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The experience of mental health problems in later life

Woodbridge, Rachel

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The experience of mental health problems in later life

Bangor University

2022

Rachel Woodbridge

Submitted as partial fulfilment of the doctorate in Clinical Psychology (DClinPsy)

Table of Contents

Thesis Abstract.....	4
Declaration	5
Acknowledgements.....	6
Word count.....	7
Chapter One.....	8
Mental health-related stigma in older adulthood: systematic review of quantitative and qualitative research.....	8
Abstract.....	10
Introduction	11
Method.....	13
Search strategy	13
Eligibility Criteria	14
Data extraction	15
Quality Appraisal	15
Results	15
Study Design.....	24
Stigma Focus	24
Study Quality	24
Stigma Measures	25
Location and Racial and/or Ethnic background.....	25
Public-Stigma	27
Self-Stigma	35
Discussion	37
Overview	37
Limitations of the evidence and further research.....	41
Limitations of this review	42
Implications.....	43
References.....	45
Appendices.....	52
Appendix 1: Data extraction form	52
Appendix 2: Quality Assessment	57
Chapter Two.....	58
Couples' lived experiences of mental health informal caregiving and care-receiving in later life	58
Abstract.....	60
Introduction	61
Method.....	64
Design.....	64
Ethical Issues	64
Recruitment / Participants.....	65
Procedures	66
Data analysis.....	67
Reflexivity Statement.....	68

Results	69
Continuity and Change	70
Caring: New or Extended Roles	72
Together and Alone	73
Not that Sort of Person	74
Preserving Identities	76
Needing them now	77
No Roadmap	78
Discussion	79
Clinical Implications	82
Limitations and future research	83
Summary	84
References	86
Appendices	92
Appendix 1: Participant Information Sheet	92
Appendix 2: Opt-in slip	101
Appendix 3: Interview Schedules	102
Appendix 4: Examples of analysis process	104
<i>Chapter Three</i>	<i>106</i>
Contributions to Theory and Clinical Practice	106
Implications for future research and theory development	107
Implications for clinical practice	110
Personal reflections	113
References	118

Thesis Abstract

This thesis explores experiences of mental health problems among older adults. The systematic review identified public stigma towards mental health problems among older adults and in the limited research on older adults with mental health problems, self-stigma, with rates varying across studies. Stigma was associated with sociodemographic factors such as racial and/or ethnic background and gender and other factors such as help-seeking behaviour and mental health symptoms. A wide variety of mental health stigma measures were used across the studies and there is a need for more consistency in the use of measures to support more meaningful comparisons across studies.

The empirical study explored the experiences of caregiving within 5 couples (n=10) when one partner experienced significant mental health problems for the first time in later life using Interpretative Phenomenological Analysis. Analysis revealed 7 themes: *Continuity and Change, Caring: New or Extended Roles, Together and Alone, Not that Sort of Person, Preserving Identities, Needing Them Now, No Roadmap*. Central to participants experiences was the importance of relationships where 'caregiving' could be seen to affect this or be an extension of relationships. Mental health stigma impacted self and couple identities which related to preservation strategies such as concealment of problems. Recommendations for how mental health services can support caregiving and identities of older couples living with mental health problems are proposed.

The final paper integrates findings from the systematic review and empirical study to discuss implications for clinical practice and future research in more depth. This also includes a personal reflective section to consider the researchers experiences and beliefs through which the interview data was interpreted and seek to make explicit motivations and biases to enable the reader to situate and interpret research findings.

Declaration

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.

Signed:

Date: 31.05.2022

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Thank you to all the participants who took part in this research and shared their experiences so generously with me. I hope I have done your words justice in my interpretation and writing. Thank you also to the People Panel members for meeting with me and sharing your ideas for this research.

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Chapter 2: Empirical Study

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Tables, figures and appendices: 4021

Chapter 3: Contributions to Theory and Clinical Practice

References: 703

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Total for references, tables, figures and appendices: 12,256

Chapter One

Systematic Review

Mental health-related stigma in older adulthood: systematic review of quantitative and qualitative research

Mental health-related stigma in older adulthood: systematic review of quantitative and qualitative research

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This article will be submitted to the *Journal of Psychiatric and Mental Health Nursing* and thus follows the submission guidelines for this journal:

<https://onlinelibrary.wiley.com/page/journal/13652850/homepage/forauthors.html>

Abstract

Introduction: It is well-established that stigma can impact negatively on the lives of people with mental health problems – including those in later life.

Aims: This systematic review aimed to describe mental health stigma in older adulthood, considering both *personal* and *perceived* public-stigma and self-stigma. It reviews the forms that stigma takes and identifies factors associated with it.

Method: Four electronic databases were systematically searched (PsycINFO, Applied Social Sciences Index and Abstracts, Medline, and CINAHL), yielding 3300 results. Twenty-four studies met the inclusion/exclusion criteria and were reviewed narratively.

Results: Personal and perceived public-stigma and self-stigma varied across the studies. A number of factors were found to be significantly associated with reported stigma, including socio-cultural variables, help-seeking behaviours, mental health symptoms, and self-esteem.

Discussion: Although findings should be interpreted cautiously due to methodological limitations such as variability in stigma measures, there is evidence to suggest that mental health stigma is an important issue for people in older age and may differ across cultures. Future research should seek to use consistent quality measures and explore further the effects of stigma in diverse older adult populations such as those from minoritised groups.

Keywords: Older adults; Stigma; Attitudes; Mental Health; Systematic Review

Registration

This review is registered with PROSPERO: January, 2022. Number CRD42022290232.

Available from:

https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42022290232

Introduction

The World Health Organisation (WHO) estimates that approximately 15% of adults over the age of 60 years have mental health problems of some kind, most often depression and/or anxiety (WHO, 2017). It has been suggested that such figures are likely to underestimate this problem, as mental health difficulties in later life often go unrecognised and unaddressed, by healthcare professionals and by older people themselves (Harris et al., 2015; Sanglier et al., 2015). It is often observed that, when compared to younger counterparts, older people are significantly less likely to seek and receive support from mental health services (Wuthrich & Frei, 2015; DiNapoli et al., 2016) and more likely to face obstacles in attempts to access specialist care (Berry et al., 2020).

