have a methodological rationale for choosing mixed methods. Halcomb (2019) also states mixed methods research can generate considerable amounts of data, is very resource heavy, and should not be embarked on without careful consideration. The choice of mixed methods approach depends on the research question and the context within
which the work will be undertaken. Creswell and Plano Clark (2017) provide a framework for choosing a suitable approach for mixed method research. The framework suggests a coherent mixed methods research approach should consider the philosophical foundations (i.e. paradigm), the mixed methods design, and the methods for the research.

6.3 Philosophical foundations

Research is shaped by a wide range of philosophical assumptions and beliefs about the world and how best to generate knowledge (Creswell and Plano Clark, 2017). Philosophical considerations include the ontological, epistemological and axiological positioning of the research and how this might impact on the methods of the study (Houghton, Hunter and Meskell, 2012). This philosophical positioning determines what the research is dealing with and the nature of reality (ontology); how best to understand and learn about the world (epistemology); and considers the reason for wanting to know what we do about the world (axiology). Dillon and Wals (2006) simplify these complex philosophical concepts into the what (ontology), how (epistemology), and why (axiology) of research and suggest these core concepts create the foundation for research methodology.

These differing philosophical concepts create several different perspectives, which are sometimes referred to as ‘paradigms’ (Kuhn et al., 1970) or ‘worldviews’ (Creswell, 2013). There is much debate about the similarities and differences between these terms (Creswell and Plano Clark, 2017), but for the purpose of this study the term ‘paradigm’ will be used to describe the philosophical foundation of the research. Deciding on an appropriate paradigm is an important first step in developing an appropriate research approach and helps bridge between the research aims and the research methods used to achieve those aims (Houghton, Hunter and Meskell, 2012).

The different philosophical concepts create four distinct paradigms: post-positivism, interpretivism, transformativism, and pragmatism (Creswell and Plano Clark, 2017). Each of these paradigms take a slightly different philosophical stance with regards ontological, epistemological, and axiological assumptions (Creswell and Creswell, 2018). Ontological (e.g. single reality
versus multiple realities), epistemological assumptions (e.g. objective versus subjective), axiological (e.g. value free versus value oriented), and methodologies (e.g. inductive versus deductive) (Reed, 2018). Selecting the most appropriate paradigms can be achieved by using different strategies: choose the ‘best’ worldview for mixed method research; use dialectical approach with two or more worldviews; select the most appropriate worldview for the research context; and/or use the worldview most commonly used within a research community (Creswell and Plano Clark, 2017). The choice of paradigms is also influenced by the researcher’s own personal assumptions and beliefs (Giddings, 2006), with some people questioning whether paradigms are necessary for making research decisions (Tashakkori and Teddlie, 2010). This variation highlights the decision-making required when choosing the most appropriate paradigms, but also shows there is more than one way of making the decision.

Pragmatism was selected as the most appropriate worldview because the ontological, epistemological, axiological, and methodological assumptions align well with the aims of the research. For instance, pragmatism can accommodate both singular and multiple realities, is highly practical, accepts multiple perspectives, and integrates methods to solve real-world problems (Zhang and Creswell, 2013). Pragmatism is well suited to this study because it is frequently used in mixed-methods research (Tashakkori and Teddlie, 2010), it is ideally suited to outcome-orientated health research (Doyle and Brady, 2009), and is compatible with the author’s own beliefs (Giddings and Grant, 2006). The author acknowledges the existence of the physical and social worlds; believes knowledge can be both constructed and based on reality; and embraces eclectic methods to solve real-world problems (Johnson and Onwuegbuzie, 2004). The pragmatic paradigm rejects the notions that research has to fully align with either qualitative (i.e. constructionism) or quantitative (i.e. post-positivism) methodologies and believes the researcher should be free to choose the most appropriate strategies for the given study (Creswell and Creswell, 2018). Although, reducing the paradigm debate into dichotomous positions does little to capture the complexity of the topic and the variation that exists within research philosophy (Durham et al., 2015). Chenail (2011) echoes this sentiment, by stating research methodologies are becoming less about strict
alignment with a singular theoretical position and more pluralistic and diverse in nature. However, Mertens (2012) suggests pragmatism can encourage researchers to overlook important philosophical considerations and focus solely on answering questions and research methods. Houghton, Hunter and Meskell (2012) believes research quality and rigour can only be achieved when the philosophical worldview is used consistently and transparently.

### 6.4 Mixed methods design

Having established an appropriate philosophical foundation for the research is it important to consider the research design (Creswell and Clark, 2018). Designing a mixed methods study involves making decisions about the sequencing, weighting, and mixing of qualitative and quantitative components (Creswell and Creswell, 2018). Sequencing decisions help determine the order of the qualitative and quantitative elements in the study and can broadly be divided into three core designs: exploratory sequential, explanatory sequential, and convergent design (Creswell and Clark, 2018). Exploratory sequential designs place qualitative methods first and then the quantitative component; explanatory sequential designs will have the quantitative elements first followed by the qualitative component; and the convergent design will use qualitative and quantitative methods concurrently (Kettles, Creswell and Zhang, 2011). Weighting within a mixed methods research refers to the emphasis placed on the qualitative and quantitative elements of the design. The weight can be placed on the qualitative element, the quantitative element, or shared equally between the two (Creswell and Clark, 2018). Johnson, Onwuegbuzie and Turner (2007) suggest mixed methods research should sit on a design continuum, with the middle ground being occupied by research using qualitative and quantitative equally, and either end of the continuum favouring one approach over the other. Deciding when and how qualitative and quantitative methods are integrated is an important part of mixed methods research (Creswell and Creswell, 2018). Mixing can happen at the design, methods, or analysis stages of the research phases (Fetters, Curry and Creswell, 2013). This might involve merging, embedding, or connecting the qualitative and quantitative elements and will vary depending on the type of design being used (Kettles, Creswell and Zhang, 2011). These decisions create multiple design
possibilities and are often illustrated using a notation system. The visual diagram shows the sequencing used in this study by using arrows, weighting by using upper case lettering, and mixing information is provided in circles (Figure 6) (Creswell and Clark, 2018). Strong arguments exist for using mixed methods approaches when researching complex interventions (Bradley et al., 1999; Pearson et al., 2005; Craig et al., 2008). Although, mixed methods research requires research expertise with both qualitative and quantitative approaches; familiarity with different mixed method designs; and can be more time consuming and resource heavy (Creswell and Plano Clark, 2017).

This research used an explanatory sequential design (Creswell and Clark, 2018), which placed the quantitative element first and weighted the qualitative component of the design. This type of mixed method design is suited for studies that want to explain initial quantitative findings and intend to purposefully select participants for the qualitative stage of the research (Creswell and Creswell, 2018). This was a useful design for this study because it allowed for participants to complete the online MBI and associated quantitative measures and for qualitative methods to be used afterwards to explain the outcomes and experience associated with using online MBI in a care partnership.

Figure 6: Explanatory sequential design

6.5 Mixed methods case study research

There is a long tradition of using group-based research designs to evaluate the efficacy and effective of clinical interventions (Craig et al., 2008; Bothwell et al., 2016). Group-based research is popular and the randomized controlled trial (RCT) method is considered the ‘gold standard’ for intervention research because it includes all the necessary features of a true experiment: manipulation, randomisation, and a control (Bondemark and Ruf, 2015). Group-based research often compares group averages and uses statistical analysis to test hypotheses, which can overlook individual differences and within group
variation (Smith and Little, 2018). The experimental features of a true experiment help reduce bias, but are not always appropriate or possible in every situation (Craig et al., 2008; Bondemark and Ruf, 2015). For example, it might be ethically questionable to use randomisation and/or delay intervention for participants in a study, if the intervention being used is known to be clinically effective (Bothwell et al., 2016). Moreover, recruitment into large group-based research can also be challenging (McDonald et al., 2006; Ridda et al., 2010). Specifically, the nature of stroke and the possibility of complex post-stroke difficulties pose particular challenges for researchers seeking to recruit stroke survivors (Boxall, Hemsley and White, 2016; McGill, Sackley, et al., 2020). Recruitment challenges sometimes experienced in clinical trials can result in small sample sizes, additional costs, extended recruitment periods, underpowered results, and make results difficult to generalise (McDonald, 2014; Singh, 2018).

A compelling alternative to group-based research is case study research (Yin, 2018). Case study research can be used to evaluate interventions (Gerrish and Lathlean, 2015) and is the ideal choice for this project because it allows for in-depth exploration of a complex phenomenon in a real-world setting (Crowe et al., 2011). Case study research can be defined as a form of inquiry that “investigates a contemporary phenomenon… in a real-world context… when the boundaries between the phenomenon and context may not be clearly evident.” (Yin, 2018, p. 15). Case study methodology, guided by a theoretical basis, copes well with complex phenomena (Yin, 2018). Case study methodology is a popular and flexible mode of enquiry, which can be used with different philosophical positions, study designs, and research methods (Hyett, Kenny and Dickson-Swift, 2014). However, the methodology does attract criticism by those who suggest case study research is not scientific and lacks rigour. Specifically, it is suggested case studies are vulnerable to research bias and their findings are not generalisable (Flyvbjerg, 2013). Yin (2013) counters these criticisms by suggesting strategies such as triangulation, rival explanations, and logic modelling can improve validity in case study research. Whilst Lincoln and Guba (2009) suggest generalisation uses a deductive polythetic premise, which is inconsistent with the inductive and idiographic approach taken in this study. Concerns about generalisation are further challenged by highlighting the
limitation of statistical generalisations and stressing the importance of analytic generalisation in case study research (Yin, 2013). Critics of statistical generalisation argue that comparing mean difference between groups can obscure individual difference and fail to capture variation within groups (Creswell and Creswell, 2018). Whilst analytic generalisation uses theory to generalised case study findings to other situations and circumstances (Yin, 2013). Gerrish and Lathlean (2015) suggest a two stage process when using theory to generalise case study findings. Stage one involves exploration and analysis of the case study (Chapter 8 on page 225), whilst stage two involves situating the case study findings in the wider literature to determine whether the new evidence is consistent with the existing literature (Chapter 9 on page 263). Equally, consumers of case study research can make their own naturalistic generalisations by reflecting on the usefulness (or otherwise) of the findings for their own situation and circumstances (Lincoln and Guba, 2009).

There is also debate about whether case study research should be considered a methodology or method. Yin (2018) believes case study research is best described as a methodology because it can incorporate a wide variety of different methods. However, this study aligns with mixed methods methodology and uses case study as a method. Mixed methods case study research combines one of the standard mixed methods designs (e.g. explanatory sequential) with case study methods and is considered a complex adaptation of mixed methods research (Creswell and Creswell, 2018). Mixed methods case study research is a good choice for research seeking to describe and understand complexity (Creswell and Clark, 2018). Mixed methods case study research also allows for data to be analysed at an individual participant level (within case) and at a group level (between cases) (Gerrish and Lathlean, 2015).

Mixed methods case study research has been used successfully with stroke research (Chen, Fujii and Schlaug, 2016), mindfulness research (Baer, Fischer and Huss, 2005; Wilkinson-Tough et al., 2009), and for evaluating interventions for people living with dementia and their family caregivers (Lazar, Demiris and Thompson, 2015). Mixed methods case study research has been used successfully to explore the use of MBI with stroke survivors (Dickinson, Friary and Mccann, 2017) and care partners (Moss, 2016). Mixed methods case study
research is also useful in situations where it is anticipated recruitment of study participants will be challenging (McDonald, 2014). Using a mixed method case study design helped explain the findings, explore differences within and between cases, whilst capturing participants’ voices (Creswell and Clark, 2018). The versatility of mixed methods case study research is a major strength of the approach and was the main reason for being used in this study.

6.6 Quantitative phase

This study employed mixed methods case study research using an explanatory sequential core design (Creswell and Creswell, 2018). The initial quantitative phase used a pre/post-test within subject case study design (Flannelly, Flannelly and Jankowski, 2018). This design involves measuring the dependent variable (0₁) (e.g. anxiety symptoms and depression symptoms) before implementing the independent variable (i.e. online MBI) (X) and reassessing the dependent variable (0₂) (e.g. anxiety symptoms and depression symptoms) to see whether or not a change occurred (Figure 7 on page 145).

Figure 7: Pre/post-test design

\[
\begin{array}{ccc}
0_1 & X & 0_2 \\
\end{array}
\]

The pre/post-test design has been used successfully with similar studies using online MBI (Krusche et al., 2012). The design did not include any control or randomisation, so is best described as a quasi-experimental design (Flannelly, Flannelly and Jankowski, 2018). This design was chosen because it would cause minimal disruption for participants, was not overly burdensome, and aligns closely with how the intervention would be delivered in practice (Parahoo, 2014). The primary focus of this phase of the study was to help identify suitable participants and generate quantitative data to explore in the secondary qualitative phase (Ivankova, Creswell and Stick, 2009).

6.7 Qualitative phase

The mixed methods case study design sequenced the qualitative element after an quantitative phase and weighted the qualitative component of the study (Creswell and Clark, 2018). In mixed methods research it is necessary to provide a rationale for why a specific qualitative approach was selected and
how best to use the qualitative approach within a mixed methods design (Mayoh and Onwuegbuzie, 2015). This study examined the experience of stroke survivors and their care partners using an online MBI together. The focus on lived experience and use of mixed methods case study research points towards mixed methods phenomenological research (MMPR) using Interpretative Phenomenology Analysis (IPA) (Smith, Flowers and Larkin, 2009). MMPR is defined as “research that combines phenomenological methods with methods grounded in an alternative paradigm” (Mayoh and Onwuegbuzie, 2015, p. 21). Mayoh and Onwuegbuzie (2014) completed a literature review to explore the use of MMPR. The review was completed in 2012 and captures 24 eligible studies. The findings revealed a growing use of MMPR, with the majority (70.8%, n=17) being from the health care sector. The analysis of MMPR revealed it was more common to prioritize the phenomenological element (50%, n=12) or to give the phenomenological and quantitative approaches equal weighting (25%, n=6). Analysis of the sequencing of MMPR revealed both nested and sequential designs were equally likely (50%, n=12) (Mayoh and Onwuegbuzie, 2014). The findings from Mayoh and Onwuegbuzie’s (2014) systematic review suggests MMPR is a suitable approach for use in health care settings and is compatible with the phenomenology dominant explanatory sequential design. This study used explanatory sequential MMPR (Mayoh and Onwuegbuzie, 2014) and combined an initial quantitative phase with a secondary phase of IPA (Smith, Flowers and Larkin, 2009). The decision to use this design was driven by an interest in understanding peoples’ experience of learning MBI in a care partnership and the necessity of accessing care partnerships with experience of using online MBI together. The specific nature of the study would have made it difficult to recruit people with the experience being studied, without first providing an opportunity for participants to undertake the online MBI together.

6.8 Interpretative phenomenological analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative approach to research that was developed by Johnathan Smith (1996). IPA was developed to counter the dominance of quantitative methodologies in health psychology and tries to place greater emphasis on the personal experiences of individuals.
(Biggerstaff and Thompson, 2008). IPA uses an inductive approach to help explore and gain insight into the meaning and experience of people with ‘lived experience’ of the phenomenon under investigation (Smith, Flowers and Larkin, 2009). IPA involves the detailed examination of participant’s lived experience and attempts to make sense of these experiences (Smith, 2011). Pringle, Hendry and McLafferty (2011) states IPA is an accessible and flexible qualitative approach, which enables the researcher to capture, hear, and understand the participants’ experience of something. Brocki and Wearden (2006) highlight the flexibility within IPA and discourage researchers from being too prescriptive in their use of IPA. The flexible and accessible nature of IPA has helped the approach spread quickly into other fields of research and across the globe (Smith, 2011). IPA is influenced by three important philosophical foundations: phenomenology, hermeneutics, and idiography (Smith, Flowers and Larkin, 2009).

Phenomenology is the first core philosophical element in IPA. The evolution of phenomenology as a philosophy and research methodology has been shaped by several influential figures. Husserl (1859-1938) is a seminal figure in world of philosophy and was one of the early pioneers of phenomenology. His academic work covered a wide number of topics and included developing our understanding of consciousness and the external world (Dowling, Cooney and Dowling, 2012). Husserl developed the idea that the external world was distinct and separate from those perceiving it, and that objects in the external world could be distilled down to essential essences (Dowling, 2007). Husserl’s approach to phenomenology involves phenomenological reduction, detailed description, and a search for essences of the phenomenon under investigation (Giorgi, 1997). Phenomenological reduction involves ‘bracketing’ past knowledge of the phenomenon and considering the phenomenon without preconceptions (Giorgi, 1997). Although, it is debatable whether this is feasible and/or desirable within phenomenology research (Finlay, 2008). Phenomenological description uses language to describe the experience or phenomenon being studied (Giorgi, 2012). Detailed description is a key feature of phenomenological research and forms a large proportion of phenomenological studies (Giorgi, 1997). The search for essences within phenomenology allow for the core features of experience to be known to the
researcher and for this to form part of the understanding of the phenomenon being observed (Christensen, Welch and Barr, 2017).

Heidegger (1889-1976) developed phenomenology by focusing his attention to how people interpret and make meaning from their experiences (Smith, Flowers, and Larkin, 2009). Interpretative phenomenology established a different perspective and an alternative way of understanding people’s experiences, by acknowledging the role individual interpretation has to play in how people experience and understand the world (Parahoo, 2014). Likewise, Heidegger stressed the importance of context and argued contextual factors will influence and shape peoples’ experience of something (Larkin, Watts, and Clifton 2006). IPA aligns closely with Heidegger’s interpretative approach to phenomenology and seeks to gain insight and understanding of participants lived experience, whilst acknowledging this will never result in a complete and true understanding of what they experienced (Smith, 1996).

The different ontological and epistemological perspectives within phenomenology are often thought to sit at either ends of a continuum; with Husserl’s descriptive phenomenology (realism) at one end and Heidegger’s interpretative phenomenology (relativism) at the other. Although, this view does not accurately reflect the variation that exists within phenomenology or the subtle differences between Husserl’s and Heidegger’s perspectives (Pringle, Hendry, and McLafferty, 2011). The IPA phenomenological position is guided by different phenomenologists and combines both a rich description and an interpretative account of the experience or phenomenon under investigation (Larkin, Watts, and Clifton 2006).

Hermeneutics is the second core theoretical element within IPA and highlights the role of interpretation within the approach (Pietkiewicz and Smith, 2014). Hermeneutics originates from methods used by scholars to interpret biblical text, but developed to help interpret other text (Smith, Flowers, and Larkin, 2009). The interpretative process in IPA uses a hermeneutic cycle and moves dynamically and iteratively between the whole phenomenon being interpreted and the component parts of the phenomenon (Shinebourne, 2011). Additionally, IPA is sometimes referred to as having a double hermeneutic because it involves the researcher interpreting a participant’s interpretation of an
experience or phenomenon (Smith, Flowers, and Larkin, 2009). The double hermeneutic within IPA acknowledges the role of the researcher in the interpretative process and accepts the researcher’s prior beliefs and assumptions about the topic will influence their interpretation (Peat, Rodriguez, and Smith, 2018). Therefore, researchers do not attempt to ‘bracket’ their preconceptions about the phenomenon, rather they actively reflect on the impact these might have had on their interpretation (Biggerstaff and Thompson, 2008) (Section 7.14 on page 217).

Ideography is the third core theoretical element within IPA and refers to the importance placed on the in-depth study of the particular (Smith, Flowers, Larkin, 2009). The idiographic focus of IPA encourages in-depth interpretation and analysis of individual cases, or a small number of cases, to examine the particular experience or phenomenon (Shinebourne, 2011). The phenomenological and idiographic focus within IPA means researchers have traditionally focused on personal accounts of people’s lived experience and used small homogenous samples to collect data (Smith, Larkin, Flowers, 2009). However, this research was interested in capturing multiple perspectives and needed to analyse data at an individual and partnership level. Working with multiple perspectives poses particular challenges for IPA researchers and has theoretical implications. Larkin, Shaw, and Flowers (2018) produced an important paper on the subject of multiplicity within IPA and justify the use of multiple perspectives by stating the researcher might be interested in what happens between people and the meaning they assign to their differing perspectives. Furthermore, taking a multiple perspectives approach within IPA is consistent with phenomenology and influenced by: where we are situated in relation to the world (profiles); the intersubjective nature of experience (intersubjectivity); and the systemic context within which people live their lives (systems) (Larkin, Shaw, and Flowers, 2018). These factors suggest taking a multiple perspectives approach using IPA is appropriate for the study of stroke survivors and their care partners learning mindfulness together.

The theoretical foundations of phenomenology, hermeneutics, and idiography within IPA help shape the approach, but have also created some tension within the wider research community. Giorgi (2011) raised concerns about whether IPA should be considered a phenomenological research methodology and
questioned the scientific basis for the approach. Similarly, van Manen (2018) raises concerns about IPA being branded as a phenomenology, and suggests using the term phenomenology in the context of IPA might inadvertently cause the scientific community to reject all phenomenological research. Tuffour (2017) reviewed the criticisms of IPA and suggested it was limited in four main areas: a lack of attention to language; whether IPA accurately captures experience, or just opinion; limited ability to grasp why certain things happened; whether a focus on cognition is appropriate in phenomenology. Despite these criticisms many researchers are using IPA because it provides an accessible and flexible approach for researchers to explore lived experience (Smith, 2011).

The IPA approach was chosen because it is compatible with the study aims and can capture the experience of care partnerships using online MBI. Pragmatically, IPA was selected because it is also flexible enough to be incorporated into mixed methods research and is appropriate for PhD studies (Smith, Flowers and Larkin, 2009; Taylor, 2015). The approach aligns with mixed methods case study research and is flexible enough to capture individual and multiple perspectives in the same study (Larkin, Shaw, and Flowers, 2018). The IPA element of the study involved post intervention semi-structured paired interviews, to capture the inter-subjective nature of using online MBI as a stroke care partnership (Allan and Eatough, 2016).

6.9 Mixing quantitative and qualitative data

A defining characteristic of mixed methods research is the integration of quantitative and qualitative data in the same study (Halcomb, 2018). Three different methods can be used to integrate quantitative and qualitative data within mixed methods research. The first method involves integrating the data after it has been analysed separately. In the second method, the researcher embeds the analysis of one set of data within the other. The third option is to use one set of data to help inform or explain the other set of data (Zhang and Creswell, 2013). In this study one set of data is used to help explain and understand another set of data. This approach to mixing quantitative and qualitative data is consistent with the sequential explanatory design used in this study (Ivankova, Creswell and Stick, 2009).
The process of integration of qualitative and quantitative data was facilitated by using dialectics. Dialectics is a form of logic that originates from philosophy and involves resolving problems or uncertainty by presenting different positions about a subject (Sherman, 1976). The process of dialectics is often associated with the thesis, antithesis, and synthesis framework developed by German philosopher Hegel (1770-1831) (Stone, 2014). Thesis, antithesis, and synthesis involves making a proposition (thesis), proposing a counter proposition (antithesis), and finally integrating of both propositions (synthesis) in an attempt to capture a true interpretation of a situation (Fagerström and Bergbom, 2010). Dialectics provide a useful framework for interpreting clinical complexity and are ideal for situations involving multiple perspectives and/or when tension exists between different perspectives (Fagerström, 2006). Dialectical tension occurs when there are two (or more) conflicting or contradictory perspectives on a given situations (Chagas et al., 2018). Within nursing research dialectics can be used as a philosophical position (Creswell and Clark, 2018) or a method for describing complex processes (Fagerström and Bergbom, 2010). Here dialectics are used to conceptualise the complex and contradictory interpretation of stroke care partnerships using online MBI together (Fagerström and Bergbom, 2010).

6.10 Summary of methodology

The study explored the experience of stroke survivors and their care partners using online MBI together. The study aligned with complex intervention literature by using mixed methods (Craig et al., 2008) and focusing on feasibility, acceptability, and effectiveness (Jordan et al., 2018) of online MBI for stroke survivors and their care partners. The overarching philosophical foundation for the study was pragmatism. The study uses explanatory sequential mixed methods case study research and combines a quasi-experimental stage with IPA (Smith, Flowers and Larkin, 2009; Creswell and Clark, 2018). Combing mixed methods case study research with IPA and using dialectics helped answer the real-world questions, allowed participants’ voices be heard, and captured the complexity within the data (Smith, Flowers and Larkin, 2009; Creswell and Clark, 2018).
Chapter 7. Methods

The previous chapter discussed the philosophical foundation and methodology used in the study. The chapter covered complex intervention literature, mixed methods methodology, and provided a pragmatic rationale for using mixed methods case study research (Creswell and Plano Clark, 2017). This chapter will explain and justify the methods used in the study and give a transparent and replicable report on how the study was completed.

7.1 Population and sampling

Research involves careful decision-making about how to define the population to ensure the right people are recruited into the study. Quantitative researchers place great importance on population characteristics, sample size calculations, representativeness, and randomised sampling (Parahoo, 2014). A recent systematic review examined the methods used by qualitative researchers to justify sample size (Vasileiou et al., 2018). The systematic review examined qualitative health research (n=214) published in three peer-reviewed journals between 2003-2017. The review gave insight into how qualitative researchers justify sample size, but did not focus specifically on IPA. The review found data saturation and pragmatism were the most common justification for sample size (Vasileiou et al., 2018). However, data saturation is usually associated with grounded theory and rarely used in IPA (Smith, Flowers and Larkin, 2009).

The idiographic nature of IPA requires researchers to identify a small homogenous group of people who are willing and able to provide an insider perspective on the experience or phenomenon being investigated (Smith, Flowers and Larkin, 2009). IPA research is less interested in whether the sample is representative of the wider population and does not use statistical methods to calculate sample size or to generalise findings (Smith, Flowers and Larkin, 2009). IPA is interested in gaining an understanding of the particular and tends to adopt purposeful sampling methods to identify people who have the necessary experiential expertise to answers the research questions (Smith, Flowers and Larkin, 2009). The sample size in an IPA study depends on the richness of data being collected, the resources available, and whether the idiographic focus is being considered with one person or a small group of
people (Smith and Osborn, 2008). Brocki and Wearden (2006) examined sample size across IPA studies (n=52) and found sample size varied from a single participant (n=1) to larger groups of participants (n=30). This research suggests IPA samples are often small, but does not give clear guidance on the correct sample size for IPA research. Smith, Flowers and Larkin (2009) suggest a sample between three and six participants is a reasonable number for student projects, but acknowledges it is difficult to offer precise recommendations. They also advise against using sample size as a gauge of adequacy or quality, because a large sample does not necessarily indicate adequacy of data or robustness of the investigation (Smith, Flowers and Larkin, 2009).

The population of interest in this study was stroke survivors and their care partners. This study aimed to purposely recruit five stroke care partnerships (i.e. ten participants) because it is small enough to maintain an idiographic focus, but large enough to allow for cross-case analysis (Smith, Flowers and Larkin, 2009). Pragmatism was the main justification for the sample size, because it was thought five care partnerships (i.e. ten participants) would be a manageable number for an novice researcher to analyse by themselves (Vasileiou et al., 2018). It was also important to not have too many participants because there was no budget available for the study and each additional participant increased costs (e.g. travel, MBI) of the study (Appendix 19: Study expenses on page 338). The pragmatic sampling strategy was consistent with IPA methodology, because it identified a small homogenous group of participants with the necessary lived experience and achieved an appropriate sample size for IPA (Brocki and Wearden, 2006; Smith, Flowers and Larkin, 2009).

7.2 Recruitment

Recruiting the right people in sufficient numbers can be a major challenge for researchers working with people affected by stroke (Berge et al., 2016; Boxall, Hemsley and White, 2016; McGill, Sackley, et al., 2020). The biopsychosocial impact of living with a stroke can make the issue of recruitment in stroke research complex (Boxall, Hemsley and White, 2016). A recent study exploring the use of online mindfulness for stroke survivors experienced considerable difficulty recruiting participants and highlighted the challenges associated with
research recruitment (Singh, 2018). Reasons for eligible people not participating in stroke research can include poor health, engagement in other treatment pathways, and/or participant refusal (Maxwell et al., 2017).

The study commenced recruitment in Scotland in November 2018, but a lack of initial response prompted the recruitment area to be extended in February 2019 to include northern England. The recruitment strategy focused on social media (i.e. Twitter) and voluntary sector organisations. This approach to recruitment mirrored the recruitment strategy used successfully in another study investigating stroke survivors and their care partners perspective on mindfulness (Jani et al., 2018). Recruitment ceased in August 2019 when the target sample size of five care partnerships (i.e. ten participants) was achieved.

7.2.1 Twitter

Twitter provides a cost-effective and accessible recruitment pathway for researchers and can help access difficult to reach populations (O’Connor et al., 2014). Research investigating the use of Twitter for participant recruitment found using Twitter can expand the reach of a study and advertising via personal accounts may reach more people than using study specific accounts (Wasilewski et al., 2019). The author used their own Twitter account to place a series of adverts and to share information about the study (Table 15 on page 154).

Table 15: Twitter advert

| #Stressed, #anxious, or #depressed after a stroke? Interested in learning #mindfulness with a family caregiver? Find out more about exciting new research happening in Scotland | https://tinyurl.com/y7aft4h9 |

The advert was tweeted on eight occasions between November 2018 and April 2019. Tweet analytics show the reach of each advert by recording the type and level of engagement they produced. It is difficult to say whether any of these engagements produced actual expressions of interest, because participants were not asked about where they heard about the study (Table 16 on page 155).
Table 16: Tweet analytics

<table>
<thead>
<tr>
<th>Advert 1</th>
<th>Advert 2</th>
<th>Advert 3</th>
<th>Advert 4</th>
<th>Advert 5</th>
<th>Advert 6</th>
<th>Advert 7</th>
<th>Advert 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impressions</td>
<td>5036</td>
<td>2238</td>
<td>1680</td>
<td>4273</td>
<td>797</td>
<td>2569</td>
<td>1480</td>
</tr>
<tr>
<td>Engagements</td>
<td>98</td>
<td>35</td>
<td>25</td>
<td>84</td>
<td>8</td>
<td>25</td>
<td>24</td>
</tr>
<tr>
<td>Links clicked</td>
<td>23</td>
<td>2</td>
<td>4</td>
<td>23</td>
<td>0</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Retweets</td>
<td>18</td>
<td>15</td>
<td>3</td>
<td>13</td>
<td>1</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Likes</td>
<td>17</td>
<td>3</td>
<td>3</td>
<td>16</td>
<td>3</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Profile clicks</td>
<td>10</td>
<td>3</td>
<td>6</td>
<td>11</td>
<td>2</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

7.2.2 Voluntary sector organisations

Voluntary sector organisations were approached to help advertise the study and became a key asset for recruitment. The organisations circulated information using either online adverts, word of mouth, or email dissemination to their membership. Both stroke specific and non-stroke specific organisations were contacted to help recruitment. The information circulated by the organisations varied, with some circulating the standard participant information sheet (Appendix 10: Participant information sheet on page 325) and others using their own format for online advertisements. Most organisations provided recruitment support free of charge, with only one organisation asking for a charitable donation for advertising on their website.

Table 17: Voluntary sector organisations involved with recruitment

<table>
<thead>
<tr>
<th>Stroke specific</th>
<th>Non-stroke specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest Heart Stroke Scotland</td>
<td>British Heart Foundation</td>
</tr>
<tr>
<td>Different Strokes</td>
<td>Contact, Help, Advice, and Information Network (CHAIN)</td>
</tr>
<tr>
<td>Headway</td>
<td>Fullarton Connexions</td>
</tr>
<tr>
<td>Stroke Association Scotland</td>
<td>Your Voice</td>
</tr>
</tbody>
</table>

7.2.3 Recruitment and consent process

Potential participants heard about the study via one of the advertisements and made contact with the author for further information. Interested stroke survivors and their care partners were given a participant information sheet, verbal details about the study, and encouraged to ask questions (Health Research Authority, 2017). During this initial contact the inclusion/exclusion criteria (Table 18 on page 160) were discussed and the screening protocol followed (Appendix 11 on
Potential stroke survivors and care partnerships meeting eligibility criteria were offered an appointment at a convenient time/place to complete the consent process. The first scheduled meeting was at least 24 hours after initial contact to allow people time to consider whether they wish to participate and to avoid coercion (Wager et al., 1995). At the meeting the author confirmed the stroke survivor and care partner’s willingness to participate, stressed the voluntary nature of the research, and reminded them of their right to withdraw (Health Research Authority, 2017). The stroke survivor and their care partner were then invited to ask questions, and when those were answered satisfactorily, they were invited to complete a consent form. No pressure or coercion was placed on participants and any participant wishing to leave the study could do so without having to give a reason and without any negative consequences.

7.3 Screening

Pre-enrolment screening was completed with all care partnerships at the start of the study. Screening was used to ensure stroke survivors and their care partners were eligible to participate in the study and to ensure participant safety. The screening process involved explaining the inclusion/exclusion criteria (Section 7.3.1 on page 157) for the study and asking care partnerships to self-assess whether they were eligible for the study. Self-assessment was used for screening because it was important to reflect the reality of what would happen when a stroke care partnership accessed the online MBI (i.e. Be Mindful) without referral from a health care professional. It was also thought a non-clinical approach might better reflect the experiences of stroke survivors who can feel abandoned by services and are not currently under the care of NHS stroke services (Clark et al., 2018; Pindus et al., 2018). Research investigating the value to self-assessed health examined population data (n=7527 participants) from the US found community dwelling older adults self-assessed health status can predict their functioning and mortality (Lee, 2000). Self-assessed health was also used in a large sample of consecutive stroke survivors (n=2190) over a five year period after they had attended a stroke unit in Sweden (Bjälkefur et al., 2020). The results found self-assessment could be
used by stroke survivors to identify a number of different post-stroke difficulties: pain, depression, and other unmet needs (Bjälkefur et al., 2020).

7.3.1 Inclusion and exclusion criteria

Inclusion and exclusion criteria were used when screening to identify participants who might not be suitable for the study (Table 18 on page 160). The focus of this study was using online MBI with stroke survivors and their care partners together in a care partnership, so the main inclusion criteria was for people to attend in a stroke care partnership (i.e. stroke survivor and their care partner together in a partnership). The study focused on adults living with stroke, so the minimum age was eighteen and there was no upper age limit. Initially the inclusion criteria was stroke care partnerships living in the community in Scotland, but this was extended to include northern England during the study (Section 7.11 on page 206). The intervention used in the study was a pre-recorded online MBI (i.e. Be Mindful) in English, so it was necessary for participants to be able to access/use the internet and communicate in English (Section 7.4 on page 161). The study took an inclusive approach to mental health and included people with self-reported anxiety symptoms and depression symptoms (with or without formal diagnosis). This approach was taken because people may experience mental health difficulties without meeting diagnostic thresholds and/or without being in contact with services (Fooladchang, Tabaeian and Bahrami Ehsan, 2019; Almhdawi et al., 2020).

The exclusion criteria for the study focused on participants’ safety and reducing the possibility of confounding factors affecting the results of the study. Dobkin, Irving and Amar (2012) recommends people are screened for trauma, substance misuse, and significant mental health difficulties (including suicidality) prior to starting MBI. Dobkin, Irving and Amar (2012) guidance on screening before MBI informed the development of a pre-course screening tool used with all participants (Appendix 11 on page 330). Participants were also asked if they had any difficulties with eating because one of the exercises used in the online MBI involved eating a raisin (Section 7.4.0 on page 166) and some people can experience difficulty swallowing post-stroke (Langhorne, Bernhardt and Kwakkel, 2011). It was also important potential participants were not receiving concurrent treatment, so they were excluded from the study if they were
attending mental health services, receiving psychological treatment, and/or involved with another MBI. Some participants had attended mindfulness taster sessions, but only those who had attended or were attending a full MBI were excluded.

Research evidence suggests cognitive impairment can affect 38% [95% CI=32-43%] \((I^2=92.5\%, \ p<0.01)\) of stroke survivors in the first year (Sexton et al., 2019) and stroke survivors cognition can decline significantly \((p <0.0001)\) over the first four years post-stroke (Mahon et al., 2017) (Section 1.1 on page 24). The high rates of cognitive impairment amongst stroke survivors is important and has clinical and ethical implications for this study. It is important to know whether MBIs can be used with people living with cognitive impairment, but there is limited research and most of the literature involves people living with dementia (Chan et al., 2020). A recent systematic review and meta-analysis examined RCTs (n=8 studies) using MBI with people living with dementia and mild cognitive impairment (Nagaoka et al., 2021). The systematic review evaluated a number of different outcomes (e.g. anxiety, depression, cognitive function) and discovered no significant difference between MBI and comparison groups in any of the outcomes. The review also found the included studies were low quality and had methodological weakness (e.g. lack of intent to treat analysis, low powered studies), which makes it hard to draw firm conclusions about MBI for people living with dementia and mild cognitive impairment (Nagaoka et al., 2021).

Another systematic review of MBI research (n=12 studies) involving people with cognitive impairment (including stroke survivors) made several recommendations to improve MBIs for people with cognitive impairment (Chan et al., 2020). The recommendations for adapting MBIs for people with cognitive impairment included making sessions shorter, using memory aids, increasing repetition, using plain language, and removing the need to attend a silent retreat (Chan et al., 2020). The recommendations align with the MBI used in this study (i.e. Be Mindful) because it used short sessions, could be watched repeatedly, used plain language, and did not include a day retreat (Section 7.4 on page 161). The online MBI used in this study may be appropriate for people with cognitive impairment, but it was decided to exclude people with cognitive impairment because of the preliminary nature of the study and ethical concerns.
about involving people with cognitive impairment in research. The ethical implications of involving people with cognitive impairment in this research relate to whether the participant can give fully informed consent and/or whether they would be vulnerable to possible coercion (Oruche, 2009).

Given the ethical implications of including people with cognitive impairment in research and the preliminary nature of this study (Oruche, 2009), it was decided to exclude potential people with cognitive impairment. Cognitive impairment can be assessed by a health care provider, using self-report, and/or with information provided by a caregiver/partner (Abd Razak et al., 2019). Health care professionals often use a formal cognitive assessment tool, which they complete and interpret to determine whether cognitive impairment is (un)likely (Janssen et al., 2017). Common cognitive assessment tools include the Mini-Mental State Examination (MMSE) (Folstein, Folstein and McHugh, 1975) and the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005). These tools provide an objective way of assessing cognitive impairment, although, they are not always accurate and clinical judgement and interpretation is required to determine the presence of cognitive impairment (Janssen et al., 2017).

Factors complicating post-stroke cognitive assessment include early-life intelligence and stroke-related difficulties. An observational study recruited stroke survivors (n=157) and evaluated their education attainment, pre-morbid intelligence, cognition, and dependency at 1-3 and 12 months following stroke (Makin et al., 2018). The study showed pre-morbid intelligence and education attainment can help predict cognition after stroke and should be considered when assessing post-stroke cognitive impairment (Makin et al., 2018). Likewise, stroke-related difficulties (e.g. impaired vision) can make it hard for people to complete formal cognitive assessments and incomplete cognitive assessments are common (Lees et al., 2017). A research study has tested the feasibility of completing commonly used cognitive assessment tools with stroke survivors (n=51) and found less than half were fully completed: MMSE (n=22/51; 43.1%) and MoCA 20/51; 39.2%). Incomplete cognitive assessments can affect validity and reliability of assessment and present a significant challenge for researchers and clinicians (Lees et al., 2017).
Instead of using formal cognitive assessment, this study took a pragmatic approach and asked participants and their care partners whether they had any concerns about their memory or cognition (Appendix 11 on page 330). This was completed prior to recruitment and helped reduce the possibility of someone with cognitive impairment being enrolled into the study (Section 7.3.1 on page 157). Asking people whether they have concerns about their memory and/or cognition can help identify subjective cognitive decline and may help identify people with, or at risk of developing, cognitive impairment (Cheng, Chen and Chiu, 2017). However, subjective cognitive decline can also be caused by other factors (e.g. mental health difficulties) and may result in false positives for cognitive impairment (Cheng, Chen and Chiu, 2017). Using an objective cognitive assessment tool (e.g. MoCA) alongside self and partner reported screening would have increased validity and reliability of assessment cognitive impairment (Abd Razak et al., 2019).

### Table 18: Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Stroke survivor and care partner together as a care partnership</td>
<td>• Currently involved in mental health/addiction services</td>
</tr>
<tr>
<td>• 18yrs plus</td>
<td>• Have difficulty eating</td>
</tr>
<tr>
<td>• Lives in the community</td>
<td>• Have suicidal thought</td>
</tr>
<tr>
<td>• Lives in Scotland or northern England</td>
<td>• Currently attending MBI course</td>
</tr>
<tr>
<td>• Can use the internet</td>
<td>• Receiving other forms of psychological care</td>
</tr>
<tr>
<td>• Access to the internet</td>
<td>• Memory problems or cognitive impairment</td>
</tr>
<tr>
<td>• Can communicate in English</td>
<td></td>
</tr>
<tr>
<td>• Currently stressed, anxious, or depressed (with or without diagnosis)</td>
<td></td>
</tr>
</tbody>
</table>

#### 7.3.2 Determining the case

An important step with case study research is to define the unit of analysis and determine what constitutes a case (Yin, 2018). This involves deciding on the boundaries for the case and the criteria used to determine whether something is a case or not (Baxter and Jack, 2008). This process creates a bounded system and situates the research within a specific context (Yin, 2018). This process helps distinguish the case from the context and stops the research from becoming unmanageable or ill defined (Andrews, 2017). Harrison et al. (2017) suggests time, space, and/or activity should be used to define a case within case study research. Although, more detailed bounding is necessary to achieve a holistic understanding of the context in which the research was undertaken.
(Hyett, Kenny and Dickson-Swift, 2014). This idiographic focus is consistent with IPA methodology, which tends to use small homogenous groups of participants and concentrates on a particular context for the research (Smith, Flowers and Larkin, 2009).

Cases were bounded by their individual identities; their relationship to each other; their living situation; their psychological wellbeing; and their lived experience of using Be Mindful (Wellmind Media and Mental Health Foundation, 2019):

- Stroke survivor or care partner
- Living in the community and residing in Scotland or northern England
- Experiencing stress, anxiety symptoms, and/or depression symptoms
- Used Be Mindful in a care partnership

7.3.3 Case vignettes

Case vignettes are used to provide a portrait of each care partnership (Appendix 21: Case vignettes on page 340). The anonymised vignettes are non-specific to reduce the risk of identification (Spalding and Phillips, 2007). The aim of the vignettes is to contextualise the care partnerships and improve trustworthiness, but inevitably these vignettes are interpretations and should not be considered absolute truths (Spalding and Phillips, 2007).