Reasons for these discrepancies are likely to be multi-faceted. Airth and Oelke (2020) suggest that a lack of age-specific policies for older adult mental health embeds ageism into the design and delivery of services. However, both service gatekeepers and older people have also been found to lack knowledge of age-variation in mental health presentations (Quinn et al., 2009; Bodner et al., 2018) and to hold personal beliefs that further decrease the likelihood of appropriate help and support being received (e.g., beliefs attributing symptoms to a 'normal' part of ageing; Burroughs et al., 2006). More broadly, within society, negative attitudes and emotions regarding mental health problems – including stigma and shame – also appear to prevent older people from seeking, and being able to access, help (Anderson, Wickramariyaratne, & Blair, 2017).

'Stigma' refers to the phenomenon wherein an individual or group is discredited or discounted by society due to a particular attribute (Goffman, 2009). Corrigan, Kerr, and Knudsen (2005) have proposed a conceptual framework to consider mental health stigma in a global and multicultural context, identifying two interrelated categories: public and self-stigma.

- *Public-stigma* refers to societal endorsements of negative stereotypes about stigmatised groups, often leading to discriminatory behaviours (Corrigan et al., 2005).

This may be considered in respect to *personal* public-stigma, expressed as an individuals' views about a stigmatised group, or *perceived* public-stigma, describing a person's perception of how others in society view the stigmatised group.

- *Self-stigma* arises where an individual, either as a member of a stigmatised group or with some connection to it, absorbs and accepts the stigma endorsed by the social groups around them (Corrigan et al., 2005). This internalised or 'felt' stigma may lead to reduced self-esteem and/or self-efficacy (Corrigan & Watson, 2002).

According to Corrigan et al. (2005) public-stigma and self-stigma occur at three interconnected levels: 1) *stereotypes*, negative beliefs about a group of people or about the self; 2) *prejudice*, agreement with, or emotional reactions to, negative beliefs about a group or the self; and 3) *discrimination*, behavioural manifestations of prejudice.

It is well-established that stigma can impact negatively on the lives of people with mental health difficulties, influencing help-seeking behaviours, engagement with services, acceptance of interventions (e.g., medication, psychological therapies), self-esteem, self-efficacy, and quality of life (QoL; Schnyder et al., 2017). A number of systematic reviews have considered mental health stigma and its impact on specific groups in society, including people with dementia (Nguyen & Li, 2020), children and adolescents (Kaushik et al., 2016; Gaiha et al., 2020), people with specific mental health conditions (e.g., bipolar disorder, Hawke, Parikh, & Mickalak, 2013; and psychosis, Eliasson et al., 2021), in the armed forces (Coleman et al., 2017), family caregivers (Shi et al., 2019), and across minoritised racial/ethnic groups (Eylem et al., 2020). Research exploring mental health stigma among people who are older in age has yet to be critically reviewed.

It has been suggested that mental health stigma may be a special issue among older adults (e.g., Katona & Livingston, 2000; Holm, Lyberg & Severinsson, 2014; Age UK, 2019); however, the relationship between age and mental health stigma does not appear straightforward (MacKenzie et al., 2019). Whilst the extant literature often identifies lower mental health stigma among older adults compared with younger populations (Mackenzie et al., 2019), some studies have found a reverse association (e.g., Segel et al., 2004). It may

be important to recognise that mental health stigma may not be a static phenomenon but socially constructed and changeable over time for different cohorts of older adults (Schomerus et al., 2015). Cultural context is also important and may relate to variability in findings by age; older adult's cultural backgrounds may influence how they understand and respond to mental health problems (Eylem et al., 2020).

This systematic review will address the following questions:

- 1) How does public and self-stigma towards mental health problems present among older adults across cultures, including consideration of stereotypes, prejudice, and discrimination.
- 2) What factors – including socio-demographic, clinical, and cultural variables – are associated with public and self-stigma in older adulthood?

Method

The PRISMA 2020 guidelines (Page et al., 2021) were consulted to guide both the methods of undertaking the review and the reporting of it. Relevant sections of the 27-item checklist for a systematic review using narrative synthesis were followed. As recommended, the 2020 flow chart was also used to report the search strategy (see Figure 1).

Search strategy

A two-part strategy was used to identify eligible studies: (1) systematic searches of four electronic databases (PsycINFO, Applied Social Sciences Index and Abstracts (ASSIA), CINAHL and Medline), followed by (2) hand-searches of reference lists/citations of eligible studies and previously published reviews. Search terms were structured using the PICO framework (Population, Intervention/Exposure, Comparison, Outcome; Higgins & Green, 2008) (see table 1). No search terms were applied for the PICO categories of comparison and outcome as they were not the focus of this review.

Table 1

Search Terms for Review for Population and Exposure (Higgins & Green, 2008)

Category	Keywords
Population: Mental Health	"Mental Health" OR Anxiety OR Depression OR psychosis OR schizophrenia OR "Post Traumatic Stress Disorder" OR PTSD OR "Bipolar"
AND	AND
Older Adults	"Older People" OR "Older Adults" OR elderly OR senior OR "geriatric" OR late* life OR Older Age OR ag?ing OR over 60 OR over 70 OR over 75 OR over 80
Exposure: Stigma	Stigma* OR attitudes OR Prejudice OR discrimination OR shame OR opinion* OR belief OR ag?ism OR social exclusion

Eligibility Criteria

Studies were included if they were written in English, published in peer-reviewed journals, and reported empirical data (quantitative or qualitative). This excluded review articles, conference presentations, discussion papers or dissertations. Date limits were imposed to ensure that data were contemporaneous: only studies published in the past 10 years (2011 – 2021) were included. Additional inclusion/exclusion criteria were then imposed:

Inclusion

- Specific focus on mental health stigma (public and/or self-stigma), with at least one direct question relating to stigma.
- Sample composed of older adults (mean age ≥ 60 years) or extractable data for this age-group.

Exclusion

- Focus only on help-seeking or treatment-related stigma (e.g., towards psychological therapy or medication).