7.4 Intervention

MBI research is currently focusing on implementing MBIs in new ways and/or different context (Crane et al., 2017). Be Mindful is designed to support individuals with stress, anxiety, and depression symptoms (Krusche, Cyhlarova and Williams, 2013). Be Mindful has been used in clinical (Singh, 2018) and non-clinical settings (Querstret, Cropley and Fife-Schaw, 2018) (Section 7.4.2 on page 169). It is designed for people to use by themselves and has not been used with care partnerships. A recent systematic review examining the use of MBIs with care partnerships found most research was completed using either MBSR or MBCT (Parkinson et al., 2019). A recent study involving care partnership affected by cancer (Price-Blackshear et al., 2020) used MBRE (Carson et al., 2004), which is an MBI designed for romantic relationships and includes eye gazing and other practices aimed at building intimacy. Using MBRE (Carson et al., 2004) with non-romantic care partnerships (e.g. siblings)
would be problematic and there are currently no protocols designed specifically for care partnerships. Using Be Mindful (Wellmind Media and Mental Health Foundation, 2019) with care partnerships affected by stroke has not been done before, so this study is about using an existing online MBI (i.e. Be Mindful) in a different way and new context.

All participants were enrolled on an existing MBI called Be Mindful (Wellmind Media and Mental Health Foundation, 2019). Be Mindful is a commercially available online MBI, which costs £30 per person. The fee for using Be Mindful (£300) was paid by the author and participants could use the intervention without payment (Appendix 19 on page 338).

The MBI was developed by respected mindfulness teachers (Krusche et al., 2012) and is based on the MBCT (Teasdale et al., 2000) protocol. Mindfulness-based cognitive therapy (MBCT) (Teasdale et al., 2000) is a widely used MBI, which was developed for people experiencing recurrent episodes of depression. MBCT integrates the original MBSR approach with elements of Cognitive Behavioural Therapy (CBT) (Crane, 2017). MBCT uses elements of CBT theory to provide a psychological framework and cognitive model of psychological distress, which forms the basis for psychoeducation within MBCT (Crane, 2017). However, Be Mindful (Wellmind Media and Mental Health Foundation, 2019) does not follow the full MBSR or MBCT curriculum and is best described as a generic MBI (Crane et al., 2017).

A comparison table using the core elements associated with MBIs (Baer, 2014) is provided to illustrate the similarities and differences between MBSR (Santorelli et al., 2017), MBCT (Segal, Williams and John, 2012; Crane, 2017), and Be Mindful (Krusche et al., 2012; Querstret, Cropley and Fife-Schaw, 2017) protocols. However, MBIs frequently diverge from the standard protocol and this can create difficulty when trying to compare one MBI with another, because even MBIs aligning with a particular protocol (e.g. MBSR, MBCT) may be implemented differently (Crane, 2017). There are also many situational and experiential elements to learning mindfulness, so MBIs involve more than just a series of practices and provide a unique learning environment for those involved (Crane, Karunavira and Griffith, 2021).
One of the advantages of using a pre-recorded MBI like Be Mindful (Wellmind Media and Mental Health Foundation, 2019), is the fact it will be delivered consistently and variation between participants/studies will be reduced. This study did not seek to directly compare Be Mindful (Wellmind Media and Mental Health Foundation, 2019) with other MBI protocols (e.g. MBSR, MBCT), but instead was interested in the experience and outcomes for people affected by stroke using Be Mindful in a care partnership.
Table 19: MBSR, MBCT, and Be Mindful comparison

<table>
<thead>
<tr>
<th></th>
<th>MBSR (Santorelli et al., 2017)</th>
<th>MBCT (Segal, Williams and John, 2012; Crane, 2017)</th>
<th>Be Mindful (Krusche et al., 2012; Querstret, Cropley and Fife-Schaw, 2017)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mode of delivery</strong></td>
<td>Group (live face-to-face)</td>
<td>Group (live face-to-face)</td>
<td>Online (pre-recorded)</td>
</tr>
<tr>
<td><strong>Course length</strong></td>
<td>8 weeks</td>
<td>8 weeks</td>
<td>4 weeks</td>
</tr>
<tr>
<td><strong>Weekly contact time</strong></td>
<td>2.5-3.5 hours</td>
<td>2-2.5 hours</td>
<td>0.5-1 hours</td>
</tr>
<tr>
<td><strong>Group size</strong></td>
<td>30 approx.</td>
<td>12 approx.</td>
<td>1</td>
</tr>
<tr>
<td><strong>Orientation session</strong></td>
<td>Sometimes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Silent retreat</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Formal practice</strong></td>
<td>45-60 minutes a day</td>
<td>45 minutes a day</td>
<td>20-30 minutes a day</td>
</tr>
<tr>
<td><strong>Informal practices</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Core practices</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Raisin exercise</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Automatic pilot</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Body scan</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sitting meditation</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Mindful yoga</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Walking meditation</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Loving-kindness</td>
<td>✓</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Mindfulness in daily life</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Inquiry (guided discussion)</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
</tr>
<tr>
<td>Monitoring (un)pleasant events</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Use of poetry/metaphor</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>3-minute breathing space</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sitting with difficulties</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Working with cognitions</td>
<td>x</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>MBSR (Santorelli et al., 2017)</td>
<td>MBCT (Segal, Williams and John, 2012; Crane, 2017)</td>
<td>Be Mindful (Krusche et al., 2012; Querstret, Cropley and Fife-Schaw, 2017)</td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------------------------------</td>
<td>--------------------------------------------------</td>
<td>----------------------------------------------------</td>
</tr>
<tr>
<td>Thoughts and feelings</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Automatic thoughts</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Thoughts not facts exercise</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Pleasure and mastery</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Relapse prevention</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Letter to self</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
</tr>
</tbody>
</table>
7.4.1 Be Mindful structure and content

Be Mindful (Wellmind Media and Mental Health Foundation, 2019) is designed to be delivered asynchronously over four weeks, which is shorter than the standard eight-week format used during MBSR (Santorelli et al., 2017) and MBCT (Teasdale et al., 2000). The asynchronous online nature of Be Mindful (Wellmind Media and Mental Health Foundation, 2019) allows participants to choose their own pace and decide how long they take to complete the MBI. The four-week duration of Be Mindful is consistent with results from a systematic review examining online MBIs, which found the normal duration for online MBIs was between 2-12 weeks (Spijkerman, Pots and Bohlmeijer, 2016). The duration of Be Mindful also exceeds the two-week timeframe needed with MBIs for change in mindfulness to occur (Baer, Carmody and Hunsinger, 2012). A recent study examined possible mechanism of change with Be Mindful (Wellmind Media, 2019) and discovered participant change was associated with increased "acting with awareness" and no other facets of mindfulness (Querstret, Cropley and Fife-Schaw, 2017, p. 153).

The intervention is delivered online asynchronously by two experienced MBI teachers (one male and one female), although, the only contact with the teachers during the course is via the pre-recorded videos and automated emails (Querstret, Cropley and Fife-Schaw, 2017). Participants need access to the internet, the ability to use (or be assisted to use) the internet, and have access to an email account. The necessary skills for participants include basic keyboard skills, ability to use an electronic mouse, ability to navigate to the correct website, and ability to log in to Be Mindful. Participants access Be Mindful for the first time using a web link, which was sent to them via email. The Be Mindful link takes participants to the Be Mindful log in webpage where they can activate the Be Mindful course using their own username and password. Once their account has been activated participants can access Be Mindful and progress through the course at their own pace. Participants are free to take breaks and repeat sections as and when necessary (Table 20 on page 169).

The content is delivered using ten therapist-led interactive videos, twelve daily practice assignments (with supportive emails), five audio downloads, and online tools for reviewing progress (Wellmind Media and Mental Health Foundation,
The instructional videos cover formal mindfulness exercises (e.g. body scan, mindful movement, sitting meditation, and three-minute breathing space) and informal mindfulness exercises (e.g. mindful eating and mindful walking) (Krusche et al., 2012). By including sitting meditation, body scan, and mindful movement Be Mindful includes the three main exercises associated with MBIs (Crane et al., 2017). A comprehensive summary of Be Mindful has been published already (Krusche et al., 2012; Querstret, Cropley and Fife-Schaw, 2017). However, images and a brief summary are provided below to illustrate what participants see when using Be Mindful and to explain the structure and content of Be Mindful (Figure 8 on page 167 and Table 20 on page 169).

Figure 8: Images from Be Mindful

Getting started: before the course starts participants are introduced to the teachers via a short video (3:12) and learn about the course by reading brief online material. Participants then complete the online stress assessment, which includes the Perceived Stress Scale (PSS) (Cohen et al., 1983), the Generalised Anxiety Disorder (GAD-7) (Spitzer et al., 2006), and the Patient Health Questionnaire (PHQ9) (Kroenke, Spitzer and Williams, 2001). Then participants are encouraged to reflect on their motivation for taking the course.

Week one: focuses on helping participants step out of automatic pilot and includes videos on mindful eating (3:17; 2:38) (i.e. the raison exercise), the body scan (3:27), and dealing with barriers (2:37). After watching the instructional videos participants gain access to the audio recorded body scan (28:57), which is used to support daily practice. The participants are provided with three assignments each week and the first week’s assignments are the body scan, a mindful meal, and a mindful routine activity (e.g. brushing teeth).
At the end of the first week participants are provided with guidance on how to deal with common barriers they might encounter when using mindfulness.

Week two: helps participants reconnect with the body and breath. The videos cover mindful breathing (7:57), mindful movement (6:06) and the physical barometer (2.23). These videos are used alongside audio recordings of mindful breathing (8.44) and mindful movement (10:30). There is also a thoughts and feeling exercise to help participants learn about the role of unhelpful thinking and the impact unhelpful thinking has on mood and bodily sensations (Teasdale et al., 2000). The home practice assignments for the second week include mindful movement and mindful breathing. They are also invited to document pleasant and unpleasant events that occur in their lives, which can be used to help reduce the acute symptoms of depression (Segal et al., 2018).

Week three: prepares participants for working with difficulties. The videos cover the 3-minute breathing space (5:36) and working with unhelpful thoughts (2:51; 0:43). These videos are complemented by an audio recording that guides a sitting meditation (22:37), a checklist of common unhelpful thoughts, and suggested strategies for dealing with unhelpful thoughts (Segal et al., 2018). The home practice assignments for the third week include noticing and accepting stress, sitting meditation, and breathing space.

Week four: starts the process of embedding mindfulness into participants’ daily lives. Videos cover mindfulness in daily lives (1:44), breathing space with action step (5:05), and mindful walking (3:13). Other activities include tips on taking care of yourself and distinguishing between nourishing and depleting activities. This week also covers strategies for noticing and managing stress. Home practice assignments for the fourth week include noticing and changing nourishing and depleting activities, breathing space, and one other formal meditation (e.g. body scan, mindful movement).

Going forward: this section of the intervention helps participants prepare for life after the course. The content includes a brief orientation video (0:13), a video (0:20) signposting participants to the online stress assessment questionnaires. Participants then repeat the Perceived Stress Scale (PSS) (Cohen et al., 1983), the Generalised Anxiety Disorder (GAD-7) (Spitzer et al., 2006), and the Patient Health Questionnaire (PHQ9) (Kroenke, Spitzer and Williams, 2001). This pre-
post data is then presented on screen using a bar chart for each of the questionnaires (i.e. stress, anxiety, and depression) and allows participants to see whether their stress, anxiety symptoms, or depression symptoms have changed. The videos and stress assessment are supported by a reflective exercise and a letter to future self. The letter to self aims to help participants remember the value of mindfulness when experiencing stress in the future (Shapiro, Thakur and De Sousa, 2015).

A final video (3:41) closes the course and congratulates participants for completing the course and encourages an ongoing commitment to mindfulness and home practice. Participants have then finished and can access the completion certificate.

Table 20: Be Mindful course overview

<table>
<thead>
<tr>
<th>Before: Getting started</th>
<th>Introduction, stress assessment, and orientation.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1: Stepping out of automatic pilot</td>
<td>Routine activity, mindful eating, and body scan.</td>
</tr>
<tr>
<td>Week 2: Reconnecting with the body and breath</td>
<td>Mindful movement, event awareness, and mindful breathing.</td>
</tr>
<tr>
<td>Week 3: Working with difficulties</td>
<td>Breathing space, stress awareness, and sitting meditation.</td>
</tr>
<tr>
<td>Week 4: Mindfulness in daily life</td>
<td>Activity awareness, stress strategies, breathing space, and action planning.</td>
</tr>
<tr>
<td>Afterwards: Going forward</td>
<td>Stress assessment and certificate.</td>
</tr>
</tbody>
</table>

7.4.2 Evidence-base for Be Mindful

Be Mindful (Wellmind Media and Mental Health Foundation, 2019) has a growing evidence-base and has been evaluated in several research studies. An early non-comparison evaluation of Be Mindful (Krusche et al., 2012) found a significant reduction ($p < 0.001$) in stress scores and a very large effect size ($d = 1.57$) for participants ($n=100$) when using Sawilowsky’s (2009) rule of thumb for describing effect sizes. This was followed by a larger non-comparison study ($n=273$) investigating the effectiveness of Be Mindful on perceived stress, anxiety symptoms, and depression symptoms (Krusche, Cyhlarova and Williams, 2013). This second study collected data at baseline, on completion (minimum four weeks), and at four-weeks follow-up. The results of the second study indicate a significant reduction in stress ($p < 0.001$), anxiety symptoms ($p < 0.001$), and depression symptoms ($p < 0.001$) immediately following Be
Mindful, and at four-week follow-up. Although, the level of significance was slightly less good for depression symptoms ($p < 0.05$) at four-week follow-up (Krusche, Cyhlarova and Williams, 2013). Using Sawilowsky's (2009) definition of effects sizes Be Mindful produced a very large effect size for stress post-intervention ($d=1.2$) and at follow-up ($d=1.39$); a very large effect size for anxiety symptoms post-intervention ($d=1.22$) and at follow-up ($d=1.42$); and a large effect size for depression symptoms post-intervention ($d=0.95$) and at follow-up ($d=1.08$) (Krusche, Cyhlarova and Williams, 2013). Moreover, a recent RCT compared Be Mindful with a waiting list control and measured stress, anxiety symptoms, and depression symptoms over a longer period of time (i.e. baseline, three months, and six months). The Findings from the RCT showed significant reductions in stress ($d=-1.25 [-1.64, -0.85]$), anxiety symptoms ($d=-1.09 [-1.47, -0.98]$), and depression symptoms ($d=-1.06 [-1.44, -0.67]$) for those who completed the intervention (Querstret, Cropley and Fife-Schaw, 2018). These studies show the potential effectiveness of Be Mindful (Wellmind Media and Mental Health Foundation, 2019), but none include people affected by stroke. One example of Be Mindful being used in a stroke context was a very small RCT ($n=2$), which was completed as part of a doctoral thesis (Singh, 2018). This study is interesting because it used Be Mindful, but the low recruitment rate and mixed findings make it difficult to draw any firm conclusions about either the acceptability or effectiveness of Be Mindful for stroke survivors (Singh, 2018).

### 7.4.3 Intervention integrity

Intervention integrity is important in research using MBIs to ensure the intervention is being delivered correctly and consistently (Crane and Hecht, 2018). Intervention integrity ensures valid inferences can be drawn from the research and promotes rigour (Crane, 2019). Treatment integrity can be divided into two dimensions: fidelity and adherence (Perepletchikova et al. 2009). Fidelity refers to whether the intervention was delivered as intended and whether there was divergence from the MBI protocol (Persch and Page, 2013). Adherence involves assessing whether participants completed the MBI as intended (Crane, et al. 2013).
Evaluating intervention integrity of MBIs is difficult and there is limited evidence to inform decision-making about the best approach to use (Crane, 2019). Evaluating intervention integrity is complicated because the tools available are designed for face-to-face group delivery of MBSR and/or MBCT (Crane and Hecht, 2018), which poses a challenge when using alternative protocols and/or modes of delivery (e.g. Be Mindful). Currently there is no agreed way of evaluating intervention integrity with Be Mindful and the methods used with other protocols are not suited to online asynchronous delivery of a generic MBI like Be Mindful (Wellmind Media and Mental Health Foundation, 2019).

When evaluating fidelity in this study it is important to remember Be Mindful (Wellmind Media and Mental Health Foundation, 2019) is a generic MBI based on MBCT (Segal et al., 2018) and does not fully align with MBCT (Section 7.4 on page 161). The pre-recorded and automated nature of Be Mindful (Wellmind Media and Mental Health Foundation, 2019) promotes consistent delivery and fidelity to the protocol used by Be Mindful. The online nature and use of care partnerships make evaluating adherence to Be Mindful challenging. Previous researchers using Be Mindful with people affected by stroke used module completion as a guide for adherence (Singh, 2018). Previous research using Be Mindful with people affected by stroke (Singh, 2018) did not involve stroke survivors and care partners together in a care partnership, which makes evaluating adherence even more difficult. Using module completion to evaluate adherence in this study has limitations because it is impossible to know how fully participants engaged with each module and who (i.e. stroke survivors or care partners) was logged into Be Mindful at the time. Another difficulty is that some of the participants downloaded items from Be Mindful and used them offline, so it is impossible to know whether module completion gives a true indication of adherence.

This study evaluated intervention integrity by measuring the number of Be Mindful modules (0-4) completed and the percentage of course completion for each participant at weeks four and eight of the study. This data provided evidence of intervention adherence and the length of time taken by participants to complete the course.
7.4.4 Intervention reporting for Be Mindful

Accurate and transparent reporting is necessary to ensure the intervention is being delivered as intended and helps determine intervention integrity (Crane, 2018). Transparent reporting also helps researchers replicate studies to see if important findings can be reproduced. Failing to reproduce findings raises questions about the validity of the original study and has implications for the dissemination of research (Earp and Trafimow, 2015). Poor reporting is one reason why researchers find it difficult to replicate research (Maxwell, Lau and Howard, 2015) and can be helped by using a reporting checklist (Equator Network, 2019). The Template for Intervention Description and Replication (TIDieR) (Hoffman et al. 2014) is recommended by the Equator Network (2019) for reporting complex interventions. Crane (2019) provides guidance on how the TIDieR (Hoffman et al., 2014) checklist can be used with MBI and will provide the basis for reporting within this study (Appendix 16 on page 335).

7.4.5 Adverse events with Be Mindful

Adverse events are regularly monitored and reported in clinical trials to help determine the safety of interventions (Lineberry et al., 2016) (8.8). Engaging in MBI can cause unpleasant experiences, but MBIs are considered relatively safe interventions (Wong et al., 2018). Few studies have used Be Mindful (Wellmind Media and Mental Health Foundation, 2019) and also documented whether adverse events occurred during the study. Those studies that have monitored adverse events which occurred when using Be Mindful (Wellmind Media and Mental Health Foundation, 2019) report that no adverse events occurred with non-clinical participants (Krusche et al., 2012; Krusche, Cyhlarova and Williams, 2013) and stroke survivors (Singh, 2018). Adverse events and serious adverse events were monitored and reported in this study to promote transparency and improve participant safety (Wong et al., 2018) (Section 8.1.3 on page 232).

7.5 Study design

The study used mixed methods case study research with an explanatory sequential design (Creswell and Clark, 2018). The study combines an initial quasi-experimental stage with interpretative phenomenological analysis (IPA) (Smith, Flowers and Larkin, 2009) (Chapter 6 on page 135).
7.6 Data collection

The data collection strategy involved gathering data at different stages of the research process. Davidson and Kaszniak (2015) state deciding when to collect data and whether to include a follow-up period are important decisions for researchers. Data collection and follow-up decision-making was influenced by methodological and feasibility considerations (Davidson et al., 2015). Using frequent data collection and including a long-term follow-up increases methodological quality (Goldberg et al., 2017), but can also become burdensome and increase the risk of participant attrition (Davidson et al., 2015). The limited research using Be Mindful with stroke survivors (Singh, 2018) and the original nature of the research made choosing the best data collection strategy difficult.

Data collection involved both scheduled data collection at pre-determined times and automated data collection via Be Mindful at different stages in the process (Wellmind Media and Mental Health Foundation, 2019) (Table 21 on page 173). Scheduled data collection occurred at weeks zero (pre), four (post), and eight (follow-up) of the study. The data collection timing was intended to provide pre-test, post-test, and one-month follow-up data for each participant (n=10). This strategy was consistent with the recommended course duration for Be Mindful (Wellmind Media and Mental Health Foundation, 2019) and the data collection timing used in previous research (Krusche et al., 2012; Krusche, Cyhlarova and Williams, 2013). Although, research published after the data collection strategy was developed discovered participants can take more than eight weeks to complete Be Mindful (Querstret, Cropley and Fife-Schaw, 2018; Singh, 2018). The automated data collection embedded in Be Mindful gathered data at the start of the course, when all four modules were completed, and four weeks after the final module was completed. The Be Mindful data collection was non-mandatory and only activated when participants completed a certain number of modules (Wellmind Media and Mental Health Foundation, 2019).

Table 21: Data collection strategy

<table>
<thead>
<tr>
<th>Data</th>
<th>Measure</th>
<th>Method</th>
<th>Schedule</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic and stroke</td>
<td>Data collection sheet</td>
<td>Face-to-face</td>
<td>Week 0</td>
</tr>
<tr>
<td>Stress</td>
<td>Perceived Stress Scale (PSS)</td>
<td>Online</td>
<td>Automated pre, post, and follow-up</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------------------------------------------</td>
<td>------------</td>
<td>------------------------------------</td>
</tr>
<tr>
<td>Anxiety symptoms</td>
<td>Generalized Anxiety Disorder (GAD-7)</td>
<td>Online</td>
<td>Automated pre, post, and follow-up</td>
</tr>
<tr>
<td>Depression symptoms</td>
<td>Patient Health Questionnaire (PHQ9)</td>
<td>Online</td>
<td>Automated pre, post, and follow-up</td>
</tr>
<tr>
<td>Anxiety and depression symptoms</td>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>Face-to-face</td>
<td>Weeks 0, 4, and 8</td>
</tr>
<tr>
<td>Mindfulness</td>
<td>Mindful Attention Awareness Scale (MAAS)</td>
<td>Face-to-face</td>
<td>Weeks 0, 4, and 8</td>
</tr>
<tr>
<td>Mutuality</td>
<td>Mutuality Scale (MS)</td>
<td>Face-to-face</td>
<td>Weeks 0, 4, and 8</td>
</tr>
<tr>
<td>Experience</td>
<td>Semi-structured interviews</td>
<td>Face-to-face</td>
<td>Week 8</td>
</tr>
</tbody>
</table>

Key:
GAD-7=Generalized Anxiety Disorder (Spitzer et al., 2006); HADS=Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983); MAAS= Mindful Attention Awareness Scale (Brown and Ryan, 2003); MS=Mutuality Scale (Archbold et al., 1990); PHQ-9=Patient Health Questionnaire (Kroenke, Spitzer and Williams, 2001); PSS=Perceived Stress Scale (Cohen et al., 1983)

### 7.6.1 Recruitment data
Anonymous recruitment data was collected during the study. The recruitment data included the number of enquiries about the study and the number of participants enrolled into the study. This data helped establish the feasibility and appropriateness of online MBI for care partnerships living with stroke.

### 7.6.2 Background information
Sociodemographic and stroke related data were collected face-to-face after each care partnership consented to take part in the study. The information (e.g. age, gender, type of stroke) was collected at week zero using a data collection tool developed for the study (Appendix 13 on page 332) and before online MBI was commenced. The purpose of this data collection was to provide background information about the care partnerships and to help contextualise the findings (Section 8.1.1.1 on page 226). The data collection tool was reviewed by the PPI advisory group and the academic supervisory team before being used in the study.

### 7.6.3 Quantitative data collection
Quantitative data was collected face-to-face during home visits at week zero, week four, and week eight of the study. Quantitative data was collected using valid and reliable tools to measure whether participants experienced changes to
anxiety symptoms, depression symptoms, mindfulness, and mutuality. Heale and Twycross (2015) state validity and reliability should be considered when selecting quantitative data collection tools. Validity is concerned with whether the tool gathers useful data accurately (Parahoo, 2014). The validity of a data collection tools depends on whether it is accurate (content validity), whether it measures what it is meant to measure (construct validity), and how well it compares to similar measures (criterion validity) (Heale and Twycross, 2015). Reliability refers to whether the selected tool is able to consistently measure what it is supposed to measure (Parahoo, 2014). Reliability is determined by whether all items on the tool measure the same thing (internal consistency), whether the tool is consistent when used on different occasions (stability), or when it is used by different assessors (equivalence) (Heale and Twycross, 2015). The internal consistency is often evaluated using Cronbach’s alpha, with the threshold of 0.8 being considered acceptable for research tools (Streiner, 2003). Heale and Twycross (2015) suggest data collection tool stability should be measured using a correlation coefficient and the following thresholds: <0.3 (weak), 0.3-0.5 (moderate), and >0.5 (strong).

7.6.3.1 Hospital anxiety and depression scale

The primary data collection tool for measuring anxiety symptoms and depression symptoms was the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). The HADS (Zigmond and Snaith, 1983) is a measure for anxiety symptoms and depression symptoms, which has been used widely in hospital, out-patient, and non-clinical settings (Stern, 2014). It includes seven anxiety questions and seven depression questions (14 questions in total) and usually takes between 2-5 minutes to complete. The 14 questions ask about the preceding seven days and are rated on a four-point scale between zero (no difficulty) and three (maximum difficulty), which produces either a HADS total score (HADS-T 0-42) or sub-scale scores for anxiety symptoms (HADS-A 0-21) and depression symptoms (HADS-D 0-21) (Zigmond and Snaith, 1983). The HADS can indicate level of severity (8-10 mild, 11-14 moderate, and 15-21 severe) (Zigmond and Snaith, 1983) for anxiety symptoms and depression symptoms and/or provide a global score of psychological distress by combining the scores from the anxiety and depression sub-scales (Crawford et al., 2001).
The HADS (Zigmond and Snaith, 1983) is considered a valid and reliable measure for anxiety symptoms and depression symptoms (Bjelland et al., 2002; Sagen et al., 2009). It has a Cronbach alpha of 0.86 for HADS-T (Crawford et al., 2001), 0.83 for HADS-A, and 0.82 for HADS-D (Bjelland et al., 2002). The tool has also been validated with stroke survivors with a Cronbach alpha score of 0.91 for HADS-T, 0.89 for HADS-A, and 0.83 for HADS-D (Sagen et al., 2009). This reliability makes the HADS a reasonable option for assessing anxiety symptoms and depression symptoms (Kneebone, Baker and O’Malley, 2010; Burton, Tyson and Burton, 2015) and is an acceptable level for research purposes (Streiner, 2003).

An important function of the HADS is to screen for clinical levels of anxiety/depression and to differentiate between clinical and non-clinical cases (i.e. symptoms). Originally anyone with a total HADS-T score 19 or a sub-scale score 10 was considered to have clinically significant difficulties (Zigmond and Snaith, 1983). Although, a more recent literature review suggests 8 for HADS-A (sensitivity 0.90 specificity 0.78) and HADS-D (sensitivity 0.83 specificity 0.79) is optimum for a clinical cut-off when using HADS sub-scales (Bjelland et al., 2002). Whilst Sagen et al. (2009) recommends 11 for HADS-T (sensitivity 0.9 specificity 0.83), HADS-A 4 (sensitivity 0.83 specificity 0.65), HADS-D 4 (sensitivity 0.84 specificity 0.73) for stroke survivors.

The HADS (Zigmond and Snaith, 1983) is held under copyright by GL Assessment (2019), so permission to use the tool was secured before commencing the study. Each participant completed paper copies of the HADS (Zigmond and Snaith, 1983) at weeks 0, 4, and 8 of the research.

7.6.3.2 Mindful attention awareness scale

Participant mindfulness is thought to be an important mechanism for change with MBIs (Alsubaie et al., 2017), so it was important to attempt to measure mindfulness during the research. Measuring changes in mindfulness is challenging because of ambiguity about what mindfulness is and the variety of different tools available (Qu, Dasborough and Todorova, 2015) (Section 2.1.2 on page 39). The Mindful Attention Awareness Scale (MAAS) (Brown, Ryan and Dovidio, 2003) is a widely used measure to quantify mindfulness in research and clinical settings (Chiesa, 2013). The MAAS is a 15-item questionnaire for
measuring mindfulness and takes less than 10 minutes to complete (MacKillop and Anderson, 2007). Each of the 15 questions is scored using a 6-point Likert scale. The mean score for all 15 questions suggests an overall level of mindfulness, with higher scores indicating higher levels of mindfulness (MacKillop and Anderson, 2007).

MAAS is considered a valid and reliable tool for measuring mindfulness in students (Brown and Ryan, 2003) and cancer populations (Carlson and Brown, 2005), but has not been fully validated with stroke survivors. Internal consistency using Cronbach’s alpha varies between 0.82 (Brown and Ryan, 2003) and 0.89 (MacKillop and Anderson, 2007), which is satisfactory for research tools (Streiner, 2003). Qu, Dasborough and Todorova (2015) state the MAAS is one of the most valid and reliable mindfulness tools currently available, but further work is needed to help establish better tools and to help validate the tools in different clinical populations. The MAAS was used in this study because it is brief, easy to complete, and provides a general measure of mindfulness (Sauer, Walach and Schmidt, 2013). The MAAS was also a good choice because it has been used successfully with other studies investigating whether care partnerships experiences changes in mindfulness when using MBIs together (Birnie, Garland and Carlson, 2010; Van Den Hurk et al., 2015; Price-Blackshear et al., 2020). The feasibility nature of this study allows for the measure to be tested with stroke care partnerships, but formal validation was beyond the scope of the study (Patel and Joseph, 2016).

The MAAS (Brown and Ryan, 2003) is in the public domain and does not require permission to be used for research purposes. Each participant completed a paper copy of the MAAS (Brown and Ryan, 2003) at weeks 0, 4, and 8.

### 7.6.3.3 Mutuality scale

The focus on care partnerships in this study makes it important to measure interpersonal factors using the Mutuality Scale (MS) (Archbold et al., 1990). Mutuality refers to the quality of the relationship between the stroke survivor and their care partner (Archbold et al., 1990). The 15-item questionnaire considers four different elements of mutuality: love, shared pleasurable activities, shared values, and reciprocity. Each of the 15-items is scored using a 0-4 scale and the
mean average provides an overall score, with higher scores indicating greater mutuality (Archbold et al., 1990).

Pucciarelli et al. (2016) examined the psychometric properties of the MS tool for stroke survivors and their care partners. The MS tool demonstrates acceptable confirmatory factor analysis (CFI=0.94; RMSEA=0.06) for the four elements of mutuality included in the MS. Likewise, Cronbach’s alpha was calculated at >0.90, which suggests it is a suitable tool for measuring mutuality between stroke survivors and their care partners (Pucciarelli et al., 2016).

The MS (Archbold et al., 1990) is held under copyright by Wiley publishers, so permission was secured to use the tool for non-commercial academic use. Each participant completed a paper copy of the MS (Archbold et al., 1990) at weeks 0, 4, and 8 of the research.

7.6.4 Automated data collection

The Be Mindful (Wellmind Media and Mental Health Foundation, 2019) course collects pre/post-test and one month follow-up outcome data online using an embedded automated system. The online automated measures were the Perceived Stress Scale (PSS) (Cohen et al., 1983), the Generalised Anxiety Disorder (GAD-7) (Spitzer et al., 2006), and the Patient Health Questionnaire (PHQ9) (Kroenke, Spitzer and Williams, 2001). The automated measures were considered secondary measures because they are not recommended in clinical guidelines for assessing stroke survivor’s mood (Kneebone, Baker and O’Malley, 2010) and did not include measures for mindfulness or relationship factors.

The automated data collection experienced a large amount of missing data because not everyone completed all modules and some participants did not complete the data collection (Section 8.1.2.1 on page 230). Due to the high level of missing data with the automated data collection, a decision was made to not include the data in the analysis. This decision was taken because the lack of post-intervention data made it impossible to determine whether online MBI had produced an effect on outcomes (e.g. anxiety/depression symptoms). However, it is important to maintain transparency and the automatic data is reported in full (Appendix 14 on page 333) (Health Research Authority, 2019).
7.6.5 Missing data

Missing data is common in clinical research and can adversely affect results (Dong and Peng, 2013; Kaciroti, Kang and Little, 2015). The negative impact of missing data can result in less precise and/or biased results (Mavridis and White, 2019). When missing data is identified it is important to consider the nature and extent of missing data and to take steps to reduce any potential bias (Kaciroti, Kang and Little, 2015). Best practice for reporting missing data is to calculate the percentage of missing data and to report the extent of missing data in a study (Schlomer, Bauman and Card, 2005) (Table 31 on page 231). Although, there is no agreed threshold to determine whether the amount of missing data is acceptable in an individual study and variation can occur in how missing data is managed and reported (Dong and Peng, 2013).

Missing data can occur at a unit level (i.e. missing questionnaire) or item level (i.e. partially completed questionnaire) (Dong and Peng, 2013). When missing data is identified it is helpful to determine whether the data is missing completely at random (MCAR), missing at random (MAR), or missing not at random (MNAR) (Dong and Peng, 2013). Strategies for dealing with missing data include different types of deletion and/or imputation methods (Schlomer, Bauman and Card, 2005). Deletion methods involve removing participants with missing data completely from the study (i.e. list wise deletion), which will reduce the sample size and potentially introduce bias (Parent, 2012). Alternatively, deletion methods might retain a participant, but only use the available data (i.e. pairwise deletion) (Schlomer, Bauman and Card, 2005). This second form of deletion is sometimes called Available Item Analysis (AIA) and is a pragmatic solution for missing data (Parent, 2012). Imputation methods use different strategies to establish a plausible substitute for the missing data (Schlomer, Bauman and Card, 2005). Six common forms of imputation are: random selection, preceding question, question mean, individual mean, single regression, and multiple imputation (Shrive et al., 2006). Out of the different options, the most common methods for handling missing data are AIA (45%), simple imputations (27%), model based strategies (19%), and multiple imputation (8%) (Bell et al., 2014).
This study took a pragmatic approach to missing data and used a combination of deletion and imputation methods. Unit-level missing data was mitigated by using pairwise deletion (Schlomer, Bauman and Card, 2005), so only completed measures were included in the pre/post-test analysis. Pairwise deletion was used because it allows for all available data to be analysed, increases transparency, and promotes validity (Schlomer, Bauman and Card, 2005).

Item-level missing data mainly affected the MAAS (Brown and Ryan, 2003) and was classified as missing not at random (MNAR) (Section 8.1.2 on page 230). Working with data MNAR is difficult because many of the strategies used to resolve missing data are aimed at resolving issues with data MCAR and MAR (Schlomer, Bauman and Card, 2005). Making valid inference with data MNAR requires the researchers to consider the explanation for the missing data and/or making assumptions about the distribution of data (Ibrahim, Chu and Chen, 2012).

The MAAS (Brown and Ryan, 2003) (Section 7.6.3.2 on page 176) does not have any sub-scales and is calculated using a mean average. The structure and design of the MAAS (Brown and Ryan, 2003) makes it a possible candidate for mean imputation (Shrive et al., 2006). The amount of missing item-level data in the MAAS (Carlson and Brown, 2005) was over the 10% threshold recommended when using mean imputation (Section 8.1.2.2 on page 231) and creates a risk of bias (Lodder, 2013). However, mean imputation methods are used regularly in published research and provides a non-technical solution for dealing with missing item-level data (Parent, 2012; Bell et al., 2014).

The mean imputation method involved calculating a participant’s mean score for the completed questions on the questionnaire and then imputing the figure into the unanswered questions (Shrive et al., 2006). Mean imputation assumes participants score items consistently throughout a questionnaire, which is often the case with ordinal-scale tools like MAAS (Shrive et al., 2006). Although, this method assumes data are MCAR and can produce biased means when data are MAR or MNAR (Schlomer, Bauman and Card, 2005). However, evidence suggests mean imputation can be appropriate when working with item-level missing data and was a pragmatic solution (Shrive et al., 2006; Parent, 2012).
7.6.6 Qualitative data collection

The importance of collecting rich first-person accounts of the experience or phenomenon under investigation make in-depth semi-structured interviews an ideal choice for IPA researchers (Smith, Flowers and Larkin, 2009). A critical review examined data collection methods used in IPA studies (n=52) and revealed semi-structured interviews and open ended questions were the most common (Brocki and Wearden, 2006).

The purpose of the semi-structured interview was to establish a safe secure environment for stroke survivors and their care partners to discuss their experience of using online MBI. Active listening skills and a non-judgmental approach to interviewing helped facilitate the discussion and created a safe environment for the interviewees (Mavhandu-Mudzusi, 2018). The intention was to help the stroke survivor and their care partners tell their story and to provide a detailed account of what they experienced (Smith, Flowers and Larkin, 2009).

A single semi-structured interview was undertaken face-to-face during a home visit with each care partnership at week eight of the study. An important decision was whether to conduct interviews with the stroke survivors and their care partners together or separately. Individual interviews are popular and are consistent with the idiographic methodology of IPA (Smith, Flowers and Larkin, 2009). However, individual interviews can overlook the interpersonal features associated with people sharing experiences together (Bjornholt and Farstad, 2014). Interviewing stroke survivors and their care partners together helped facilitate analysis of both individual and shared experiences (Wawrziczny et al., 2016). It provided a common shared reflective space and facilitated production of rich data (Bjornholt and Farstad, 2014). Interviewing stroke survivors and their care partners together is appropriate for IPA and helped gather interpersonal data that may have been missed if interviewing people by themselves (Wawrziczny et al., 2016; Mavhandu-Mudzusi, 2018).

Advantages associated with interviewing stroke survivors and their care partners together include having two people present to recall events and explore their experience of using online MBI (Mavhandu-Mudzusi, 2018). This interaction helped interviewees corroborate each other’s experiences and prompt one another’s exploration of the topic (Bjornholt and Farstad, 2014).
Disadvantages of interviewing stroke survivors and their care partners together included the potential for one partner to dominate the other and for existing power imbalances to manifest themselves in the interview (Mavhandu-Mudzusi, 2018). Another concern is whether disagreement will occur during the interview and whether one person’s account might overshadow the other (Bjornholt and Farstad, 2014).

### 7.6.6.1 Interview schedule

The semi-structured interviews were completed with the aid of an interview schedule. A typical IPA interview schedule contains between 6-10 questions and is used to provide a loose structure for the interview (Smith, Flowers and Larkin, 2009). Developing an interview schedule for an IPA study in an iterative process and involves several steps (Smith, Flowers and Larkin, 2009). The initial stage involved reviewing the research questions and the range of topics being explored. Consideration was then given to how best to use open questions in the interview and the type of prompts needed to encourage in-depth exploration of the topic. Then the sequencing and phrasing of each question was considered to ensure and logical flow of clarity. Finally, the interview schedule was reviewed by the supervisory team and the PPI advisory group to check suitability of questions. This process achieved an interview schedule with eight questions (Table 22 on page 183).
### Table 22: Interview schedule

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of stroke</td>
<td>Can you tell me how stroke has affected your life?</td>
</tr>
<tr>
<td>Experience of the course</td>
<td>What has the experience of using the course been like?</td>
</tr>
<tr>
<td>Experience of mindfulness</td>
<td>What has the experience of learning mindfulness been like?</td>
</tr>
<tr>
<td>Experience of online</td>
<td>What has the experience of learning mindfulness online been like?</td>
</tr>
<tr>
<td>Experience of learning together</td>
<td>What has the experience of learning mindfulness together been like?</td>
</tr>
<tr>
<td>Psychological wellbeing</td>
<td>What changes (if any) have you noticed since learning mindfulness?</td>
</tr>
<tr>
<td>Research</td>
<td>What has the experience been like for you both to be involved in this research?</td>
</tr>
<tr>
<td>Anything else</td>
<td>Is there anything else you think is important that I have not asked about?</td>
</tr>
<tr>
<td><em>On average how much time have you spent practicing mindfulness</em></td>
<td></td>
</tr>
</tbody>
</table>

**Key**
- *Question added to schedule during the study*

Consideration was given to the best way of piloting the interview schedule. Some IPA researchers advocate for piloting interview schedules (Mavhandu-Mudzusi, 2018), whilst others suggest a more flexible and pragmatic approach to piloting interview schedules (Smith, Flowers and Larkin, 2009). The focus on using online MBI together and necessity of having two interviewees with appropriate lived experience made it difficult to pilot the interview schedule. Instead a pragmatic approach was taken and the interview schedule was piloted with the first participants and reviewed afterwards to see whether changes were required (Smith, Flowers and Larkin, 2009). After the first interview it was thought asking about the average amount of time spent practicing mindfulness would be useful, so an additional question was added to the schedule.

#### 7.7 Data analysis

The study aims were answered by integrating qualitative and quantitative data (Creswell and Clark, 2018). The process involved within case and cross-case
Table 23: Overview of analysis methods

<table>
<thead>
<tr>
<th>Questions</th>
<th>Data collection methods</th>
<th>Data analysis</th>
</tr>
</thead>
</table>
| **Is it feasible to study online mindfulness with stroke survivors and their care partners together in a care partnership?** | Recruitment data  
Outcome measure completion rates  
Monitoring adverse events  
Qualitative interviews | Mixed |
| **Do stroke survivors and their care partners find it appropriate to use online MBI together?** | Recruitment data  
Number of modules completed by each participant at weeks four and eight  
Qualitative interviews | Mixed |
| **Do stroke survivors and their care partners experience changes in mindfulness after using MBI together?** | Mindful Attention Awareness Scale (MAAS) completed weeks zero, four, and eight  
Qualitative interviews | Mixed |
| **Do stroke survivors and their care partners experience interpersonal changes after using MBI together?** | Mutuality Scale (MS) completed weeks zero, four, and eight  
Qualitative interviews | Mixed |
| **Does online MBI have the potential to reduce anxiety symptoms for stroke survivors and their care partners?** | Hospital Anxiety and Depression Scale (HADS) completed weeks zero, four, and eight  
Qualitative interviews | Mixed |
| **Does online MBI have the potential to reduce depression symptoms for stroke survivors and their care partners?** | Hospital Anxiety and Depression Scale (HADS) completed weeks zero, four, and eight  
Qualitative interviews | Mixed |

Key
HADS=Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983); MAAS=Mindful Attention Awareness Scale (Brown and Ryan, 2003); MS=Mutuality Scale (Archbold et al., 1990)

7.7.1 Quantitative analysis

Recruitment and retention data was collected to establish the feasibility of the study and the appropriateness of online MBI. The total number of inquiries, the total number of enrolments, and the drop-out rate were calculated. Recruitment data also provides information about why people making inquiries were not enrolled into the study and explains the reasons for drop-out during online MBI. The rate of recruitment was also calculated by dividing the number of complete enrolments by the number of months recruitment was taking place (Section 8.1.1 on page 225). The number of care partnerships recruited and the length of time taken to recruit was the primary measure of feasibility and appropriateness for the study. Recruitment was considered complete when the intended sample size of five care partnerships was achieved.
Sociodemographic and stroke related data were collected after consent and were analysed using descriptive statistics (Section 7.7.1.3 on page 187). The data was tabulated to describe individual participants and to illustrate the similarities and differences between participants. Cross-case analysis was completed by providing percentages, mean average, and data range for key sociodemographic information (Gerrish and Lathlean, 2015) (Section 8.1.1.1 on page 226).