Data extraction

Data were extracted from eligible papers using a standardised data extraction proforma (Appendix 1).

Quality Appraisal

To assess the quality of included studies, the following quality checklists were applied: the 20-item AXIS checklist for observational cross-sectional studies (Downes et al., 2016), 8-item Joanna Briggs Checklist for analytical cross-sectional studies (Briggs, 2021) and the 10-item Critical Appraisal Skills programme (CASP) checklists (casp-uk.net) for qualitative studies. Assessments were carried out independently by two authors (RW, LP) and cross-checked to ensure consensus.

Results

Searches identified 3300 papers: 1467 duplicates were removed. Of the remaining 1833 articles, 1781 were screened by title/abstract and 52 scrutinised in full-text review. Initial screening of titles and abstracts was completed by the first author (RW). Full-text reviews were undertaken independently by the first and second authors (RW, LP) and then cross-checked. Full agreement was reached regarding each paper included in the review. This process confirmed 21 papers as eligible for inclusion. Three additional papers were identified by reference and citation searches (*Figure 1*), bringing the final total to 24.

Figure 1

PRISMA Flow Diagram depicting literature search and screening process

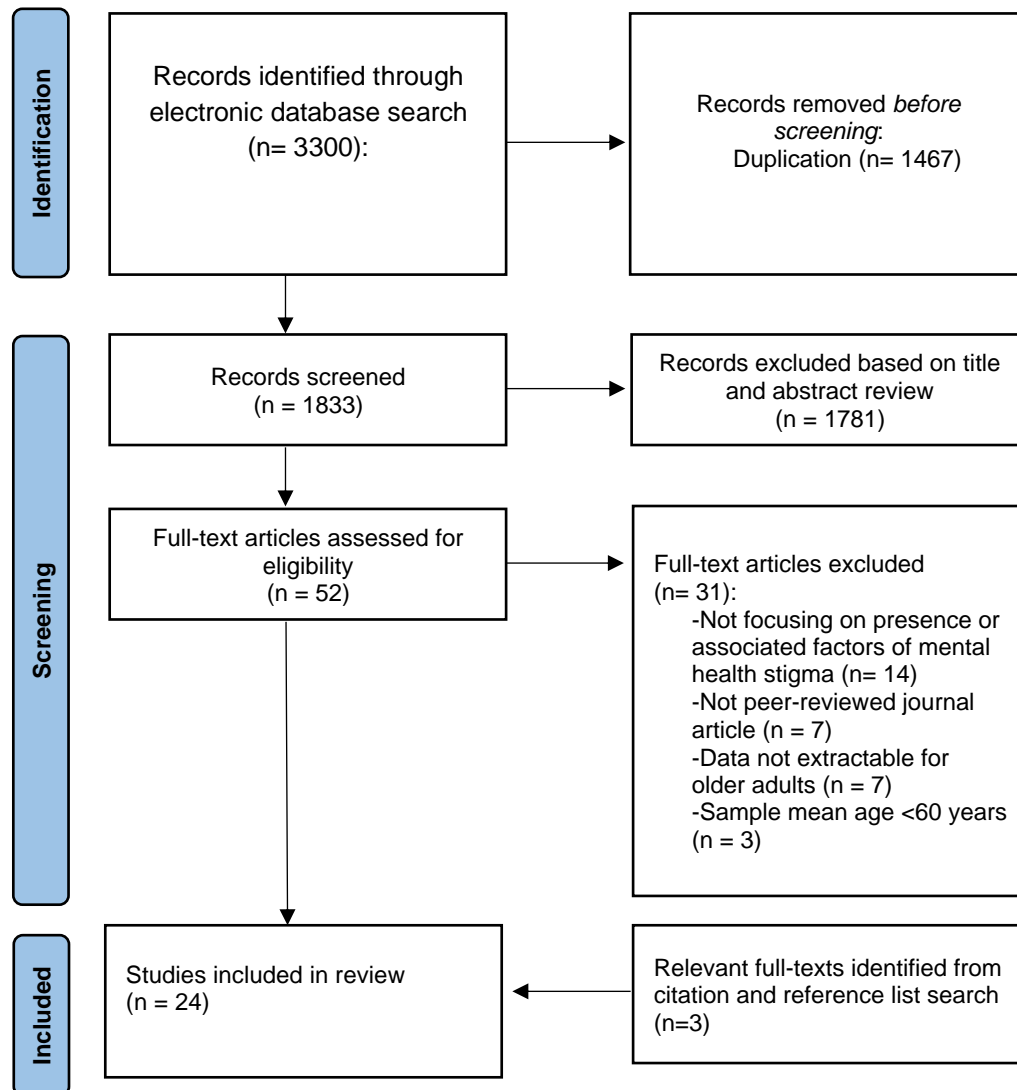


Table 2 provides a summary of the 24 studies including type of stigma examined and measures used and the results in terms of (1) presence of stigma and (2) associated factors.