The number of completed Be Mindful (Wellmind Media and Mental Health Foundation, 2019) modules was used to measure adherence. A systematic review evaluating adherence with online interventions found adherence was often calculated by measuring the number of completed modules in an intervention (Donkin et al., 2011). Individual adherence was calculated by analysing the number of modules (1-4) completed at weeks four and eight (Table 32 on page 233) of the study and by calculating a percentage. Cross-case adherence was measured using the mode average for stroke survivors and care partners and presented as a percentage.

The MAAS (Brown and Ryan, 2003) was the main measure for change in mindfulness, whilst the MS (Archbold et al., 1990) was used to measure mutuality (Section 7.6.3.3 on page 177). These measures were evaluating non-clinical phenomena, so there are no clinical thresholds for determining whether change was clinically important. The analysis of mindfulness and mutuality focused on whether there was a change and the direction of that change (e.g. increased, decreased, no change). Change in mindfulness and mutuality were determined through effect direction (Boon and Thomson, 2020) and both descriptive and inferential statistics (Parahoo, 2014) (Section 7.7.1 on page 184).

HADS (Zigmond and Snaith, 1983) data were analysed to evaluate whether online MBI reduced anxiety and depression symptoms for care partnerships living with stroke. Within and across case analysis was completed for each participant. Determining change in case studies is challenging with different approaches being available. A systematic review of N-of-1 trials (n=108) discovered using statistical cut-offs (49%), graphical presentation (25%), and clinical cut-offs (20%) were common methods for evaluating change (Gabler et
This study analysed HADS (Zigmond and Snaith, 1983) data using effect direction (Boon and Thomson, 2020), minimal clinically important difference (MCID) (Wright et al., 2012), visual analysis (McDonald et al., 2017a), and inferential statistical tests (Parahoo, 2014) (Section 7.7.1 on page 184). Full raw data are reported for each measure and all participants, which increases transparency (Health Research Authority, 2019) and facilitates future meta-analysis (Gabler et al., 2011).

### 7.7.1.1 Effect direction and minimal clinically important difference

Effect direction was used as a standardised metric with all validated measures. Effect direction helps determine the effect of an intervention and can be used with a wide range of measures and study designs (Campbell et al., 2020). Effect direction analysis involved determining whether change occurred and using the direction of effect to classify the change as either positive (i.e. things are better), negative (i.e. things are worse), or no change (i.e. things stayed the same) (Boon and Thomson, 2020).

Minimal clinically important difference (MCID) is an estimation of the least amount of change needed on a measure for some benefit to be experienced by participants (Puhan et al., 2008). This study used MCID to evaluate whether small changes in the HADS had any clinical benefit for participants (Lemay et al., 2019). There is much debate about the use of MCID and uncertainty about the best methodology for establishing an accurate MCID (Wright et al., 2012). A recent study formally established an MCID on the HADS (Zigmond and Snaith, 1983) for people with cardiovascular disease. The study triangulated distribution-based, anchor-based, and Delphi methodology to determine the MCID of >1.7 (Lemay et al., 2019). The MCID of >1.7 on either of the HADS anxiety or depression sub-scales was used to indicate effectiveness of online MBI for care partnerships experiencing anxiety symptoms and/or depression symptoms after stroke (Lemay et al., 2019).

### 7.7.1.2 Visual analysis

All available data is reported for each participant using raw data. The results are presented using tables and line graphs, which facilitates visual analysis and future meta-analysis (Evans et al., 2014). Visual analysis involves looking at graphed data to see whether change occurred and is used widely in case study
research (McDonald et al., 2017a). Visual analysis involves inspecting the graphed data to look for direction of change and the amount of change experienced by each participant (Kratochwill et al., 2010). Visual analysis is more accurate when the study collects multiple data points in each phase of the study (Kratochwill et al., 2010). This study only used three data points (i.e. one in each phase) for each participant, so the visual analysis should be interpreted cautiously.

7.7.1.3 Statistical analysis

Statistical tests were completed with stroke survivors and care partners for HADS (Zigmond and Snaith, 1983), MAAS (Carlson and Brown, 2005), and MS (Archbold et al., 1990). Statistical analysis was completed using IBM SPSS (IBM SPSS Statistics for Windows, version 25).

Descriptive statistics are used to understand the basic characteristics of the data set. Descriptive statistics can be divided into measures of central tendency, measures of variability, and measures of shape (McCarthy et al., 2019). This study used frequency, percentages, mean, mode, and standard deviation to understand and explain quantitative data (Halcomb, 2016). Hypothesis testing and inferential statistics are used to calculate $p$ values and to determine whether there was a statistically significant change to the measures used during the study. Hypothesis testing involved establishing the null hypothesis ($H_0$), an alternative hypothesis ($H_1$), and using a specific statistical test to calculate the $p$ value and deciding whether the null hypothesis should be accepted or rejected (Table 24 on page 187).

Table 24: Hypothesis testing

<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Null ($H_0$)</td>
<td>Online MBI does not change participant outcomes (e.g. anxiety symptoms and depression symptoms)</td>
</tr>
<tr>
<td>Alternative ($H_1$)</td>
<td>Online MBI does change participant outcomes (e.g. anxiety symptoms and depression symptoms)</td>
</tr>
</tbody>
</table>

Several different statistical methods can be used during hypothesis testing, depending on the data being used and the purpose of the test (Gerrish and Lathlean, 2015). Expert guidance was sought from a statistician when deciding on the most appropriate statistical test for the study. Following guidance from the statistician, hypothesis testing was completed using a Friedman’s Test on
stroke survivors, care partners, and the whole sample (MacFarland et al., 2016). The Friedman’s test helped establish whether change occurred during the study and whether the change was statistically significant. The Friedman’s Test is a non-parametric statistical test used when working with two or more related groups (Field, 2018). Friedman’s Test was chosen because of the small sample size, the repeated data points, and concern about whether data was normally distributed (MacFarland et al., 2016).

The statistical tests produce a $p$ values (e.g. 0.25), which indicate the probability of obtaining the study results, if the null hypothesis was true (Gerrish and Lathlean, 2015). A $p$ value is normally gauged against a pre-determined threshold, which is used to decide whether the finding is statistically significant and if the null hypothesis can be rejected (Parahoo, 2014). The $p$ value threshold of ≤0.05 is frequently used in biomedical literature (Chavalarias et al., 2016) and was used in this study to indicate statistical significance and to decide whether the null hypothesis can be rejected. Common criticisms of $p$ values include the focus on statistical significance (instead of clinical significance) and the arbitrary nature of the thresholds being used (Ou, Hall and Thorne, 2017). The limitation of hypothesis testing and $p$ values highlight the importance of using a broad range of analysis methods and reinforce the mixed methods approach to analysis used in this study (Gabler et al., 2011; Chavalarias et al., 2016).

Completing the Friedman’s test on stroke survivors, care partners, and the whole sample created a situation where multiple tests were being carried out on the same data. Conducting multiple statistical tests on the same outcome increases the Family-Wise Error Rate and risk of a type I error (i.e. a false positive) (Ranstam, 2016). For example, if two statistical tests are completed on the same outcome, with a significance level of 0.05, then the risk of finding a false positive increases to 0.098 (Vickerstaff, Omar and Ambler, 2019). The increased Family-Wise Error rate can be corrected by using the Bonferroni correction method (Dunn, 1961; White, van der Ende and Nichols, 2019). Calculating a Bonferroni correction involves either multiplying the $p$ value by the number of tests or dividing the significance level by the number of tests (Vickerstaff, Omar and Ambler, 2019). The Bonferroni correction is widely used, but divides opinion: some people argue it is unnecessary, whilst others believe
it should always be performed (Armstrong, 2014). The main concern with the Bonferroni correction is the fact it is a very conservative calculation and can increases the risk of type II errors (i.e. false negative) (Armstrong, 2014). A Bonferroni correction would have been used in this study if a statistically significant change ($p \leq 0.05$) was found because it addresses concerns about Family-Wise Error Rate (Vickerstaff, Omar and Ambler, 2019). This approach reduces the chances of making a type I error (i.e. a false positive) (Ranstam, 2016) and claiming something happened, when it was just a statistical artefact.

7.7.2 Qualitative analysis

Interpretative phenomenological analysis (IPA) (Smith, Flowers and Larkin, 2009) was used to explain the quantitative findings and explore the experience of participants involved in the research. Data analysis in IPA often takes an iterative process: becoming familiar with the data; making notes on the transcript; identifying emergent themes; reviewing the themes and checking for connections between themes; presenting the shared themes in an appropriate manner (Osborn and Smith, 1998; Biggerstaff and Thompson, 2008). Smith, Flowers and Larkin (2009) discourage people from taking a strict step-by-step approach to IPA, but instead recommend selecting the most appropriate strategies for a specific study. The analysis strategies used are detailed below (Table 25 on page 189) and were completed one case at a time to maintain an idiographic focus (Smith, Flowers and Larkin, 2009).

Table 25: IPA analysis strategies

| • Reading and explorative commenting |
| • Identify emergent themes |
| • Search for connections across themes |
| • Repeat the process with the next case |
| • Search for patterns across cases |
| • Use collaborators to review the coherence and plausibility of themes |
| • Write a detailed narrative of the analytic process and findings |

(Smith, Flowers and Larkin, 2009)

7.7.2.1 Reading and explorative commenting

The first stage involved transcribing the interview using a Microsoft Word and repeated reading of the transcript to become familiar with the content (Smith
and Osborn, 2008). This was followed by explorative commenting, which involved making descriptive, linguistic, and conceptual comments on the transcript (Table 26 on page 190). Descriptive comments described contextual information, linguistic comments focused on language used by participants, whilst conceptual commenting covered important theoretical and conceptual content in the transcript (Smith, Flowers and Larkin, 2009). Pietkiewicz and Smith (2014) suggest it is also useful to add reflections that occur during the process because these capture researcher reflexivity. The explorative commenting was also completed using Microsoft Word added to the original transcript to create a much larger data set for analysis (Smith, Flowers and Larkin, 2009). Explorative commenting is an important aspect of IPA and helps produce an initial interpretation of the phenomenon and helps situates the researcher within the analytic process (Smith and Osborn, 2008).

Table 26: Transcribing and explorative commenting (care partnership 3)

<table>
<thead>
<tr>
<th>Original transcript</th>
<th>Exploratory comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>B = Ben</td>
<td>Normal text = descriptive comments</td>
</tr>
<tr>
<td>S = Stroke survivor</td>
<td>Italics = linguistics comments</td>
</tr>
<tr>
<td>C = Care partner</td>
<td>Bold = conceptual comments</td>
</tr>
<tr>
<td></td>
<td>Underlined = researcher reflexivity</td>
</tr>
</tbody>
</table>

S. Aye, and that is quite hard, and… my life has change now… it was working for a year and I was getting better. But now, the last year, I know is [inaudible]… I can’t even talk all the time. It has changed, the first year I was getting better, plus over the years I am probably getting old anyway… tired and that now so. The last couple of months it has been really bad… tired. I don’t know I can’t really remember…

C. No I think that is about right.

Describing ups and downs of stroke recovery. Was making progress, but now appears to be struggling. Repeats that the first year he was getting better to stress point and to perhaps highlight how things have changed. Stresses how bad things have been over recent months. It was really disappointing to see him like this, because he had been doing so well at week four and was really bright in mood and using MBI. However, we had struggled to arrange the week eight meeting and it looks like he had deteriorated back to how he was when I first saw him. Stroke recovery is not liner and has ups and downs.

Caregiver corroborates situation.

7.7.2.2 Identify emergent themes

Most qualitative analysis software (i.e. NVivo) is not designed for explorative coding and many IPA researchers complete the whole process using paper/pens (Wagstaff et al., 2014). This study completed the explorative commenting using Microsoft Word (Table 26 on page 190) and imported the file into NVivo (QSR International) afterwards. Once the explorative commenting
was imported to NVivo (QSR International) the analysis process involved identifying emergent themes. This process involved working primarily with the explorative comments, but also remained close to the original transcript to retained the first person account of the experience (Smith, Flowers and Larkin, 2009). Identifying emergent themes involved looking at the data and conceptualising the phenomenon at a higher level of abstraction (Pietkiewicz and Smith, 2014). The constant moving between the whole transcript and explorative comments provides a good example of the hermeneutic cycle being used in IPA (Pietkiewicz and Smith, 2014).

**7.7.2.3 Search for connections across themes**

Identifying emergent themes produced a list of preliminary themes that mirrored the transcript (Smith and Osborn, 2008). These preliminary themes were reviewed and arranged into clusters and/or hierarchies to help organise the themes and make sense of how they fit together (Pietkiewicz and Smith, 2014). The process was completed using NVivo (QSR International) and involved visually inspecting the list and arranging the themes into a conceptually coherent framework (Figure 9 on page 192). Several different methods were used to help identify connections and relationships between the themes. Abstraction involved grouping similar themes together into larger clusters and polarization helped determine whether themes had any oppositional relationship with other themes (Smith, Flowers and Larkin, 2009). This analytic process created a series of themes and subthemes that were listed with relevant excerpts and transcript line numbers to facilitate transparency and help provide an audit trail (Pietkiewicz and Smith, 2014).
7.7.2.4 Repeating the process with next case

When moving from one case to the next it is important to decide whether to use the themes from the first case or whether to go back to the beginning of the analysis process with the new case (Smith and Osborn, 2008). In this study the cases were analysed one at a time because this is more consistent with the ideographic epistemology of IPA (Smith, Flowers and Larkin, 2009). After themes were developed for one case a different case was selected and initial reading and explorative commenting commenced with the new case. It was important to try and suspend or bracket any existing ideas and preconceptions about the new case, but inevitably the previous cases influenced the subsequent analysis (Smith and Osborn, 2008; Alase, 2017). This contradictory
process highlights the challenges of bracketing and why it can be a controversial topic in IPA (Biggerstaff and Thompson, 2008).

7.7.2.5 Search for patterns across cases

After all cases had been analysed individually a cross-case analysis was completed to identify similarities and differences between the cases (Smith and Osborn, 2008) (Figure 10 on page 193). This involved searching for superordinate themes that appear consistently in the data and across different cases (Biggerstaff and Thompson, 2008). Analysis was a continual process and further analysis occurred during the initial write up, when it became apparent that every theme had a counter theme or oppositional element (Smith, Flowers and Larkin, 2009). This discovering helped articulate the superordinate theme dialectical tension (Section 8.7 on page 242), which was used to illustrate the complexity within the findings (Fagerström and Bergbom, 2010). Dialectical tension is not always a feature of IPA, but was used in this study to capture the conflicting and sometimes contradictory findings from the study (Fagerström and Bergbom, 2010).

Figure 10: Searching for patterns across cases using NVivo

7.7.2.5.1 Dialectical tension

Clinical and social situations frequently involve conflicting or contradictory dimensions, which adds to the complexity of the phenomenon and makes them difficult to conceptualise (Fagerström and Bergbom, 2010). Theme development normally aims to assimilate ideas and perspectives into unified concepts and articulate them so others can understand (Parahoo, 2014). Frequently clinical settings and/or research produce heterogeneous findings, so assimilation would create an oversimplified interpretation and fail to capture the nuance and context associated with the complex phenomenon (Clark et al., 2012).
Dialectics allow for complex contradictory phenomenon to be articulated and has been used successfully in IPA (Smith, Flowers and Larkin, 2009) studies to interpret the experience of parenting a child during surgery (David Vainberg, Vardi and Jacoby, 2019). Dialectics have also been used in IPA (Smith, Flowers and Larkin, 2009) to understand the experience of living with, and receiving treatment for a mental health difficulty (Murphy and Perera-Delcourt, 2014). The final IPA themes were articulated using dialectical tension because it captured a range of experiences, the complexity of the phenomena, and the nuance associated with care partnerships using online MBI after stroke (Figure 20 on page 243).

7.7.2.6 Collaborators review coherence and plausibility

Academic supervisors and a PPI advisory group reviewed the themes and provided feedback on the coherence and plausibility of the findings (Smith, Flowers and Larkin, 2009). This process provided valuable peer-review by academics and people with lived experience of stroke and/or using mindfulness.

7.7.2.7 Write narrative of the findings

The final report was written so each theme was described, contextualised, and supported by participant excerpts from the transcript (Pietkiewicz and Smith, 2014). It was important to use participant excerpts so readers can make their own judgements about the analysis and to retain the participant’s voice in the report (Smith, Flowers and Larkin, 2009). The themes are presented using a narrative summary of the analytic process and with a detailed interpretation of the findings (Pietkiewicz and Smith, 2014).

7.8 Data integration

A necessary element of mixed methods research is the integration of quantitative and qualitative data (Ivankova, Creswell and Stick, 2009). Mixed methods integration can involve data transformation (i.e. converting one form of data to another); visual presentation (i.e. joint displays); following a thread (i.e. use one data set to explore the other); and triangulation (i.e. checking for convergence or divergence between different data) (Johnson et al., 2017).
Quantitative and qualitative components in this study were integrated at a design, methods, interpretation, and reporting level (Guetterman, Fetters and Creswell, 2015). This study used mixed methods case study research and an explanatory sequential design (Creswell and Clark, 2018). When using mixed methods case study research the purpose of data integration is to provide a comprehensive understanding of the case (or cases) being investigated (Yin, 2018). This was achieved by analysing the quantitative and qualitative data separately and then combining the findings to understand the outcomes and experiences of each case. Then cross-case analysis was undertaken to identify similarities and differences between cases (Creswell and Clark, 2018).

The explanatory sequential element of the design resulted in the quantitative data being collected and analysed before the qualitative data (Creswell and Creswell, 2018). The research methods encouraged quantitative and qualitative data to be linked at different stages of the research process. Methods integration occurred when each participant provided quantitative and qualitative data (connecting); when quantitative findings informed the qualitative data analysis (building); and when both sets of data were brought together to help understand each case (merging) (Guetterman, Fetters and Creswell, 2015).

The quantitative and qualitative data was integrated during the interpretation and reporting of the study. Creswell and Clark (2018) believe narrative discussion provides a useful way of interpreting different forms of data in mixed methods research. Narrative discussion is the primary method of integration in this study, but was used in conjunction with a joint display (Fetters, Curry and Creswell, 2013). Johnson et al. (2017) states joint displays provide an essential tool for mixed methods researchers to present their findings and demonstrate the integration of quantitative and qualitative data. The integrated findings were presented in a joint display using a side-by-side comparison table (Table 37 on page 262), which helps illustrate the analysis and shows the added value to mixed methods integration (Guetterman, Fetters and Creswell, 2015).

7.9 Research quality and rigor

Research quality is determined by whether findings are valid and reliable (Noble and Smith, 2015). Validity considers whether outcomes can be attributed to the
independent variable (internal validity) and whether the findings can be
generalised to other situations or context (external validity) (Parahoo, 2014).
Reliability refers to whether the methods used are consistent and if the research
could be reproduced in a different context (Noble and Smith, 2015). Qualitative
researchers often prefer to think of quality in terms of credibility, transferability,
dependability, and confirmability (Lincoln and Guba, 1986). The concepts used
to evaluate qualitative research share similarity with quantitative validity
(credibility), external validity (transferability), reliability (dependability), and
objectivity (confirmability) (Tobin and Begley, 2004), but better reflect the
philosophical perspectives of qualitative research (Lincoln and Guba, 1986).
Onwuegbuzie and Johnson (2006) argue mixed methods researchers require a
different criteria for evaluating quality and suggest legitimation should be used
instead of validity. Legitimation is preferred for mixed methods research
because it considers the study holistically and provides an acceptable term for
mixed methods researchers (Onwuegbuzie, Johnson and Collins, 2011).

The study was mixed methods case study research and combined an initial
quasi-experimental phase with a secondary qualitative phase. The initial quasi-
experimental phase was weighted less than the qualitative phase and was
primarily used to identify suitable participants with the necessary lived
experience of using online MBI in a care partnership (Mayoh and Onwuegbuzie,
2015). The quasi-experimental phase is vulnerable to different threats to
validity, which can bias the results and jeopardise the research (Flannelly,
Flannelly and Jankowski, 2018). Threats to validity are particularly important in
this explanatory sequential study because the intention is to explain whether
change occurred and whether the change had potential therapeutic benefit (Yin,
2018).

Threats to validity for mixed methods case study design include not giving
enough attention to core research design (e.g. explanatory sequential), poorly
defining the cases, lack of integration of data, and little cross-case analysis
(Creswell and Clark, 2018). These threats to validity were mitigated by being
explicit in the use of explanatory sequential core design, clearly defining the
cases, being transparent about data integration, and completing cross-case
analysis. Further attempts to promote validity include using: multiple sources of
evidence (construct validity), explanation building (internal validity), replication
logic (external validity), using a case study protocol (Parkinson et al., 2018b), and providing evidence of an audit trail (reliability) (Yin, 2018). The main threats to validity with explanatory sequential designs come from not identifying or explaining important quantitative findings and not connecting the qualitative data to the quantitative data (Creswell and Clark, 2018). Several factors were used to facilitate the identification and explanation of interesting quantitative findings. These included using validated data collection tools to gathered data at different time points and analysing data on an individual basis (Creswell and Clark, 2018).

Evaluating quality of mixed methods research can involve using generic checklists, evaluating individual qualitative/quantitative components, and/or using criteria to holistically evaluate the whole study (Younas, Rasheed and Zeb, 2020). The evaluation of quality used a combination of methods: Mixed Methods Appraisal Tool (MMAT) (Nha Hong et al., 2018); Yardley's (2000) criteria for evaluating qualitative research; and the legitimation framework for mixed methods research (Onwuegbuzie and Johnson, 2006b).

The Mixed Methods Appraisal Tool (MMAT) (Nha Hong et al., 2018) is a generic checklist developed to evaluate mixed methods research. The MMAT consists of two screening questions followed by up to 15 other questions, which vary depending on the type of quantitative methods used (e.g. randomised, non-randomised). Scoring the MMAT is discouraged and instead each criteria should be considered and/or discussed separately (Nha Hong et al., 2018). The MMAT is an efficient and reliable tool for appraising mixed methods research (Pace et al., 2012), which has been updated recently to improve reliability (Queiroga Souto et al., 2015; Nha Hong et al., 2018).

The IPA phase of the study uses rich data and employs detailed interpretation to focus on the particular (Smith, 2011). The subjective and contextual nature of IPA makes assessing quality difficult (Leung, 2015). It is recommended IPA be evaluated using broad criteria specific to qualitative methodology (Smith, Flowers and Larkin, 2009). Yardley's (2000) criteria for evaluating qualitative research is the preferred method of evaluating IPA (Smith, Flowers and Larkin, 2009) and was used to provide a detailed evaluation of the qualitative component in this study. The Yardley (2000) criteria for evaluating IPA covers
four broad areas of sensitivity to context, commitment to rigour, transparency and coherence, and impact/importance. Sensitivity to context ensures the research is situated in the real-world and takes account of differing contextual factors that might influence the research (Smith, Flowers and Larkin, 2009). Commitment and rigour refers to the necessary engagement, thoroughness, and competence needed by researchers to produce good qualitative research (Yardley, 2000). Transparency and coherence relates to the importance of having an open and clearly presented research report available for others to read and appraise (Smith, Flowers and Larkin, 2009). Impact and importance is arguably the most important criteria used to judge research and is determined by the usefulness (or otherwise) of the research (Yardley, 2000).

The final method of evaluation used was the legitimation framework (Onwuegbuzie, Johnson and Collins, 2011). The legitimation framework integrates existing typologies for evaluating mixed methods research (Greene, 2006; Onwuegbuzie and Johnson, 2006b) and specifies criteria for establishing the validity and rigour of mixed methods research (Onwuegbuzie, Johnson and Collins, 2011). The legitimation framework is used to establish philosophical and methodological validity and can be applied to different mixed methods research designs (Younas, Rasheed and Zeb, 2020). Establishing legitimation is a continuous and iterative process and can be demonstrated using a variety of different strategies and at different stages of the research process (Onwuegbuzie, Johnson and Collins, 2011; Younas, Rasheed and Zeb, 2020). The results of the quality appraisal are fully reported in the strengths and limitations sections of the thesis (Section 9.7 on page 289).

7.10 Patient and public involvement

Patient and public involvement (PPI) refers to research carried out in partnership with people with chronic conditions and/or the public (INVOLVE, 2018). Brett et al. (2014) reviewed PPI and discovered a number of benefits, including person-centred research objectives, improved participant documentation, better recruitment, and enhanced dissemination. PPI is an important aspect of research, but does create several practical and ethical dilemmas (Parkinson, Lawrence and Booth, 2020). During the PhD the author and academic supervisors published a peer-reviewed paper discussing the
practical and ethical dilemmas associated with PPI. An accepted authors’ manuscript is provided in the appendix (Parkinson, Lawrence and Booth, 2020).

Hoddinott et al. (2018) suggests PPI should be voluntary, non-burdensome, inclusive, properly compensated, and involve true partnership working. However, PPI is often criticised for being tokenistic and superficial (Ocloo, Matthews and Mathews, 2016). PPI can also be poorly reported, which makes it difficult to know what occurred and whether it influenced the study (Brett et al., 2017). A study by Price et al. (2018) examined PPI reporting in research papers (n=152) published in the BMJ between 2015-2016. The study found low levels (n=16, 11%) of reporting, despite authors being told to report PPI activity (Price et al., 2018). Poor reporting of PPI is also a feature of IPA research, which to date has provided little evidence of meaningful PPI (Larkin and Thompson, 2012). Importantly, this PhD study uses a recognised PPI reporting framework to report the PPI that occurred within the study. It is hoped reporting PPI transparently will add to the PPI literature and provide an original real-world example of PPI in a study using IPA (Larkin and Thompson, 2012).

The Guidance for Reporting Involvement of Patients and the Public (GRIPP2) short form (Staniszewska et al., 2017) was developed specifically to improve consistency and transparency of PPI reporting. The GRIPP2 short form is divided into several different sections: aim, methods, results, discussion, and reflections (Staniszewska et al., 2017). This study will use the GRIPP2 (Staniszewska et al., 2017) to report how, when, and to what extent PPI contributed to the study.

7.10.1 Aim

To establish an advisory group to guide development, implementation, and dissemination of a PhD study investigating online mindfulness for people affected by stroke.

7.10.2 Methods

The methods section provides a summary of how, when and to what extent PPI was used in the study (Staniszewska et al., 2017). The advisory group was formed in September 2018 and continued until September 2020. The advisory group was created after the systematic review was completed and whilst the
study protocol was being developed. Recruitment began by using local stroke networks to reach people affected by stroke who might be interested in forming an advisory group. This strategy relied on the distribution of an invitation letter and attracted one person. The slow response prompted a review of recruitment and the decision to advertise using People in Research (2019) and to offer a financial incentive (£50 voucher). The financial incentive was less than recommended for PPI (INVOLVE, 2018), but did show appreciation for the work of the advisory group and was provided in the context of an unfunded study.

The advisory group was geographically dispersed and communicated via phone and/or email. Interaction with the advisory group was flexible and involvement of individual members varied depending on their availability and/or health issues. It was important to be flexible and understanding with PPI members because they may be experiencing stroke-related difficulties or other problems (Johnson et al., 2020). The advisory group was consulted at different times during the study and received occasional progress updates.

7.10.3 Results

The results section reports the positive and negative outcomes of the PPI (Staniszewska et al., 2017). The recruitment strategy achieved an advisory group consisting of stroke survivors (n=4, 67%) and care partners (n=2, 33%). Some PPI members had experience using mindfulness (n=3, 50%), some had PPI experience (n=3, 50%), and the group contained a couple in a stroke care partnership (n=1, 17%). PPI members came from different parts of the United Kingdom (n=5, 83%) and Germany (n=1, 17%). The group remained consistent during the study, but sadly reduced to four members after one of the PPI members died and their partner decided to leave the group.

The first contact focused on recruiting people to the advisory group and establishing a working relationship. The advisory group included people (n=2, 33%) with significant experience in PPI, so this contact enabled them to share their expertise on the subject. Specific examples of the contribution made by the advisory group at this stage was raising awareness of the importance of regular communication/updates and the value of using a reporting framework to document PPI activity. An advisory group member recommended using the
GRIPP2 reporting guidelines to document PPI activity and this recommendation was incorporated into the thesis (Staniszewska et al., 2017).

The second contact with the advisory group occurred early in the process and involved reviewing the study protocol and documentation. The advisory group (n=6, 100%) provided feedback on the study design and accessibility of the participant documentation. PPI members have not given permission to share their comments, but their suggestions focused on improving the clarity of the participant information sheet and questioned the necessity of gathering certain information. The advisory group also identified some grammatical errors and the fact the wrong contact details were provided on the expression of interest form. This feedback from the advisory group reinforced the importance of the work, but also made the project more accessible to potential participants.

The third contact with the advisory group consisted of reviewing preliminary findings. Fewer PPI members participated (n=1, 17%) in this stage and the feedback focused on whether lay people would be able to understand the outcome measures used (e.g. Hospital Anxiety Depression Scale) or if alternative ways of presenting findings were needed. This discussion highlighted the importance of using both visual and numerical data when reporting findings and was incorporated into the thesis (Parahoo, 2014).

The fourth contact with the advisory group happened towards the end of the study and focused on the final results and plain language summary. Two (n=2, 33%) advisory group members provided feedback at this stage. Again the advisory group highlighted ways to improve the readability of the plain language summary, but no formal evaluation of readability was completed. In hindsight it would have been useful to formally evaluate (e.g. Flesch-Kincaid Grade Level) the readability of the text and measure the impact of suggested changes. PPI members also commented on the lack of diversity within the participant group and suggested several changes to the summary. The most important suggested change to the plain language summary was to add something about the role of patient and public involvement in the study. All the suggested changes were incorporated and the plain language summary was improved through feedback from the advisory group (Plain language summary on page 3).
The advisory group was discontinued in September 2020. The decision to discontinue the advisory group was made because it had been in existence for two years and the study had been completed. Another consideration was payment and wanting to ensure advisory group members received their £50 voucher for their involvement. Discontinuing the advisory group provided closure for the PPI members and provided an opportunity to thank them for the involvement and contribution with the study. After discontinuing the advisory group, two members have remained in contact with the author and occasionally share information about their other PPI activity (Section 7.10.5 on page 205).

7.10.4 Discussion

The discussion section will consider the nature and extent of PPI and how it influenced the study (Staniszewska et al., 2017). Evaluating PPI can sometimes focus too heavily on effectiveness and whether the PPI activity achieved certain predefined outcomes (e.g. recruitment) (Staley and Barron, 2019). However, it is important to consider the varied ways PPI might influence a study and look beyond objective evidence and include experiential knowledge (Staley, 2015).

There are different ways of clarifying and categorising the nature and extent of PPI (Smits et al., 2020). Ives, Damery and Redwood (2013, p. 182) differentiate between transactional and cooperative PPI and suggest PPI can be either a “means to an end” or an “end in itself”. Thinking critically about PPI in this study, it could be argued that PPI was undertaken as a “means to an end” as it involved consultation by invitation rather than true partnership working. It would have been better to involve PPI members sooner and have them more involved with decision-making or other activities (Smits et al., 2020).

Recently the involvement matrix (Smits et al., 2020) has been developed to accurately determine the role of PPI. The involvement matrix was used retrospectively to articulate when (e.g. preparation, execution, implementation) and how (e.g. listener, co-thinker, advisor, and decision maker) PPI was undertaken in the study (Smits et al., 2020). Using the involvement matrix (Smits et al., 2020) shows PPI was used at every stage of the study and involved PPI members being co-thinkers/advisors. Using the involvement matrix (Smits et al., 2020) highlights how the advisory group could have played a greater role in the study and been partners and/or decision-makers. Although, it
is important to value every level of involvement and not to assume one level of involvement is better or worse than another.
### Table 27: Involvement matrix

<table>
<thead>
<tr>
<th>Stage of research</th>
<th>Role</th>
<th>Listener</th>
<th>Co-thinker</th>
<th>Advisor</th>
<th>Partner</th>
<th>Decision maker</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preparation</strong></td>
<td></td>
<td>Review study protocol</td>
<td></td>
<td>Give advice on study protocol</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Review participant documentation</td>
<td></td>
<td>Give advice on appropriateness of participants documentation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discuss PPI activity</td>
<td></td>
<td>Make recommendations about PPI activity (e.g. GRIPP2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Execution</strong></td>
<td></td>
<td>Review preliminary results</td>
<td>Review and comment on results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Review final results</td>
<td>Review and comment on results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Implementation</strong></td>
<td></td>
<td>Review lay summary</td>
<td>Read and give thoughts of lay summary content and tone.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

(Smits et al., 2020)
A crucial element of PPI is finding the ‘right’ people with the right experience (Johnson et al., 2020). The recruitment was successful in attracting sufficient PPI members and attracted people with a broad range of stroke, mindfulness, and PPI expertise. Having PPI members with knowledge and experience of PPI was a real asset and helped the PPI have greater impact. The advisory group influenced the study in a number of different ways and made a positive contribution to the study.

The advisory group used their experiential knowledge of living with stroke to ensure the research aims/design were appropriate. Providing guidance on research topic and study design is a common aspect of PPI and was an important contribution to this study (Staley, 2015). Feedback from the advisory group about the value and appropriateness of the study provided important quality assurance for the study and gave confidence that the work was going to be of value for people. Another common contribution of PPI is to provide guidance and support with participant documentation (Staley, 2015). The advisory group reviewed all participant documentation to ensure the wording and presentation was appropriate for the intended audience.

An unanticipated influence of the advisory group was receiving support and encouragement with PPI. The advisory group recommended reporting using the GRIIPP2 framework and advised the role PPI be mentioned in future dissemination (Staniszewska et al., 2017). Other examples include members of the advisory group sharing their knowledge of PPI and providing links to papers they have published on PPI evaluation (Johnson et al., 2020). The advisory group added value and was sustained throughout the study, however, the involvement does appear to have tapered down towards the end. During the first two phases with the advisory group all members contributed, but this became less as the study progressed. Contact with the advisory group was sporadic at times and this might have contributed to the amount of contribution towards the end of the study.

### 7.10.5 Reflections

This section will critically evaluate the role of PPI and articulate any learning from the experience (Staniszewska et al., 2017). PPI was initially thought to be a tool to use in the study, but this conceptualisation changed to thinking of PPI
as a meaningful dialogue between different parties and with a focus on learning (Staley and Barron, 2019). Key learning from this project includes the importance of PPI and a realisation that it could have played a more significant role in the study. On reflection, it would have been better to establish a PPI advisory group sooner and have them involved during the systematic review. PPI can make a positive contribution to systematic reviews and should be involved from the start of a review and remain involved throughout the review process (Pollock et al., 2021). However, limited money and/or time pressures often means PPI does not occur in systematic review (Boote, Baird and Sutton, 2011). Limited money and time pressure were certainly factors in this study, but a lack of understanding and awareness about the value of PPI in systematic reviews was the main reason.

PPI played an important role in the study, but evaluating the contribution using the involvement matrix (Smits et al., 2020) revealed PPI could have been more meaningful. Initial attempts at PPI can be difficult because the trusting relationships necessary for meaningful PPI have yet to be established (Hahn et al. 2016). Developing a relationship with PPI members is an essential element of meaningful PPI (Johnson et al., 2020), but it is possible this is something that occurs gradually over a period of time and/or a number of studies. This particular experience of PPI occurred as a novice researcher, without PPI training, and within the context of an unfunded PhD. This experience has facilitated contact with a group of individuals who will remain an important connection throughout my career. Evidence of the continued involvement includes maintaining contact with one of the PPI members who shares their published work on PPI (Johnson et al., 2020).

7.11 Research ethics

Research involving human participants must consider research ethics and seek ethical approval (Health Research Authority, 2017). Several important research ethics frameworks exist to improve the ethical governance of research involving human participants. The Declaration of Helsinki (World Medical Association, 2013) recommends all research involving human participants is reviewed by an independent review board (an ethics committee), is carried out on the basis of informed consent, and any potential harms do not exceed the possible benefits
for the research. The Belmont Report (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979) also sets out key principles for research involving human participants: respect the person (autonomy), beneficence (participant welfare), non-maleficence (do no harm), and justice (fairness). These overarching principles can be demonstrated in different ways: seeking informed consent (respect the person), evaluating the harms and benefits of the research (beneficence/non-maleficence), and fair recruitment (The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979).

These internationally recognised frameworks provide guidance for researchers, but ethical research is also governed by professional and organisational regulation. Researcher integrity and professionalism was maintained by being accountable to the Nursing and Midwifery Council (NMC) Code (Nursing and Midwifery Council, 2018) and adherence with the Glasgow Caledonian University’s research policies (Glasgow Caledonian University, 2015b). The standards and expectations of ethical research practice were maintained and monitored through regular contact with the supervisory team and in accordance with the Glasgow Caledonian University guidelines for research student supervision (Glasgow Caledonian University, 2015a). An important part of the research governance process was seeking ethical approval.

### 7.11.1 Ethical approval

The type of ethical approval required for a study depends on whether it is research and whether it involves the NHS (George, 2016). These questions were answered using Health Research Authority guidance (Health Research Authority, 2017; Health Research Authority, 2018), which helped determine the study was research and did not required NHS research ethical approval. Having decided the project was research and did not need NHS ethical approval, it was important to seek ethical approval from Glasgow Caledonian University. Seeking ethical approval was complicated because the thesis author (Ben) is the chair for the Nursing Department ethics committee, so it was necessary to avoid any possible conflict of interest and have the application reviewed by another department. A copy of the protocol (Appendix 5 on page 311) was submitted for independent scrutiny by the Psychology, Social Work and Allied
Health Sciences ethics committee at Glasgow Caledonian University. After revisions to the research ethics application approval was granted (HLS/PSWAHS/17/293) in November 2018 (Appendix 6 on page 317). Minor amendments were later submitted for ethical approval in February 2019. The minor amendments were to widen the recruitment to include Northern England and to use public posters to aid recruitment to the study. The minor amendments were approved by in February 2019 (Appendix 7 on page 318).

7.11.2 Ethical considerations

The main ethical considerations will be presented using the research ethics toolkit (Li et al., 2016). The ethics toolkit (Li et al., 2016) was developed to establish a framework to use when writing (or reviewing) applications to research ethics committees. The ethics toolkit helps identify possible ethical dilemmas with research projects and improves transparency in the review process. Eleven items are covered by the ethics tool kit and will illustrate how this study was conducted ethically (Table 28 on page 208).

Table 28: Ethics toolkit

<table>
<thead>
<tr>
<th>Addressing relevant questions</th>
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<td>Choice of control and standard of care</td>
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<td>Potential benefits and harms</td>
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7.11.2.1 Addressing relevant questions

Ethical research should be socially, theoretically, and scientifically justified (Li et al., 2016). This research is socially justified because it aligns with stakeholder priorities (Cowan and Oliver, 2013). Pollock et al. (2014) completed a consensus study with stroke survivors, care partners, and health professionals to determine research priorities. The priorities established included helping people living with stroke and dealing with the secondary consequences of
stroke. Similarly, stroke nursing research priorities have also been established and include managing altered mood after stroke, improving self-management after stroke, and helping stroke survivors and their care partners come to terms with the uncertainty of living with stroke (Rowat et al., 2016). Alignment with these priorities ensures the research is consistent with the wishes of key stakeholders and makes the research socially justified.

The ethical justification for this research was strengthened further by completing the systematic review into MBIs for people living with long-term conditions and their care partners (Parkinson et al., 2019). The systematic review highlighted a theoretical model for people learning mindfulness together (Smith et al., 2015) and identified a lack of research with people affected by stroke using MBI together (Parkinson et al., 2019). Therefore, the systematic review provides a theoretical and scientific justification for the current research.

7.11.2.2 Choice of control and standard of care

The choice of control arm and the standard of care for any comparator group needs to be fully explained and ethical (Li et al., 2016). This study used mixed methods case study research and did not have either a control or comparator group (Yin, 2018). Part of the rationale for choosing this research design was to reduce the ethical concern associated with control groups and the necessity to withhold a potentially effective intervention from those participants (Craig et al., 2008). Not using an control group does create a methodological weakness, but is common with mindfulness research (Goldberg et al., 2017) and is consistent with case study research (Yin, 2018).

7.11.2.3 Choice of study design

Choosing the most appropriate study design is an important ethical consideration. The primary concern is whether the study design is able to answer the research questions and whether the design is appropriate (Li et al., 2016). The research questions posed and the design choice align with complex intervention literature (Pearson et al., 2005; Craig et al., 2008) and is appropriate for the stage of development. The design was chosen because it provides a pragmatic solution for a complex area of study (Section 6.5 on page 142).
Li et al. (2016) states another important ethical consideration is whether the data collection strategy is excessively burdensome for research participants. The concern about the data collection burden is particularly important in stroke research because 25-85% of stroke survivors experience fatigue (Cumming et al., 2016). Concern about data collection burden prompted a major revision in this study design in 2018, when a decision was taken to not collect weekly time-series data and use a pre/post strategy instead. This revision is documented transparently in the prospective registration and demonstrates how ethical decision-making evolved during the design process (Parkinson et al., 2018b).