Table 2

Studies included in the narrative review

Author, year	Study design and methods	Sample	Type(s) of stigma examined	Stigma measure(s)	Results: presence of stigma	Results: associated factors
Abo-Rass, Werner & Altman, 2021	Cross-sectional, convenience sample, interview	N=75 older adults (≥65yrs), N=85 younger adults (18-64yrs)	Self-stigma	SSMIS	Higher scores indicating more public stigma. Stereotype awareness M=6.34/9, SD= 1.8, stereotype agreement M=4.86/9, SD= 1.73, self-concurrence M=4.10/9, SD=1.30	Age: older adults significantly higher scores in all three stages Self-esteem: lower self-esteem significantly associated with higher levels of stereotype agreement ($p<.05$) and self-concurrence ($p<.001$) but not stereotype awareness for older adults
Anderson, Wickram-ariyaratne & Blair, 2017	Cross-sectional, convenience sample, postal questionnaires	N=105 older adults (60-92yrs) living in independent living units	Public stigma: Personal	Attitudes to anxiety developed by authors	% of agreement: 76% 'anxiety is a significant illness', 72% 'anxiety is a real illness', 53% 'people with anxiety make me uncomfortable', 23% 'natural part of getting old', 8% 'they should just get over it', 4% 'intelligent people don't experience anxiety', 3% 'anxiety reflects weakness of character', 2% 'anxiety caused by defect in brain'	Help-seeking: Legitimacy of anxiety as an illness ($\beta=2.41$, $p<.01$) and comfort level and disclosing to others ($\beta=3.14$, $p<.01$) predicted if a person thought they would seek help if they experienced anxiety.
Bańbura & Opoczyńska-Morasiewicz, 2020	Cross-sectional, convenience sample, focus groups	N=46 older adults (≥60yrs)	Public stigma: personal		Beliefs about causes of the illness: illness as an excuse, hereditary conditions, traumatic experiences Emotional attitude towards people suffering from mental illness: fear, acknowledgement Ways of interacting with people suffering from mental illness: controlling, hospitality	
Brenes et al., 2015	Cross-sectional, convenience sample, telephone administered measures	N=478 rural older adults (60-95yrs) diagnosed with generalised anxiety disorder	Self-stigma and Public stigma: Perceived	3-items developed by authors	% of agreement: 39.8% embarrassment, 39.8% worry about what others would think, 6.5% racial/cultural discrimination 6.5%	Age: older age related to less stigma ($r= -0.14$, $p< .01$). Mental health symptoms: increased worry severity positively correlated with stigma ($r= 0.18$, $p<.0001$)
Conner et al., 2015	Peer-educator intervention, mixed methods,	N=19 older adults (60-75+yrs)	Self-stigma and public stigma: perceived	ISMI; PDD	Baseline: self-stigma $m=63.3/126$ (SD=11), public-stigma $m=31.5/48$ (SD=5.87). Higher	Mental health symptoms: relationship between depression severity and stigma measures not significant

	convenience sample, interviews	diagnosed with depression			scores indicate more stigma.	
					Themes: age-related concerns, shared understandings, improved mental health literacy, mutual support	
Conner et al., 2018	Peer-educator intervention, convenience sample, interviews	N=21 older adults (60-75+yrs) diagnosed with depression	Self-stigma and public stigma: perceived	ISMI; PDD	Baseline: self-stigma, m=64.38/126 (SD=11.2), public-stigma m= 33.19/48 (SD=6.19). Higher scores indicate more stigma.	Age: being younger-older marginally significant higher self-stigma. Not related to public-stigma. Race: public stigma positively related to race ($r = .527$, $p < .05$). Race not related to self-stigma. Gender: not significantly related to public or self-stigma
Currin, Hayslip & Temple, 2011	Repeated measures between-subjects convenience sample, self-administered questionnaires	1977: N= 90 older adults (m=70.22, SD= 6.48), 1991: N=101 older adults (m= 70.81, SD= 4.22), N= 131 younger adults (m= 21.14, SD= 3.85) 2000: N= 99 older adults (m= 69.83, SD= 4.95), N= 147 younger adults (m= 20.62, SD= 2.12)	Public stigma: personal	Breadth of conceptions about causes of mental illness developed by authors (more breadth= less stigma)		Age: older adults significantly higher breadth than younger adults ($F(1, 454) = 14.19$, $p < .001$) Historic effects: the 1991 and 2000 samples of older adults had significantly higher breadth than in 1977 ($F(2, 284) = 41.83$, $p < .001$) no significant difference between 1991 and 2000 Gender x History: older women higher breadth scores than older men in 2000 but not significant in 1997 and 1991 ($F(1, 454) = 14.19$, $p < .001$). Gender x Age x History: Older men lower breadth scores than younger men in 2000 but not in 1991 ($F(1, 454) = 4.92$, $p < .027$)
Gitlin et al., 2012	Cross-sectional, convenience sample, depression vignette, interviews	N=153 African American older adults (≥ 55 yrs, m=73)	Public stigma: personal and perceived	3-items developed by authors: sign of personal weakness, scared others would find out, feel ok if community knew of diagnosis	% of agreement: 28.9% sign of personal weakness, 27.5% scared others would find out, 46.7% depression normal part of ageing	Gender: Fewer women than men believed depression sign of personal weakness (χ^2 (df=1)=4.6, $p = .032$), no significant differences for other stigma items Mental health symptoms: close to twice the number of older adults with depression than non-depressed would be scared others would find out (χ^2 (df=1)=4.20, $p = .040$), no differences for other stigma items

						Help-seeking: 'Feeling ok if community knew' were more willing to seek physician help (OR=0.98, 95% CI: 1.06, 2.66, p=.027). Other stigma items were not associated. Stigma not associated with willingness to use medication.
Jang et al., 2011	Cross-sectional, convenience sample, face-to-face interviews	N= 297 Hispanic older adults (60-105yrs)	Public stigma: personal and perceived	Attitudes towards depression survey (Cooper et al., 2003)	% of agreement: 51% 'depression is a normal part of ageing', 35% 'depression is a sign of personal weakness', 8.2% 'family would be disappointed' 2.7% 'associated with shame'	Attitudes towards mental health services: belief that having depression would make family members disappointed (t= -2.15, p<.05) and counselling brings up too many bad feelings (t=-4.98, p<.001) significant predictors of negative attitudes towards mental health services
Jimenez et al., 2013	Cross-sectional, convenience sample, face-to-face or telephone interviews	N= 2198 older adults (≥65yrs) diagnosed with depression, anxiety or at-risk alcohol use	Public stigma: personal	SAMHSA mental health and alcohol use stigma assessment (King-Kallimanis et al., 2012)		Race: significant differences by race for 'shame/embarrassment if had mental illness' (15.3% white older adults; 12.9% African-American older adults; 25.9% Asian-American older adults; 40.3% Latino older adults; $\chi^2=117.9$, p<.01)
Mehra et al., 2020	Cross-sectional, convenience sample	N= 104 older adults (60-75yrs) from rural background	Public stigma: personal	CAMI	M= 132.5/200 (SD= 13.8). Higher scores indicate less stigma.	Age: age significant negative relationship with social restrictiveness (r= -.196, p<.05), not other subscales Gender: No significant differences by gender. Family history: family history of mental illness significantly higher on social restrictiveness indicating less stigma (t= -2.205; p= 0.03). Education: Education had a significant positive correlation with subscales of benevolence, social restrictiveness, and community mental health ideology but not authoritarianism. Income: No significant differences by income. Socioeconomic background: Older adults from middle socioeconomic background significantly higher score on subscale of social restrictiveness indicating more stigma compared to lower socioeconomic status (t= 2.279, p= .025).
Min, 2019	Cross-sectional, secondary data	N= 171,572 older adults (≥55yrs)	Public stigma: perceived	One-item developed by authors 'people	High levels of stigma in 31.2%-46% of whole sample	Age: ≥65yrs lower stigma than 55-64yrs (p<.001).