### 7.11.2.4 Choice of study population

Li et al. (2016) states the choice of study population needs to be clearly articulated and ethically justified. The complex health difficulties experienced by people affected by stroke can make it difficult to recruit the right participants in sufficient numbers (Singh, 2018). Concern about the health of participants can also result in researchers becoming paternalistic, which can hamper recruitment and/or alter the representativeness of the participants (Boxall, Hemsley, and White 2016). These issues were resolved by having realistic inclusion/exclusion criteria (Table 18 on page 160) and by accommodating participant’s health needs and schedules (Hadidi et al., 2012). Furthermore, initial difficulties recruiting participants prompted a minor amendment to the research protocol and the decision to widen recruitment to allow people from northern England to participate.

### 7.11.2.5 Potential benefits and harms

Ethical research requires for the potential benefits of the research to exceed any potential harms (Li et al., 2016). The main benefit for participants was free access to Be Mindful (Wellmind Media and Mental Health Foundation, 2019), which has a value of £30 per person. MBIs have been shown to have biopsychosocial benefits for stroke survivors (Lawrence et al. 2013) and care partners (Li, Yuan, and Zhang, 2016). Be Mindful (Wellmind Media and Mental Health Foundation, 2019) has been evaluated and found to produce significant improvement in stress, anxiety symptoms, and depression symptoms for participant’s post-intervention and at one-month follow-up (Krusche, Cyhlarova, and Williams, 2013). However, there is a lack of evidence for people affected by
stroke (Singh, 2018). Although, some online MBIs have been evaluated with stroke survivors and found to produced positive psychological benefits for participants (Johansson, et al. 2015).

The potential harms associated with the research include possible adverse events or unpleasant side-effects related to the intervention. Mindfulness is sometimes thought to be a risk free intervention, but evidence suggestions unwanted side effects can occur (Baer et al., 2019). Be Mindful (Wellmind Media and Mental Health Foundation, 2019) has few reported adverse events, but the possibility could not be fully ruled out. Therefore, it was necessary for information about possible risks to be included in the participant information sheet (Appendix 10 on page 325) and for any adverse events to be properly reported (Section 8.1.3 on page 232).

The research process can also be a source of potential harm due to distressing information being shared and/or loss of personal information (Mealer and Jones, 2014). In this study participants were required to undertake a potentially sensitive post-intervention interview and provide personal information. Stroke survivors were asked to review the interview guide before it was used to reduce the chances of the interview questions being intrusive or challenging. The potential for emotional distress was mitigated further by having interviews completed by a registered mental health nurse (Ben) who has experience conducting research interviews (Parkinson and Marks, 2017) and working with people experiencing emotional distress (Thesis author on page 21). This background experience ensured the interviewer was able to monitor emotional expression during the interview and respond appropriately to any signs of distress (Dempsey et al., 2016). Although, it was also necessary to navigate the dual role of nurse/researcher by maintaining clear boundaries and being explicit about my status as a student researcher during the interviews (Judkins-Cohn et al., 2014).

With regards personal information, it was necessary to protect participants against any harm caused by data breaches (George, 2016). This involved making sure research data management was concordant with data protection legislation (Home Office, 2018) and Glasgow Caledonian University policies and procedures (Glasgow Caledonian University, 2015b). This commitment was
complicated by the introduction of the General Data Protection Regulation (European Parliament, 2016) in 2018, which changed the legal basis for processing data and strengthened research participants rights (Chassang, 2017). Alignment with these legal requirements is evidenced in the research protocol (Appendix 5 page on 307) and participant information sheet (Appendix 10 on page 325).

Participant anonymity and confidentiality were key strategies to mitigate the possible harm caused by loss of personal data. All feasible steps were taken to maintain participant anonymity and confidentiality, however, this was complicated because the research was delivered in partnership between Be Mindful (Wellmind Media and Mental Health Foundation, 2019) and Glasgow Caledonian University. Be Mindful (Wellmind Media and Mental Health Foundation, 2019) were responsible for online data and used a cloud-based system that is compliant with payment card industry data security standards (PCI DSS) (Calder and Williams, 2016). Data security was also required by the author and Glasgow Caledonian University. Data security measures included anonymization, secure storage, restricted access, password protection, and safe destruction of data. The data management was in accordance with the necessary data security policies and procedures at Glasgow Caledonian University (2019).

Interview data was collected using a password protected and encrypted digital voice recorder. The only person with access to the voice recorder was the author (Ben) who produced an anonymous transcript of each interview and deleted the recording once data analysis was completed. This approach helped accurately document the interview, but also ensured participants identity was not disclosed (Smith, Flowers and Larkin, 2009). Although, interviewing care partnerships did present some potential ethical dilemmas, because full anonymity cannot be maintained (Larkin, Shaw, Flowers, 2018). Inevitably both people in the care partnership heard the other person’s comments and/or were able to identify them in the final research report. To overcome this potential ethical dilemma all participants were informed about the nature of the interview prior to giving consent and were able to moderate and self-censor any comments they did not wish for the other person to hear (Bjornholt and Farstad 2014).
It is difficult to remove all possible risk from research, but ethical research requires for there to be a favourable risk-benefit ratio and for all risks to be disclosed to participants (George, 2016). A risk assessment (Appendix 8 on page 319) was completed to highlight possible risks and clarify steps taken to mitigate the risks. Likewise, the participant information sheet included potential risks and outlined the commitment involved in taking part in the study (Appendix 10 on page 325).

7.11.2.6 Informed consent

Informed voluntary consent is a key element of ethical research (World Medical Association, 2013). The stroke survivor and care partner in each care partnership was consented as an individual participant and with their own consent form. The recruitment process ensured all participants provided voluntary informed consent and could withdraw consent at any time. The potential for cognitive impairment following stroke makes the issue of informed consent potentially challenging (Boxall, Hemsley and White, 2016). Although, specific inclusion/exclusion criteria and the use of a care partner reduced the likelihood of recruiting someone with significant cognitive impairment. Full informed voluntary consent was a prerequisite for participation in the study (Section 7.2.3 on page 155).

7.11.2.7 Community engagement

Patient and public involvement (INVOLVE, 2018) and community engagement are integral to ethical research (Li et al., 2016). Patient and public involvement played an important role in the conduct and dissemination of the research (Section 7.10 on page 198). Community engagement is also evidenced by attending the participants home on multiple occasions, getting to know the participants, and discussing results with them during the visits.

7.11.2.8 Return of research results and incidental findings

Incidental findings occur when important health-related information is discovered during a research study (Wolf et al., 2008). Dealing with incidental findings has ethical and clinical implications (Li et al., 2016), but little guidance is available to help decide on the best approach for dealing with incidental findings (Wolf et al., 2008).
Using the HADS (Zigmond and Snaith, 1983) as a data collection tool raised the possibility of incidental findings being discovered during home visits. The likelihood of discovering clinical level of psychological distress was high because participants were selected on the basis they self-identified as having stress, anxiety symptoms, or depression symptoms (Table 18 on page 160). The possibility of having incidental findings was anticipated at the design phase and incorporated into the ethics protocol and risk assessment. The strategy for dealing with incidental findings involved scoring each HADS (Zigmond and Snaith, 1983) after completion and providing immediate feedback to participants about whether the score indicated mild, moderate, or severe levels of distress (Section 7.6.3.1 on page 175). Moreover, anyone scoring 11 or more on the HADS (or expressing suicidal thinking) was signposted to their General Practitioner (Zigmond and Snaith, 1983).

7.11.2.9 Post-trial access

Ethical research requires participants to have continued access to the intervention, especially if they found the intervention helpful during the research (Li et al., 2016). All participants were given permanent access to Be Mindful (Wellmind Media and Mental Health Foundation, 2019), so they could continue to use the intervention after the study had finished. However, it is also important to make sure offering post-trial access does not become an unethical inducement (Li et al., 2016), so post-trial access was only disclosed to participants who had committed to the study.

7.11.2.10 Payment for participation

Payment for participation in clinical research can have significant ethical implications. Participants should have expenses covered, but excessive payment could be seen as a form of inducement and is discouraged (Li et al., 2016). In this study no direct payments were made to participants, but they were all provided with free access to Be Mindful (Wellmind Media and Mental Health Foundation, 2019).

7.11.2.11 Study related injury

Reporting any and all study related injuries is important and has ethical implications (Li et al., 2016). All adverse events and serious adverse events
occurring in the study were documented and disseminated (Section 8.1.3 on page 232). Indemnity insurance was provided by Glasgow Caledonian University (sponsor) and available to participants in the event of a compensation claim.

7.12 Prospective protocol registration

In 2004 the International Committee of Medical Journal Editors (ICMJE) (International Committee of Medical Journal Editors, 2019) responded to concerns in the academic community about publication bias and/or selective reporting by recommending all research be registered on a public registry and for prospective registration to become a prerequisite for academic publication (Angelis et al., 2004). The intention was for researchers to prospectively register their research protocols and allow people to audit whether the published report matches the initial research plan. The prospective registration is now seen as an important quality indicator and is sometimes mandated by academic publishers, funders, and ethics committees (Krleža-Jerić, 2005). The registration of research does improve transparency, but the system does have limitations. A recent observational study of 181 clinical trials discovered only 60 (33.1%) of the included studies were prospectively registered and had clearly identified primary outcome measures (Scott, Rucklidge and Mulder, 2015). When looking at nursing literature specifically, a review of 135 clinical trials found only 24 (18%) of studies were prospectively registered, which means nursing research is falling behind other health professions with regards prospective registration of clinical trials (Gray et al., 2017). However, whether researchers prospectively register their work is only one side of the problem, because there is also a need for consistency between the registered protocol and what is published. Hartung et al. (2014) compared the ClinicalTrial.gov register with the subsequent peer-reviewed publications and found large discrepancies between the two records. Likewise, Scott, Rucklidge and Mulder (2015) scrutinised 181 published psychiatric clinical trials to see whether they had been prospectively registered and whether there was consistency between the registration record and published work. This process revealed a large number of unregistered clinical trials (11.6%) and irregularities between outcome measures used, timing of data collection, and reported sample size.
(Scott, Rucklidge and Mulder, 2015). These observations suggest trial registers might not be achieving the initial goals of reducing publication bias and/or selective reporting. To meet the ethical and scientific expectations of the ICMJE, this study was prospectively registered with ClinicalTrials.gov (Zarin and Keselman, 2007) in March 2018 (NCT03473054) (Parkinson et al., 2018).

### 7.13 Reporting

Reporting findings fully and transparently is an important part of the research process (Sarver and McNett, 2020). The Equator Network (2019) hosts a collection of reporting guidelines for different research designs (Altman and Simera, 2016) and recommends new guidelines are developed using an expert informed consensus based methodology (Moher et al., 2010). However, the Equator Network (2019) does not have reporting guidelines for every type of research methodology and not all reporting guidelines are established using an explicit methodology (Virués-Ortega and Moreno-Rodríguez, 2008). A decision-making tool has been developed to help researchers select the most appropriate reporting guideline for their study (Shanahan, Lopes de Sousa and Marshall, 2017). However, the decision-making tool is not designed for all study designs and was unable to identify a suitable reporting guideline for this study. The most appropriate reporting guideline in the decision-making tool was the CAse REport (CARE) guideline for reporting case reports (Gagnier et al., 2013). The CARE reporting guideline is endorsed by the Equator Network (2019) and uses consensus-based methodology (Moher et al., 2010). A decision was made to use the CARE reporting guideline (Gagnier et al., 2013) for this study because it aligns with the design and provides some structure to the reporting process (Appendix 20: The CAse REport guidance checklist for clinical case reporting (CARE) on page 339).

The findings are reported using a cross-case structure (Chapter 8 on page 225). A cross-case structure does not devote specific sections to individual cases, but provides a cross-case summary of the topics being explored (Yin, 2018). Quantitative data for stroke survivors and their care partners is presented using tables, line graphs, whole numbers (n), means (M), standard deviation (SD), p values ≤0.05 (*), and percentages (%) (Parahoo, 2014). The qualitative interview data is presented using interpretative phenomenological analysis, with
themes, anonymous participants quotes, and a visual representation of the themes (Smith, Flowers and Larkin, 2009) (Section 8.7 on page 242).

7.14 Reflexivity

Reflexivity is a reflective process used to improve quality and rigour in research (Parahoo, 2014). Reflexivity involves researchers considering how they themselves, and their own subjectivities, have influenced the research process (Gemignani, 2016). Woolgar (1988) conceptualised reflection (benign introspection) and reflexivity (radical constitutive reflexivity) as being at either end of a continuum and originating from different philosophical positions. Reflection aligns with a positivist ontology and tries to achieve accuracy and truth about the nature of reality, whilst reflexivity is positioned within an interpretivist ontology and acknowledges the many and varied interpretations of reality (Shaw, 2010).

The different philosophical positions within reflection and reflexivity are important considerations because they should align with the chosen methodology. IPA is an interpretative methodology and places great emphasis on the use of reflexivity (Smith, Flowers and Larkin, 2009). The double hermeneutic within IPA makes the researcher an integral part of the interpretative process and requires in-depth reflexivity (Smith, Flowers and Larkin, 2009). It is important IPA researchers reflexively evaluate their own position in their research and how this might have influenced each stage of the research process (Finlay, 2002). This self-aware analysis should consider how a person’s sociodemographic characteristics, personal experiences, and professional background might have influenced their research (Berger, 2015). The process of reflexivity in this study involved detailed analysis of my own role at each stage of the research process (Finlay, 2002). The reflexive content of the thesis is presented using first person language because it aids transparency and situates myself (Ben) in the research (Berger, 2015).

7.14.1 Positioning self (Ben) in the thesis

During the research my (Ben) personal identity, lived experience, and professional background have shape the research process (Thesis author on page 21). As a white male in my forties, it still comes as a shock to think I am
undertaking a PhD. I grew up in England and left school with very few qualifications. Both parents worked in health care, but neither had University education, and I assumed my formal education was finished after leaving school. However, I returned to education as a mature student and graduated from Glasgow Caledonian University as a mental health nurse age 30. Since graduation I have continued my academic development and have completed various postgraduate courses, including an MSc (with distinction) in psychosocial interventions (2015). My nursing career has involved working in addiction service, primary care mental health, and higher education. The main focus of my clinical work was using psychosocial interventions (e.g. cognitive behavioural therapy) to help people with common mental health difficulties (e.g. anxiety and depression). During my 10 years in clinical practice I encountered many people struggling with the psychological consequences of chronic conditions. I also worked with many people experiencing psychological difficulties because they were caring for someone with a chronic condition. This experience gave me an insight into the challenges of living with chronic conditions and insight into how psychosocial interventions can help people affected by chronic conditions. Clinical practice also made me realise not everyone benefits from psychosocial intervention and recovery is particularly difficult when living with a chronic condition and experiencing mental health difficulties (Marks, 2018).

On a personal level my own lived experience has taught me how chronic conditions can have a negative impact on people’s lives. Personal insight was gained by witnessing my mother live with anxiety and vascular dementia for many years before finally losing her to dementia in 2019. Watching my mother struggle with dementia was tough, but it did give me an understanding of the detrimental impact living with a chronic condition can have on someone and how it can affect those close to them.

These professional and personal experiences showed me the difficulties of living with chronic conditions, the impact this can have on the wider family unit, and the role psychological approaches can play in helping people affected live with chronic conditions. When looking to start my PhD I was particularly interested in the mindfulness and family-orientated research being studied by Professor Lawrence (Lawrence et al., 2013). Professor Lawrence’s work
combines many aspects I was keen to study and provided a perfect opportunity to examine the use of mindfulness with care partnerships experiencing anxiety symptoms and depression symptoms after stroke.

7.14.2 Allegiance with mindfulness

Reflexivity should consider how professional background and personal experience might influence our perspective on a topic and whether we have any bias towards the topic (Berger, 2015). Researcher allegiance is one form of bias that can alter research outcomes and needs to be disclosed by researchers (Dragioti, Dimoliatis and Evangelou, 2015). Luborsky, Singer and Luborsky (1975) first highlighted how researcher allegiances might intentionally or unintentionally influence research findings. Researcher allegiance effect occurs in situations where a researcher has a strong vested interest in particular therapeutic approach (Leykin and Derubeis, 2009). Allegiance effect can occur in all forms of research and is most likely when researchers have a particular enthusiasm for the therapeutic approach being studied (Leykin and Derubeis, 2009).

Mindfulness is an experiential activity with a large emphasis on personal practice. There is an expectation people practice daily and considerable interest in the therapeutic value of the MBIs (Kabat-Zinn, 2013). The enthusiasm for MBIs creates an ideal environment for people to overemphasise the evidence-base (Farias and Wikholm, 2016). A recent meta-re-analysis (Goldberg and Tucker, 2019) re-examined papers (n=68) to see whether the superiority of MBI over other treatments was due to allegiance effect. The meta-re-analysis found research allegiance can be a factor in MBI research and concluded research allegiance should be considered in all MBI research (Goldberg and Tucker, 2019). The potential for allegiance effect in MBI research makes it important to disclose prior involvement in mindfulness and possible allegiance with MBIs (Dragioti, Dimoliatis and Evangelou, 2015).

My involvement with mindfulness started when I attended several mindfulness workshops during my training as a cognitive behavioural therapist (circa 2009). Later my wife and I attended a one-day workshop on mindfulness in the local Buddhist centre. Shortly after attending the one-day workshop we both attended an eight week MBSR (Santorelli et al., 2017) course because we wanted to
learn more about mindfulness. This course helped us learn the basic meditation practices, which we have both continued to practice over the years. Since learning mindfulness, I have used MBI sporadically and tend to incorporate informal mindfulness (e.g. mindful movement) into my daily life. I rarely use formal sitting mindfulness and have never attended a residential retreat. My use of mindfulness tends to increase when experiencing work-related stress and I have found it particularly helpful whilst studying for my PhD.

In 2017 I completed the Be Mindful (Wellmind Media, 2019) course because I was considering using it for my PhD study and wanted to become familiar with the course. Alongside my PhD exploring the use of MBIs with care partnerships, I have also become involved with other research involving mindfulness. Since 2018 I have been involved in HEADS: UP, which is a large research programme examining an adapted version of MBSR for people experiencing anxiety and depression symptoms after stroke (Lawrence, 2019). This active involvement in two studies using MBIs with people affected by stroke does raise concerns about possible professional allegiance because my professional life is heavily invested in MBIs. This allegiance is exacerbated by the tendency for research with statistically significant findings to be published and cited more than research without statistically significant findings (Fanelli, 2012). The pressure to publish and preference for research with statistically significant findings does create a perfect environment for results to be presented in the most favourable way and can cause bias (Joober et al., 2012).

On a personal level, I consider myself to be an occasional user of MBIs and my use tends to vary depending on my level of stress. Although, learning mindfulness with my wife did probably influence my thinking about the possible value to learning with a partner. I believe mindfulness has proved helpful for me, but I still continue to use other coping strategies alongside MBIs. I am concerned about the widespread use of MBIs and particularly when it presented as a panacea for everyone and all their problems (Van Dam et al., 2018). I am also concerned about publication bias (de Abreu Costa et al., 2019) and allegiance effect (Goldberg and Tucker, 2019) in some literature and the impact this might have on our understanding of the effectiveness of MBIs. This perspective gives me a healthy scepticism about the value of MBIs and helps mitigate possible allegiance effect in this study. Other mitigation to reduce
possible allegiance effect includes prospective registration and full reporting. Fully reporting all results (e.g. positive, negative, and neutral effects) increases transparency and reduces the chances of results be presented in a selective or bias manner (Dragioti, Dimoliatis and Evangelou, 2015b).

7.14.3 Reflexive journal
A reflexive journal was used during the study to capture reflexivity and selective excerpts will be presented to demonstrate applied reflexivity and show some of the learning that occurred during the study (Vicary, Young and Hicks, 2017). Using a reflexive journal can provide a powerful tool for improving validity, increasing transparency, and forms part of the audit trail for IPA (Smith, Flowers and Larkin, 2009). An audit trail provides an important quality component of IPA research (Smith, Flowers and Larkin, 2009) and further information about the audit trail in this study is provided in the strengths and weaknesses section (Section 9.7.2 on page 293).

7.14.3.1 Developing as a researcher
Early in the study the reflexive journal focused on thoughts and decision-making about study design and methods. One journal note considered whether to pilot the interview schedule prior to using it with participants and highlights some of the challenges associated with finding suitable people to pilot an interview schedule.

“Considering whether to pilot the interview schedule or not. Part of me thinks of using the first couple as a pseudo pilot, because it is difficult to find people who can be interviewed as a couple and who have experienced using Be Mindful together. Although, wonder whether interviewing someone from advisory group would be adequate to give a general impression of the interview structure” (Ben).

The outcome of this reflexivity was to consult my academic supervisors and to revise the content/structure after the first and subsequent interviews, if necessary. The advisory group were also consulted about the content of the interview schedule prior to it being used and to check whether it was appropriate for the intended audience. The approach to interviewing was
discussed later in the journal and highlights my growing confidence over the course of the study. The journal notes show how my approach to interviews changed from following the interview schedule to becoming less formal and more conversational.

“Interesting listening back to interview. Conscious of the loose approach to interview schedule and more unstructured conversational style of interview. Also interesting to see that I am starting to interpret what I am reading, which is inevitable and an argument for transcribing own interviews” (Ben).

My development as an researcher helped me develop a relaxed conversational style during IPA interviews and highlights the process of becoming a more proficient interviewer (Pietkiewicz and Smith, 2014).

7.14.3.2 Dealing with problems

The reflexive journal was often used when I was dealing with problems or having difficulties. Dealing with problems can generate a lot of thoughts and it was useful to capture some of the thinking and document how I solved the problem. One of the biggest problems in the study was the amount of missing data, which was partly caused by me making a mistake when collecting data.

“Research error when using MAAS. The rating scale in on two sided page, but was printed on one side only. Therefore, only 11 of the 15 questions were completed by participants. Unable to use data because there is missing data for questions 12-15 for all participants at every data collection point. Hugely disappointing and down to own human error. Considered whether to report what has been collected or whether to retrospectively ask people to complete the additional questions, be neither option is satisfactory. Making changes to the data collection tool would weaken the validity of the tool” (Ben).

The data collection error caused a huge amount of personal stress, but did produce an opportunity for learning. Having identified the issue, I thought it would be useful to consult my academic supervisors about the best way to proceed. The following excerpt was added to the reflexive diary after
supervision and highlights how I combined academic support with self-directed learning to resolve the issue.

“Discussed issue of missing data with supervisors and read about different strategies for managing missing data. Decided to collect full data set moving forward and explicitly and transparently deal with the missing data within the thesis” (Ben).

The process of resolving the issue of missing data provided a huge learning opportunity during the thesis. The process taught me about the commonality of missing data in clinical research and some of the different strategies (e.g. imputation) for dealing with missing data (Ibrahim, Chu and Chen, 2012) (Section 7.6.5 on page 179).

### 7.14.3.3 Learning from experts

A common occurrence during the study was to consult and seek guidance from my academic supervisors. My academic supervisors provided a huge amount of support and encouragement during the study, but they also pushed me to improve and make the study better. A good example of how my academic supervisors pushed me to improve was when they reviewed my initial IPA (Smith, Flowers and Larkin, 2009).

“Supervisor feedback is whether I need to have higher conceptual themes in the analysis i.e. analysis needs to be more conceptual. I agree to some extent, but also concerned about coming too far away from the questions and how this can be done within a mixed methods study. Thinking this might be an issue with using IPA in mixed methods feasibility study and due to different epistemologies i.e. inductive vs deductive. Considering changing to thematic analysis/generic qualitative analysis, but will sleep on it…” (Ben).

These comments were made because my initial analysis was very descriptive and did not reflect the interpretative nature of IPA (Smith, Flowers and Larkin, 2009). This feedback promoted me to continue data analysis and was the impetus needed to become more interpretative and use dialectical tension to explain the complexity in the data (Section 8.7 on page 242).
The above excerpt also highlights doubts about the choice of IPA and whether it was suitable for the study, although, the final decision was to continue using IPA (Smith, Flowers and Larkin, 2009). The decision to continue using IPA was made because it aligns with the methodology (e.g. phenomenological, idiographic) and can be used with mixed methods designs (Smith, Flowers and Larkin, 2009; Mayoh and Onwueguzie, 2014). 

“Contemplating whether IPA is the best qualitative approach for study and how best to fit IPA into a mixed methods designs. There is some doubt as to whether IPA is purely inductive or whether it can be used in a more deductive sequential mixed design… will stick with IPA because it is flexible and appropriate for mixed methods design” (Ben).

After supervision and the process of reflexivity, I was able to be more interpretative with the IPA and produced a more coherent analysis (Smith, Flowers and Larkin, 2009) (Section 8.7 on page 242). These excerpts demonstrate how reflexivity was used during the study and provide illustrative examples of key learning that occurred (Vicary, Young and Hicks, 2017). The use of reflexivity helps situate me in the study and promotes validity and transparency (Smith, Flowers and Larkin, 2009).
Chapter 8. Findings

The previous chapters have presented the methodology and methods used in the study of online MBI with care partnerships experiencing anxiety symptoms and depression symptoms after stroke. This chapter will present the study findings and answer the study questions (Section 5.3 on page 133). The findings are reported using a cross-case structure, so each study question will be considered in sequence (Yin, 2018). Case vignettes are provided for each care partnership to contextualise the findings (Appendix 21 on page 340). The study uses mixed methods case study research with an explanatory sequential design (Creswell and Clark, 2018) (Section 7.5 on page 172). The quantitative findings will be reported first, followed by the qualitative, and the final integration of quantitative and qualitative findings (Section 8.8 on page 261).

8.1 Feasibility

The first study question asked: is it feasible to study online mindfulness with stroke survivors and their care partners together in a care partnership (Section 8.1 on page 225)? Feasibility of the study was examined in terms of participant recruitment/retention, data completeness, and adverse events.

8.1.1 Recruitment and retention

Recruitment commenced in November 2018 and continued until August 2019. Fifteen people responded to recruitment adverts and were screened for eligibility using the screening protocol (Appendix 11 on page 330). Five care partnerships (n=10 participants) were enrolled into the study and five individuals were excluded. The reasons for exclusion included: no history of stroke (n=1); living outside the recruitment area (n=2), and loss of contact after initial email exchange (n=2). Nine of the ten enrolled participants completed the study, with one care partner withdrawing due to a deterioration in a pre-existing health condition. All nine participants who completed the study were interviewed and included in the final analysis.

A CONSORT flow diagram is provided (Figure 11 on page 226) to illustrate participant recruitment and retention and to increase transparency in the research processes (Vohra et al., 2015).
8.1.1.1 Demographic information

Five stroke care partnerships were recruited into the study and each care partnership consisted of a stroke survivor and a care partner (n=10 participants). Care partnerships all resided in Scotland (n=4) or northern England (n=1). Care partnerships from Scotland identified as being white Scottish and the care partnership from northern England identified as being white British. Age of participants ranged from 40-65 years (mean 53.9 years) for both stroke survivors and care partners, 48-60 years (mean 55.8 years) for stroke survivors only and 40-65 years (mean 52 years) for care partners only. The sex of the sample included both male (n=5) and female (n=5) participants. Most stroke survivors were male (n=4) and most care partners were female (n=4). All stroke survivors had completed some form of higher education and some were graduates (n=3). Care partner’s education level was more varied and included some with standard grade education (n=1) and one with degree level education (n=1). Most care partnerships (n=4) were in intimate
relationships (n=4) and had been together from 8-21 years (mean 15.5 years),
but the sample also included one father-daughter care partnership (n=1). Three
stroke survivors and three care partners were employed, with all other
participants being retired (Table 29 on page 228).
Table 29: Case demographic information

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Sex</th>
<th>Ethnic Background</th>
<th>Education</th>
<th>Relationship (years)</th>
<th>Living Together</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Care partnership one</strong>&lt;br&gt;Stroke survivor&lt;br&gt;Care partner</td>
<td>55</td>
<td>Male</td>
<td>White Scottish</td>
<td>Degree</td>
<td>Couple</td>
<td>Yes</td>
<td>Employed Retired ill health</td>
</tr>
<tr>
<td></td>
<td>49</td>
<td>Female</td>
<td>White Scottish</td>
<td>HNC</td>
<td>(15 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care partnership two</strong>&lt;br&gt;Stroke survivor&lt;br&gt;Care partner</td>
<td>57</td>
<td>Male</td>
<td>White Scottish</td>
<td>Degree</td>
<td>Couple</td>
<td>Yes</td>
<td>Employed Employed</td>
</tr>
<tr>
<td></td>
<td>56</td>
<td>Female</td>
<td>White Scottish</td>
<td>Standard grades</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care partnership three</strong>&lt;br&gt;Stroke survivor&lt;br&gt;Care partner</td>
<td>60</td>
<td>Male</td>
<td>White Scottish</td>
<td>HND</td>
<td>Father-daughter</td>
<td>No</td>
<td>Retired ill health Employed</td>
</tr>
<tr>
<td></td>
<td>40</td>
<td>Female</td>
<td>White Scottish</td>
<td>Degree</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care partnership four</strong>&lt;br&gt;Stroke survivor&lt;br&gt;Care partner</td>
<td>48</td>
<td>Female</td>
<td>White Scottish</td>
<td>HNC</td>
<td>Couple</td>
<td>Yes</td>
<td>Retired ill health Employed</td>
</tr>
<tr>
<td></td>
<td>50</td>
<td>Male</td>
<td>White Scottish</td>
<td>A levels</td>
<td>(8 years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care partnership five</strong>&lt;br&gt;Stroke survivor&lt;br&gt;Care partner</td>
<td>59</td>
<td>Male</td>
<td>White British</td>
<td>PgC</td>
<td>Couple</td>
<td>Yes</td>
<td>Self-employed Retired</td>
</tr>
<tr>
<td></td>
<td>65</td>
<td>Female</td>
<td>White Scottish</td>
<td>Secondary education</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Key:<br>HNC=higher national certificate; HND=higher national diploma; PgC=postgraduate certificate
8.1.1.2 Stroke characteristics

Self-reported stroke data was collected from all five care partnerships using a data collection tool developed specifically for this study (Appendix 13: Demographic data collection tool on page 332). Participants reported having experienced haemorrhagic (n=2), ischaemic (n=2), and stroke of unknown aetiology (n=1). The stroke survivors had experienced between one and three strokes each and had been living with stroke between two and nine years (mean 3.6 years).

Some stroke survivors said they experienced right sided weakness (n=2) and others said they experienced left-sided weakness (n=3) following their stroke. Stroke survivors self-reported difficulties with mental health and physical health following stroke. When asked about mental health difficulties, stroke survivors reported difficulty with anxiety symptoms (n= 5), stress symptoms (n=2), panic symptoms (n=2), and depression symptoms (n=1). When asked about other health difficulties, stroke survivors reported difficulty with mobility (n=3), mild aphasia (n=1), fatigue (n=1), poor memory (n=1), vision difficulties (n=1), and seizures (n=1) (Table 30 on page 229).

Table 30: Stroke information

<table>
<thead>
<tr>
<th>Care Partnership</th>
<th>Type of stroke</th>
<th>Number of strokes</th>
<th>Most recent stroke</th>
<th>Stroke related difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Haemorrhagic</td>
<td>1</td>
<td>2017</td>
<td>Left-sided weakness, Reduced mobility in left arm and hand, Stress and panic symptoms</td>
</tr>
<tr>
<td>Two</td>
<td>Unsure</td>
<td>2</td>
<td>2017</td>
<td>Right-sided weakness, Reduced mobility and power in the arm and leg, Anxiety symptoms</td>
</tr>
<tr>
<td>Three</td>
<td>Ischaemic</td>
<td>1</td>
<td>2017</td>
<td>Right-sided weakness, Mild aphasia, Stress, anxiety, and depression symptoms</td>
</tr>
<tr>
<td>Four</td>
<td>Haemorrhagic</td>
<td>3</td>
<td>2016</td>
<td>Left-sided weakness, Balance difficulties, Poor memory, Fatigue, Vision difficulties, Anxiety symptoms</td>
</tr>
<tr>
<td>Five</td>
<td>Ischaemic</td>
<td>1</td>
<td>2010</td>
<td>Left-sided weakness, Seizures, Anxiety and panic symptoms</td>
</tr>
</tbody>
</table>
8.1.2 Data completeness

The study experienced a large amount of unit and item level missing data. Data completeness has been reported to maintain transparency and to determine feasibility of data collection methods (Health Research Authority, 2019).

8.1.2.1 Unit level missing data

Unit-level missing data occurred to a large extent when using the automated quantitative data collection embedded in Be Mindful (Wellmind Media and Mental Health Foundation, 2019). The missing unit-level data was MNAR (Dong and Peng, 2013) because those participants affected (two stroke survivors and five care partners) did not complete any of the measures for weeks four and/or eight (Appendix on page 333). The automated unit-level missing data constituted 40% (n=36 units) of the total units collected by Be Mindful (Wellmind Media and Mental Health Foundation, 2019) and appears to be linked to participants choosing not complete the intervention and/or measures (Akl et al., 2015).

Measures completed during home visits also demonstrated unit-level missing data, but to a lesser extent. Care partnership one did not complete measures at week four (stroke survivor and care partner) and eight (care partner only). This unit-level missing data equates to 10% (n=9 units) of the total outcome units collected during the study. This missing data occurred because the care partner experienced health difficulties during the study, which affected their ability to complete the measures. The underlying cause of this missing data was health related (Akl et al., 2015) and described as MNAR (Dong and Peng, 2013) because it only affected one care partnership, during a specific time period, and there was an identified explanation for the data being missing.

The unit-level missing data occurred with automated and non-automated data collection. The overall combined level of automated and non-automated unit-level missing data in this study was 25% (n=45 units), with a large majority of missing unit-level data coming from automated (n=36 units, 80%) data collection (Table 31 on page 231). The extent of automated unit-level missing data (>40%) and the fact it affected follow-up data for the majority of participants (n=7) made it difficult to calculate treatment effect for stress, anxiety
symptoms, and/or depression symptoms. The amount of unit-level automated missing data and the fact these were secondary data collection measures resulted in a decision to remove the automated data from the analysis and to focus this report on the primary non-automated measures (Section 7.6 on page 173). To ensure transparency the automated data is available and reported in full (Appendix 14 on page 333).

8.1.2.2 Item level missing data

Item-level missing data occurred because whole data collection units were not completed (Section 8.1.2.1 on page 230) and each of these non-completed data collection units consisted of between seven and fifteen items each. Non-completed automated (i.e. Be Mindful) (n=36) and non-automated (i.e. self-completion) (n=9) data collection units produced 22.4% (n= 470 items) missing item data (Table 31 on page 231). Item-level missing data also occurred because of a data collection error that resulted in the non-automated (i.e. self-completed) MAAS (Brown, Ryan and Dovidio, 2003) tool not being fully completed on some occasions. During the error only the first eleven questions were asked and the final four were left unanswered. This error affected the majority of participants (n=8, 80%) and nearly half the MAAS (Brown and Ryan, 2003) (n= 12, 44.4%) measures completed in the study. The item-level missing data from the MAAS (Carlson and Brown, 2005) represented a small percentage of the overall item-level data collected in the study (n=48, 2.29%), but a larger percentage (n=48 items, 11.85%) of the item-level data for that particular measure. The underlying cause of this missing data was human error and categorised as a technical issue (Akl et al., 2015) with data MNAR (Dong and Peng, 2013) (Section 7.6.5 on page 179).

Table 31: Missing data

<table>
<thead>
<tr>
<th></th>
<th>Complete data</th>
<th>Missing data</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Automated collection (Be Mindful)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unit</td>
<td>90</td>
<td>36</td>
<td>40.0%</td>
</tr>
<tr>
<td>Item</td>
<td>780</td>
<td>338</td>
<td>43.3%</td>
</tr>
<tr>
<td>Timetabled data collection (0, 4, and 8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unit</td>
<td>90</td>
<td>9</td>
<td>10.0%</td>
</tr>
<tr>
<td>Item</td>
<td>1320</td>
<td>180</td>
<td>13.6%</td>
</tr>
<tr>
<td>Combined data collection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unit</td>
<td>180</td>
<td>45</td>
<td>25.0%</td>
</tr>
<tr>
<td>Item</td>
<td>2100</td>
<td>518</td>
<td>24.7%</td>
</tr>
</tbody>
</table>
8.1.2.3 Qualitative data collection

The semi-structured interviews were all audio recorded and carried out in the participant’s own homes at week eight of the study. All interviews were conducted face-to-face by the researcher/student using the study interview schedule (Appendix 17 on page 336). Interviews were either individual (n=1, 10%) or with care partnerships (n=4, 40%), and lasted between 40 and 56 (mean 44, SD 6) minutes after introductions and verbal renewal of consent.

8.1.3 Adverse events and serious adverse events

The study monitored adverse events (AEs) and serious adverse events (SAEs) (Health Research Authority, 2017) (Section 7.11.2.11 on page 214). During the study one care partner experienced a SAE, which involved them being admitted to hospital due to exacerbation of a pre-existing health condition (Care partnership one on page 340). The SAE is thought to be unrelated to their use of online MBI or involvement in the study (Section 9.2.4 on page 276).

8.2 Appropriateness

The second study question asked: do stroke survivors and their care partners find it appropriate to use online MBI together (Section 8.2 on page 232)? The appropriateness of Be Mindful (Wellmind Media and Mental Health Foundation, 2019) was evaluated primarily by measuring adherence and engagement with the interventions at weeks four and eight of the study (Section 7.4.3 on page 170).

Stroke survivor adherence with online MBI at week four varied between 25% (n=1), 75% (n=3), and 100% (n=1). Adherence for stroke survivors at week eight varied between 75% (n=1) and 100% (n=4). Modal adherence for stroke survivors was three modules (75%) at week four and four modules (100%) at week eight. Care partner adherence at week four varied between 0% (n=2), 50% (n=2), and 75% (n=1). Adherence for care partners at week eight varied between 0% (n=2), 50% (n=1), and 75% (n=2). Modal adherence for care partners was zero and two modules (0% and 50%) at week four and zero and three modules (0% and 75%) at week eight. Most stroke survivors (n=4) completed the course in eight weeks, but none of the care partners completed
the course during the study. This analysis revealed better adherence for stroke survivors compared to care partners (Table 32 on page 233). Adherence by stroke survivors was better in four partnerships at week four and all partnership by week eight, which indicates consistently better engagement by stroke survivors.

Table 32: Number of modules (percentage) completed

<table>
<thead>
<tr>
<th>Care partnership</th>
<th>Stroke survivor</th>
<th>Care partner</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Week 4</td>
<td>Week 8</td>
</tr>
<tr>
<td>One</td>
<td>4 (100%)</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>Two</td>
<td>3 (75%)</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>Three</td>
<td>3 (75%)</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>Four</td>
<td>3 (75%)</td>
<td>4 (100%)</td>
</tr>
<tr>
<td>Five</td>
<td>1 (25%)</td>
<td>3 (75%)</td>
</tr>
</tbody>
</table>

8.3 Change to mindfulness

The third study question asked: do stroke survivors and their care partners experience changes in mindfulness after using MBI together? The MAAS (Brown and Ryan, 2003) data produced participant scores between: 3.36 and 4.45 (mean 3.85, SD 0.41) at week zero; 3.63 and 4.5 (mean 4.06, SD 0.25) at week four; and 4 and 5.27 (mean 4.64, SD 0.51) at week eight. Effect direction analysis of the MAAS (Brown and Ryan, 2003) data suggests increased mindfulness for stroke survivors (n=4) and care partners (n=4) overall. Only one (n=1) stroke survivors reported a reduction in mindfulness during the study.
Table 33: Mindful attention awareness scale

<table>
<thead>
<tr>
<th>Care partnership</th>
<th>Stroke survivor</th>
<th>Care partner</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Week 0</td>
<td>Week 4</td>
</tr>
<tr>
<td>One</td>
<td>3.64M</td>
<td>NR</td>
</tr>
<tr>
<td>Two</td>
<td>3.45M</td>
<td>4.0M</td>
</tr>
<tr>
<td>Three</td>
<td>4.18M</td>
<td>4.27M</td>
</tr>
<tr>
<td>Four</td>
<td>3.91M</td>
<td>4.5</td>
</tr>
<tr>
<td>Five</td>
<td>3.53</td>
<td>4.07</td>
</tr>
</tbody>
</table>

Key
▲=positive effect (i.e. increased mindfulness); ▼=negative effect (i.e. decreased mindfulness); NR=not reported; M=missing item level data

Visual analysis of the MAAS (Carlson and Brown, 2005) line charts reveal stroke survivors had a tightly clustered group of scores at weeks zero and four, but more divergence at week eight. Four of the five stroke survivors improved mindfulness overall during the study (Figure 12 on page 234). The line chart for care partner MAAS (Carlson and Brown, 2005) scores appears more complex. Four care partners' mindfulness increased overall at week eight, but three experienced a reduction in mindfulness at week four (Figure 13 on page 235).

Figure 12: Mindful attention awareness scale chart: stroke survivors
Figure 13: Mindful attention awareness scale chart: care partners

A non-parametric Friedman’s Test (MacFarland et al., 2016) of difference among repeated MAAS (Carlson and Brown, 2005) scores revealed a non-statistically significant increase for stroke survivors ($\chi^2(2)=3.500, p=0.174$), care partners ($\chi^2(2)=3.500, p=0.174$), and the whole group ($\chi^2(2)=4.000, p=0.135$).

### 8.4 Interpersonal changes

The fourth study question asked: do stroke survivors and their care partners experience interpersonal changes after using MBI together (Section 8.4 on page 235)? The Mutuality scale (MS) (Archbold et al., 1990) was completed to measure interpersonal change with each partnership at weeks zero, four, and eight. The MS (Archbold et al., 1990) data provided pre, post, and follow-up mutuality scores for nine participants. The scores varied between 3.13 and 4 (mean 3.61, SD=0.30) at week zero, 3.4 and 4 (mean 3.67, SD=0.22) at week four, and 3.0 and 4.0 (mean 3.64, SD= 0.33) at week eight. Effect direction analysis (Boon and Thomson, 2020) revealed improved mutuality for stroke
survivors (n=2) and a care partner (n=1). However, a stroke survivor (n=1) and some care partners (n=3) experienced a lowering of mutuality during the study.