analysis, random
sample

are generally
caring and
sympathetic to
people with
mental illness'

Ethnicity: Significant differences ($\chi^2= 820.3$, $p<.001$). Older non-Hispanic black participants showed lowest level of perceived public stigma (31.2%), Hispanic adults (55-64yrs) (46%) and non-Hispanic white adults (55-64yrs) (45.2%) highest stigma.

Gender: Females lower levels of public stigma than men ($p<.001$).

Education: higher education increased likelihood of public stigma, most pronounced among educated Hispanic adults (odds ratio= 2.82, $p<.001$).

Mental health symptoms: Psychological distress and frequency significantly associated with public stigma. Non-Hispanic White adults with distress 55% more likely than those without distress to hold perceived public stigma (odds ratio= 1.55, $p<.001$), compared with 41% for white adults, 28% for Hispanic and non-Hispanic Black adults.

Help-seeking: Higher perceived public stigma associated with greater likelihood of seeking mental health help (odds ratio=1.32, $p<.001$ for non-Hispanic White participants, 1.22, $p<.01$ for non-Hispanic Black participants, and 1.29, $p<.001$ for Hispanic participants).

Ng et al., 2011	Cross-sectional design, probability sampling, interviews	N=1092 older adults (≥ 60 yrs, M= 69.7) from various religious affiliations	Public stigma: personal.	One-item developed by authors 'are you embarrassed/ ashamed about mental ill health'	<p>Religious affiliation: 'Feeling to a great extent embarrassed or shameful about mental illness' least common among Christians (2.2%) and Islamic participants (2.7%), and most common among Buddhists/Taoism (6.2%) (Hinduism 4.5% and non-religious 4%) ($p<.001$)</p> <p>Help-seeking: embarrassment/ shame not significantly associated with mental health service use.</p>
Park et al., 2015	Cross-sectional design, multi-stage stratified cluster sampling, interviews	N= 857 older adults (60-74yrs), N=2198 adults (18-59yrs)	Public stigma: perceived	PDD	Age: public stigma significantly increased with age ($p<.001$), 41% of 60-74yrs in high stigma group compared with 17% in 18-39yrs and 25% in 40-59yrs

						Help-seeking: Older adults who perceived lower stigma significantly more likely to use mental health services (AOR=4.14, $p<.006$). Also significant for middle-aged cohort (AOR=2.39, $p<.05$) but not for young cohort (AOR=0.9).
Park, Jang & Chiriboga, 2018	Cross-sectional design, convenience sample, self-administered questionnaires	N=420 Korean older adults (60-98yrs, $m=71.62$)	Public stigma: personal	Attitudes towards depression survey (Cooper et al., 2003)	% of agreement: 55% depression normal part of ageing, 68% depression sign of personal weakness, 26% having a mentally ill family member brings shame to the whole family	Mental health symptoms: Believing depression normal part of aging ($r=.20$, $p<.01$, $r=.29$, $p<.01$) and brings family shame ($r=.15$, $p<.01$, $r=.13$, $p<.01$) significantly associated with anxiety and depressive symptoms (not personal weakness). Help-seeking: Believing depression brings shame to family decreased willingness to use mental health counselling and anti-depressants by about 50% (OR= .55, $p<.05$). Other stigma items not significantly correlated with treatments.
Préville et al., 2015	Cross-sectional, convenience sample, interviews	N= 1765 older adults (≥ 65 yrs, $m= 73.4$)	Public stigma: personal and perceived	7-item author developed stigma measure (STIG)	39% agreed with 5-7 items of public stigma, 12.2% agreed with all items. % of agreement: 83.6% 'most people would not say to anyone that they have a mental health problem', 76.3% 'most people would not hire an individual with a mental health problem', 72.3% 'most people, individuals with a mental health problem are unpredictable' 38% 'people with mental health problems are abnormal', 43% 'not a true medical problem', 43% 'sign of personal weakness'	Age: no association Gender: no association Mental health symptoms: Public stigma had direct negative effect on presence and severity of mental health symptoms ($b= -.10$) Help-seeking: Public stigma significant indirect negative effect on use of health services for psychological distress symptoms ($b= -.07$), mediated by perceived need for improved mental health.
Raeifar et al., 2017	Cross-sectional, convenience sample, RCT only reporting baseline results as stigma only recorded at baseline	N=70 older adults (≥ 60 yrs, $m=75.8$) with diagnosis of major depression	Public stigma: perceived	One-item author-developed "worry others will treat me differently if they know I am depressed"		Mental health symptoms: Greater public stigma was positively associated with greater depression ($t[67] = 2.059$, $p = 0.040$). However, when older adults were separated into high- and low-mastery groups, anticipated stigma remained significant only among participants with low mastery ($t[34] = 2.152$, $p = 0.039$).
Raue et al., 2011	Cross-sectional, convenience sample, interviews	N=256 older adults (65-96yrs, $m=78.2$) receiving homecare	Public stigma: personal and perceived	3-items from PDD using 'most people' and 'I' for each item		Help-seeking: less personal stigma independently associated with preference for active treatment, not significant for perceived stigma

Scazufca et al., 2016	Cross-sectional, depression vignette, random sampling, interviews	N=1291 older adults (≥60yrs)	Public stigma: personal and perceived	3-items author developed, perceived negative reactions, discrimination, dangerousness	33.45% perceived negative reactions, 28.9% perceived discrimination, 35.7% dangerousness	<p>No significant differences by area, age, gender, education, marital status, family income.</p> <p>Mental health symptoms: Older adults with depression significantly more likely to report others would have negative reactions (RR= 1.12, p<.05) and discriminate against (RR= 1.17, p<.05) case in the vignette, but not for perceived dangerousness.</p> <p>Physical health: Older adults with physical morbidities or limitations significantly more likely to report others would discriminate against the case (RR= 1.07, p<.05) in the vignette but not have negative reactions or aggression.</p> <p>Identifying mental health problem: Those who identified the vignette as a case of mental disorder were significantly more likely to report others would have negative reactions (RR= 1.09, p<.05), discrimination (RR= 1.12, p<.05) and dangerousness (RR= 1.15, p<.05).</p>
Sirey et al., 2014	Cross-sectional, secondary data analysis, convenience sample	N=732 older adults (≥60yrs, m=82) receiving home meal services	Public stigma: perceived	7-item author developed anticipated cost of stigma scale	M=2.09/4 (SD=.51). Higher scores indicate more stigma.	<p>Race: African American older adults endorsed high stigma more frequently than white older adults (chi= 13.66, p<.001).</p> <p>RaceXGender: Significant differences in high stigma across the four race by gender groups (chi= 14.42, p<.01) with African American men endorsing highest rates of anticipated stigma.</p> <p>Mental Health symptoms: depressed subgroup significantly more likely to endorse high anticipated stigma than non-depressed group (Chi= 7.32, p<.01).</p> <p>Help-seeking: Lower anticipated stigma, younger age, and race by gender interaction, significantly (p<.05) predicted who successfully received a mental health treatment referral.</p>
Smilowitz et al., 2020	Cross-sectional, convenience sample, RCT but only reporting baseline results as stigma only	N=40 older adults (≥55yrs, m=60.28), N=144 younger adults (<55yrs, m=	Self-stigma	ISMI		<p>Age: Older adults had significantly lower ISMI scores (M=61.95) than younger adults (M=69.27) indicating lower self-stigma (p=.001). Significant for 4/5 ISMI subscales: Alienation (p=.017), Stereotype endorsement (p=.002), discrimination (p=.001) experience,</p>

	recorded at baseline, face-to-face interviews	43.82 (SD= 8.84) with diagnosis of bipolar disorder				and social withdrawal (p=.013). No significant differences for resistance.
Smith, 2012	Cross-sectional design, convenience sample, self-administered questionnaires	N=158 older adults (≥65yrs)	Public stigma: personal	Adapted ISMI for personal stigma		Help-seeking: Depressive symptoms, resilience and stigma accounted for less than 16% variance in willingness to seek care for depressive symptoms. Stigma did not independently predict willingness to seek care. Mental health symptoms: Depressive symptoms correlated with stigma (r= .18, p <.05).
Turvey, Frolova & Jogerst, 2012	Cross-sectional design, convenience sample, self-administered questionnaires	N=1094 older adults (≥60yrs)	Public stigma: personal	Author developed, beliefs about depression scale	% of agreement: depression is a personality trait (Korea 46%, Russia 55%, America 29%), having depression means the person is weak (Korea 78%, Russia 61% America 6%), depression is a normal part of ageing (Korea 42%, Russia 54%, America 29%)	
Tzouvara, Papadopoulous & Randhawa, 2018	Cross-sectional design, convenience sample, qualitative individual face-to-face interviews	N=10 older adults (60-100yrs) with mental health problems living in nursing home	Self-stigma and Public stigma: personal and perceived		Insight into mental illness identified as having key influence on self-stigma experiences, perceptions (lacking control, public stigma), attitudes (sympathy, disinterest) and behavioural reactions (avoidance, fear)	

Note: SSMIS: Self-Stigma of Mental Health scale (Corrigan et al., 2006); ISMI: Internalized Stigma of Mental Illness Scale (Ritsher, Otilingham & Grajales, 2003); PDD: perceived devaluation and discrimination scale (Link et al., 1989); CAMI: Community Attitudes Towards the Mentally Ill Scale (Taylor & Dear, 1981); PhQ-9: patient health questionnaire-9 (Kroenke, Spitzer & Williams, 2001)
M= mean, SD= standard deviation, %= percentage

Study Design

Most studies (n=21) were quantitative, with two qualitative studies and one mixed-methods design. The majority used self-administered scales or semi-structured interviews, asking people to reflect on personal experiences or perspectives (n=21). Two studies used mental health case-vignettes, another study asked participants to reflect on interactions with people they had met with mental health problems.

Stigma Focus

Most studies (n=22) examined public-stigma: personal (n=10) and perceived (n=13). Only six studies investigated self-stigma. Twelve studies explored stigma towards mental health difficulties in general, ten focused on stigma towards depression, one on stigma towards anxiety and depression, and one on stigma towards anxiety alone. Eight studies examined mental health stigma from the perspective of older adults diagnosed with a mental health problem.

Study Quality

The quality assessment is included in Appendix 2. The observational cross-sectional studies (n=20) were categorised according to scores into quartiles according to the proportion of AXIS criteria met: those scoring ≥ 15 , 10-14, 5-9, and ≤ 4 (see Bull et al., 2019). In total, 11 studies scored ≥ 15 , whilst the remaining nine scored 10-14 of the criteria. Higher scores were indicative of higher quality.

Fourteen studies did not justify sample size and 13 used convenience sampling, which may have been prone to response bias and lack of generalisability. Only 12 studies used a validated stigma measure (further discussed below). The two cross-sectional analytical papers were part of the same research project and met most quality criteria (apart from not identifying or correcting for confounding variables). The two qualitative studies

varied in quality; the study by Tzouvara, Papadopoulos and Randhawa (2017) met 8/10 criteria, whilst the study by Banbura & Opoczynska-Morasiewicz (2020) met 4/10 criteria.