Table 34: Mutuality scale

<table>
<thead>
<tr>
<th>Care partnership</th>
<th>Stroke survivor</th>
<th>Care partner</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Week 0</td>
<td>Week 4</td>
</tr>
<tr>
<td>One</td>
<td>3.33</td>
<td>NR</td>
</tr>
<tr>
<td>Two</td>
<td>3.13</td>
<td>3.6</td>
</tr>
<tr>
<td>Three</td>
<td>3.6</td>
<td>3.93</td>
</tr>
<tr>
<td>Four</td>
<td>4</td>
<td>3.8</td>
</tr>
<tr>
<td>Five</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

Key
▲=positive effect (i.e. increased mutuality); ▼=negative effect (i.e. decreased mutuality); □ =no effect; NR =not reported

Visual analysis of the MS (Archbold et al., 1990) data shows generally high scores for both stroke survivors and care partners at weeks zero, four and eight. Four stroke survivors maintained or increased their mutuality during the study (Figure 14 on page 237). One care partner increased their high level of mutuality during the study, however, three care partners did appear to have lowered their mutuality during the study (Figure 15 on page 237). The initial high scores on the MS (Archbold et al., 1990) for both stroke survivors and care partners do make it difficult for the measure to show any increases in mutuality during the study and might suggest a ceiling effect (Salkind, 2012).
Non-parametric Friedman’s Test (MacFarland et al., 2016) of difference in repeated MS (Archbold et al., 1990) scores produced a non-statistically significant increase for stroke survivors ($\chi^2(2)=0.545$, $p=0.761$), care partners ($\chi^2(2)=2.533$, $p=0.282$), and the whole group ($\chi^2(2)=0.538$, $p=0.0764$).
8.5 Change to anxiety symptoms

The fifth study question asked: does online MBI have the potential to reduce anxiety symptoms for stroke survivors and their care partners? Anxiety symptoms were evaluated at weeks zero, four, and eight using the Hospital Anxiety Depression Scale (HADS) (Zigmond and Snaith, 1983). Data is reported using the anxiety sub-scale (HADS-A) (Crawford et al., 2001). Stroke survivors reported HADS-A scores between 8 and 15 (mean 10.6, SD 2.42) at week zero, 5 and 11 (mean 8.5, SD 2.8) at week four, and 2 and 11 (mean 7.8, SD 3.12) at week eight (Zigmond and Snaith, 1983). Care partner HADS-A scores were between 4 and 8 (mean 6, SD 1.67) at week zero, 2 and 7 (mean, SD) at week four, and between 3 and 5 (mean 3.75, SD 0.83) at week eight.

Data analysis showed four stroke survivors and two care partners were experiencing clinical levels of anxiety symptoms at the start of the study (Bjelland et al., 2002; Sagen et al., 2009). Effect direction analysis (Boon and Thomson, 2020) revealed improvements in anxiety symptoms during this study occurred for four stroke survivors (n=4) and three care partners (n=3). However, one stroke survivor (n=1) and one care partner (n=1) experienced a deterioration in anxiety symptoms during the study. A change of >1.7 on the HADS-A represents a minimal clinically important difference (MCID) (Lemay et al., 2019) and occurred by week four and was maintained at week eight of the study for three stroke survivors (n=3) and two care partner (n=2).

Table 35: Anxiety sub-scale

<table>
<thead>
<tr>
<th>Care partnership</th>
<th>Stroke survivor</th>
<th>Care partner</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Week 0</td>
<td>Week 4</td>
</tr>
<tr>
<td>One</td>
<td>11</td>
<td>NR</td>
</tr>
<tr>
<td>Two</td>
<td>15</td>
<td>9*</td>
</tr>
<tr>
<td>Three</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Four</td>
<td>9</td>
<td>5*</td>
</tr>
<tr>
<td>Five</td>
<td>10</td>
<td>11</td>
</tr>
</tbody>
</table>

Key
▲=positive effect (i.e. decreased anxiety symptoms); ▼=negative effect (i.e. increased anxiety symptoms); □ =no effect; N/A =not applicable; NR =not reported; * =minimal clinically important difference (MCID)
Visual analysis of HADS-A (Zigmond and Snaith, 1983) data shows improvement (n=4) and deterioration (n=1) in anxiety symptoms for stroke survivors (Figure 16 on page 239). Visual analysis of the care partner anxiety sub-scale data shows tightly clustered data at each time points and limited gradient (Figure 17 on page 239). The clustered nature and shallow gradient of care partner HADS-A (Zigmond and Snaith, 1983) data suggests they experienced similar levels of anxiety symptoms throughout.

**Figure 16: Anxiety sub-scale: stroke survivors**

![Graph showing anxiety sub-scale data for stroke survivors](image)

**Figure 17: Anxiety sub-scales: care partners**

![Graph showing anxiety sub-scales data for care partners](image)
A non-parametric Friedman’s Test (MacFarland et al., 2016) of difference in anxiety sub-scale scores on the HADS (Zigmond and Snaith, 1983) produced a non-significant improvement in anxiety symptoms for stroke survivors ($\chi^2(2)=1.500, p=0.472$), care partners ($\chi^2(2)=0.933, p=0.627$), and the whole participant group ($\chi^2(2)=2.000, p=0.368$).

### 8.6 Changes to depression symptoms

The sixth study question asked: does online MBI have the potential to reduce depression symptoms for stroke survivors and their care partners? Depression symptoms were evaluated at weeks zero, four, and eight using the Hospital Anxiety Depression Scale (HADS) (Zigmond and Snaith, 1983). HADS-D (Zigmond and Snaith, 1983) scores for stroke survivors were between 1 and 10 (mean 6, SD 3.63) at week zero, 3 and 6 (mean 4.25, SD 1.3) at week four, and 3 and 7 (mean 4.4, SD 1.67) a week eight. Care partner HADS-D scores were between 0 and 5 (mean 2.2, SD 1.72) at week zero, 0 and 3 (mean 1.5, SD 1.11) at week four, and between 0 and 2 (mean 1.5, SD 0.83) at week eight. Effect direction analysis (Boon and Thomson, 2020) of the HADS-D (Zigmond and Snaith, 1983) scores showed improvement for three stroke survivors and one care partner during the study. Although, one stroke survivor did experience a worsening of depressive symptoms. The MCID threshold of $>1.7$ was achieved on the HADS-D (Lemay et al., 2019) at week four and eight for two stroke survivors (Table 36 on page 240).

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<th>Care partnership</th>
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Key

▲=positive effect (i.e. decreased anxiety symptoms); ▼=negative effect (i.e. increased anxiety symptoms); □=no effect; N/A =not applicable; NR =not reported; * =minimal clinically important difference (MCID)
Visual analysis of the HADS-D scores (Zigmond and Snaith, 1983) revealed two stroke survivors where slight outliers at week zero, suggesting they had higher depression symptoms at the start. Further analysis showed the two outliers improved depression scores over the duration of the study. It also appears one stroke survivor experienced a worsening of depression scores during the study (Figure 18 on page 241). Care partner HADS-A (Zigmond and Snaith, 1983) data was clustered tightly at the bottom of the measure at each data collection point. This indicates low levels of depression symptoms and minimal change over the duration of the study (Figure 19 on page 242).

Figure 18: Depression sub-scale: stroke survivors
Statistical analysis of HADS-D (Zigmond and Snaith, 1983) using Friedman’s non-parametric test (MacFarland et al., 2016) of difference produced a non-statistically significant change for stroke survivors ($\chi^2(2)=0.143$, $p=0.931$), care partners ($\chi^2(2)=0.667$, $p=0.717$), and the whole participant group ($\chi^2(2)=0.348$, $p=0.840$).

8.7 Interpretative phenomenological analysis

The interpretative phenomenological analysis (IPA) (Smith, Flowers and Larkin, 2009) revealed much variation within and between care partnerships, which is articulated using the overarching theme of dialectical tension (Section 7.7.2.5.1 on page 193). Dialectical tension is a way of understanding contradictory information and reflects a continuum of experience and outcomes for care partnerships using online MBI together (Baxter and Scharp, 2015).

The IPA (Smith, Flowers and Larkin, 2009) conducted in this study produced a superordinate theme of dialectical tension and four subordinate themes. The subordinate themes are: curious; usage; togetherness; and change. The four subordinate themes reflect a range of different experiences and cover the appropriateness of online MBI for stroke care partnerships, the use of online MBI during the study, partnership factors in the study, and change for participants. The subordinate themes identified in the IPA are articulated using
dialectical tension. The themes reflect a continuum of experience between two dialectical positions, rather than the experiences being seen as polarised or mutually exclusive of each other (Figure 20 on page 243).

Figure 20: Superordinate and subordinate themes

8.7.1 Curiosity

The first subordinate theme explores the feasibility and appropriateness of online mindfulness for stroke care partnerships. The analysis involved integrating the quantitative recruitment data with the qualitative interview data to create the theme: curiosity. The recruitment data provides evidence that some stroke care partnerships were curious enough about online MBI to respond to an advert and enrol into the study. The curiosity of stroke care partnerships towards online MBI is corroborated by the interview data where participants explained their reasons for wanting to enrol into the study and access online mindfulness.

“I thought the course was very useful for myself, at this point in my life, for someone with a stroke. I knew I needed something to help me, erm, mental and emotionally as they call it and hence why I contacted you originally” (stroke survivor one).

The above stroke survivor was curious about online MBI because he was wanting something to help his mental health and the timing was right. This
suggests he was not fixed on the idea of learning mindfulness, but was willing to try different things that might help his mental health. It also suggests timing is important because he may not have been curious about online MBI, if it was not the right time in his recovery.

“That is why I phoned, when it was advertised, that time I thought that’s probably the kind of the intervention my dad needs. I am saying dad, when I see that advert that time it is the kind of the exactly the thing that you needed at that particular point in time. To feel better” (care partner three).

Being curious about online MBI is also evident by the fact one stroke survivor was keen to encourage other stroke survivors to engage with mindfulness.

“You know, I just think, I think there is a benefit from it, so why not spread the word and little bit. Particularly to other stroke victims, because when I was talking on Saturday … we had two workshops … there was probably about 25 people in each of them. You know, and I said ‘have you done mindfulness’?” (stroke survivor two).

These excerpts illustrate that stroke survivors and care partners were curious about online mindfulness and suggest they thought it was appropriate for people affected by stroke. This analysis also considered online delivery and discovered a strong preference for online delivery by some stroke care partnerships. One stroke survivor appreciated the flexibility and convenience of online delivery, whilst another liked the lack of social interaction and the functionality of the intervention.

“Online sounds yes, you could actually do it when you wanted to do it, without having to … travel anywhere … [or] meet people” (stroke survivor five).
“At this point I don’t think I would have been ready to sit in a circle as a group to do the course … I didn’t find any issues getting online once you got your password, you got a reminder and few emails a week, you just clicked into the email and you are straight in. Erm, and you navigated your way around the library and pick off what you wanted, so yeah that was great and it didn’t bombard you with feedback or information, they just had a couple of session where you had to do a little score or answer questions at the start and at the end, which was good and we did. It suited me yeah. I am not saying it would suit everyone to go that was, but it suited me” (stroke survivor one).

This initial analysis indicates stroke care partnerships were curious about online MBI and that they thought it was appropriate for people affected by stroke. However, further interpretation reveals not all stroke care partnerships were curious about online MBI. This contradictory picture between being curious and not being curious about online MBI is evidence of dialectic tension and creates a continuum of curiosity in the theme.

Evidence for stroke care partnerships not being curious about online MBI is also present in the initial quantitative recruitment data, because only fifteen people enquired about the study. This low figure of enquiries for online MBI could suggest stroke care partnerships are not curious about online MBI and perhaps it is inappropriate. This interpretation is strengthened when considering the three care partners who also expressed that they did not want or feel the need for online MBI.

“I feel as if I cope with things that’s happened very well. I didn’t feel I needed mindfulness to cope with what is going on day to day” (care partner three).

“I think, with me being kind of, as I say on an even keel if you want to put it that way, erm, it probably not such a good thing for me but I would say if you have got someone who that is a bit more highly strung then definitely doing it together would help” (care partner four).
“It is probably not the kind of thing that I would pick up on a regular basis. I wouldn’t consciously at the moment think of incorporating it into my lifestyle” (care partner five).

These comments suggest some care partners were not curious about online MBI, but it is interesting none said online MBI was unsuitable or inappropriate. Equally, not everyone liked online delivery and some participants expressed a preference for a face-to-face group delivery. Although, one of the care partners acknowledged their work schedule would make it difficult to attend regular group sessions and another thought it would be best to use online and group delivery together.

“What I didn’t like was not being able to engage with the person. Because I could have gone yuck and they would have known. Whereas actually, for me if you are actually with a person learning something or … you get a rapport going” (care partner five).

The above excerpt illustrates how one care partner disliked online delivery, because they thought the asynchronous delivery prevented human interaction with the MBI teacher. Conversely, a stroke survivor appeared to develop a bond with the MBI teachers, despite the videos being asynchronous.

“I enjoyed the whole course and I have to say to you when I finished I felt a little bit sad. I thought oh, and then a couple of days later they [an automated message from the Be Mindful teachers] pop up: ‘hi …’ oh they are back” (stroke survivor four).

Another care partner also thought group MBI would have helped their father cope with his stroke because he would have liked the routine and meeting other stroke survivors, but she also thinks group and online MBI could augment each other. The interpretation of not being curious about online MBI in this theme is subtle and pertains to care partners primarily.
“I think online has got a place, but I personally think you would get more out of a group, dad. You went to your stroke … groups and got a lot out of going to that group and you went every single time. I think it is always good to have it on that [points to tablet], because even if you were going to a group just now you would still be able to pick the online stuff up. Whenever you wanted in-between times. If you were going to a group once a week, online still has a place, to pick it up and do it” (care partner three).

The dialectical tension of curiosity about online MBIs is complex. Stroke care partnerships appear to be curious about online MBI and are curious enough to enrol into a study to access online MBI. Curiosity appears to be stronger with stroke survivors compared to care partners, with some care partners not being curious about online MBI. However, care partners often became curious about online MBI when thinking about how it might help the stroke survivor. This indicates stroke survivors are more likely to be curious about online MBI and care partners are more likely to be interested in how online MBI might help the person with a stroke.

8.7.2 Usage

The theme usage focuses on participants use of online MBI and captures the complexity surrounding their engagement and practice of mindfulness. The analysis also explores reasons for non-engagement during the study. The experience of stroke care partnerships using online MBI is captured in the following excerpts where they describe the ease of using the online MBI and the thoughts about some of the exercises.

“When they are sitting down and they are telling me what to do I was, what is the word, when they were telling me sit down and do that, I liked that, they are talking, telling me what to do” (stroke survivor three).
“It was actually different to when I have done body scans before, I found it, it was more interesting, I did it sat in the chair and it was actually about feeling the chair against you and things like that, breathing right through your body. You are feeling the breaths, but rather than it actually stopping in the lungs, you sort of were breathing down to your feet. I found that aspect of it quite interesting” (stroke survivor five).

“Very easy to use in terms of actually being able to use them, it was not a problem. Easy to log onto, as long as you remember your password, erm, and just following the steps. I didn’t do so much of the kind of, electronic diaries” (stroke survivor two).

Some engagement was evident with most of the participants, however, initial quantitative data suggests the amount of engagement varied considerably. The quantitative data found stroke survivors were more engaged with online MBI and tended to adhere to the intervention better than care partners. Qualitative analysis corroborates the quantitative findings and suggests engagement was highly individual and dependent on the participant’s role within the partnership. Despite this variability, several participants engaged well with online MBI and appeared to be embedding MBI in their daily lives.

A common example of how participants used online MBI is provided in the following excerpt, which describes how one participant was using MBI to help cope with high levels of anxiety symptoms.

“Erm, I have struggled a couple of time in the hospital last month and I have had to use mindfulness to try and help me out of that immediate moment. I find myself getting really anxious, erm, that tends to link with me thinking that my blood pressure is going up” (stroke survivor one).

Whilst other participants used MBI in a more routine manner by incorporating MBI into their daily lives.
“I have enjoyed it. To begin with my mum said to me mindfulness is something that comes naturally and I suppose in some ways it does and erm, I don’t know it kind of relaxed me more, making me feel, paying attention to things, paying attention to wildlife or flowers. Erm, one thing that does make some laugh is that the sometimes when you, they say to you, lie down on your bed and you go through this wee phase [laughs] you end up waking up a wee while later” (stroke survivor four).

A participant even used online MBI despite initially being a little sceptical about the intervention.

“Aye, it is like I say, I am sceptical about these things, but there are times now through the day like I have set my watch up for breathing exercises. So I do them like every hour or roughly every hour or couple of hours, something like that. So I do that and we have gone for walks, what I am doing is I get the calendar out [inaudible] I will take picture of things, so I have got some memory of, it not like my, I am not losing it or anything like that. It is just to see, be in the moment, type thing” (stroke survivor two).

There is also evidence participants were experiencing MBI in different ways, with some adapting certain MBI practices and others developing their own unique ways of practicing MBI. Examples of how formal practices were adapted to overcome stroke related difficulties include:

“I was struggling to keep my arm in that position for the length of time watching the lady do it. So I probably had to break off or do it more on my right hand side. So I sort of adapted, erm but yeah after I got into my own rhythm or technique” (stroke survivor one).

An example of how MBI practices were personalised by participants during the study include:

“I do it just throughout the day type of thing, just paying attention to flowers in the garden, bumble bees in the lavender, yeah just paying attention to what is going on” (stroke survivor four).
These examples demonstrate the experiential differences that exist within the study and the phenomenological variation between how people use MBI. One stroke survivor even expressed sadness and regret at having stopped using online MBI.

“I shouldn’t have stopped doing it, I wish I was doing it the now, but I stopped because I was fed up [with life]” (stroke survivor three).

Alongside evidence of using online MBI there was also evidence of not using online MBI. The reasons given for not using MBI varied, but included feeling MBI was a chore, lack of interest, or dislike of the mode of delivery.

“It was, it was, I didn’t get very far because it sorts of became a chore. Whereas doing other things I am absorbed in, for me, that was much more beneficial. And also I tend not to be sort of a worrier too much. I tend to be a bit daft, so I don’t know maybe when I went into it I wasn’t really feeling the need for something like mindfulness. I mean I could be completely wrong” (care partner five).

“It hasn’t had that much affect in my life, know? I have just dipped in and out of it for a bit of interest. I haven’t been that focused on it no” (stroke survivor five).

“I always before I seen it, I always thought it was never something I was interested in. It is just when I see it, I thought, I will do it because I really think that is what my dad needs. I did do it but I feel I didn’t personally get anything out of it, but I did it because I wanted to be able to speak to my dad. I could discuss it that way, but it is not something I would continue to be honest” (care partner three).

Initial analysis of this theme appeared to suggest stroke survivors were using online MBI whilst their care partners were not using online MBI. However, further analysis revealed the usage theme was more complex. Interpretation of the interview data revealed many of the stroke survivors were using online MBI, but in a very specific way. What appeared to be happening was that the stroke survivors were using the online MBI to develop coping skills for future. The approach to using MBI as a coping strategy or safety net was most prominent with stroke survivors and contrasts with the recommendation of daily practice.
This interpretation reinforced the dialectical tension evident in the usage theme because stroke survivors were using online MBI, but not as intended.

“I picked, I probably picked a couple of the techniques to use and do that. I wouldn’t say that I sit down daily and do it now, but I know it is there and I get to use it, I have used it, probably, I want to try and get some techniques to use either when I am walking or when you have that spell in the car when you are doing nothing else, you know” (stroke survivor one).

“Now I have actually noticed with the breathing exercise, how that has been, it has had a positive effect on me. I think if I get to a stage in life where I need another crutch to fall back on I will, could look at mindfulness to actually, to help with that” (stroke survivor five).

“I enjoyed it, as I said I have not finished the course yet. But I like the fact it is there and I can go to it. There are certain bits of it that I have taken out. It’s like if I feel I am getting stressed I kind of centring myself, follow my breathing, and watch, er, and then I just feel as if, phewww, stress [indicates with hands that stress disappears]” (care partner two).

The theme usage integrates quantitative and qualitative evidence and highlights dialectical tension in the participants use of online MBI. The complex and contradictory picture shows how stroke care partnerships used online MBI, whilst not using online MBI. Specifically, it appears stroke survivors are more eager to use online MBI, but tend to use it as a coping strategy and not as recommended in most protocols (Santorelli et al., 2017). Likewise, the analysis of interview data corroborates the quantitative evidence and suggests care partners did not fully use online MBI in the study. This variation and complexity creates dialectical tension in the usage theme.

8.7.3 Togetherness

This subordinate theme conceptualises relational dimensions within the analysis and explores the different ways participants worked together and supported each other. Initial quantitative analysis revealed all stroke care partnerships had
high levels of mutuality throughout the study (Section 8.4 on page 235), which suggests the participants had positive reciprocal relationships with their partner (Pucciarelli et al., 2016). The consistently high mutuality reported on the Mutuality Scale (Archbold et al., 1990) highlights the togetherness of the participants and forms one side of dialectic. The high level of mutuality observed in the quantitative data was echoed by one stroke care partnership during a qualitative interview.

“We call ourselves team [surname] … [laughs]” (stroke survivor four).

“I agree it [the relationship] has been good to begin with” (care partner four).

“If anything, I would say the one thing we have got is we are both willing to compromise, but sometimes that actually gets in the way. You are sitting there: what would you like to do, I don’t know what would you like to do [laughs]?” (stroke survivor four).

This sentiment was shared by another stroke survivor who also reported a good level of mutuality prior to starting the study and during the study.

“I know, I know as husband and wife you obviously support each other hopefully in what you do” (stroke survivor one).

In some cases, having to face adversity together after the stroke has strengthened the relationship.

“Then suddenly the stroke, it took away your independence for a long time didn’t it. But it was yeah, this might sound strange, but it was nice in a way because you get that real closeness where, I suppose it might work other ways for other couples, but I found it was a real, I don’t know, it was nice to need each other that much in some ways” (care partner five).

Whilst this care partnership reported that the necessary changes to work following the stroke had resulted in the family spending more time together and had an unexpected positive impact on the relationship.
“We see a lot more of each other because I was working away from home a lot. I don’t think that’s been a problem” (stroke survivor two).

“I think it, we’re getting more of a family life. OK, you are not getting the same financial benefits, but we have got more of a family life” (care partner two).

The experience of living with stroke also appears to have resulted in some care partners being more attentive and helping the stroke survivor live with stroke.

“One thing I would say is I am probably a lot more mindful about [wife] now, when I am doing things. So er, if we are planning something. I mean I got upset on Saturday because when we were coming back, and I had been wanting to have a drink at the [sporting event] and it just didn’t pan out that way and coming home, it just seemed no matter what decision you took, it seemed to be the wrong one to get home and then [wife] was tired, sore, it was raining. And that, I got upset and angry with myself” (care partner four).

This part of the analysis highlights the strong interpersonal connection within the care partnerships prior to the study and mirrors the quantitative findings. The dialectic of togetherness when using online MBI represents the experience of stroke care partnerships being in relationships with high mutuality and commencing the study together, whilst also experiencing some separation when using MBI. Although, the separation appears to be predominantly physical and not emotional.

“No we didn’t, we didn’t, we never actually sat down and used it at the same time” (stroke survivor two).

“No. We kind of done it separately” (care partner two).

“Aye, so when I got up in the morning I’d do it, because I get up at six o’clock in the morning and they [their care partner] lie in their bed til …” (stroke survivor two).

“No I am not an early riser, I would rather stay up until later at night and do something” (care partner two).
The pattern of practising apart was the norm and evident with all care partnerships. On one occasion the care partnership was very separate and apart when learning mindfulness.

“We did the work, we always worked separately, and we did have some chats, what each other was doing and what we thought of it. So I think it is definitely beneficial to have somebody, just to kind of bounce off each other, how you felt about it” (care partner three).

“We didn’t do it together as such, because I didn’t get that much out of it, I don’t have any feelings about doing it alongside each other. We didn’t really discuss it much did we?” (care partner five).

So the first part of the dialectic reflects the fact participants were together prior to the study and that the stroke had made them closer in some ways. The mutuality evident in the care partnerships appears to have contributed to them becoming involved in the study and motivated them to learn MBI together. However, once the study started it appears the stroke care partnerships completed the course apart and not with their care partner. Superficial interpretation of this might suggest participants completed the course as individuals alongside each other, but it appears the interpersonal dimension was more nuanced.

“I think so because, you know [husband] didn’t really do the course as much as I did, but he was there at my side. Erm, so I was able to tell him how things were going, what I had been doing …” (stroke survivor four).

“Well it was good because I was able to ask my dad, have you done this exercise, oh I am away behind, so we were kind of comparing where we were and what we were doing and we would discuss the different exercises. What ones he liked. I couldn’t get to the 30 minutes of the body scan, so we used to just talk about that, 30 minutes was too long for me. We kind of discussed things like that, but I definitely think it is something, it has been a positive thing to do, because we know when my dad did do it is being helpful, it was helpful” (care partner three).
These excerpts demonstrate the stroke survivors and their care partners did not complete the course simultaneously, but highlights how they were working together. This analysis shows the care partner’s role was primarily supportive and encouraging for the stroke survivor. It also shows both the stroke survivor and care partners thought having a partner was helpful when using online MBI.

“You need somebody, because if I was doing it on your own and your partner thought it was a load of mumbo jumbo and you went into the corner and practice your mindfulness, yes it would be hard. Because really you need to be quite open to say, I’m just going to do this. So if you are getting that support, it makes the whole process much easier” (stroke survivor one).

“I think for me in the sense of getting you less anxious, I actually recommended you doing mindfulness when you were in [place name]. I feel as if the fact that I knew a bit about it, I probably would never have suggested that to you before, if he had only done it himself, I might not have, well try doing your mindfulness. That helps relax you relax your mind takes you stress away, takes the anxiety away” (care partner two).

“I was still engaging with it because, I am consciously aware of [wife] all the time, erm and that’s it. Something might not work for me, but if it works for her, then I pay attention” (care partner four).

Another way care partners supported stroke survivors was by listening to their experiences and talking to them about MBI. This communication appears to have created opportunity to reflect on the experience of using MBI.

“Erm, I kept my wife [name removed] in the loop of where I was, she was part of it, she was asking me about the mindfulness and what I was doing at the time” (stroke survivor one).

“Well it was good because I was able to ask my dad … have you done this exercise, oh I am away behind … so we were kind of comparing where we were and what we were doing and we would discuss the different exercises. What ones he liked” (care partner three).
The interpersonal dimensions are subtle and complex and appear to represent a dialectical tension of togetherness when learning MBI. The care partnerships are together throughout the process of learning mindfulness, even though they are apart during exercises. The role of the care partner is important and involves offering support and providing opportunity to reflect on the use of online MBI. The role of the care partner appears to be more about support and encouragement, rather than doing the course simultaneously with the stroke survivor.

8.7.4 Change

The change theme illuminates a dialectic experienced by participants who continue to experience anxiety and depression symptoms (remaining the same), whilst also reporting change in their level of anxiety and depression symptoms (changing with MBI). The theme reveals the conflicting findings discovered in the study and highlights subtle changes in anxiety and depression symptoms. The dialectic was discovered when integrating the findings from the quantitative phase and using IPA (Smith, Flowers and Larkin, 2009) to explain and contextualise the experience of participants (Section 7.8 on page 194).

This theme takes cognisance of the quantitative results, which suggests some participants remained the same during the study, but also reflects change expressed during interviews. The continuing difficulties experienced by some participants presented in different forms. One participant reported anxiety symptoms due to external stress associated with their partner having health difficulties and being admitted to hospital.

“It is probably good in a way because of what has gone on since we last met, it has been more stressful, more anxiety, so that if I didn’t have this mindfulness going on it might have been worse” (stroke survivor one).

This participant acknowledges the continued stress and anxiety symptoms in their life, but also recognises the impact MBI is having. In this case it appeared MBI was helping, but the increase in external stress had resulted in the participant’s level of anxiety symptoms to remain the same. For this participant MBI was an important coping strategy for dealing with recent stressors.
However, MBI is also being used alongside other interventions, so it is difficult to determine whether MBI or one of the other interventions is helping. However, the participant themselves suggests MBI is helping.

“Mental health, I am struggling just now, but I am trying to get through as best I can and mindfulness I can see it helping me. So I can’t look at past examples and say I am worse or better but the way I am just now, I am trying to deal with it. The way things have got in my life, it is hard. You know, medication, counselling, and mindfulness have been a part of it” (stroke survivor one).

Another participant also reported money worries and pressure to earn an income continued to cause worry and stress, although, he acknowledges things have improved.

“I still get stressed. Things are tight financially erm, you know and that, the worry is that I am not getting any money coming in the house and I am the sole provider. So that’s there, at the same time I am not getting as stressed out as I would have been, you know two years ago” (stroke survivor two).

This participant quote highlights the dialectic in the change theme and highlights a complex and sometimes contradictory experience of using online MBI. A third participant also reported that they continue to experience panic attacks and worry about reoccurrence of seizures.

“Then the panic attacks come on, I might just be watching television and I get this feeling of, like, like something awful is going to happen. Early on they did, some did turn into seizures in some instances, so I am still nervous that they will do” (stroke survivor five).

Continued anxiety and depression symptoms in conjunction with minimal change for some participants suggest participants are remaining the same. However, remaining the same is only one side of the dialectic and participants also reported experiencing changes in anxiety and depression symptoms when using online MBI. One stroke survivor found online MBI could help resolve unhelpful thought processes and reduce anxiety symptoms when dealing with difficult situations.
“Yeah, mindfulness has helped with that thought process. Trying to break, if you are sort of having a bad spell, going into a mindfulness technique to try and break that train of thought, that has helped and I have had a couple of incidences when, it seems to have worked at that moment in time. My anxiety level just dropped totally dealt with the situation in the hospital and she got out later on that evening” (stroke survivor one).

Another care partner was also able to corroborate positive changes they had observed in the stroke survivor during the study, despite there being little evidence of improvement using the HADS (Zigmond and Snaith, 1983).

“I thought it really helped my dad when he was using it and so did my mum. We used to talk about it at the time, you used to do the body scan exercise remember? The thirty minutes one and you did that a lot and you started to change it, there were all different kinds of ones … and he did get something out of it … it made a difference” (care partner three).

A care partner also reported being more relaxed following online MBI, which suggest changes were occurring for participants despite little change being evident on the quantitative data.

“That just kind of, when I start it, everything else goes out your mind, you just concentrating on that, and I just find it so relaxing to get you into sleep. So even if you are more stressed about something, you know about something during the day and you go to bed and you mind starts racing, right stop that, think of the body scan, do the body scan. Usually by the time I have got to which ever part you about ready to drift” (care partner two).

The dialectic nature of this theme is captured by another stroke survivor who continues to experience high levels of anxiety symptoms sometimes, but uses online MBI techniques to help reduce anxiety symptoms and to stay calm. This quote highlights how using online MBI has had a big impact in their life, despite still experiencing difficulties with anxiety symptoms.
“Well from a physical and mental point of view it has had a big impact in my life. I would say that after my stroke I was more anxious about my health and the slightest thing and I was up, I was up [hospital name] getting checked out, since I started that has calmed down quite a bit. It has happened once last week, but I think there were other things in the background there, like my chest infection and things like that. As I said, it cascaded into me feeling the way I did” (stroke survivor two).

The above quote appears to suggest online MBI has helped them keep calmer, but doesn’t completely remove anxiety symptoms and might not work in certain highly stressed situations. This experience raises questions about the role of online MBI and whether the intention is to remove and eliminate difficulties or whether mindfulness is about acceptance and/or living with difficulties (Sauer et al., 2011). The ambiguity about the purpose and intention of online MBI in the context of the dialectic of change is evidenced by one care partnership who experienced improvements in mood and change their approach to dealing with difficulties. The dialogue between a stroke survivor and their care partner illustrates different perspectives about mindfulness and how participants can continue to experience difficulties, whilst also experiencing change.

“… erm, I think I have said I am happy quite a bit. I went through a phase, and I don’t remember this, I went through a phase and I kept telling [care partner] that apparently I wasn't happy” (stroke survivor four).

“For me I would say it is the mindfulness that has helped. As I said, instead of winding yourself up you are winding yourself down, and, and learning to accept your situation. Rather than letting it drive you into a bit of a depression or something and make you anxious you know. It has lifted you and keeping a plateau rather than go up or down” (care partner four).

This perspective suggests change from online MBI might not just be related to anxiety/depression symptoms, but also the level of mindfulness participants experience. Several participants were able to describe how their level of mindfulness had changed since using the course. It is important to notice the
change in mindfulness reported by participants are articulated in terms of
developing positive psychological wellbeing rather than the reduction of
distress.

“For myself, I would say it is more kind of a serenity and an
acceptance of your circumstances. I just get a peacefulness, you
switch off to everything else around you and you just you know. I
would not say for myself it is like concentrating on myself, but as I
say you just kind of sit there and you just accept where you are, in
that moment, erm everything around you just switches off and that is
how I find [certain location]” (care partner four).

“I don’t know really just, I do it just throughout the day type of thing,
just paying attention to flowers in the garden, bumble bees in the
lavender, yeah just paying attention to what is going on” (stroke
survivor four).

Conversely, one stroke survivor found little change in their mindfulness, even
though their mindfulness measurement showed a small increase.

“It hasn’t had that much affect in my life no. I have just dipped in and
out of it for a bit of interest. I haven’t been that focused on it no”
(Stroke survivor five).

The experience of mindfulness for participants appears to be closely linked to
increases in awareness and acceptance developed through using online MBI
together. This analysis reveals the complex and sometime contradictory
experience of stroke care partnerships using online MBI. Stroke care
partnerships continue to experience tension between: continued difficulties and
experiencing improvements; or being mindful and not being mindful. This
contradictory picture creates the dialectical tension evident in the analysis and
the theme of change. It also highlights the complex nature of using online MBI
and recovery within the context of stroke care partnership.
8.8 Data integration

Data integration is reported using a cross-case joint-display (Johnson et al., 2017) (Table 37 on page 262). The cross-case joint display presents a simplified summary of the main quantitative findings and integrates IPA themes (Smith, Flowers and Larkin, 2009). A simplified version is used to help interpretation of the findings and to facilitate cross-case analysis, however, a full and more detailed cross-case joint display is provided in the appendices for transparency (Appendix 15 on page 334) (Health Research Authority, 2019). The cross-case joint display is separated into stroke survivors and care partners and shows change between weeks zero and week eight for the main rating scales used in the study. The rating scale data is integrated with the themes of dialectical tension discovered in the IPA (Smith, Flowers and Larkin, 2009).

The cross-case joint display shows that most stroke survivors improved anxiety/depression symptoms (n=3) and increased mindfulness (n=4) during the study. It also showed several stroke survivor’s mutuality either increased (n=2) or stayed the same (n=2). However, not all stroke survivors showed improvements during the study with some stroke survivors showing worse anxiety/depression symptoms (n=1), decreased mindfulness (n=1), and decreased mutuality (n=1) during the study. The cross-case analysis showed improvement in anxiety/depression symptoms (n=3) and mindfulness (n=4) for the majority of care partners, but some care partners experienced a worsening in anxiety/depression symptoms (n=1) and mutuality (n=4). These mixed findings corroborate the dialectical tension evident with stroke care partnerships using an online MBI together. The complexity and variation within and between care partnerships make it difficult to form a clear picture about the findings. Using dialectical tension as a framework helps illuminate the clinical complexity and nuances associated with the findings (Fagerström and Bergbom, 2010).
Table 37: Cross-case joint display

<table>
<thead>
<tr>
<th></th>
<th>HADS-A</th>
<th>HADS-D</th>
<th>MAAS</th>
<th>MS</th>
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<tbody>
<tr>
<td><strong>Stroke survivors</strong></td>
<td>▲▲▲▲</td>
<td>▲▲▲</td>
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<tr>
<td><strong>Care partners</strong></td>
<td>▲▲▲</td>
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**Dialectical tension**

- Curiosity
- Usage
- Togetherness
- Change

**Key**

▲ = positive effect (i.e. better); ▼ = negative effect (i.e. worse); □ = no effect (i.e. stayed the same); HADS-A = Hospital Anxiety and Depression Scale: anxiety (Zigmond and Snaith, 1983); HADS-D = Hospital Anxiety and Depression Scale: depression (Zigmond and Snaith, 1983); MAAS = Mindful Attention Awareness Scale (Brown and Ryan, 2003); MS = Mutuality Scale (Archbold et al., 1990)
Chapter 9. Discussion

The previous chapter reported findings from a study exploring online MBI with care partners experiencing anxiety symptoms and depression symptoms after stroke (Chapter 7 on page 152). This discussion chapter provides an overview of the study and interprets the findings (Chapter 8 on page 225) in the context of wider literature (Parahoo, 2014). This chapter concludes by exploring strengths/weaknesses of the study, the implications for practice, the impact of the study, and the dissemination strategy.

9.1 The study

The mixed methods case study research used an explanatory sequential design (Section 7.5 on page 172). The study asked if it is feasible to study online MBI with stroke survivors and their care partners together; whether stroke survivors and their care partners find it appropriate to use online MBI together; if stroke survivors and their care partners experience changes in mindfulness after using MBI together; whether stroke survivors and their care partners experience interpersonal changes after using MBI together; and if online MBI has the potential to reduce anxiety symptoms and depression symptoms for stroke survivors and their care partners?

Five stroke care partnerships (n=10 participants) commenced Be Mindful (Wellmind Media and Mental Health Foundation, 2019) in 2019 and data was collected at weeks zero, four, and eight. Stroke survivors had experienced either ischaemic or haemorrhagic and lived with stroke between 2-9 years. The variable length of time since stroke is important because research suggests stroke survivors post-stroke adjustment changes and evolves with time (Pindus et al., 2018). A longitudinal qualitative study interviewed stroke survivors (n=55) and care partners (n=27) at several stages over the first three years post-stroke (Theadom et al., 2019). The study discovered participants had to adjust their recovery depending on their current level of functioning, support available, and any associated co-morbidities. The length of time since stroke is also relevant because stroke survivors and their care partners can feel abandoned by services and it is important to support stroke survivors at each stage of their recovery (Pindus et al., 2018).
All stroke survivors reported multiple difficulties following stroke and all had co-morbid mental health and physical health difficulties (Section 8.1.1.2 on page 229). The high rates of co-morbid mental health difficulties were expected because of the eligibility criteria used in the study and awareness of the prevalence of anxiety symptoms and depression symptoms after stroke (Section 7.1 on page 152). Research on the prevalence of post-stroke anxiety symptoms and depression symptoms does vary, but between 18-33% of stroke survivors are thought to experience either post-stroke anxiety symptoms and/or depression symptoms (Broomfield et al., 2014; Medeiros et al., 2020). Post-stroke anxiety symptoms affected all five stroke survivors in this study (n=5, 100) and only one stroke survivor was affected by post-stroke depression symptoms (n=1, 20%). The higher rates of anxiety symptoms amongst stroke survivors seen in this study may reflect a higher prevalence of post-stroke anxiety symptoms (Broomfield et al., 2014), but the self-selecting nature of the recruitment may have also resulted in certain people being more likely to volunteer than others (Parahoo, 2014).

The disproportionate number of highly educated white participants in the study does mirror what is often seen in mindfulness research and raises concerns about the representativeness of participants (Waldron et al., 2018). Research investigating publication trends in MBI literature suggest the diversity of study participants has increased between 2010-2019 (Toniolo–Barrios, Brasil and Pitt, 2020), but MBI research does still appear to lack diversity (Waldron et al., 2018). Possible strategies for improving diversity in MBI research include targeted recruitment, flexible MBI formats (e.g. online), and better representation of people from diverse communities in the MBI field (Chin, Anyanso and Greeson, 2019). It is also possible targeted recruitment and better stakeholder involvement with people from diverse background might be needed improve the diversity (Quay et al., 2017).

9.2 Feasibility

Evaluating whether it was feasible to study online MBI with care partnerships experiencing anxiety/depression symptoms after stroke was a key focus of the study. Feasibility of the study was determined by recruitment, retention,
completeness of data, and occurrence of adverse events (Table 21 on page 173).

9.2.1 Participant recruitment

Participant recruitment involved using social media (i.e. Twitter) and voluntary sector organisations (i.e. adverts, email dissemination, word of mouth) (Section 7.2 on page 153). The recruitment strategy used in this study was similar to other studies investigating MBIs with stroke survivors and/or their care partners (Jani et al., 2018; Langé, 2019). Previous research investigating different recruitment strategies for people affected by stroke examined recruitment data in a stroke rehabilitation trial (Pires et al., 2018). The rehabilitation trial used traditional methods (e.g. posters, medical professionals, websites) and social media platforms (e.g. Facebook, Twitter) to recruit participants and found most participants were recruited using social media or via a medical professional. There is limited research on the recruitment of care partners into MBI research, so there is limited evidence-base to use when making recruitment decisions. An example of MBI research exploring recruitment of care partners for people living with dementia used diverse recruitment methods and were able to enrol adequate care partners for their research (Whitebird et al., 2011). The recruitment strategies used in the MBI research achieved varied amounts of enrolment and give an indication about effective strategies for recruiting care partners into MBI research. The sample of care partners of people living with dementia was achieved through using health professionals (n=18, 23.2%), paid advertising (n=15, 19.2%), outreach (n=15, 19.2%), press (n=15, 19.2%), voluntary sector organisation (n=6, 7.7%), word of mouth (n=8, 10.3%), and unknown (n=1, 1.2) (Whitebird et al., 2011).

The recruitment strategy used in this study enrolled two-thirds of the people who enquired about the study and successfully achieved the intended sample size of five stroke care partnerships (Section 8.1.1 on page 225). The rate of recruitment was slower than expected and took approximately ten months (November 2018-August 2019), which raises questions about the feasibility of this recruitment strategy for a larger study. A recent systematic review examined the efficacy of recruitment into stroke rehabilitation RCTs between 2005-2015 and found studies enrol between one or two participants every
month per site (McGill, Sackley, et al., 2020). The recruitment rate in this study was about one participant per month or one stroke care partnership every two months. The rate achieved in this study is slightly below the average of one to two per month (McGill, Sackley, et al., 2020), but was achieved in the context of an unfunded PhD project and involved recruiting stroke survivors and care partners together in a care partnership.