Stigma Measures

Only twelve studies used a validated stigma measure or a measure that had been used elsewhere. Measures included: the Perceived Devaluation and Discrimination Scale (PDD; Link, 1989; n=4), the Internalized Stigma of Mental Illness Scale (ISMI; Ritsher et al., 2003; n=5), Misconceptions and Personal Beliefs Associated with Depression (Cooper, 2003; n=2), Community Attitudes Towards the Mentally Ill Scale (CAMI; Taylor & Dear, 1981; n=1), the SAMHSA Mental Health and Alcohol Abuse Stigma Assessment (Chen, 2006; n=1) and a survey from the National Mental Health Association (Jang, 2009; n=1). In a review of mental health stigma measures, Wei et al. (2017) evaluated the PDD, ISMI and CAMI, finding that none met criteria for limited-strong positive level evidence for psychometric properties. Eleven studies developed unique measures, which varied in the number/type of mental health stigma questions included. This was a noted weakness in the review by Wei et al. (2018), which identified over 100 different stigma measures.

Location and Racial and/or Ethnic background

Of the 24 included studies, 13 were conducted in America, two were across multiple countries and the remaining nine were undertaken across various countries internationally. Studies also varied in the cultural, racial, and/or ethnic backgrounds and majority/minority statuses of participants. Five studies included participants from minoritised racial and/or ethnic backgrounds and 10 studies included participants from several racial and/or ethnic backgrounds. Eight studies did not specify racial and/or ethnic background despite being conducted in multinational countries and only 10 studies reported on the association of racial and/or ethnic background in relation to mental health stigma (Table 3).

Table 3**Racial and/or ethnic backgrounds and minority/majority statuses by country**

Author, year	Country	Racial and/or ethnic backgrounds (%) and minority/majority statuses by country	Racial and/or ethnic background considered in relation to mental health stigma?
Abo-Rass, Werner & Altman, 2020	Israel	Israeli Arabs; minority	Y
Anderson, Wickramariyaratne & Blair, 2017	Australia	Not reported	N
Bańbura & Opoczyńska-Morasiewicz, 2020	Poland	Not reported	N
Brenes et al., 2015	America	American Indian 3.8%; minority African American 15.3%; minority Hispanic 0.2%; minority White 80.8%; majority	N
Conner et al., 2015	America	African American 26%; minority Non-Hispanic White 74%; majority	N
Conner et al., 2018	America	African American 19%; minority Non-Hispanic White 81%; majority	Y
Currin, Hayslip & Temple, 2011	America	Not reported	N
Gitlin et al., 2012	America	African Americans; minority	Y
Jang et al., 2011	America	Hispanic; minority	Y
Jimenez et al., 2013	America	African-American 24%; minority Asian American 5%; minority Latino 13.7%; minority Non-Latino White 56.7%; majority	Y
Mehra et al., 2020	India	Not reported	N
Min, 2019	America, Columbia, Puerto Rico	White 87% Black 6.5% Hispanic 6.5% (unable to comment on minoritisation as race not reported per country)	Y
Ng et al., 2011	Singapore	Chinese 48%; majority Malay 33%; minority Indian 19%; minority	N
Park et al., 2015	South Korea	Korean; majority (homogeneous ethnicity)	Y
Park, Jang & Chiriboga, 2018	America	Korean; minority	Y
Préville et al., 2015	Canada	Not reported	N
Raeifar et al., 2017	America	Non-Hispanic 84.3%, 'Other' 15.7%	N
Raue et al., 2011	America	11.7% black 87.8% white or Hispanic does not report race or other make-up and does not report effects of race/ethnicity on stigma	N
Scazufca et al., 2016	Brazil	Not reported	N
Sirey et al., 2014	America	White 74% (including 2% Hispanic, does not report separately for Hispanic) African 26%	Y
Smilowitz et al., 2020	America	African-American 75% minority, white 22.5%, 'other' 2.5% Does not report by race	N
Smith, 2012	America	African American participants, minority	Y
Turvey, Frolova & Jogerst, 2012	Multi-national: America, Russia, Korea	Not reported	N

Tzouvara, Papadopoulos & Randhawa, 2018	UK	Not reported	N
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Note: Y= yes, N= no

Given variability across samples and measures, a method of narrative synthesis was considered most appropriate. This entails a written narrative and summary of findings without statistical analysis (Edwards & Kaimal, 2016). Findings have been synthesised by type of stigma (public/self) and levels of stigma (i.e., stereotypes/beliefs, prejudices/emotional reactions, and discrimination/behaviours; Corrigan et al., 2005). For each type of stigma, factors related to stigma (e.g., sociodemographic factors) are considered.

Public-Stigma

Personal Public Stigma: Stereotypes (Beliefs)

Most studies describing *personal* public-stigma focused on beliefs held by older adults about other people with mental health problems. Stigmatising beliefs varied across and within studies. For example, Anderson et al. (2017), reporting results from older adults in residential care in Australia, found relatively low agreement with statements such as '*intelligent people don't experience anxiety*' (4%) and '*people with anxiety should just get over it*' (8%), compared with higher agreement for statements '*anxiety is not a significant illness*' (24%) and '*people with anxiety make me feel uncomfortable*' (53%).

Cultural differences were also evident across studies. Agreement with the stereotypical belief '*mental health problems are a natural part of getting old*' appeared highest among older adults in Russia (54%, Turvey, Frolova & Jogerst, 2012) and South Korea (42%, Turvey et al., 2012), and lower among older adults in Australia (23%, Anderson, Wickramariyaratne & Blair, 2017) and America (29%, Turvey et al., 2012). Park, Jang, and Chiriboga (2018) found higher agreement (55%) amongst minoritised South Koreans living in America, than those in the majority ethnicity in South Korea (42%; Turvey

et al., 2012). Minoritised Hispanic older adults living in America (51%, Jang et al., 2011) and minoritised African American older adults in America (46.7%, Gitlin et al., 2012) also reported higher agreement than 29% of older people in America overall (Turvey et al., 2012). Variation was also evident for the stereotype '*mental health problems are a sign of personal weakness*', where 68% of minoritised South Koreans living in America (Park et al., 2018), 78% of majority South Koreans (Turvey et al., 2012), and 6% of older adults in America overall (unspecified racial and/or ethnic background) were in agreement. It was also reported that 61% of older adults in Russia reported agreeing with this view, compared with 43% of older adults in Canada (Préville et al., 2015), 35% minoritised Hispanic older adults (Jang et al., 2011), 28.9% minoritised African American older adults (Gitlin et al., 2012), and 3% of older adults living in Australia (Anderson, Wickramariyaratne & Blair, 2017).