Enrolling participants together in a care partnership is more challenging than recruiting stroke survivors and care partners separately, because one person might be more motivated than the other and both have to agree to participate (Quinn et al., 2010). It is also common for studies using MBI with people living with chronic conditions (including stroke) and their care partners together to offer participants the opportunity to attend with or without their care partner (Van Den Hurk et al., 2015; Marconi et al., 2016; Jani et al., 2018). However, this study was particularly interested in the partnership aspects of stroke survivors and their care partners using online MBI together, so it was important to only recruit care partnerships (Section 5.3 on page 133).

Achieving the intended sample size in this study suggests the recruitment strategy was appropriate for mixed methods case study research, but recruitment was slow and would need modified for an RCT or other group-based design. A larger study could potentially increase participant recruitment by using a bigger geographical catchment area. The recruitment strategy (i.e. social media, voluntary sector organisations) and online MBI used in this study are ideal for wide geographical recruitment. However, this study was geographically limited by having to visit the home of each care partnership on three occasions for consent and data collection (Section 7.6 on page 173). The practical and financial implications of multiple home visits with each care partnership were mitigated by limiting recruitment to Scotland and northern England. Limiting recruitment to Scotland and northern England prevented two potential care partnerships, who lived outside the catchment area, from participating in the study (Section 8.1.1 on page 225).

Gathering consent and data remotely using video conferencing technology (e.g. Zoom) would have enabled for a wider catchment area to be used, reduced costs (e.g. travel), and possibly increased recruitment (Reñosa et al., 2021).
Video conferencing technology has been shown to be acceptable for use in stroke research and when delivering MBIs to people affected by stroke (Johansson and Bjuhr, 2016). Although, evidence suggests a key aspect of successful recruitment and retention in stroke research is developing meaningful partnerships with study participants (Boden-Albala et al., 2015). So it is possible removing home visits may have limited opportunity to develop a partnership with participants and negatively affected recruitment and/or retention. Using a flexible approach with the option of either home visits and/or video conferencing would have increased flexibility and allowed for a wider catchment area to be used.

Another option to increase participant recruitment is to involve the National Health Service (NHS). The NHS is involved in stroke research and has contact with large numbers of potential participants. Involving the NHS in participant recruitment would require additional ethical approval from the NHS Research Ethics Committee (Health Research Authority, 2017), but would give access to a large number of potential participant who otherwise could be missed. Guidance aimed at increasing recruitment of stroke survivors into clinical research recommends involving medical professionals in the recruitment process and adopting a team-based approach to recruitment (Boden-Albala et al., 2015; Boxall, Hemsley and White, 2016). Involving medical professionals in the identification and referral of potential participants would possibly increase participant numbers and may reduce the bias sometimes seen when studies only include participants who self-select to participate (Guo et al., 2017; Pires et al., 2018). Another option would be to use NHS stroke registers to identify and invite potential stroke survivors into the research (Mullis et al., 2019).

Involving medical professionals and the NHS stroke registers would increase the reach of recruitment and possibly identify people who may have been missed with the recruitment strategy used in this study (Section 7.2 on page 153). However, this study was interested in those stroke survivors who live in the community and may feel abandoned by services and who could be overlooked if the recruitment strategy relied fully on medical professionals and the NHS (Clark et al., 2018; Pindus et al., 2018). Ideally recruitment would involve multiple pathways: social media, voluntary sector organisations, word of mouth, medical professionals, and the NHS. Although, using multiple
recruitment pathways in the same study makes it difficult to determine the success (or otherwise) of individual strategies and persisting with ineffective methods increases research waste and costs (Frampton et al., 2020).

Using social media to recruit participants was a key strategy in this study and involved posting a series of recruitment messages via Twitter (Section 7.2.1 on page 154). Twitter is a cost-effective way to recruit study participants, although, evidence supporting the use of Twitter in health research is limited (O’Connor et al., 2014). A systematic review exploring the use of Twitter in peer-reviewed health research (n=137) found limited evidence of Twitter being used as a recruitment method (n=9) (Sinnenberg et al., 2016). A similar scoping review examined the use of social media for recruitment into medical research (n=30) and found Twitter was an effective tool recruitment tool, but that it was never used by itself and normally used in conjunction with Facebook (Topolovec-Vranic and Natarajan, 2016).

Facebook is another popular social media platform that is used to recruit participants into medical research (Topolovec-Vranic and Natarajan, 2016). A systematic review examined published medical research (n=35) using Facebook to recruit study participants and found it was an effective recruitment strategy and able to access younger and/or harder to reach populations (Christopher, Stevelink and Fear, 2017). However, using Facebook does have cost implications because it is often necessary to pay for adverts to be promoted (i.e. boosted) and the costs involved may limit use in unfunded research (Herbell and Zauszniewski, 2018). It is also necessary to consider whether recruitment via Facebook and/or Twitter is appropriate for people affected by stroke.

A research study recruiting stroke survivors found Twitter and/or Facebook were acceptable recruitment methods and stroke survivors were more likely to be recruited using Facebook (n=29/43, 67.4%) compared with Twitter (n=1/43, 2.3%) (Pires et al., 2018). Another study examined the effectiveness of both Facebook and Twitter at recruiting stroke care partners into an online study (Herbell and Zauszniewski, 2018). Again the study showed participants who completed the study (n=230) were more likely to be recruited via Facebook (n=220, 95.7%) than through Twitter (n=10, 4.3%) (Herbell and Zauszniewski,
This evidence suggests social media may be appropriate for recruiting research participants affected by stroke and Facebook might be more effective than Twitter for recruiting people affected by stroke (Herbell and Zauszniewski, 2018; Pires et al., 2018). Although, neither study recruited care partnerships and outcomes may change when recruiting stroke survivors and their care partners together. On reflection, using Facebook alongside Twitter and other traditional recruitment methods (e.g. voluntary sector organisations) does appear to be an effective strategy and may have improved recruitment in this study.

Using varied recruitment pathways and increasing the geographical area of recruitment is no guarantee the recruitment of people affected by stroke would be improved. A small UK-based qualitative study interviewed nurse researchers (n=12) about their experiences of recruiting stroke survivors into research (Boxall, Hemsley and White, 2016). The study discovered a number of factors that can influence the recruitment of stroke survivors into research. Factors thought to increase recruitment include endorsement by others (e.g. medical professional, relative); availability of a partner; skills, competence of the nurse researcher; and the perceived benefits of participating. Factors thought to decrease recruitment include the level of post-stroke impairment; mental health difficulties; paternalism; poor participant information; and/or restrictive eligibility criteria (Boxall, Hemsley and White, 2016). Another qualitative study interviewed stroke researchers (n=20) from different countries (n=13) and found many of them experienced difficulty recruiting stroke survivors into research studies (McGill, McGarry, et al., 2020). Common difficulties reported by the stroke researchers include poor decision making about recruitment, difficulties motivating recruiters, and excessive research governance. This research shows there are multiple factors that may affect recruitment in stroke research (Boxall, Hemsley and White, 2016; McGill, Sackley, et al., 2020). However, the evidence focuses on the perceptions of stroke researchers and does not consider the difficulty of recruiting stroke survivors and their care partner together in a partnership.

An alternative approach and possible solution for the challenges of recruiting large numbers of people affected by stroke is to use N-of-1 trial designs. N-of-1 trials are used to test hypotheses with an individual participant(s) using
repeated measures over a period of time (McDonald et al., 2017). N-of-1 trials can contain all the necessary elements of a true experiment (e.g. manipulation, control, and randomisation) and are capable of producing high quality evidence and informing clinical guidelines (Bradbury, Avila and Grace, 2020). Using an N-of-1 trial could reduce some of the bias commonly seen with case study methods and may increase validity of findings (Margolis and Giuliano, 2019). Despite the appeal of N-of-1 trials they do require repeated measurement and the possibility of excessive burden may be a factor for some participants (Davidson et al., 2015).

The IPA (Smith, Flowers and Larkin, 2009) produced a subordinate theme: curiosity. This theme illustrates the dialectical tension within the findings and highlights the fact some participants wanted to access online MBI and others were less interested. The curiosity theme is similar to the theoretically-based dialectic theme of wanting vs non-wanting, which is thought to exist within mindfulness practice (Sauer et al., 2011). Although, the wanting vs non-wanting theme relates to the extent people strive and seek to achieve a certain state when practising mindfulness (Sauer et al., 2011). In contrast, the theme of curiosity discovered in this study highlights the feasibility and appropriateness of recruiting stroke care partnerships into a study using online MBI.

9.2.2 Participant retention

Nine participants (n=9, 90%) completed the study and one participant (n=1, 10%) withdrew from the study due to ill health (Section 8.1.1 on page 225). The participant who withdrew from the study was a care partner, but also living with their own chronic condition (Appendix 21: Case vignettes on page 340). Poor ill health is a common reason for attrition in MBI research, but can create bias in the results because only those people who remain in the study are included in the analysis (Nam and Toneatto, 2016). Attrition rates in MBI research do vary, with a large meta-analysis (n=209 studies) suggesting attrition of approximately 16.25% (Khoury et al., 2013) and a more recent review (n=22 studies) suggesting attrition of 29% (Nam and Toneatto, 2016). Both these figures are higher than the 10% attrition experienced in this study and suggests the retention rate for this study was better than often seen in MBI research.
Research shows longitudinal studies with high retention (>80%) rates use different strategies to help to promote retention (e.g. reminders, study visits) (Abshire et al., 2017). Several strategies were incorporated into the study, which may have enhanced participant retention. The retention strategies included using home visits for data collection, having all visits completed by the same person, and arranging appointments at a convenient day/time for participants. These strategies may have helped achieve a retention rate above what is typically seen in MBI research, but the sample is small and the retention rate is unlikely to be maintained with large numbers of participants.

9.2.3 Data collection

An important aspect of feasibility is whether the data collection methods were appropriate, necessary, sufficient for the study (Arain et al., 2010). The study collected data at weeks zero, four, and eight and aligned with the quantitative-qualitative explanatory sequential design (Creswell and Clark, 2018). The data collection combined automated PSS (Cohen et al., 1983), GAD-7 (Spitzer et al., 2006), and PHQ9 (Kroenke, Spitzer and Williams, 2001) embedded in Be Mindful (Wellmind Media and Mental Health Foundation, 2019). Data collection also involved timetable use of the HADS (Zigmond and Snaith, 1983), MAAS (Carlson and Brown, 2005), and MS (Archbold et al., 1990) at weeks zero, four, and eight of the study. Qualitative interviews were also completed with each care partnership at week eight of the study.

The self-report quantitative data collection measures appear appropriate in this context because only one stroke survivor needed assistance completing their questionnaires and this was provided by the care partner. The data collection was also adequate because they answered the study questions and is similar to what has been used by other researchers (Lawrence et al., 2013; Querstret, Cropley and Fife-Schaw, 2018; Singh, 2018). One area where data collection was inadequate was in the recording of home practice. Documenting home practice gives an indication of how much someone has been using MBI and is important because home practice is associated with positive treatment outcomes (Parsons et al., 2017). Documenting practice would have given a better insight into participants use of MBI, but would not have necessarily helped establish the quality of the practice being completed (Davidson et al.,
Monitoring both quantity and quality of home practice is important because both time spent and quality is linked to outcomes (Goldberg et al., 2019). The data collection strategy in this study could have been improved by incorporating a practice log for recording the method (e.g. sitting), duration (e.g. 30 minutes), frequency (e.g. every morning), and quality (e.g. the experience of mindfulness) of home practice (Parsons et al., 2017). The Practice Quality Mindfulness (PQ-M) measure provides a brief (1-2 minutes) validated tool that could be used to measure the quality of mindfulness practice (Del Re et al., 2013). The PQ-M would be useful addition to this study because it has moderately strong convergent validity with the Mindful Attention Awareness Scale (MAAS) (Brown, Ryan and Dovidio, 2003). Although, the validation of the PQ-M was established using a small (n=19) non-clinical sample and further work is need before being confident in the results with clinical populations (Del Re et al., 2013).

It was anticipated the scheduled timing of data collection would allow for pre/post and one-month follow-up data collection, but the slower than expected completion rates for some participants (n=8, 80%) extended the treatment phase and reduced the follow-up period (Section 7.6 on page 173). The length of time taken to complete Be Mindful was similar to another study with stroke survivors (Singh, 2018) and changed the data collection to a pre/post intervention for most participants (n=8, 80%). The slower than expected rate of completion by participants suggests a different and/or more flexible data collection schedule would be advisable in future research using Be Mindful (Wellmind Media and Mental Health Foundation, 2019).

Combining scheduled data collection at weeks zero, four, and eight with automated pre/post and one month follow-up was also problematic (Section 7.6 on page 173). The timetabled data collection of the HADS (Zigmond and Snaith, 1983) MAAS (Carlson and Brown, 2005) and MS (Archbold et al., 1990) was problematic because it was fixed and not altered to allow for slower than expected completion rates. Conversely, the automated PSS (Cohen et al., 1983), PHQ9 (Kroenke, Spitzer and Williams, 2001), GAD-7 (Spitzer et al., 2006) allowed for the slower than expected completion, but did not capture non-completers and/or those participants who did not complete the final automated data collection (n=6, 60%). The low completion rate and automated data
collection resulted in a large amount of missing data and made it difficult to measure potential for effectiveness using the automated system (Section 7.6.5 on page 179).

9.2.3.1 Missing data

A full data set for this study would have required complete unit-level data (n=180) and complete item-level data (n=2100) (Table 31 on page 231). Scheduled data collection experienced unit-level (n=9) and item-level missing data (n=180), which was caused by a combination of human error and participant drop-out. The automated data collection experienced unit-level (n=36) and item-level missing data (n=338), which was due to participants drop out, some participants not completing the intervention and/or choosing not to complete the data collection. It appears the paper-based scheduled data collection improved completeness of the data compared to the automated system, but the reason for this would need to be fully investigated before drawing firm conclusions. This observation differs from research comparing automated and scheduled paper-based data collection, which found automated data collection significantly improved completion rates (p <0.001) (Bond et al., 2020). One problem with both scheduled paper-based and automated data collection systems was missing data.

A review of RCTs published in quality medical journals during 2013 discovered 95% (n=73) of studies reported missing data and missing data affected between 0-70% (median 9%) of participants (Bell et al., 2014). Another systematic review of RCTs found a similar number of studies (96%; n=51) experienced missing data in a primary outcome, but found a much higher median (44%) of participants were affected (Sullivan et al., 2017). These papers suggest missing data is common in clinical trials, with roughly 95% of studies experiencing missing data (Bell et al., 2014; Sullivan et al., 2017). However, the different ways of reporting missing data make it difficult to compare the amount of missing data in this study with what is usually seen in clinical trials. In total two participants (10%) experienced unit-level missing data and eight participants (80%) experienced item-level missing data. The combined figures for all unit-level missing data and all item-level missing data within the study were 25.0% (n=45 units) and 24.7% (n=518 items) respectively. Although, removing automated data from the final report reduced this figure to 10% (n=9 units;
n=132 items). These figures would appear to be higher than those typically seen in clinical trials (Bell et al., 2014; Sullivan et al., 2017), but inconsistency in reporting makes it difficult to draw any firm conclusions. The amount of missing data in this study may have been reduced by reducing the amount of data being collected, better researcher preparation to avoid human errors, and robust monitoring of missing data during the study (Little et al., 2012).

### 9.2.3.2 Adequacy of qualitative data

It is important to consider whether qualitative data collection methods gathered enough data to answer the questioned posed in the study and whether data adequacy was achieved (Vasileiou et al., 2018). Adequacy of data is evaluated in terms of quantity and richness of data, but there is no agreed threshold established to decide whether data adequacy is acceptable (Glenton et al., 2018). Data will also vary depending on the topic, so data adequacy should always be contextualised to a particular study and evaluated on its own merit (Vasileiou et al., 2018). The quantity of data can be evaluated in terms of the number of interviews/participants and the amount of data collected from these interviews (Glenton et al., 2018). Qualitative data was gathered during in-depth interviews (n=5) with nine participants at week eight of the study. One care partner declined to be interviewed due to ill health, but all other participants provided qualitative data (Section 8.1.2.1 on page 230). This was an inclusive and comprehensive data collection strategy, which captured a range of experiences from every stroke care partnership. It was important to interview all available participants regardless of engagement to ensure we captured a range of experiences and not just those of people who completed (Stjernswärd and Hansson, 2020). However, the qualitative data was only collected at one-time point, so the quantity of data is limited to what was available at week eight of the study. An alternative approach would have been to gain a longitudinal perspective by completing repeated interviews at different stages in the study, but this adds further complexity to the analysis process (Fadyl et al., 2017) and does not align with the explanatory sequential design (Ivankova, Creswell and Stick, 2009). In hindsight, in-depth interviews should have also been completed at week four because this could have given useful insight into how the experience of online MBI evolved for stroke care partnership during the study (Fadyl et al., 2017).
The length of interview is an important consideration in IPA (Smith, Flowers and Larkin, 2009) because of the importance placed on the richness of data and concern short interviews might lack depth. Interviews lasted 40-56 (mean 44, SD 6) minutes after consent had been secured, which is just below the normal range of 45-90 minutes of IPA interviews (Smith, Flowers and Larkin, 2009). Although, not all IPA interviews fall within 45-90 minutes and some published studies report interview lengths similar to those achieved in this study (Tutelman et al., 2019). It is also debatable whether interview length is a worthwhile metric for evaluating data quantity because factors such as rate of speech, succinctness of responses, and the amount of focus within the interview can all affect the length and richness of data (Ogden and Cornwell, 2010). Evidence also suggests it is also possible to achieve sufficient quantity and richness of data without any interviews and by using alternative methods (e.g. email) (Brocki and Wearden, 2006). It can also be preferable when interviewing stroke survivors to keep interviews short in length to reduce the participant burden and avoid excessive participant fatigue (Juth et al., 2018).

Length of interview is one metric for determining richness of data, but does not always give a true indication of data richness. Research investigating factors which predict richness in qualitative interviews discovered open questions, framed in the past or present tense, are most helpful in gathering rich data (Ogden and Cornwell, 2010). The interview schedule (Appendix 17 on page 336) aligned with these recommendations, so was appropriate for gathering rich data. The explanatory sequential design of this study and the use of qualitative interviews added contextual richness to the initial quantitative data (Guetterman, Fetters and Creswell, 2015). The data was also sufficiently rich to allow for thick description of the experience and to illuminate the complexity and dialectical tensions within the phenomenon (Given, 2012). This study appears to have acceptable adequacy of qualitative data for this particular study, because it captures insights from all stroke care partnerships, is sufficiently rich to reveal conceptual content, and illuminate’s dialectical tensions experienced by participants.
9.2.4 Adverse events

The study experienced one serious adverse event, which involved a care partner and the exacerbation of an pre-existing health condition (Section 8.1.3 on page 232). This event became known when trying to arrange the final visit at week eight of the study. Once notified about the AE it was important to consider the seriousness, causality, and expectedness (Senior, 2015). This AE was considered a SAE because it resulted in hospitalisation (International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use, 1996). However, the SAE was thought to be unrelated to the intervention because it involved a pre-existing condition and was an unexpected consequence of MBIs (Senior, 2015). After the hospitalisation the care partner discontinued their use of online MBI and data collection, but continued to support their partner who was still engaged in the study and using online MBI. Neither member of the care partnership attributed the occurrence of the SAE to Be Mindful (Wellmind Media and Mental Health Foundation, 2019).

It is important to be cautious when considering the safety of MBIs because adverse event reporting is inconsistent (Wong et al., 2018). A systematic review exploring the safety of MBIs discovered very few RCTs monitor adverse events, which raises concerns about transparency and participant safety (Wong et al., 2018). Two online surveys have been completed to investigate unwanted effects associated with meditation-based interventions. The first online survey (n=342) discovered 25.4% (n=87) of participants experienced some form of unwanted effects when meditating, although, most unwanted effects were brief and did not require medical attention. The survey found unwanted effects were more likely when meditating alone and when meditation lasted longer than twenty minutes (Cebolla et al., 2017). The second larger online survey recruited participants (n=1232) with two months’ experience of meditation practice and asked them about unpleasant meditation experiences. This study found 25.6% (n=315) participants reported unpleasant meditation-related difficulties. The study found unpleasant meditation experiences were more common for people with negative thought processes, who were engaging in certain meditation practices (e.g. vipassana), and for those who had attended a meditation retreat previously (Schlosser Id et al., 2019). Adverse events can occur with
meditation-based intervention, but these appear less likely to occur when practicing MBIs because of the short duration, lower intensity, and lack of insight-based meditation (Cebolla et al., 2017; Schlosser Id et al., 2019).

9.3 Appropriateness

The appropriateness of online MBI for stroke care partnerships experiencing anxiety symptoms and depression symptoms was evaluated by considering recruitment, adherence, and use of Be Mindful (Wellmind Media and Mental Health Foundation, 2019). The recruitment rates indicate some stroke care partnership saw the intervention as appropriate for themselves and other people affected by stroke (Section 9.2.1 on page 265).

Recruitment to the study was usually driven by stroke survivors, who tended to be the first person from the stroke care partnership to enquire about the study. This suggests stroke survivors were more likely to instigate enrolment to the study, but either person in the partnership might initiate accessing online MBI. The difference in help seeking between stroke survivors and care partners may partly be explained by the different level of psychological distress experienced by each group at the start of the study. HADS (Zigmond and Snaith, 1983) data indicates all stroke survivors (n=5) and none of the care partners (n=0) had clinical levels of psychological distress at the start of the study. This difference in baseline global psychological distress might have been a factor in stroke survivors seeking help for anxiety/depression symptoms. It is also possible a perceived lack of community-based rehabilitation for stroke survivors and feelings of abandonment might have also motivated stroke survivors to seek out opportunities for support (Lutz et al., 2011).

The appropriateness of online MBI for stroke care partnerships is influenced by participant’s views on MBI and also their views on online delivery. Stroke care partnerships opinion towards MBI varied and appears to represent a dialectic between being curious whilst not being curious. Some participants saw MBI as a possible solution for their mental health difficulties and something they could use as a coping strategy when highly stressed (Section 8.7.2 on page 247). The perception of MBI being a useful coping strategy for psychological distress appears a common experience and is often reported in the literature (Schanche
et al., 2020). However, not everyone thought it would be useful and some care partners did not think it was something they would use. Interestingly no participants thought MBI was inappropriate and/or unsuitable for stroke care partnerships, but the degree of appropriateness varied within and between stroke care partnerships.

These findings add to other research investigating the appropriateness of MBI for people affected by stroke. A recent qualitative study investigated the appropriateness of brief MBSR taster sessions with stroke survivors (n=21) and their care partners (n=7) (Jani et al., 2018). The study found the majority of participants had a positive experience with MBI, but a few did have difficulty maintaining concentration and thought shorter sessions may help. This research provides useful evidence about the appropriateness of MBI for care partnerships affected by stroke, but used a single face-to-face group session and not all participants were in care partnerships. The evidence of online MBI being appropriate for stroke care partnerships discovered in this study is promising and adds to the literature on the subject. Existing research demonstrates people affected by stroke might want to attend face-to-face MBI in a partnership (Henderson et al., 2017; Jani et al., 2018) and are willing to engage in online MBI (Singh, 2018; Langé, 2019). Perceptions about online MBI were uncovered in the study and form part of the wanting and not wanting dialectic (Section 8.7.1 on page 243). The IPA (Smith, Flowers and Larkin, 2009) demonstrated how some participants liked the flexibility of online MBI, whilst others thought face-to-face group MBI might be preferable. The difference in opinion between online and face-to-face delivery in the study reflects participant’s choice and echoes the findings from a survey exploring individual preferences for receiving MBI. A recent survey explored participants (n=500) preference for MBI delivery and found the majority wanted individual (n=384, 77%) or online (n=356, 71%), and that group MBI was the least popular (n=245, 49%). The most common first choice was online (n=212, 43%), then individual (187, 38%), and finally group MBI (n=97, 20%) (Wahbeh, Svalina and Oken, 2016). This survey highlights the variation in peoples’ preferences for receiving MBI, but indicates online MBI was the preferred option for most participants. It is also important to remember the survey on preference for MBI delivery was completed before COVID-19 and it is unknown whether people’s
views about their preferred way of receiving MBI have changed since the pandemic. Holmes et al. (2020) predict a huge change in how services are delivered after COVID-19 and it is possible more people (and services) will use online delivery in the future.

It is also important to consider the type of online MBI and whether it is better for the MBI to be delivered synchronously/asynchronously, and with or without a facilitator/teacher (Toivonen et al., 2017). In this study participants appeared to like the facilitated nature of the MBI with several participants referring to the recorded therapist by name during the interviews. Participants also appeared to like the fact it was an asynchronous and could engage at a time and pace of their choosing. These findings appear to echo another survey which asked participants (n=646) about their attitude towards online interventions and found the majority (n=523, 81%) were willing to use online intervention, but most preferred guided (n=252, 39%) over non-guided interventions (n=124, 19.2%) (Apolinário-Hagen et al., 2018). Although, a large systematic review of online MBIs for people with physical health conditions discovered little difference in clinical outcomes between synchronous/asynchronous and supported/un-supported MBIs (Toivonen et al., 2017).

The appropriateness of online MBI was also evaluated in terms of adherence and the extent to which participants engaged with MBI. Measuring adherence to online interventions by counting the number of completed module is common and particularly useful when interested in psychological outcomes (Donkin et al., 2011). By week eight of the study four stroke survivors and zero care partners had completed the course (Section 8.2 on page 232). The low rate of completion seen by care partners in this study appears similar to that found in another study using online MBI with stroke care partners. Langé (2019) adopted a similar recruitment strategy to this study and successfully enrolled 15 stroke care partners into a feasibility study, but only five completed the intervention. It is difficult to know what factors might affect adherence with online MBI, but it appears to be influenced by participant motivation, conscientiousness, and trait mindfulness (Forbes, Gutierrez and Johnson, 2018).

Research evidence suggests only 11.1% (n=5) of participants complete Be Mindful (Wellmind Media and Mental Health Foundation, 2019) in four weeks
and it can take eight weeks for 95.5% (n=43) of participants to have completed the online MBI (Querstret, Cropley and Fife-Schaw, 2018). Likewise, Singh (2018) found stroke survivors (n=2, 100%) averaged more than nine weeks to complete Be Mindful (Wellmind Media and Mental Health Foundation, 2019). A recent study using Be Mindful (Wellmind Media and Mental Health Foundation, 2019) with people experiencing occupational health difficulties (n=87) tried to increase completion by offering vouchers (£50) to participants, but they still reported an average completion rate of 6-7 weeks and it took a full 12 weeks for all participants to complete the course (Querstret, Cropley and Fife-Schaw, 2017). This study highlights how incentives can be used to enhance completion rates, but also suggests the amount of time needed for all participants to complete the intervention was beyond the eight-week timeframe used in this study.

Even with most stroke survivors (n=4) completing the MBI, an interesting feature of the IPA (Smith, Flowers and Larkin, 2009) was that they were using MBI intermittently and not as recommended in the MBSR/MBCT protocols (Teasdale et al., 2000; Santorelli et al., 2017). The amount of home practice is important because there is evidence to suggests more home practice is linked with better outcomes for participants (Parsons et al., 2017). A recent systematic review of MBI studies (n=43) found the average amount of home practice to be thirty minutes most days, although, the amounts of home practice was highly variable (95% CI 60-69%) (Parsons et al., 2017). The duration of time spent practicing mindfulness is important, but quality of practice also matters (Davidson et al., 2015). Goldberg et al. (2019) examined the role of quality in mindfulness outcomes and found practice duration, improved practice quality, which improved self-reported mindfulness. Although, a recent mixed methods study of Scottish students (n=269) looked at patterns of MBI practice when using an app and found intermitted practice, rather than daily practice, was most beneficial (Clarke and Draper, 2020). This unexpected results challenges conventional thinking that daily MBI practice is best (Parsons et al., 2017) and raises questions about how we make online MBIs most effective. There remains uncertainty about the advice and guidance to offer people using online technology and apps to access their MBI (Toivonen et al., 2017; Clarke and Draper, 2020).
9.4 Mindfulness

The mindful attention awareness scale (MAAS) (Brown, Ryan and Dovidio, 2003) data revealed most participants experienced increased mindfulness during the study, however, improvements in mindfulness were not statistically significant. Comparing MAAS results with normative data for non-clinical community adults suggests participants began with lower than expected levels of mindfulness, but achieved mindfulness levels higher than normative data by week eight (Brown and Ryan, 2003). The findings in this study are consistent with results from other studies, which found changes in mindfulness can occur after only two weeks of face-to-face MBI (Baer, Carmody and Hunsinger, 2012) and after four weeks of online MBI (Querstret, Cropley and Fife-Schaw, 2017, 2018).

It was important to consider changes in mindfulness because few studies have evaluated mindfulness with care partnerships using MBIs (Section 4.5.6 on page 95) and increased mindfulness is thought to be an important mechanism for change (Shapiro et al., 2006; Baer, Carmody and Hunsinger, 2012; Querstret, Cropley and Fife-Schaw, 2017). Measuring mindfulness is challenging because of the different conceptualisation used and the subjective experience of mindfulness (Davidson et al., 2015). Concerns about the subjective nature of mindfulness and the use of self-report questionnaires in mindfulness research has highlighted the need to develop objective measures for mindfulness (Wong et al., 2018). Levinson et al. (2014) have developed a valid and reliable objective behavioural measure of mindfulness. The measure is called ‘breath counting’ and involves the person being assessed counting their breath for 20 minutes and pressing different keys depending whether they take a breath or their mind wonders (Wong et al., 2018). Breath counting has been shown to differentiate between meditators and non-meditators and correlates well with self-report mindfulness measures (Levinson et al., 2014).

Understanding the impact of MBIs on mindfulness is further complicated because some studies with stroke survivors do not measure mindfulness (Lawrence et al., 2013; Lazaridou et al., 2013). The limited use of mindfulness measures in stroke research is due partly to the lack of validated measures for people affected by stroke (Park, Reilly-Spong and Gross, 2013; Salter et al.,
Also measuring mindfulness is a contentious issue because it is driven by a positivist Western perspective and seen by some as being inconsistent with the Buddhist origins of MBIs (Sauer, Walach and Schmidt, 2013). However, not measuring mindfulness and/or using non-validated measures makes it difficult to determine if changes in mindfulness occurred and whether changes in mindfulness influenced clinical outcomes (Davidson et al., 2015).

Sauer, Walach and Schmidt (2016) suggest qualitative data can provide a more nuanced interpretation of change and provides a useful adjunct to quantitative measures. Lundh (2020) echoes this assertion by highlighting the importance of experimental phenomenology in MBI research and stressing the value of understanding the subjective nature of using MBIs to improve mood. This mixed methods study collected qualitative data, which appears to support the quantitative evidence and suggests participants experienced changes in their mindfulness and these changes resulted in improved mood.

The theme where the changes in mindfulness are most evident is in the theme change (Section 8.7.4 on page 256). The change theme illustrates how some participants developed greater levels of awareness and acceptance by using online MBI together. The change theme highlights the sometimes contradictory experiences of using online MBI and appears to share similarity with the wellness theme developed during the systematic review stage of this thesis (Section 4.5.12.3 on page 113). However, the change theme developed in this study extends this understanding by highlighting tension that exists when using online MBI in a care partnership.

Change with online MBI illustrates the subtle and sometimes inconsistent experience of becoming mindful and improving wellness. It appears change with online MBI may also reflect an evolving dynamic process, which may change over a period of time as people become more (or less) mindful (Section 4.5.12.2 on page 112). A meta-ethnography (n=14 studies) discovered participants learning MBI go through distinct phases: perceived safe certainty, safe uncertainty and grounded flexibility (Malpass et al., 2012). Wider literature also appears to support the interpretation that MBIs can manifest as dialectical tension. Sauer et al. (2011) wrote a theoretical paper suggesting dialectical tension exist within MBIs. Dialectical tension is thought to exist in MBIs as:
activity vs passivity; wanting vs non-wanting; changing vs non-changing; non-judging vs non-reacting; active acceptance vs passive acceptance. The five different dialectical positions articulated by Sauer et al. (2011) illuminate the dialectical tensions that exist with mindfulness, but were not supported by empirical evidence or developed in a clinical context. The dialectical tension discovered in this study adds empirical evidence from a clinical perspective and supports the understanding that dialectical tension can exist when using MBIs.

9.5 Mutuality

Research investigating MBIs with care partnerships is limited and inconsistent (Henderson et al., 2017; Jani et al., 2018; Parkinson et al., 2019). Some existing research suggests learning MBI in a care partnership can have a positive impact on the relationship (Smith et al., 2015). There is also evidence to suggest using MBI can improve relationship quality without having to attend in a care partnership (Moran, 2018). It is also possible relationship quality may increase organically after stroke and without using MBIs (Simeone et al., 2016).

Results in this study suggest mutuality increased for some participants when using online MBI together. Although, improvements in mutuality were inconsistent and some care partners experienced a worsening of mutuality (Table 34 on page 236). The improved mutuality observed with a minority of participants (n=3, 30%) was not statistically significant and methodological issues make it unclear whether online MBI produced changes in mutuality for stroke care partnerships.

The mutuality scale (MS) is validated for stroke survivors and their care partners (Pucciarelli et al., 2016), which suggests it is appropriate for the study. However, all participants scored very high throughout the study, which raises questions about the validity of the findings. A possible explanation for the high MS (Archbold et al., 1990) scores during the study is ceiling effect. Ceiling effect occurs when a measure is unintentionally designed so a large number of participants score close to the maximum and further increases cannot be recorded (Dell-Kuster et al., 2014). It is doubtful whether ceiling effect was a factor in this study because MS has been validated with the population.
(Pucciarelli et al., 2016) and only one stroke survivor gave maximum marks during the study.

An alternative explanation for the consistently high MS (Archbold et al., 1990) scores is self-selection bias and the possibility only stroke care partnerships with existing high levels of mutuality enrolled into the study (Parahoo, 2014). The argument for self-selection bias is strengthened by the higher than expected MS (Archbold et al., 1990) scores for stroke survivors and care partners at week zero (Section 8.4 on page 235). The initial MS scores recorded in this study are higher than what has been documented previously with stroke survivors and care partners, which raises questions about the representativeness of the participants (Pucciarelli et al., 2016). Furthermore, social desirability bias might also have affected completion of the MS (Archbold et al., 1990) because participants could have felt social pressure to rate their mutuality high when completing the questionnaire alongside their partner (Phillips et al., 2018). Social desirability is a particular issue when using self-report measures with terminology that is open to interpretation (Holtgraves, 2017). Collecting observational data and behavioural outcomes (e.g. problem solving) would have been a useful adjunct for the MS (Archbold et al., 1990) because they are less influenced by social desirability bias and would have provided further evidence of relationship factors (Sprenkle, 2012).

The IPA (Smith, Flowers and Larkin, 2009) highlighted the theme: togetherness (Section 8.7.3 on page 251), which illustrates a dialectical tension that can exist when stroke care partnerships use online MBI together. The togetherness theme captures the experience of stroke care partnerships being close together whilst also supporting each other at a distance. The together side of the dialectic is evidenced through participant’s willingness to enrol on the study and their initial high levels of mutuality. It was also observed that some care partnerships experienced enhancements to their relationship following stroke. A phenomenological study exploring the lived experience of community-based care partners found some stroke care partnerships experienced an increased appreciation of the relationship after stroke (Simeone et al., 2016). Although, many care partnerships experience significant interpersonal challenges following stroke and can find it difficult to live with the stroke-related impairments and continue to function as a partnership (McCarthy et al., 2020).
is possible the interpersonal changes observed in this study may be a normal process after stroke and could have occurred without using online MBI (Simeone et al., 2016).

An interesting part of the togetherness theme is how stroke care partnerships engaged with online MBI separately, whilst still being together. At the start of the study participants were given no instruction on whether to practice concurrently and each care partnership was able to use online MBI in a manner of their choosing. It was interesting to observe none of the participants practiced formal (e.g. sitting meditation) together, but some would engage in informal (e.g. mindful walks) MBI practices together. Care partnerships would also provide informal support by prompting each other and/or making space for the other to practice. The informal support appears valuable to stroke survivors and is similar to findings from a qualitative systematic review, which found families had an important role in creating the right environment for self-care to occur (Whitehead et al., 2018). It is also unclear whether concurrent formal MBI practice (e.g. sitting meditation as pair) would have been beneficial, because it is mainly used with healthy couples seeking to enhance their relationship (Carson et al., 2004). Moreover, the one study identified in the systematic review using concurrent formal MBI practice with care partnerships affected by cancer (Price-Blackshear et al., 2020) found that interpersonal relationships deteriorated during the study (Section 4.5.5 on page 93). So it is unclear whether concurrent formal practice is necessary and/or desirable when using online MBI with care partnerships affected by stroke.

9.5.1 Partner assisted mindful coping model

An important way care partners supported stroke survivors was through listening to their experiences of online MBI and providing opportunity for reflection. Supporting active reflection on the experience of online MBI could be an important role for care partners because reflection is thought to help people using MBI cope better (Santorelli et al., 2017). Guided reflection is a core component of group MBSR/MBCT (Teasdale et al., 2000; Santorelli et al., 2017) and talking to people about the experience of living with stroke is important for people attending MBI groups (Jani et al., 2018).
Garland, Gaylord and Park (2009) developed a mindful coping model to explain the role reflection might play in helping people using MBI to adjust to difficult situations. The mindful coping model (Garland, Gaylord and Park, 2009) is underpinned by the cognitive model of psychological distress and closely linked to the stress, appraisal, and coping model (Lazarus and Folkman, 1984). The stress, appraisal, and coping model (Lazarus and Folkman, 1984) proposes stress is caused by an unhelpful appraisal of life events, which can be reduced if people reappraise the situation. The mindful coping model (Garland, Gaylord and Park, 2009) hypothesizes that mindfulness and active reflection can help people reappraise their situation and reduce stress levels. The mindful coping model (Garland, Gaylord and Park, 2009) can be adapted to include a partner and shows how assisted reflection and MBI can help stroke survivors reappraise living with stroke and improve their thoughts and feelings (Figure 21 on page 286).

**Figure 21: Partner assisted mindful coping model**

![Partner assisted mindful coping model](image)

(Adapted from Garland, Gaylord and Park, 2009)

The partner assisted mindful coping model provides a novel representation and possible mechanism for stroke care partnerships using online MBI together. The partner assisted mindful coping model provides tentative justification for using online MBI with a care partner and illustrates how involving a care partner might enhance reflection and mitigate the lack of human contact associated with some online interventions (Andersson and Titov, 2014).

### 9.6 Changes to anxiety symptoms and depression symptoms

The potential effectiveness of online MBI at reducing anxiety symptoms and depression symptoms for stroke care partnerships was evaluated using the HADS (Zigmond and Snaith, 1983) and through qualitative interviews (Ivankova, Creswell and Stick, 2009). It is important to consider the most
accurate and fair way of evaluating the potential effectiveness of online MBI. Observing numerical change in the HADS (Zigmond and Snaith, 1983) is useful, but does not necessarily explain whether the change was clinically important. Instead minimal clinically important difference (MCID) was used to determine whether a change had a clinical impact. MCID provides an indication of clinical effectiveness for individual participants, but MCID is better suited to situations where full recovery is unlikely (Wright et al., 2012). The advantage of MCID is that it provides an estimation of the least amount of change needed for participants to experience some clinical benefit and is not dependent on clinical thresholds or whether someone fully recovers (Cook, 2008). The least useful measure of effectiveness used in this study was hypothesis testing, inferential statistics, and $p$ values. The concern with hypothesis testing and inferential statistics in this study is that the epistemology was not compatible with the mixed methods case study research and ideographic focus of the study (Yin, 2013; Creswell and Plano Clark, 2017). There is also much debate about the use and misuse of $p$ values in medical research and many argue there needs to be greater clarity about the interpretation and thresholds used to evaluate research (Aguinis, Vassar and Wayant, 2019). On balance, MCID appears to be the most useful tool for evaluating the potential effectiveness of online MBI in this study and indicated improvement in anxiety symptoms ($n=5, 50\%$) and depression symptoms ($n=2, 20\%$) for some people affected by stroke (Section 8.5 on page 238). The majority of care partnership ($n=4, 80\%$) experienced either a MCID in anxiety symptoms or depression symptoms after online MBI, but one care partnership did not experience a MCID. Care partnership one was the only care partnership to not experience a MCID in anxiety symptoms or depression symptoms during the study, but the study coincided with the care partner becoming seriously unwell and dropping out of the study (Appendix 21: Case vignettes page 340).

The mixed HADS (Bjelland et al., 2002) results observed in this study appear similar to other research using online MBI with people affected by stroke. Singh (2018) completed a feasibility study using online MBI with stroke survivors ($n=2$) and discovered one participant experienced a reliable and clinically significant change for depression symptoms and the other participant experienced a reliable deterioration in anxiety symptoms. The mixed results in both studies
highlight the variable effectiveness of online MBI for people affected by stroke. Although, it is difficult to make direct comparisons between this study and Singh (2018), because of the different measures used in each study and the limited number of participants in both studies.

The results from this study add to the growing evidence base supporting the use of Be Mindful (Krusche et al., 2012; Krusche, Cyhlarova and Williams, 2013; Querstret, Cropley and Fife-Schaw, 2017, 2018) and online MBI (Spijkerman, Pots and Bohlmeijer, 2016; Toivonen et al., 2017). This body of research suggests online MBI can have a small to moderate effect on mental health difficulties (Spijkerman, Pots and Bohlmeijer, 2016) and improve physical health difficulties (Toivonen et al., 2017). However, much of this evidence on online MBI comes from RCTs and other group designs, so individual differences and personal experience is lost (Cohen, Stavri and Hersh, 2004; Yin, 2018).

One of the major strengths of this study was being able to evaluate the effectiveness at an individual level and to explore variation both within and between partnerships (Yin, 2018).

The idiographic lens used in this study and with IPA (Smith, Flowers and Larkin, 2009) added value by illuminating the variable and sometimes contradictory results recorded in the quantitative data (Guetterman, Fetters and Creswell, 2015). The theme most closely associated with potential effectiveness is the theme change (Section 8.7.4 on page 256). The theme change illustrates the dialectical tension that can exist when care partnerships use online MBI together after stroke. The analysis revealed some participants continue to experience anxiety symptoms and depression symptoms, whilst also reporting changes in the nature and extent of anxiety symptoms and depression symptoms. The experience of getting better, but wanting to improve further is a common experience for participants using MBI and was recently reported in a qualitative study exploring change in a clinical trial (Schanche et al., 2020). There is also similarity with how some stroke survivors describe themselves as ‘being the same’ and ‘being different’ following stroke (Taubner, Hallén and Wengelin, 2020) (Section 1.2 on page 27). This similarity suggests dialectical tension may exist for some stroke survivors before they use online MBI in a care partnership.
The theme change echoes within another dialectical tension: change vs non-change, which was articulated in a theoretical paper (Sauer et al., 2011). Change vs non-change illustrates the dialectical tension that can exist when people want MBI to alleviate unwanted symptoms instead of developing an alternative more accepting relationship with difficulties (Sauer et al., 2011). This perspective shares similarity with the mindfulness with care partnership themes developed during the mixed studies systematic review (Section 4.5.12 on page 109). Wellness is a key theme in the mindfulness with care partnerships themes and stresses the role of MBIs in developing positive health states, rather than reducing of psychological distress. This distinction is at the very heart of MBI practice, which tries to achieve acceptance rather than amelioration of difficulties (Kabat-Zinn, 2013). The change theme discovered in this study highlights the fact participant’s difficulties remained the same and also showed some signs of improvement. The theme change identified in this study is empirically based and revealed the nuance and subtle changes that can occur when using online MBI with stroke care partnerships.

9.7 Strengths and weaknesses

MBI research is often criticised for having conceptual and methodological limitations (Davidson et al., 2015; Goldberg et al., 2017; Van Dam et al., 2018). A self-evaluation was completed to identify strengths and weaknesses in the study (Khan et al., 2003). The self-evaluation used a combination of approaches and included the Mixed Methods Appraisal Tool (MMAT) (Nha Hong et al., 2018), Yardley's (2000) criteria for evaluating qualitative research, and the legitimisation framework for mixed methods research (Onwuegbuzie and Johnson, 2006).

9.7.1 Mixed methods appraisal tool (MMAT)

Self-evaluation with the MMAT (Nha Hong et al. 2018) shows the study only meets one of the quantitative criteria (appropriate measurements), but meets all the qualitative, and mixed methods criteria. Critical appraisal using MMAT (Nha Hong et al. 2018) highlighted the study is weak in the quantitative domains, but strong in the qualitative, and mixed methods domains (Table 38 on page 290).
### Table 38: Mixed methods appraisal tool version 2018 (MMAT)

<table>
<thead>
<tr>
<th>Methodology quality criteria</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td><strong>Screening</strong></td>
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<tr>
<td>Are there clear research questions?</td>
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<td>Do the collected data address the research questions?</td>
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<td><strong>Qualitative</strong></td>
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<td>Is the qualitative approach appropriate to answer the research question?</td>
<td>X</td>
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<td>Are the qualitative data collection methods adequate to address the research question?</td>
<td>X</td>
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<tr>
<td>Are the findings adequately derived from the data?</td>
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<tr>
<td>Is the interpretation of results sufficiently substantiated by data?</td>
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<tr>
<td>Is there coherence between qualitative data sources, collection, analysis, and interpretation?</td>
<td>X</td>
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<td><strong>Quantitative non-RCT</strong></td>
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<tr>
<td>Are the participants representative of the target population?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Are measurements appropriate regarding both the outcome and intervention?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Are there complete outcome data?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Are the confounders accounted for in the design and analysis?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>During the study period is the intervention administered as intended?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td><strong>Mixed methods</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is there adequate rationale for using a mixed methods design to address the research questions?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Are the different components of the study effectively integrated to answer the research question?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Are the outputs of the integration of the qualitative and quantitative components adequately addressed?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

(Nha Hong et al. 2018)

Areas of weakness identified by the MMAT (Nha Hong et al. 2018) include concern about the representativeness of the sample, concerns about missing data, the possible influence of confounders, and whether the intervention was delivered as intended (Table 38 on page 290). The lack of representativeness in the sample raises questions about whether participants reflect the people...
normally seen in clinical practice. Concerns about the lack of diversity in MBI research are common (Waldron et al., 2018; Wang et al., 2019) and this study shares similar criticisms because all participants were white and most were highly educated.

Having a non-representative group of participants does cause methodological weaknesses because it affects the generalisability of the findings (Parahoo, 2014). However, this study used mixed methods case study research and it is important of distinguish between statistical generalisation and analytic generalisation when using case study research (Yin, 2018). Case study research does not seek statistical generalisability, but instead wants to provide theoretical insight by focusing on a small number of cases (Yin, 2018). Similarly, IPAs seeks to recruit a small homogenous group of people and study them closely to understand the experience and meaning from their perspective (Brocki and Wearden, 2006). Therefore, the lack of diversity is not necessarily a methodological problem for this particular study, because it takes an idiographic perspective (Smith, Flowers and Larkin, 2009). However, the lack of diversity in this study reflects a wider issue in MBI research and future MBI research should try increase diversity (Waldron et al., 2018).

Missing data is an important limitation highlighted by the MMAT (Nha Hong et al., 2018) and was a serious problem in the study. Missing data can adversely affect the validity of a study (Bell et al., 2014), but was mitigated by using a combination of imputation and pairwise deletion methods (Shrive et al., 2006; Parent, 2012) (Section 7.6.5 on page 179). The MMAT (Nha Hong et al., 2018) identified possible confounders as a weakness in the study. A confounder is a variable that may influence the outcome of a study and can sometimes be difficult to identify and/or quantify (Parahoo, 2014). Possible confounders in the study include one participant (stroke survivor one) commencing anti-depressant medication and another participant (care partner five) commencing additional non-mindfulness activities, which appear to have had a positive impact of their mood (Appendix 21: Case vignettes on page 340). These external factors may have produced therapeutic benefit, which could be mistakenly attributed to online MBI and influence internal validity (Parahoo, 2014). A less obvious confounder could have been expectancy effect, which refers to a situation where participants have a pre-existing belief the intervention will be helpful
Expectancy effect is difficult to avoid in MBI research because it is impractical to blind participants to treatment condition (Davidson et al., 2015). Although, there is mixed evidence about expectancy effect in MBI research, with recent evidence suggesting expectancy effect may not impact outcomes as much as previously thought (Hicks, Hanes and Wahbeh, 2016; Haddad et al., 2020). However, the self-selecting nature of recruitment and the fact most participants had some experience with MBI prior to the study suggests participants may have high expectancy for online MBI. Although, formal evaluation of expectancy effect was not undertaken and would be required to establish whether expectancy effect was a factor (Devilly and Borkovec, 2000).

The final weakness identified by the MMAT (Nha Hong et al., 2018) was whether the intervention had been delivered as planned. Treatment fidelity refers to the extent an intervention is delivered as intended and is an important element in MBI research (Crane, 2019). The online automated nature of Be Mindful (Wellmind Media and Mental Health Foundation, 2019), published content (Krusche et al., 2012; Querstret, Cropley and Fife-Schaw, 2017), and transparent reporting using TIDieR (Hoffmann et al., 2014) (Appendix 16 on page 335) provide some assurances the intervention was delivered as intended. Although, the reason this item was highlighted on the MMAT (Nha Hong et al., 2018) is because not everyone completed the intervention and no formal measure of fidelity was completed (Goldberg et al., 2017; Kechter, Amaro and Black, 2019). The amount of non-completers (n=6, 60%) suggests the intervention was not delivered as intended for the majority of participants and raises the possibility maturation and/or regression to the mean may have influenced outcomes (Marsden and Torgerson, 2012). Likewise, the lack of formal fidelity checks make it impossible to know whether Be Mindful (Wellmind Media and Mental Health Foundation, 2019) is consistent with the MBCT (Teasdale et al., 2000), although, it was developed in conjunction with respected MBCT teachers (Krusche et al., 2012) and contains all the core elements of an MBI (Crane et al., 2017).
9.7.2 Yardley’s criteria

The four criteria used to evaluate the quality of the IPA are: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (Yardley, 2000). Sensitivity to context is demonstrated by having the study ethically approved before commencement (Yardley, 2000), taking an idiographic perspective, and using case study methods (Smith, Flowers and Larkin, 2009). Commitment and rigour is demonstrated by recruiting multiple cases, using in-depth interviews, engaging in detailed analysis, using peer validation, and incorporating reflexivity (Smith, Flowers and Larkin, 2009). A key strategy for demonstrating quality and validity is a comprehensive audit trail of the research process and documentation (Leung, 2015). An audit trail provides transparent evidence of the research journey and can be used to evaluate the rigour and coherence of IPA (Smith, Flowers and Larkin, 2009). The audit trail in this study includes academic supervision notes, prospective registration, study documentation, participant transcripts, data analysis sheets, reflexive journal, and the final report. Peer validation (by supervisors and advisory group) and audit are powerful tools for promoting research quality and were used in this study (Larkin and Thompson, 2012). Transparency and coherence is demonstrated by securing prospective trial registration and using recognised reporting guidelines (Equator Network, 2019). The impact and importance of the research is difficult to determine at this stage because it can take several years for research findings to influence practice (Hanney et al., 2015), however, an summary of current impact is provided (Section 9.9 on page 300). The thesis also articulates the original contribution to knowledge and highlight possible implications for practice (Section 9.8 on page 296).
Table 39: Yardley’s criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Sensitivity to context    | Sensitive to sociocultural setting reflects participants’ perspectives, and is ethically sound | • Ethical approval  
                                  |                                                                                   | • Idiographic perspective  
                                  |                                                                                   | • Case study methods |
| Commitment and rigour     | In-depth engagement in topic and methodologically sound                      | • Recruited multiple cases  
                                  |                                                                                   | • Used in-depth interviews  
                                  |                                                                                   | • Engaged in detailed analysis  
                                  |                                                                                   | • Used peer validation  
                                  |                                                                                   | • Incorporated reflexivity  
                                  |                                                                                   | • Audit trail |
| Transparency and coherence| Transparent methods and findings                                              | • Prospective trial registration  
                                  |                                                                                   | • Reporting guidelines |
| Impact and importance     | Adds value to theory policy or practice                                       | • Impact of study made explicit  
                                  |                                                                                   | • Implications for practice discussed |

(Yardley, 2000)

9.7.3 Legitimation framework

The quality of the study was further self-evaluated using a legitimation framework (Onwuegbuzie, Johnson and Collins, 2011). The legitimation criteria contains nine categories, which were achieved at different stages of the research process and by using different strategies (Onwuegbuzie, Johnson and Collins, 2011; Younas, Rasheed and Zeb, 2020). The table below provides an overview of the legitimation criteria and the strategies used in the study to promote legitimation.
### Table 40: The legitimation framework

<table>
<thead>
<tr>
<th>Legitimation criteria</th>
<th>Description</th>
<th>Legitimation strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample integration</td>
<td>Appropriate sampling and use of generalisation</td>
<td>• Same participants involved in both quantitative and qualitative stages</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Sample appropriate for mixed methods case study research using IPA (Smith, Flowers and Larkin, 2009)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Statistical generalisations not used in the study</td>
</tr>
<tr>
<td>Inside-outside</td>
<td>Taking both an insider and outsider perspective</td>
<td>• Subjective and objective data collected during the study</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• IPA uses ideographic perspective (Smith, Flowers and Larkin, 2009)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Narrative summary used to integrate insider/outside perspectives (Dixon-Woods et al., 2005)</td>
</tr>
<tr>
<td>Weakness minimisation</td>
<td>Using qualitative and quantitative approaches to complement each other</td>
<td>• Qualitative data used to explain and contextualise quantitative data (Creswell and Clark, 2018)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Quantitative and qualitative data reported in the thesis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Supervisors with expertise in quantitative, qualitative and mixed methods research</td>
</tr>
<tr>
<td>Sequential</td>
<td>Reducing impact of qualitative and quantitative sequencing</td>
<td>• Explored same issues in both stages of study</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Quantitative stage used to identify people with necessary lived experience of using online MBI in a care partnership</td>
</tr>
<tr>
<td>Conversion</td>
<td>Converting qualitative data into quantitative data and vice versa</td>
<td>• Narrative summary used to report quantitative findings (Dixon-Woods et al., 2005)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Dialectical themes captured quantitative and qualitative findings</td>
</tr>
<tr>
<td>Paradigmatic mixing</td>
<td>Mixing of ontological, epistemological, and axiological perspectives</td>
<td>• Coherent philosophical position</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Pragmatic use of methodology</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Alignment of aims, methodology, methods, findings</td>
</tr>
<tr>
<td>Commensurability</td>
<td>The compatibility of quantitative and qualitative paradigms</td>
<td>• Supervisory team consisted of academics with qualitative, quantitative, and mixed methods expertise</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Both quantitative and qualitative perspectives seen as valuable</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Separate and integrated analysis of quantitative and qualitative data</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mixed methods data used to compliment and enrich understanding of topic</td>
</tr>
<tr>
<td>Multiple validities</td>
<td>The extent quality criteria was applied to qualitative, quantitative, and mixed phases of study</td>
<td>• Mitigated threat to validity for the quantitative, qualitative, and mixed methods sections of the study</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• MMAT used because it considered quality of qualitative, quantitative, and mixed methods components</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Thesis explores quality of qualitative, quantitative, and mixed methods elements of the study</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Used specific qualitative quality criteria (Yardley, 2000) for dominant IPA section of the study</td>
</tr>
<tr>
<td>Political</td>
<td>The extent consumers value the mixed methods findings</td>
<td>• Lay summary reviewed by PPI advisory group</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Third sector organisations requested summary of findings</td>
</tr>
</tbody>
</table>

(Onwuegbuzie, Johnson and Collins, 2011)
9.8 Implications for practice

It is important to consider how the findings from this study may impact on practice. This section will consider implication for clinical practice, future research, and policy.

9.8.1 Clinical practice

The study is clinically oriented, but the preliminary nature and weaknesses associated with the study mean implications for practice have to be viewed cautiously. The study addresses an important area of clinical practice by seeking to help people affected by stroke self-manage anxiety symptoms and depression symptoms (Rowat et al., 2016). Evidence supporting the use of MBI for people affected by stroke is growing (Lawrence et al., 2013) and this study suggests using online MBI in a care partnership is feasible and possibly advantageous for some people. Using online MBI in a stroke care partnership appears low risk and might positively impact people's anxiety symptoms, depression symptoms, and/or mindfulness.

The evidence-base for using online MBI with stroke care partnerships is preliminary and not robust enough to make firm recommendations for clinical practice. However, health care professionals working in stroke rehabilitation may want to become familiar with online MBI and the possible benefits of learning MBI in a care partnership. It is important for health care professionals to know about MBIs because some participants in this study had attended taster sessions, which suggests stroke survivors are already accessing MBI and health care professionals will likely encounter stroke survivors using MBIs. Being familiar with the evidence-base for MBIs and the different ways they can be delivered (e.g. group, online) will be useful information for health care professionals working with people affected by stroke. This knowledge will help health care professionals advise stroke survivors and their care partners about the preliminary nature of evidence for using MBIs with people affected by stroke and reduce the chances of the strength of evidence being misrepresented. It is also possible health care professional could use this knowledge to talk to stroke survivors and their care partners about the possibility of using MBIs online.
and/or together. Although, the health care professional would have to ensure they disclose the preliminary nature and inconclusive evidence on the subject.

It is important health care professionals are able to give an accurate impression of the current evidence-base for MBIs and that includes saying the evidence is not available or robust enough at this stage to recommend a particular intervention or approach. In this scenario, it is necessary for the health care professional to distinguish between no evidence of effect and evidence of no effect. No evidence of effect occurs in situations where there is insufficient high quality evidence and/or the evidence is inconclusive. Whilst evidence of no effect is for situations where the evidence clearly shows that the intervention does not work (Healy, 1999). Currently the guidance for online MBIs with care partnerships affected by stroke falls into the, no evidence of effect category, and signals the need for future research on the subject.

9.8.2 Future research

Robust research is required before making firm recommendations for clinical practice. The Medical Research Council’s framework provides guidance for developing complex interventions and could be used for the development, feasibility, evaluation, and implementation of online MBI for stroke survivors and their care partners (Craig et al., 2013; Skivington et al., 2021). Future research should include conducting more studies into the use of online MBI with care partnerships affected by stroke. The future research could continue using Be Mindful (Wellmind Media and Mental Health Foundation, 2019) and compare online MBI with individual stroke survivors against online MBI with care partnerships living with stroke. This direct comparison could be achieved using an RCT and would help determine what value (if any) the partnership element provides compared to using online MBI as an individual. Research involving large groups would need to widen recruitment and include people from the whole of the United Kingdom and/or those involved with the NHS. It is also possible the challenges experienced in this study (e.g. low recruitment, mixed adherence) would make large-scale RCTs unfeasible and further developmental work is required before moving onto larger clinical trials.

It would also be good to see future research attempt to increase the diversity of participants and to make sure people from different ethnic backgrounds and
social groups are involved in the study (Waldron et al., 2018). Clark et al. (2019) investigated strategies for increasing diversity in clinical trials and found building trust, improving communication, and being flexible were key for making clinical trials more inclusive. Another recommendation would be to increase the diversity within the research team and patient and public advisory group because this can improve trust and communication with certain groups (George, Duran and Norris, 2014).

Mindfulness measurement should be included in future research because it is an important mechanism for MBI research (Alsubaie et al., 2017). Objective behaviour measurement (e.g. breath counting) should be used in conjunction with self-report measures (Levinson et al., 2014). Using objective mindfulness measurement would help reduce the subjectivity associated with self-report questionnaires and may be more appropriate in situations where communication barriers exist (e.g. non-English speakers, aphasia) (Wong et al., 2018).

Other recommendations include using home practice diaries or recording devices to monitor the quantity and quality of home practice (Parsons et al., 2017). Stroke care partnership should be given more time (e.g. twelve weeks) to complete the intervention and incentives might be needed to help encourage people to complete the intervention and associated data collection (Querstret, Cropley and Fife-Schaw, 2017). In-depth interviews completed at week four would also be a useful addition and help capture how the experience of using online MBI evolved for stroke care partnerships (Fadyl et al., 2017). Extending the follow-up period to six months would also give a better indication of how participants use online MBI over a longer period of time (Querstret, Cropley and Fife-Schaw, 2018).

Other research plans for this body of work include developing and/or adapting online MBI for people affected by stroke. A common focus of MBI research is developing and/or adapting MBIs for specific clinical population (Crane et al., 2017). Be Mindful (Wellmind Media and Mental Health Foundation, 2019) used in this study was not designed for people affected by stroke and it would be helpful to tailor online MBIs for people affected by stroke. The HEADS: UP (Lawrence, 2019a) research programme has adapted MBSR (Santorelli et al.,
for people affected by stroke and has been delivered to stroke survivors and their care partners together using online interactive groups sessions. There is currently no stroke specific version of MBCT (Crane, 2017) or Be Mindful (Wellmind Media and Mental Health Foundation, 2019), so future research could involve developing an online version of MBCT (Teasdale et al., 2000) for people affected by stroke. The plan is to work in partnership with people affected by stroke to co-create an online MBCT (Teasdale et al., 2000) for people affected by stroke. Once the stroke specific online MBCT (Teasdale et al., 2000) has been developed, then it would be necessary to conduct feasibility studies to determine whether it is feasible and acceptable for people affected by stroke (Craig et al., 2013).

Another option for future research would be to combine the HEADS: UP programme with this study and develop an asynchronous (i.e. pre-recorded) online MBI for people affected by stroke. An asynchronous online MBI for people affected by stroke would be a logical continuation of the work completed by HEADS: UP and in this study. The asynchronous online MBI would offer people affected by stroke greater flexibility by removing the need to attend regular group sessions and allow them to complete the MBI at their own pace (Toivonen et al., 2017). Using asynchronous online MBI will also reduce the need for large numbers of MBI teachers and reduce costs if/when online MBI is implemented into practice (Spijkerman, Pots and Bohlmeijer, 2016).

This study found poor adherence with Be Mindful (Wellmind Media and Mental Health Foundation, 2019) by care partners (Section 8.2 on page 232), but value in using online MBI in a care partnership (Section 8.7 on page 242). These findings suggest future research should explore ways of helping care partners support stroke survivors using online MBI, without them having to complete the online MBI. Future research in this area could involve developing orientation sessions and/or other resources (e.g. manuals) for care partners who want to support a stroke survivor without committing themselves to having to complete the online MBI. This could help maximise care partner support for stroke survivors and reduce the additional burden of care partners having to attend the full online MBI.
9.8.3 Implications for policy

The preliminary nature of the study makes it difficult to suggest policy changes, although, several organisations (e.g. Chest Heart Stroke Scotland and the Stroke Association) requested a summary of the findings, which suggest there is interest in the study. Interest in this study might raise awareness of online MBI and might influence future grant funding. Any future changes to policy will also occur within the context of COVID-19. The unprecedented events surrounding COVID-19 highlight the importance of having interventions that can be delivered online and without the need for therapist contact (Holmes et al., 2020). Online MBI is well placed for a post COVID-19 world and can provide a remote intervention for people affected by stroke and would offer a degree of future proofing for certain types of global threats.

9.9 Impact

Researchers are expected to demonstrate impact and show how their work contributes to society (Kuruvilla et al., 2006). Research impact is an integral part of the Research Excellence Framework (REF), is used to rank research institutes, and can be demonstrated in different ways (Chowdhury, Koya and Philipson, 2016). Demonstrating impact involves producing evidence (e.g. citations, narratives) that shows how research has made a difference to people’s lives or wider society (Penfield et al., 2014). Despite the varied ways of demonstrating impact, research using data from REF 2014 suggests impact is mainly evaluated using publications, grant income, and/or associated esteem indicators (Chowdhury, Koya and Philipson, 2016).

A key mechanism for demonstrating impact in a PhD is through the production and assessment of a thesis (Hodgson, 2020). A good thesis demonstrates quality research, provides evidence thorough critical appraisal (Hodgson, 2020), and shows originality (Gelling, 2014). An excellent thesis also requires creativity and evidence of publication in a peer-reviewed journal (Mullins and Kiley, 2002). This thesis has demonstrated critical appraisal during the systematic review and when self-evaluating the strengths and weaknesses of the work. Originality is exhibited by doing something for the first time, exploring new areas, asking novel questions, using different methods, or completing work
within a new context (Gill and Dolan, 2015). This section will report the impact and originality of this thesis, although, impact often occurs after the study has been completed and can take a while to be fully realised (Penfield et al., 2014).

Addressing research priorities is an important way of increasing the impact and value research adds to society (Petit-Zeman, Firkins and Scadding, 2010). This study addresses stroke research priorities by exploring how best to support people living with the long-term consequences of stroke (Pollock et al., 2014) and how to manage post-stroke anxiety symptoms and depression symptoms (Rowat et al., 2016). This study aligns with these stroke research priorities and used an existing online MBI course to help stroke care partnerships experiencing anxiety symptoms and depression symptoms. The study used Be Mindful (Wellmind Media and Mental Health Foundation, 2019), which has been positively evaluated in clinical and non-clinical settings (Krusche et al., 2012; Krusche, Cyhlarova and Williams, 2013; Querstret, Cropley and Fife-Schaw, 2017). To our knowledge very few studies have used Be Mindful (Wellmind Media and Mental Health Foundation, 2019) with people affected by stroke (Singh, 2018) and no studies have used the intervention with care partnerships (Parkinson et al., 2019).

An original element of this study was using Be Mindful (Wellmind Media and Mental Health Foundation, 2019) with stroke care partnerships, but originality was also evident in the choice of methodology. The study used mixed methods case study research and an explanatory sequential design (Creswell and Clark, 2018). The qualitative component was the main focus of the study and used IPA (Smith, Flowers and Larkin, 2009). This study could be classified as mixed methods phenomenological research (MMPR), which is a new conceptualisation of mixed methods research that explicitly aligns with phenomenology (Mayoh and Onwuegbuzie, 2015). Another original component of the study is the discovery of dialectical tension (Section 8.7 on page 242) when using online MBI in a care partnership and the development of the partner assisted mindful coping model (Figure 21 on page 286). These interpretations and the mixed studies synthesis (Chapter 5 on page 132), demonstrate an original contribution to knowledge and provide insight into the experience for care partnerships using online MBI after stroke.
The impact of this work is demonstrated through several academic outputs, which have been produced during the PhD. The academic outputs produced during the PhD include peer-reviewed conference abstracts (Parkinson et al., 2017a, 2017b, 2018a, 2018b, 2018c) and peer-reviewed journal papers (Parkinson et al., 2019, 2020). A common way of demonstrating impact of academic outputs is to use online technology to quantify alternative metrics (or altmetrics) (Barnes, 2015). PlumX is an online tool designed to evaluate academic outputs and can quantify the impact of academic outputs (Champieux, 2015). PlumX combines traditional metrics (e.g. citations) with altmetrics (e.g. bookmarks, social media) to evaluate academic impact of journal papers (Lindsay, 2016). PlumX data in April 2021 revealed the published systematic review (Parkinson et al., 2019) achieved citations (n=3), captures (n=33), and social media engagements (i.e. tweets) (n=20). The systematic review (Parkinson et al., 2019) also generated downloads (n=108) from the University repository and received social media interest from researchers in Australia (n=1) and Japan (n=1). Other academic impact includes evidence from the systematic review (Parkinson et al., 2019) being used in a successful grant application (£365,000) with the Stroke Association for the HEADS: UP study (Lawrence, 2019a) investigating the feasibility of an adapted MBI for stroke survivors and their care partners. Preliminary results from this study also contributed to the optimisation stage of HEADS: UP and informed the refinement of the course prior to being delivered online. Another peer-reviewed paper exploring the ethical and practice issues associated with patient and public involvement (PPI) in mental health research was also published during the PhD (Parkinson, Lawrence and Booth, 2020). Data from the University repository shows the paper has been downloaded several times (n=25) and received attention via twitter. Copies of both published papers are available in the appendices (Appendix 1: Journal publication from the thesis 2019 on page 307 and Appendix 2: Journal publication from the thesis 2021 on page 308).

Non-academic impact also has an important role to play in determining the value of research (Kuruvilla et al., 2006). During COVID-19 the value of online interventions was highlighted and the important role they play when traditional face-to-face services are reduced (Holmes et al., 2020). The use of online MBI
in this study received attention from the Caledonian News and appeared as a Glasgow University communication during the COVID-19 pandemic (Parkinson, 2020). The news release was followed by a podcast, which discussed the value of online MBI and received several likes (n=5) likes and multiple plays (n=123) by April 2021. Triparthy et al. (2017) suggest podcasts widen the audience and increase impact of research. The podcast was developed in conjunction with Glasgow Caledonian and formed part of their podcast for the common good series (Parkinson, 2020).

9.10 Future dissemination

Dissemination of research findings is an essential step in the research process and can help reduce the research practice gap. The research practice gap refers to the time taken for research evidence to be utilised in practice, which can be as much as seventeen years (Morris, Wooding and Grant, 2011). Although, dissemination alone is unlikely to reduce the research practice gap and implementation solutions are needed for research findings to be better used in clinical areas (Kristensen, Nymann and Konradsen, 2015).

Dissemination is most effective if it is timely, accessible to a wide audience, and reported transparently (Sarver and McNett, 2020). Results from the thesis were published in a timely manner during the PhD using conference abstracts and journal publications (Section 9.9 on page 300). Early publication of the systematic review (Parkinson et al., 2019) helped disseminate findings and was achieved within the twenty-four month benchmark used for timely publication (Chen et al., 2016).

Plans for future dissemination include publishing the study in an international peer-reviewed journal and presenting at international conferences. The plan is to publish the paper open access, so the findings are easily accessible online (Triparthy et al., 2017), although, this is likely to exceed the twenty-four months benchmark for timely publication (Chen et al., 2016). An abstract was accepted for an international conference in Thailand, but unfortunately the conference was postponed due to COVID-19. Publications and conference presentations are popular dissemination strategies, but typically cater to an academic audience (Wilson et al., 2010). It is important to engage in wider dissemination,
so the plan is to record another podcast, use social media (e.g. twitter), participate in GCU research day 2021, and provide key stakeholders (e.g. Stroke Association, study participants) with a lay summary (Triparthy et al., 2017). Using varied dissemination methods and a lay summary will help make the research findings accessible to a wide audience and is more inclusion than using academic dissemination methods (Wilson et al., 2010). A full dissemination plan is provided in the appendix (Appendix 23 on page 346).
Chapter 10. Conclusion

This thesis focused on the experience and outcomes for care partnerships using MBIs together. A systematic mixed studies review was completed to update and improve a systematic review published in the early part of the PhD (Chapter 4 on page 65). The updated systematic review found care partnerships can experience improved mindfulness, anxiety symptoms, and depression symptoms when using MBI together. The systematic review also produced the mindfulness with care partnerships themes (Figure 5 on page 109), which show how care partnerships can experience: togetherness, becoming mindful, and wellness when using MBI together. However, none of the studies in the systematic review researched the use of online MBI with care partnerships affected by stroke and several studies had methodological weaknesses.

This thesis adds to the MBI literature by being the first study to research online MBIs with care partnerships experiencing anxiety symptoms and depression symptoms after stroke (Chapter 5 on page 132). The mixed methods case study research showed it is feasible to study online MBI with care partnerships affected by stroke. However, the slow recruitment rate, limited participant diversity, and amount of missing data should be addressed in future research (Section 9.8.2 on page 297). Online MBI appears appropriate for care partnerships affected by stroke, but stroke survivors engaged with online MBI more than their care partners. Some participants improved their levels of mutuality, mindfulness, anxiety symptoms, and depression symptoms. Clinically important improvements were achieved for anxiety symptoms and depression symptoms with some people. Not all participants experienced improvements and variation existed in how beneficial online MBI was for care partnerships living with anxiety symptoms and depression symptoms after stroke. The variation experienced by care partnerships using online MBI after stroke is articulated using themes and dialectical tension: curiosity; usage; togetherness; and change. The dialectical tension provides a new interpretation of the complex and sometimes contradictory nature of care partnerships using online MBI after stroke.
The findings produced in this thesis make an original contribution to knowledge by reporting the experience and outcomes for care partnerships using MBIs together. The thesis articulates for the first time the mindfulness in care partnerships themes and the dialectical tension associated with care partnership using online MBI together after stroke. However, this is a new area of study and the findings need to be interpreted cautiously. Future research should align with complex health intervention methodology and improve methodological quality. Future research should consider using alternatives to large group design and try to increase the diversity of participants being recruited into MBI research. Mixed methods research with appropriate control conditions and longer follow-up would help improve research quality. It is also important for future MBI research to ensure use of MBI is being properly monitored and for objective measurement of mindfulness to be used in addition to self-report questionnaires. It would also be helpful to include wellness outcomes, so positive changes in wellbeing can be captured alongside changes in clinical conditions.

This thesis makes an original contribution to knowledge by exploring the experience and outcomes for care partnerships using MBI together. The evidence for using online MBI with care partnerships experiencing anxiety symptoms and depression symptoms after stroke is limited and very preliminary. It is too early to know whether using online MBI with stroke care partnerships experiencing anxiety symptoms and depression symptoms after stroke is recommended, but early indications suggest it may be beneficial for some people. This thesis will help future MBI researchers better understand the use of online MBI with care partnerships and could help improve the lives of care partnerships living with anxiety symptoms and depression symptoms after stroke.
Appendix 1: Journal publication from the thesis 2019

https://researchonline.gcu.ac.uk/en/persons/ben-parkinson
Appendix 2: Journal publication from the thesis 2021

https://researchonline.gcu.ac.uk/en/persons/ben-parkinson
### Appendix 3: Papers excluded from the systematic review update

<table>
<thead>
<tr>
<th>Citations</th>
<th>Decision</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compernolle and Sledge (2020)</td>
<td>Exclude</td>
<td>Delivered in in-patient setting Mind-body activity with mindfulness elements</td>
</tr>
<tr>
<td>Kimmes 2020</td>
<td>Exclude</td>
<td>No intervention used</td>
</tr>
<tr>
<td>Smith 2019</td>
<td>Exclude</td>
<td>Unpublished thesis</td>
</tr>
<tr>
<td>Milbury 2020</td>
<td>Exclude</td>
<td>Intervention not pure MBI (includes other methods)</td>
</tr>
<tr>
<td>Price-Blackshear 2020</td>
<td>Include</td>
<td></td>
</tr>
<tr>
<td>Henderson 2017</td>
<td>Exclude</td>
<td>Only abstract available. Tried contacting author, but received no reply</td>
</tr>
<tr>
<td>Jani 2018</td>
<td>Exclude</td>
<td>Mixed sample</td>
</tr>
<tr>
<td>Lin 2019</td>
<td>Exclude</td>
<td>Main outcome is sexuality for women with epilepsy Exclude because aimed at improving romantic relationships Exclude because sexual counselling combined with mindfulness</td>
</tr>
<tr>
<td>Bajaj 2017</td>
<td>Exclude</td>
<td>Excluded on second reading because the intervention is MBSR combined with group therapy. The group therapy component included cognitive reappraisal rather than acceptance.</td>
</tr>
<tr>
<td>Berk 2019</td>
<td>Include</td>
<td></td>
</tr>
<tr>
<td>McDonnell 2020</td>
<td>Include</td>
<td></td>
</tr>
<tr>
<td>Swannel 2017</td>
<td>Exclude</td>
<td>Thesis</td>
</tr>
<tr>
<td>Cottingham 2019</td>
<td>Exclude</td>
<td>Not pure MBSR include action planning and other components</td>
</tr>
<tr>
<td>Kubo 2019</td>
<td>Include</td>
<td>Waiting for partnership data</td>
</tr>
<tr>
<td>Lopez 2018</td>
<td>Exclude</td>
<td>Meditation, not mindfulness</td>
</tr>
<tr>
<td>Johns 2020</td>
<td>Exclude</td>
<td>Not pure MBSR include action planning and other components</td>
</tr>
<tr>
<td>Malm 2018</td>
<td>Exclude</td>
<td>Not pure MBI, uses CBT and positive psychology</td>
</tr>
<tr>
<td>Milbury 2018</td>
<td>Exclude</td>
<td>Intervention not pure MBI (includes other methods)</td>
</tr>
<tr>
<td>Kubo 2018</td>
<td>Include</td>
<td>Waiting for partnership data</td>
</tr>
<tr>
<td>Atreya 2018</td>
<td>Exclude</td>
<td>Partnership data not available</td>
</tr>
<tr>
<td>Milbury 2020</td>
<td>Exclude</td>
<td>Intervention not pure MBI (includes other methods)</td>
</tr>
<tr>
<td>Beer 2020</td>
<td>Exclude</td>
<td>Participants did not complete or use app. i.e. no intervention</td>
</tr>
<tr>
<td>Owens 2020</td>
<td>Exclude</td>
<td>Participants did not complete or use app. i.e. no intervention in current study</td>
</tr>
<tr>
<td>*Hankin 2009?</td>
<td>Exclude/ Remove</td>
<td>Thesis Included in first systematic review, but excluded in the 2020 update</td>
</tr>
<tr>
<td>Cox 2014</td>
<td></td>
<td>Partnership data not available</td>
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Appendix 4: Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA)

<table>
<thead>
<tr>
<th>Section/Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
<td>65</td>
</tr>
<tr>
<td>Structure summary</td>
<td>2</td>
</tr>
<tr>
<td>Rationale</td>
<td>65</td>
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<td>Objective</td>
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<td>Protocol and registration</td>
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<td>Eligibility criteria</td>
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<td>Information sources</td>
<td>71</td>
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<td>Search</td>
<td>69</td>
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<tr>
<td>Study section</td>
<td>74</td>
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<td>Data collection process</td>
<td>76</td>
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<td>Data items</td>
<td>76</td>
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<td>Risk of bias in individual studies</td>
<td>76</td>
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<tr>
<td>Summary of measures</td>
<td>77</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>77</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>76</td>
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<tr>
<td>Additional analysis</td>
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</tr>
<tr>
<td>Study section</td>
<td>81</td>
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<td>Study characteristics</td>
<td>81</td>
</tr>
<tr>
<td>Risk of bias within studies</td>
<td>115</td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>93-105</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>107-109</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>118</td>
</tr>
<tr>
<td>Additional analysis</td>
<td>NR</td>
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<tr>
<td>Summary of evidence</td>
<td>118</td>
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<td>Limitations</td>
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<td>Conclusions</td>
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</tbody>
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(Moher et al., 2009)
Appendix 5: Study protocol

Online mindfulness for stroke survivors and caregivers
(Version: V03)
Chief Investigator (CI): Ben Parkinson
Supervisors: Dr. Maggie Lawrence, Dr. Evelyn McElhinney, and Prof. Jo Booth

Background
Mood disturbance is common following stroke: anxiety [29%] and depression [24%] (Broomfield, et al. 2014). Capaldi and Wynn (2010) highlight the cost of post-stroke mood disturbance by suggesting it is associated with worse rehabilitation outcomes and greater use of rehabilitation services. Family caregivers are a key partner for stroke rehabilitation and developing combined stroke survivor and family caregiver interventions is a priority (Bakas, et al. 2017). This dyadic perspective for stroke rehabilitation is important since evidence suggests the emotional wellbeing of the stroke survivor and family caregiver might be interconnected (Atteh, et al. 2015; Klinendorst, et al. 2009). Deek, et al. (2016) believes combining family involvement with self-management strategies could reduce reliance on hospital-based services and might improve psychological wellbeing for people affected by stroke.

Mindfulness-based interventions (MBIs) use regular meditation to help develop ‘present moment awareness’ (Kabat-Zinn, 2013). MBIs can provide bio-psychosocial benefit for stroke survivors (Lawrence, et al. 2013) and caregivers (Jaffray, et al. 2016). Research into group-based mindfulness for stroke survivors discovered participants welcome the chance to have a family caregiver attend the sessions and prefer more flexible and accessible formats (Jani, et al. 2018). Parkinson, et al. (2018) explored the effects of people attending MBI with a family caregiver and found people attending in partnerships can experience improved psychological wellbeing, increased coping, and better engagement. Whilst online delivery could offer stroke survivors and family caregivers a more flexible and accessible form of MBI (Spijkerma, Pots, and Bohlmeijer, 2016). However, no research has been conducted using online MBI with stroke survivor and family caregiver partnerships.

Aims
This mixed-method study will explore the experience of stroke survivors and family caregivers learning mindfulness in a partnership via an online course.

Questions
1. Is it feasible to recruit stroke survivors and family caregiver partnerships into a study using online MBI?
2. Do participants adhere to using online MBI?
3. Do participants find the experience of using online MBI appropriate?
4. What meaning do participants make from the experience of learning MBI together via an online platform?
5. What psychological effects (if any) do participants experience using online MBI?
6. What effect do interpersonal/partnership factors have on the experience or outcomes associated with using online MBI?

Participants and recruitment methods
Community-dwelling adult stroke survivors and their family caregivers will be purposively recruited as a partnership (N=10 dyads maximum) from Scotland. Invitation flyers and participant information sheets (appendices 1 & 2) will be circulated on social media (e.g. twitter) and within voluntary sector organisations (e.g. Chest, Heart Stroke Scotland and Stroke Association) following gatekeeper approval. Interested stroke survivor and family caregiver partnerships will ‘opt-in’ together by contacting the chief investigator (CI). Interested stroke survivors and family caregiver partnerships will each be given participant information sheets, verbal details about

1
the study, and encouraged to ask questions. During this initial contact the inclusion/exclusion criteria (table 1) will be discussed and the screening protocol followed for both the stroke survivor and family caregiver (appendix 3). Those potential stroke survivor and family caregiver partnerships meeting eligibility criteria and who are interested in participating will be offered an appointment at a convenient time/place with the CI to complete the consent process. This meeting will be at least 24 hours after initial contact. This will allow people time to consider whether they wish to participate and to avoid coercion. At the meeting the CI will confirm the stroke survivor and family caregiver’s willingness to participate, stress the voluntary nature of participation, the right to withdraw, and invite further questions. Then the stroke survivor and family caregiver will each be invited to complete a consent form (appendix 4). After consent each participant will choose a pseudonym for themselves. The CI will keep a log of participant’s pseudonyms (appendix 7) and use pseudonyms on all future documents (e.g. demographic details forms outcomes measures). The CI will keep the consent form and provide a copy to participants.

| Table 1: Inclusion and exclusion criteria for stroke survivors and caregivers |
|---------------------------------|---------------------------------|
| **Inclusion**                   | **Exclusion**                   |
| • Stroke survivor and family caregiver partnership (as a dyad) | • Currently using MBI |
| • 18yrs plus                    | • Attending for other Psychosocial intervention |
| • Based in Scotland             | • Difficulty eating             |
| • Community-dwelling            |   (NB: raisin exercise)         |
| • Able to use internet          | • Current or recent involvement with mental health services |
| • Access to internet            | • Current or recent involvement with addiction services |
| • Computer literate             | • Current or recent suicidal thinking |
| • Able to communicate in written and spoken English | • Cognitive impairment |
| • Self-identifies as stressed, anxious, or depressed | |

Methods
The study will use a mixed method sequential explanatory multiple case study design and the Be Mindful course (www.bemindfulonline.com). The course is delivered by Wellmind Media (www.wellmindmedia.com). The course is a four-week online MBI using Mindfulness-Based Cognitive Therapy (Teasdale, et al. 2000). Participants watch ten videos (30 minutes each), practice meditation, listen to audio downloads, and review progress using online tools. Participants will have unlimited access to the course and can decide when and how they use the course. The course can reduce stress, anxiety, and depression (Krusche, et al. 2013; Querstret, et al. 2018). Online data will be shared with the research team through Wellmind Media’s password protected secure system. The CI will also collect paper-based and interview data (table 3). CI data collection will most likely take place at the participants’ own home at a date and time of their choosing. It might also take place via telephone or online, if participants prefer. The CI will adhere to Glasgow Caledonian University Lone Working policy when visiting participants’ homes.

| Table 2: The Be Mindful course |
|-------------------------------|---------------------------------|
| Before                        | Introduction and orientation.  |
| Week 1                        | Routine activity, mindful eating, and body scan. |

2
Week 2 | Mindfulness movement, event awareness, and mindful breathing.
---|---
Week 3 | Breathing space, stress awareness, and sitting meditation.
Week 4 | Activity awareness, stress strategies, breathing space, and action plan.
Follow-up | Certificate and additional resources.

| Table: 3 Data collection strategy for stroke survivors and family caregivers |
|-----------------|----------------|-----------------|
| Outcome         | Method                  | Collector          | Timing           |
| Demographic data | Demographic information (appendix 5) | Chief Investigator | Week 0           |
| Stress          | Perceived Stress Scale [PSS] (Cohen, Kamarck, and Mermelstein, 1994) | Wellmind Media | Automated Pre/post |
| Anxiety         | Generalised Anxiety Disorder [GAD-7] (Spitzer, et al. 2006) | Wellmind Media | Automated Pre/post |
| Depression      | Patient Health Questionnaire [PHQ9] (Spitzer, Kroenke, and Williams, 1999) | Wellmind Media | Automated Pre/post |
| Anxiety and depression | Hospital Anxiety and Depression Scale [HADS] (Zigmond and Snaith, 1983) | Chief Investigator | Weeks 0, 4, and 8 |
| Mindfulness     | Mindfulness Attention Awareness Scale [MAAS] (Brown and Ryan, 2003) | Chief Investigator | Weeks 0, 4, and 8 |
| Experience      | Semi-structured interviews (appendix 6) | Chief Investigator | Week 8           |

Data analysis
Quantitative analysis will use descriptive statistics and clinical/reliable change indicators (Jacobson and Traux, 1991). The qualitative analysis will use Interpretive Phenomenological Analysis (Smith, et al. 2009) to help illuminate the experience and meaningfulness of online mindfulness within a partnership.

Consent, confidentiality and anonymity
Participation will be fully informed and voluntary. Stroke survivors and their family caregivers will ‘opt-in’ in response to an advert and will then each receive a participant information sheet. They will speak to the CI about the study and be able to ask questions. Once all questions have been answered the stroke survivor and family caregivers will be given time to consider their involvement before meeting the CI for consent and to begin the study. No inducement will be used to encourage participation, although, the MBI course will be provided free of charge (worth £30). Participants will be free to leave at any time and without any repercussions or negative consequences. Participants can leave the study without giving a reason, but will be asked whether they wish to have their records destroyed or not. Anyone leaving the course will continue to have access to the course. All feasible steps will be taken to maintain participant anonymity and confidentiality. The online course is hosted by Wellmind Media (www.wellmindmedia.com) who are responsible for the management and data security of the course related materials (e.g. site access, quantitative outcomes data, and online records). The Wellmind Media data is held on a cloud-based system and is compliant with payment card industry data security...
standards (PCI DSS). The Wellmind Media platform adheres to strict security, compliance, and risk management controls, and aligns with the National Cyber Security Centre Cloud Security Principles (www.ncsc.gov.uk). Study participants will be asked by Wellmind Media if they consent to sharing their online data with the research team for the purposes of the study.

The CI will seek consent, collect demographic data, collect paper-based outcome data, and interview participants (table 3). After giving consent participants will choose a pseudonym, which will be used for the duration of the study and help maintain anonymity. Only the participant themselves and the CI will know the pseudonym (appendix 7). The consent forms, pseudonym log, and demographic records will be held separately from the pseudonymised outcome data and transcripts. All research documents will be held securely in locked cabinets at Glasgow Caledonian University and/or on a personal password protected computer drive. Personal identifiable information will only be accessible to the CI and the supervisory team. Data management will be in accordance with data security policies and procedures at Glasgow Caledonian University. This means research documentation, will be held securely for five years after the study has been completed. After five years all documents (excluding published work) will be destroyed using confidential waste disposal. The interviews will be digitally recorded and stored on a password protected voice recorder. The CI will have access to the digital recordings and produce an anonymous transcript. The digital voice recording will be stored on the password protected voice recorder and erased after all data analysis has been completed. The transcripts will be stored securely on a personal password-protected computer drive. Anonymity of participants will be ensured by providing each participant with a pseudonym and removing any identifiable information from published work.

Risks to participants/self (risk assessment attached)
Mindfulness has occasionally been associated with negative mental, physical, and spiritual consequences, although, this is usually when used at higher intensity than will be used in this study (Lustyk et al. 2009). Likewise, Lawrence et al. (2013) did not identify negative consequences in their review of MBI for stroke survivors, which suggests the risk associated with MBI are low. Potential harm will be considered for both stroke survivors and family caregivers. It will be minimised during this study by using the specified inclusion/exclusion criteria (table 1), stressing the importance of working within one’s own limitations, and not pushing any exercise to the point of distress or discomfort. Stroke survivors and family caregivers psychological wellbeing will be monitored using outcome measures. Anyone scoring 11+ on the HADS or indicating suicidal thinking will be signposted to their General Practitioner. If the researcher becomes concerned about the participant’s mental health (e.g. suicidal planning/intent or significant deterioration in mental health) they will speak to participant about their concerns and refer to the participant’s General Practitioner. The interviews will also be a possible source of unintended harm. The study inclusion/exclusion criteria will reduce the likelihood of vulnerable groups being recruited. The CI (a registered mental health nurse) has experience of working with vulnerable people and conducting clinical/research interviews. The CI will informally monitor emotional expression during the interviews and discontinue the questioning if either member of the partnership becomes distressed. Should this happen, then immediate emotional support will be provided by the CI. Plus, provision can be made for formal emotional support and/or debriefing afterwards, if necessary.

Arrangements for debriefing
The CI will provide debriefing to both stroke survivors and family caregivers following the interviews. The debriefing will help ensure people are not experiencing any
difficulties following the interview. If difficulties are identified the CI will use their mental health nursing skills to provide initial support and signpost the participant to appropriate services (e.g. General Practitioner; Chest, Heart, Stroke Scotland; Breathing Space etc.).

**Ethical considerations**

Ethical approval will be secured from Glasgow Caledonian University’s School of Health and Life Sciences Ethics Committee. The research team will adhere to the Declaration of Helsinki (World Medical Association, 2005) and the United Kingdom Framework for Health and Social Care Research (Health Research Authority, 2017). The CI completed Good Clinical Practice training (International Conference on Harmonisation Working Group, 1996), secured copyright permission for all outcome measures (e.g. MS, HADS, and MAAS), and is being supervised by experienced academics.

**References**


[Accessed 09.03.18].


Appendix 6: Ethical approval

From: HLS Ethics
To: Parkinson, Ben; Lockhart, Alison; HLS Ethics
Cc: Lawrence, Nga; McEhinney, Evelyn; Booth, Jo
Subject: HLS/PSWAHS/17/293 Ethics Approval
Date: 15 November 2016 11:43:02

Dear Ben,

**Title: Project Title:** Online mindfulness for stroke survivors and caregivers

The Research Committee has completed its scrutiny of your application and I can confirm that this has now been approved.

Good luck with your studies.

on behalf of
Dr Phil Dalgarno, Chair
PSWAHS Research Ethics Committee
Appendix 7: Ethical approval amendment

Dear Ben,

Project Title: Online mindfulness for stroke survivors and caregivers

Chairs action has been taken on your request for minor amendments to be made to your previously approved ethics application HLS/PSWAHS/17/293. This has now been approved.

Alexis Henderson, On behalf of
Dr Phil Dalgarno, Chair
PSWAHS Research Ethics Committee
## Appendix 8: Study risk assessment

### Identifications of hazards

Please indicate in the table below hazards identified as pertinent to your research project and rate them and indicate your rating of the likelihood of the identified hazard causing actual harm. Please refer to research related risk assessment guidelines (Forms A & B).

**Level of Risk = severity of harmful event x likelihood of event occurring**

**Risk Assessment and Response Matrix**

<table>
<thead>
<tr>
<th>Likelihood of Occurrence</th>
<th>4 Tolerate/ Treat</th>
<th>7 Treat/ Transfer</th>
<th>9 Treat/Transfer/ Terminate</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medium</td>
<td>2 Tolerate/ Treat</td>
<td>5 Treat/ Transfer</td>
<td>8 Treat/Transfer/ Terminate</td>
</tr>
<tr>
<td>Low</td>
<td>1 Tolerate</td>
<td>3 Tolerate/ Treat</td>
<td>6 Treat/Transfer</td>
</tr>
</tbody>
</table>

**Impact of Risk ⇒**

- Low
- Medium
- High

*eg.* Hazard 1: medium likelihood of occurrence x low impact = tolerable or treat

*eg.* Hazard 2: high likelihood of occurrence x high impact = treat, transfer or STOP

<table>
<thead>
<tr>
<th>Hazard</th>
<th>Severity</th>
<th>Likelihood</th>
<th>Treatment of Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vulnerable groups might be inadvertently recruited</td>
<td>High</td>
<td>Low</td>
<td>Treat</td>
</tr>
<tr>
<td>Difficulties associated with learning mindfulness.</td>
<td>Medium</td>
<td>Low</td>
<td>Tolerate</td>
</tr>
<tr>
<td>Online data breach within Wellmind media.</td>
<td>High</td>
<td>Low</td>
<td>Treat</td>
</tr>
<tr>
<td>Distress experienced by stroke survivors and family caregivers during the interview.</td>
<td>Low</td>
<td>Medium</td>
<td>Tolerate</td>
</tr>
<tr>
<td>Severe mental health difficulties might emerge during study.</td>
<td>High</td>
<td>Low</td>
<td>Treat</td>
</tr>
<tr>
<td>Potential Risks Identified</td>
<td>Medium</td>
<td>Low</td>
<td>Treat</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------------</td>
<td>--------</td>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>Stroke survivors and family caregivers might experience exacerbation of health difficulties/stress during study.</td>
<td>Medium</td>
<td>Medium</td>
<td>Treat</td>
</tr>
<tr>
<td>Suicidal intent might be revealed during outcome monitoring or interview.</td>
<td>Medium</td>
<td>Low</td>
<td>Tolerate</td>
</tr>
<tr>
<td>Researcher might be exposed to travel/environmental hazards when completing interviews in participants homes.</td>
<td>Low</td>
<td>Low</td>
<td>Tolerate</td>
</tr>
<tr>
<td>Loss of paper-based research documents containing personal identifiable information.</td>
<td>High</td>
<td>Low</td>
<td>Treat</td>
</tr>
<tr>
<td>The study might not be able to recruit intended number of participants.</td>
<td>Low</td>
<td>Low</td>
<td>Tolerate</td>
</tr>
<tr>
<td>Poor management of the study might result in bad publicity for GCU.</td>
<td>Medium</td>
<td>Low</td>
<td>Tolerate</td>
</tr>
</tbody>
</table>

**Measures taken to minimize the potential risks identified**

- **Vulnerable groups might be inadvertently recruited**
  - The risk of inadvertently recruiting vulnerable people will be reduced by:
    1. Inclusion and exclusion criteria will be used to screen stroke survivors and family caregiver before recruitment
    2. Stroke survivors and family caregivers will be recruited as a partnership, so one or other of the dyad will be able to advise/support the other person
    3. Stroke survivors and family caregivers will be fully informed about what the study involves and be given adequate time to consider their involvement
    4. No pressure will be put on stroke survivors and family caregivers to participate
    5. Stroke survivors and family caregivers will be free to leave at any time
    6. The CI is a mental health nurse with experience of identifying and working with vulnerable people

- **Difficulties associated with learning mindfulness and/or the intervention.**
  - The MBI has been specifically chosen to reduce the likelihood of causing difficulties for people:
    1. Low intensity MBI is associated with fewer difficulties and will be used within this study
    2. MBI based on established mindfulness protocol (i.e. MBCT)
    3. MBI used within NHS [although, not routinely in stroke services]
    4. The course guides people to only practice within their comfort zone and to not continue if becoming distressed
    5. Stroke survivors and family caregivers will be advised to contact the CI and/or their GP if they experience any difficulties associated with the course
    6. Stroke survivors and family caregivers will be advised to cease using the mindfulness if they experience any adverse events during the study
    7. All adverse events and serious adverse events will be recorded and reported in published work
| Online data breach within Wellmind media. | The risk of an online breach with Wellmind media will be reduced by:  
1. The Wellmind Media data being held on a cloud-based system that is compliant with payment card industry data security standards (PCI DSS)  
2. Wellmind Media adheres to strict security, compliance, and risk management controls, and aligns with the National Cyber Security Centre Cloud Security Principles ([www.ncsc.gov.uk](http://www.ncsc.gov.uk))  
3. Stroke survivors and family caregivers will be asked by Wellmind Media if they consent to sharing their online data with the research team for the purposes of the study  
4. Online data will be accessed by the research team directly from Wellmind Media’s online password protected secure system, so limited opportunity for data loss |
| --- | --- |
| Distress experienced by participants during the interview. | The potential risk of distress being experienced by participants during the interview will be reduced by:  
1. The CI (a registered mental health nurse) being experienced working with vulnerable people and conducting clinical/research interviews  
2. The CI will informally monitor emotional expression during the interviews and discontinue questioning if either member of the partnership becomes distressed. Should this happen, then immediate emotional support will be provided by the CI  
3. The CI will provide debriefing to all stroke survivors and family caregivers following the interviews. The debriefing will help ensure people are not experiencing any difficulties following the interview. If difficulties are identified the CI will use their mental health nursing skills to provide initial support and signpost the participant to appropriate services (e.g. General Practitioner; Chest, Heart, Stroke Scotland; Breathing Space etc.) |
| Severe mental health difficulties might emerge during study. | The potential risk of serious mental health difficulties emerging during the study will be reduced by:  
1. Stroke survivors and family caregivers psychological wellbeing being monitored using outcome measures. Anyone scoring 11+ on the HADS or indicating suicidal thinking will be signposted to their General Practitioner. If the researcher becomes concerned about a stroke survivor or family caregiver’s mental health (e.g. suicidal planning/intent or significant deterioration in mental health) they will speak to participant about their concerns and refer to the participant’s General Practitioner. |
| Stroke survivors and family caregivers might experience exacerbation of health difficulties/stress during study. | The risk of stroke survivors and family caregivers experiencing an exacerbation of health difficulties/stress during the study will be reduced by:  
1. Stroke survivors and family caregivers psychological wellbeing will be monitored using outcome measures. Anyone scoring 11+ on the HADS or indicating suicidal thinking will be signposted to their General Practitioner. If the researcher becomes concerned about the participant’s mental health (e.g. suicidal planning/intent or significant deterioration in mental health) they will speak to participant about their concerns and refer to the participant’s General Practitioner. |
<table>
<thead>
<tr>
<th>Risk Area</th>
<th>Risk Description</th>
</tr>
</thead>
</table>
| Suicidal intent might be revealed during outcome monitoring or interview | The risk of stroke survivors and family caregivers reporting suicidal intent will be managed by:  
1. Stroke survivors and family caregivers psychological wellbeing being monitored using outcome measures. Anyone scoring 11+ on the HADS or indicating suicidal thinking will be signposted to their General Practitioner.  
2. If the researcher becomes concerned about a stroke survivor or family caregivers mental health (e.g. suicidal planning/intent or significant deterioration in mental health) they will speak to participant about their concerns and refer to the participants General Practitioner. |
| Researcher might be exposed to travel/environmental hazards when completing interviews in participants homes | Possible risk to the CI completing interviews in the community will be reduced by following the GCU Lone Working Policy. Specifically, the risk will be reduced by:  
1. The CI having no medical issues and being fully mobile  
2. The CI being an experienced community health worker who has many years’ experience visiting patients within their own homes  
3. The CI will only attend known addresses for the participants within daylight hours and normal working hours  
4. The CI will terminate and exit the premises if they feel threatened or in danger  
5. The CI will inform their supervisory team about when and where they are attending and notify them once the interview is complete and they are back home safely |
| Loss of paper-based research documents containing personal identifiable information | Risk associated with using paper-based documents will be reduced by:  
1. Using secure electronic documents where possible  
2. Only recording necessary information (data minimisation)  
3. Using pseudonyms and anonymisation where possible  
4. Only transporting paper documents when necessary and directly between place of completion (i.e. participant’s home) to safe secure storage at GCU  
5. Reporting any loss of documents to data protection team at GCU and seeking guidance about the what steps are needed following the loss |
| The study might not be able to recruit intended number of participants | The risk of not recruiting enough participants will be reduced by:  
1. Using case study and IPA methodology, which only requires small numbers of participants  
2. Using existing networks accessible within the research team |
| Poor management of the study might result in bad publicity for GCU. | The risk associated with poor management of the study will be reduced by:  
1. Setting specific goals and realistic targets for the work  
2. Maintaining regular supervision throughout the project  
3. Having an experienced supervisory team |

- Working with an advisory group to ensure the study is relevant and accessible for people affected by stroke  
- Regularly reviewing the interest rate and recruitment numbers to ensure we are meeting expected deadline
Appendix 9: Study advert

Mindfulness for stroke survivors and family caregivers

Stressed, anxious, or depressed after a stroke? Interested in learning mindfulness online and with a family caregiver? Want to take part in exciting research?

To find out more contact:
Ben Parkinson at Glasgow Caledonian University
Email: ben.parkinson@gcu.ac.uk
Telephone: 0141 331 3114
Appendix 10: Participant information sheet

Participant Information Sheet

Online mindfulness for stroke survivors and caregivers

Introduction
Stroke survivors and family caregivers can experience psychological difficulties. These include stress, anxiety, and depression. The psychological wellbeing of stroke survivors and caregivers is linked, so helping them together makes sense. Mindfulness meditation helps increase present moment awareness and can improve stroke survivors and caregivers psychological wellbeing. Usually individuals learn mindfulness in groups on set days, at set times. Learning mindfulness in a group is not always practical and overlooks the connection between stroke survivors and caregivers. Another way to learn is online. Stroke survivors and caregivers could learn mindfulness together, at times that suit them. This study will look to see if stroke survivors and caregivers find using mindfulness online helpful. It will also see if learning in a partnership makes a difference. Ben Parkinson (PhD student) is carrying out the research and is supervised by an experienced team from Glasgow Caledonian University.

What will I have to do if I take part?
You will be asked to sign a consent form and use an online mindfulness course called ‘BeMindful’ (https://bemindful.co.uk/). You will be given a personal login for the course. This course may reduce stress, anxiety, and depression. The course is four weeks long and will take about half an hour each day. You can use the course at any time day or night. You have to use the course online (via the Internet). It includes videos to help you learn and practice.
During the study we will ask you questions. We will ask about you and your partner (e.g. age, ethnicity, and gender etc.). We will ask about your health (e.g. type of stroke and associated difficulties) and living situation (e.g. whether you live together and how well you get on). We will also ask you to fill in questionnaires. The questionnaires ask about your psychological wellbeing (e.g. stress, anxiety, and depression) and take about ten minutes to complete. You can see the questionnaires before agreeing to take part. At the end of the study, you and your partner will be interviewed by the researcher. The interview will last about one hour. The interview will be arranged to suit you. The interviewer will ask you questions about the course and what you thought of learning mindfulness together. You do not have to answer questions if you do not want, and you can ask the researcher to ‘skip’ questions.

**Do I have to take part?**
No. You decide if you want to take part. You can stop at any time. You do not have to give a reason. Leaving the study will not affect your care or legal rights. If you want to leave the study you can decide what happens to your data. We can destroy your data or you can have the data used.

**What are the benefits of taking part?**
If you take part in the study you will access the course for free (worth £30). Previous research found the course helped people reduce stress, anxiety, and depression. Not everyone benefits from the course.

**What are the possible disadvantages and risks of taking part?**
Most people do not experience problems learning mindfulness. A small number of people report difficulties (e.g. agitation, anxiety, discomfort,
Mindfulness is not recommended if you have a history of major trauma or psychosis. Risk is less if you follow the guidance provided in the course and stop if you experience discomfort. Please tell the researcher if you experience any discomfort during the study.

**What happens when the research study ends?**
The researchers will try to find out if the course helps stroke survivors and caregiver partnerships. The study is part of a PhD and will be published. It will not be possible to identify you in the published work.

**What will happen to the information that you give?**
Online information will be held by Wellmind Media (https://www.wellmindmedia.com/) and shared with Glasgow Caledonian University for this research. Wellmind Media is the organisation that developed the course and will be running the course for this research. All information gathered by the researcher will be held securely by Glasgow Caledonian University. Documents will be held in a locked cabinet or a password protected computer drive. Information will be anonymised. The interview recording will be held on a password protected voice recorder. Only the interviewer will be able to listen to the recording and it will be deleted when the study is finished. The interview will be transcribed and have all personal information removed. Documents will be stored for five years. After five years the documents will be destroyed. The research will meet data security standards for Glasgow Caledonian University and data protection legislation. The new General Data Protection Regulation (2018) requires a legal basis for certain data to be used. The legal basis for this study is that data will be used to complete a task that is in the public interest. The data controller for this study will be Glasgow Caledonian University.
What if there is a problem?
Feedback or complaints should be sent to Des Cornes (Assistant Head of Department) at Glasgow Caledonian University. Telephone 0141 331 8353 or email D.Cornes@gcu.ac.uk. Enquiries relating to Data Protection should be made to the University’s Data Protection Officer. Email dataprotection@gcu.ac.uk.

Will my taking part in this study be kept confidential?
Yes. All information you provide will be confidential. No personal identifying information will be shared outside the research team. Published work will not include identifying information. The only time information would be shared is if we became concerned about your mental health and safety. If this happens we would try and keep you safe by contacting your General Practitioner.

Who is organising and funding the research?
Glasgow Caledonian University and Ben Parkinson are organising and funding this research. Glasgow Caledonian will be the research sponsor and data controller for the study.

What will happen to the results of the research study?
The results will be published. It will not be possible to identify participants.

Who has reviewed the study?
Glasgow Caledonian University has given ethical approval for the study.
What happens next?
Please contact Ben or return the interest slip below if you want to know more.

Ben Parkinson (PhD student)
Glasgow Caledonian University
Cowcaddens Road, G4 0BA
Email ben.parkinson@gcu.ac.uk
Telephone 0141 331 3114

................................................. CUT HERE ...........................................

Expression of interest slip

I would like to speak to Ben about the "Online mindfulness for stroke survivors and caregivers" project.

Signature: ___________________________ Date: ______________

Print: _______________________________ Telephone: ____________

Email: _______________________________

----------------------------------------

Version V03 Date of Version 22.10.18
Appendix 11: Screening protocol

Online mindfulness for stroke survivors and caregivers

(Version: V03)

Screening Protocol

Introduction
Hello, my name is Ben and I want to thank you for taking the time to speak to me today. The purpose of this conversation is to tell you about the research and to answer any questions you might have about the research. It is also an opportunity to see whether this research is something you would like to get involved with.

You are under no obligation to participate and will not have to give an answer today. Hopefully, you have read the participant information sheet (if not, provide one and/or read it out). Would you like me to tell you about the research? Do you have any questions about the research?

Screening
We are looking to recruit stroke survivors and family caregivers together (i.e. in pairs). We want to see whether using an online mindfulness intervention in a pair/partnership is useful or not. Do you have someone who would be willing to learn mindfulness with you? This can be a relative, friend, or spouse.

We are specifically looking for:
- Stroke survivors and family caregivers who want to learn mindfulness together
- Are aged 18 or over
- Live in Scotland
- Live in the community
- Can use the internet
- Have access to the internet
- Can communicate in English
- Are currently stressed, anxious, or depressed (with or without diagnosis)

The study is not appropriate if you:
- Are currently using mindfulness
- Receiving other forms of psychological care
- Have difficulty eating
- Are currently involved with mental health/addiction services
- Have suicidal thoughts
- Have memory problems or cognitive impairment (e.g. self (or carer)-disclosed or evaluated by interaction with person during screening and their ability to retain/comprehend information)

Given what you have been told about the study, is this something you would like to know more about?

If yes, the next step is for us to arrange an initial meeting (face-to-face or on the phone) to complete the consent process and to start the research.

If no, thank you very much for your time today.
Appendix 12: Consent form

Online mindfulness for stroke survivors and caregivers

CONSENT FORM

1) I understood the participant information sheet (V03). I have asked all the questions I want. All my questions have been answered.

2) I am under no pressure to volunteer for the study. I can leave at any time. I do not have to give a reason. Leaving early will not negatively affect my partner or me.

3) I understand online data will be held securely by Wellmind Media. Online data will be shared with the research team at Glasgow Caledonian University.

4) I understand Glasgow Caledonian University will manage my data securely. Data management will meet legal and organisational requirements.

5) I know the interview will be recorded and my comments may be published. It will not be possible to identify me in published work.

6) In an emergency the researcher may ask to contact my General Practitioner. This will only happen if the researcher is concerned about my mental health.

7) I agree to take part in the study.

Initial box

Participant (print) Date Signature

Researcher (print) Date Signature

Version V03 Date of version 22.10.18
Appendix 13: Demographic data collection tool

<table>
<thead>
<tr>
<th>Sociodemographic (both stroke survivor and family caregiver)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age (years)</td>
</tr>
<tr>
<td>• Employment (current and/or previous occupation)</td>
</tr>
<tr>
<td>• Gender (self-identified)</td>
</tr>
<tr>
<td>• Ethnic background (self-assigned ethnic group)</td>
</tr>
<tr>
<td>• Education background (include highest level of education attained)</td>
</tr>
<tr>
<td>• Relationship details (e.g. married for ten years or friends for two years)</td>
</tr>
<tr>
<td>• Living with caregiver</td>
</tr>
<tr>
<td>• Previous use of mindfulness</td>
</tr>
<tr>
<td>• Current medication for stress, anxiety, or depression (name/dose)</td>
</tr>
<tr>
<td>• General Practitioner (emergency use only)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stroke survivor (only)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Type of stroke</td>
</tr>
<tr>
<td>• Number of strokes</td>
</tr>
<tr>
<td>• Time since first/last stroke</td>
</tr>
<tr>
<td>• Current stroke related difficulties</td>
</tr>
</tbody>
</table>
Appendix 14: Automated outcome data from Be Mindful

<table>
<thead>
<tr>
<th>ID</th>
<th>PSS 0</th>
<th>PSS 1</th>
<th>PSS 2</th>
<th>GAD7 0</th>
<th>GAD7 1</th>
<th>GAD7 2</th>
<th>PHQ9 0</th>
<th>PHQ9 1</th>
<th>PHQ9 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>SS1</td>
<td>20</td>
<td>20</td>
<td>19</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>CP1</td>
<td>18</td>
<td></td>
<td></td>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>SS2</td>
<td>23</td>
<td>12</td>
<td>13</td>
<td>11</td>
<td>0</td>
<td>1</td>
<td>11</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>CP2</td>
<td>20</td>
<td></td>
<td></td>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>SS3</td>
<td>21</td>
<td>21</td>
<td></td>
<td>6</td>
<td>10</td>
<td></td>
<td></td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>CP3</td>
<td>12</td>
<td></td>
<td></td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>SS4</td>
<td>5</td>
<td>6</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>CP4</td>
<td>12</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>SS5</td>
<td>9</td>
<td></td>
<td></td>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>CP5</td>
<td>14</td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

Key
D1-5 = dyad 1-5
SS = stroke survivor
CP = care partner
PSS = (Cohen et al., 1983)
GAD7 = (Spitzer et al., 2006)
PHQ9 = (Kroenke, Spitzer and Williams, 2001)
## Appendix 15: Cross-case joint display (detailed)

<table>
<thead>
<tr>
<th>Care Partnership</th>
<th>HADS-T (Pre-Mid-Post)</th>
<th>MAAS (Pre-Mid-Post)</th>
<th>MS (Pre-Mid-Post)</th>
<th>IPA Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>One Stroke Survivor Care partner</td>
<td>17-NR-15 13-NR-NR</td>
<td>3.64*-NR-5.07 3.36-NR-NR</td>
<td>3.33-NR-3.33 3.27-NR-NR</td>
<td><strong>Dialectical tension</strong> <strong>Curiosity</strong> <strong>Usage</strong> <strong>Togetherness</strong> <strong>Change</strong></td>
</tr>
<tr>
<td>Two Stroke Survivor Care partner</td>
<td>25-12-11 4-5-5</td>
<td>3.45*-4.0*-4.87 4.27*-3.63*-5.07</td>
<td>3.13-3.6RC-3.93 3.53-3.53-3.0</td>
<td></td>
</tr>
<tr>
<td>Three Stroke Survivor Care partner</td>
<td>18-14-18 6-7-5</td>
<td>4.18*-4.27*-4.0 4.45*-4.10*-5.27</td>
<td>3.6-3.93-3.8 3.67-3.6-3.4</td>
<td></td>
</tr>
<tr>
<td>Four Stroke Survivor Care partner</td>
<td>12-11-5 7-4-5</td>
<td>3.91*-4.5-5.13RC 3.45*-4.1-4</td>
<td>4-3.8-3.8 3.73 - 3.47-3.53</td>
<td></td>
</tr>
<tr>
<td>Five Stroke Survivor Care partner</td>
<td>11-14-12 11-7-5</td>
<td>3.53-4.07-4.02 4.27-3.8-4.33</td>
<td>4-4-4 3.8-3.4-3.87</td>
<td></td>
</tr>
</tbody>
</table>

**Key**
- HADS-T = Hospital Anxiety and Depression Scale total score (Zigmond and Snaith, 1983)
- IPA = Interpretative Phenomenological Analysis (Smith, Flowers and Larkin, 2009)
- MAAS = Mindful Awareness Attention Scale (Brown and Ryan, 2003)
- MS = Mutuality Scale (Archbold et al., 1990)
- NR = Unit level missing data
- * = Item level missing data
## Appendix 16: Template for Intervention Description and Replication checklist (TIDieR)

<table>
<thead>
<tr>
<th>Description</th>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide the name or a phrase that describes the intervention. 161</td>
<td>161</td>
</tr>
<tr>
<td>Describe any rationale, theory, or goal of the elements essential to the intervention.</td>
<td>51</td>
</tr>
<tr>
<td>Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).</td>
<td>166</td>
</tr>
<tr>
<td>Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.</td>
<td>166</td>
</tr>
<tr>
<td>For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.</td>
<td>166</td>
</tr>
<tr>
<td>Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.</td>
<td>166</td>
</tr>
<tr>
<td>Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.</td>
<td>166</td>
</tr>
<tr>
<td>Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.</td>
<td>166</td>
</tr>
<tr>
<td>If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.</td>
<td>166</td>
</tr>
<tr>
<td>If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).</td>
<td>166</td>
</tr>
<tr>
<td>Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.</td>
<td>183</td>
</tr>
<tr>
<td>Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.</td>
<td>232</td>
</tr>
</tbody>
</table>

(Hoffmann et al., 2014)
## Appendix 17: Interview schedule

<table>
<thead>
<tr>
<th>Experience of stroke</th>
<th>Can you tell me how stroke has affected your life?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of the course</td>
<td>What has the experience of using the course been like?</td>
</tr>
<tr>
<td>Experience of mindfulness</td>
<td>What has the experience of learning mindfulness been like?</td>
</tr>
<tr>
<td>Experience of online</td>
<td>What has the experience of learning mindfulness online been like?</td>
</tr>
<tr>
<td>Experience of learning together</td>
<td>What has the experience of learning mindfulness together been like?</td>
</tr>
<tr>
<td>Psychological wellbeing</td>
<td>What changes (if any) have you noticed since learning mindfulness?</td>
</tr>
<tr>
<td>Research</td>
<td>What has the experience been like for you both to be involved in this research?</td>
</tr>
<tr>
<td>Anything else</td>
<td>Is there anything else you think is important that I have not asked about?</td>
</tr>
</tbody>
</table>
### Appendix 18: IBM SPS statistical analysis

<table>
<thead>
<tr>
<th>Friedman's Test</th>
<th>Whole group</th>
<th>Stroke survivor</th>
<th>Care partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS-A</td>
<td>0.368</td>
<td>0.472</td>
<td>0.627</td>
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<tr>
<td>HADS-D</td>
<td>0.840</td>
<td>0.931</td>
<td>0.717</td>
</tr>
<tr>
<td>MAAS</td>
<td>0.135</td>
<td>0.174</td>
<td>0.174</td>
</tr>
<tr>
<td>MS</td>
<td>0.764</td>
<td>0.761</td>
<td>0.282</td>
</tr>
</tbody>
</table>
## Appendix 19: Study expenses

<table>
<thead>
<tr>
<th>Date</th>
<th>Description</th>
<th>Cost</th>
<th>Paid</th>
<th>By whom/when</th>
</tr>
</thead>
<tbody>
<tr>
<td>2018-20</td>
<td>Advisory group fees</td>
<td>£150</td>
<td>Yes</td>
<td>Ben 25.09.20</td>
</tr>
<tr>
<td>29.01.19</td>
<td>Be Mindful course costs (n=6) (£30+VAT per participant)</td>
<td>£216</td>
<td>Yes</td>
<td>Ben 29.01.19</td>
</tr>
<tr>
<td>22.10.18</td>
<td>HADS screening tool</td>
<td>£118</td>
<td>Yes</td>
<td>Ben 22.10.19</td>
</tr>
<tr>
<td>06.03.19</td>
<td>Different stroke advert</td>
<td>£100</td>
<td>Yes</td>
<td>Ben 06.03.19</td>
</tr>
<tr>
<td>25.03.19</td>
<td>Be Mindful course costs (n=4) (£30+VAT per participant)</td>
<td>£144</td>
<td>Yes</td>
<td>Ben 25.03.19</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>£728</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 20: The CAse REport guidance checklist for clinical case reporting (CARE)

<table>
<thead>
<tr>
<th>Description</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
<td>132</td>
</tr>
<tr>
<td>Key words</td>
<td>NR</td>
</tr>
<tr>
<td>Abstract</td>
<td>2</td>
</tr>
<tr>
<td>Introduction</td>
<td>19</td>
</tr>
<tr>
<td>Patient information</td>
<td>226</td>
</tr>
<tr>
<td>Clinical findings</td>
<td>229 and 261</td>
</tr>
<tr>
<td>Timeline</td>
<td>152</td>
</tr>
<tr>
<td>Diagnostic assessment</td>
<td>238</td>
</tr>
<tr>
<td>Therapeutic intervention</td>
<td>161</td>
</tr>
<tr>
<td>Follow-up and outcomes</td>
<td>261</td>
</tr>
<tr>
<td>Discussion</td>
<td>263</td>
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<tr>
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(Gagnier et al., 2013)
Appendix 21: Case vignettes

Care partnership one

Care partnership one live in a rural community in Scotland with their teenage daughter. The couple have been together for 15 years and are married. They are white Scottish and have completed post compulsory higher education. The stroke survivor is a male in his 50s who experienced a stroke in 2017. Prior to the stroke he was working full-time and had a passion for sailing. Since his stroke he has been off work and struggled with mobility and panic attacks. The care partner is female, in her late 40s, and retired due to ill health. This couple highlight the complexity in some care partnerships because both parties are living with chronic conditions and are also supporting each other with their own chronic condition. This care partnership highlights the difficulty of using dichotomous caregiver and care recipient terminology and highlights the duality within some care partnerships (Bennett et al., 2017).

The care partnership was highly motivated to engage with the study and made contact after seeing the study protocol registered online. They had some experience of MBI prior to the study and had attended a one-day introduction to MBI, purchased a self-help book, and had tentatively started learning about MBI. Although, neither the stroke survivor or the care partner had any substantial experience with MBI prior to the study.

During the study the care partner experienced a deterioration in her existing health condition and became unwell. The deterioration resulted in the second study visit being cancelled and data not being collected at week four. At the third visit the partner was too unwell to participate in the interview or complete the data collections questionnaires. The deterioration in health of the care partner affected the stroke survivor significantly and he was commenced on an anti-depressant during week four of the study. Commencing anti-depressant medication during the study does pose a possible confounding variable (Parahoo, 2014), but was in the participants best interest and reflects real life.

Despite significant stressors during the study, the stroke survivor engaged well with online MBI and found learning MBI helpful. He practised regularly and used
the meditation practices when experiencing stress, such as his visiting partner in hospital. He was keen to continue his engagement in MBI and was exploring whether MBI groups were accessible nearby, although, he was unsure whether he would be able to attend a group and preferred learning online and/or using self-help books.

**Care partnership two**

Care partnership two are a white Scottish couple in their 50s who have been together 21 years. They live with their teenage son in a deprived post-industrial town in central Scotland. The stroke survivor is a male and experienced two strokes in 2017. He has made a good recovery following the strokes and has managed to continue working, but is now more selective about the work he does and limits the amount of time he is away from home. He has also managed to maintain some of his hobbies following his stroke. The care partner works on a casual basis and looks after the house. The current issue for this family are money worries, anxiety symptoms, and fear about stroke reoccurrence.

The care partnership was highly motivated and had participated in other stroke research before agreeing to be involved with this study. The stroke survivor is also heavily involved in the local stroke community and is keen to access as much support as possible for people affected by stroke. Of all the care partnerships in the study this partnership appeared to use online MBI the most with both stroke survivor and care partner using the intervention and talking about the value of MBI in their lives.

Both stroke survivor and their care partner used MBI to manage stress in their lives and would encourage the other person to use MBI when they noticed them becoming stressed. The stroke survivor became a big advocate for MBI during the study and would talk to other stroke survivors about the value of MBI and was keen to engage in further MBI training after the study.
Care partnership three

Care partnership three was the only non-spousal relationship and consisted of a father-daughter partnership. The stroke survivor had experienced a stroke in 2017 and continued to struggle with anxiety symptoms, low mood, and mild aphasia. The care partnership lived close to each other in a post-industrial town in central Scotland. The stroke survivor lived with his wife, but had chosen to enrol on the study with his daughter. The daughter was a qualified nurse and was an active support in her father’s stroke recovery. Care partnership three made excellent progress during the first four weeks of the study and reported regular engagement with MBI and improved mood by week four. Unfortunately, the early progress and improvement ceased after week four of the study. From speaking to care partnership three, it appears they went on holiday and the stroke survivor stopped using the MBI whilst they were away. After returning home from the holiday the care partnership struggled to resume the use of MBI. Care partnership three cancelled their third meeting (week eight) and a delay in rescheduling the meeting resulted in the meeting occurring at week fourteen of the study.

During the third meeting the stroke survivor was experiencing similar difficulties to what he was experiencing at the start of the study and had not managed to resume using of MBI. The care partnership linked the deterioration in mood to the lack of use of MBI and were keen to resume using MBI. At the end of the study the care partnership was keen to use MBI and were also exploring other opportunities to learn MBI. Specifically, they were keen to try group MBI and were investigating group MBI in their local area.

Care partnership four

Care partnership four were a married couple who lived in an urban area of Scotland. They were the youngest care partnership in the study and were in their late 40s early 50s. The stroke survivor had experienced three strokes in quick succession shortly after receiving treatment for cancer in 2016. The stroke occurred when the person was in their 40s and has resulted in a wide range of difficulties. The stroke survivor continues to struggle with left sided weakness, balance difficulties, memory problems, fatigue, and anxiety symptoms. The
stroke survivor had ceased employment and had a difficult time coping with their ongoing health difficulties. The care partnership was extremely supportive of each other and motivated to use MBI. The stroke survivor had some experience of using MBI, but had not received any formal training. The care partner was not very interested in MBI, but thought it would help their partner and was willing to be involved.

Over the course of the study the stroke survivor really committed to using MBI and found it extremely useful. The care partner did not really engage with the MBI, but was very support of their partner using MBI. The care partner would often talk about MBI and encourage the stroke survivor to use MBI. After the study the stroke survivor expressed interest in learning more about MBI and continued using the online MBI.

**Care partnership five**

Care partnership five were a couple in their late 50s and mid 60s who lived together in a rural part of northern England. They had been together for about 18 years and one was self-employed and the other retired. The male member of the care partnership experienced a stroke in 2010 and had been living with stroke longer than anyone else in the study. The stroke survivor experiences left-sided weakness, epilepsy, and anxiety/panic symptoms since having the stroke. This care partnership has some limited experience of MBI prior to starting the study and had attended a short taster session in their local community. They were keen to learn more about MBI, but were also a little sceptical about whether it would be something they would enjoy.

During the study care partnership five appeared to engage least with the intervention and were the most sceptical about MBI. Neither the stroke survivor or their care partner completed the course and both either struggled or disliked aspects of the MBI. Both parties reported improvement during the study, but it is doubtful whether these improvements could be attributed to MBI. Other factors are thought to have contributed to the improvement seen and include the stroke survivor writing a book and the care partner starting a new hobby. Both these additional activities are thought to have produced an improvement in
psychological wellbeing during the study and highlight a possible confounding variable for the care partnership.
Appendix 22: GRIPP2 (Guidance for Reporting Involvement of Patients and the Public)

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<td>Reflections</td>
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(Staniszewska et al., 2017)
## Appendix 23: Dissemination plan

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<td>Explorathon, Podcast for the common good, and GCU</td>
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<td>research day</td>
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<td>Online mindfulness for care partnerships experiencing anxiety and</td>
<td>Conference presentation</td>
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<td>Peer-reviewed journal publication</td>
<td>Mental Health Practice</td>
<td>2022</td>
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Glossary

Be Mindful: A four-week online asynchronous mindfulness course based on Mindfulness Based Cognitive Therapy.

Body scan: A common mindfulness exercise used within most mindfulness course.

Caregiver: An unpaid person (e.g. family member, friend, or neighbour) who provides unpaid care to someone else.

Care partner: Someone who assist another person with a health condition and helps them self-manage the health difficulty.

Care partnership: An informal partnership between someone with a chronic condition and a care partner/caregiver.

Chronic condition: A health conditions that is chronic in nature, has a significant impact on health, and requires long-term management.

Clinical change: Whether the final results of a clinical measure for a participant is below the clinical threshold for that particular outcome scale.

Complex multimorbidity: The presence of four or more chronic conditions.

Disability-adjusted life-years (DALY): a method for calculating impact of chronic conditions, which combines the numbers of years of life lost and years lived with disability.

MBCR: Mindfulness-based cancer recovery, which is an adapted version of MBSR for people with cancer.

MBCT: A common mindfulness protocol called mindfulness based cognitive therapy, which was originally developed to reduce depression relapse.

MBI: Mindfulness-based intervention

MBRE: Mindfulness-based relationship enhancement, which is adapted version of MBSR for couples.
MBSR: The original secular mindfulness protocol called mindfulness-based stress reduction, which was initially developed for physical health difficulties.

Minimal clinically important difference (MCID): The smallest amount of change needed in an outcome that an individual patient/participant would find important.

Mindfulness: A state of mind that involves paying attention, on purpose, and in a particular way.

Multimorbidity: The presence of two or more chronic conditions.

Patient and public involvement (PPI): Research carried out in partnership with patients and/or the public.

Stroke: A medical condition that involves the blood supply to the brain becoming disrupted and results in damage to the brain tissue.

Stroke survivor: Someone who has experienced one or more strokes.

Stroke care partnership: A partnership consisting of both a stroke survivor and a caregiver. Often this is a spousal relationship, but could also be two siblings or parent and child.
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