Some studies identified stereotypical beliefs around unpredictability, lack of control, and dangerousness. Préville et al. (2015) found that 72.3% of older adults sampled in Canada agreed with the statement that people with mental health problems were unpredictable. In Brazil, Scazufca et al. (2016) found that 35.7% of their sample (n=1291) believed a person who appeared low in mood (e.g., expressing sadness and loss of interest in usual activities) was dangerous, despite not having any explicitly violent or socially undesirable characteristics.

Negative beliefs were also identified in qualitative data. Older adults in Poland, reflecting on experiences of contact with people with mental health problems, expressed beliefs about mental illness being an excuse to escape responsibility or claim benefits, alongside beliefs that people did not improve due to bad will or laziness. However, they also identified positive beliefs about mental health difficulties as natural reactions to traumatic events (Bańbura & Opoczyńska-Morasiewicz, 2020).

Perceived Public-Stigma: Stereotypes (Beliefs)

In respect to *perceived* public-stigma, Conner et al. (2018) identified an average score of 33.19 out of 48, with higher scores indicating more public stigma using the PDD

Scale amongst older adults with depression, whilst Sirey et al. (2014) identified more agreement than disagreement with perceived negative social responses from others among older adults receiving home-meal service. Scazufca et al. (2016) reported 33% of their sample of older adults in rural and urban areas in Brazil anticipated negative reactions from others. Similarly, a considerable proportion (31-46%) of a large older adult multi-national sample (n=171,572) reported disagreeing with the statement '*People are generally caring and sympathetic to people with mental illness.*' (Min, 2019).

Personal Public-Stigma: Prejudice (Emotions)

Personal stigmatising emotional reactions were captured in a smaller number of studies. In one qualitative study, Bańbura et al., (2020) identified fear about meeting people with mental health problems, including fear of being assaulted, whilst Tzouvara et al., (2018) identified fear and uncertainty related to beliefs that people with mental health problems lacked control and were aggressive or violent.

Perceived Public-Stigma: Prejudice (Emotions)

Jang et al. (2011) reported on perceived emotional reactions from others, where 8.2% of their sample of Hispanic older adults (n=297) predicted that having depression would make family members feel disappointed. Park et al. (2018) reported that 26% of their sample of South Koreans living in America expressed beliefs about mental health problems bringing shame on families.

Personal Public Stigma: Discrimination (Behaviours)

Older adults' own behavioural reactions were described as motivated by a perceived need for control and coercion (Bańbura et al., 2020; Mehra et al., 2020), as well as avoidance or wanting to keep a distance from people with mental health problems (Mehra et al., 2020; Tzouvara et al., 2018).

Perceived Public Stigma: Discrimination (Behaviours)

Behavioural reactions to – and perceived behavioural consequences of – public-stigma relate to keeping mental health problems hidden (Goffman, 1963). Prévile et al. (2015) identified that 83.6% of their sample of older adults in Canada (n=1765) predicted that most people would not share with others if they developed mental health problems. Need for secrecy and concealment, due to others' negative perceptions and stereotypes, was also reported in qualitative data (Tzouvara et al., 2018; Conner et al., 2015). In the study by Prévile et al. (2015), 76.3% expressed the belief that most people would not employ an individual with mental health problems. Scazufca et al. (2016) found that 28.9% of older adults (n=1291) believed others would likely discriminate against a person with depression.

Public Stigma: Sociodemographic Factors

- *Age*

Findings from studies exploring the association between public-stigma and age varied. In India, Mehra et al. (2020) found increasing age associated with increased personal stigma for social restrictiveness, though not authoritarianism, benevolence, or community mental health ideology. In South Korea, Park et al. (2015) found increasing age was associated with *increased* perceived stigma, where 41% of 60–74-year-olds were in the high stigma group, compared to 17% of 18–39-year-olds, and 25% of 40–59-year-olds. However, Brenes et al. (2015), with older adults aged 60-95 years, and Min (2019), with older adults (>55 years) in America, Columbia, and Puerto Rico, found that older age was related to *lower* levels of perceived stigma. Currin et al. (2011), with older adults (M=70.29yrs) and younger adults (M= 20.88yrs) in America found older age related to less personal stigma. Prévile (2015), Conner et al. (2018), and Scazufca et al. (2016) found no association between age and public-stigma. This variation in findings may relate to differences in ages (and cohorts) across samples, as well as cultural variations and measures used. Interestingly, studies within Western populations appeared to suggest attitudes towards

mental health problems were more stigmatising amongst younger people, whereas Eastern populations expressed attitudes more stigmatising amongst older people.

- *Racial/ethnic backgrounds*

All studies examining these factors reported significant associations between public-stigma and race/ethnicity. Sirey et al. (2014) and Conner et al. (2018) identified that African Americans perceived more public-stigma towards depression than white participants in America, whilst Jimenez et al. (2013) identified significant differences by race for personal shame and embarrassment in relation to mental health diagnosis. This study observed that Latino participants reported the most shame/embarrassment, whilst African American and white participants reported the least.

Race also intersected with other sociodemographic factors. Sirey et al. (2014) identified significant differences in perceived stigma for race by gender groups, with African American men endorsing the highest rates of perceived stigma and white women endorsing the lowest rates. Min (2019) identified significant differences by race and age group, with older non-Hispanic black participants showing the lowest level of perceived public stigma (31.2%) and Hispanic adults (aged 55-64yrs; 46%) and non-Hispanic white adults (45.2%) showing the highest levels.

- *Gender*

Of the seven studies exploring public-stigma and gender, three identified some evidence of lower public-stigma among older women, whilst others found no association. Gitlin (2012) found fewer women than men believed a depression diagnosis was a sign of personal weakness; however, there were no significant differences by gender as regards worry about others finding out about mental health problems. Interestingly, Currin et al. (2011) found historic effects for gender; in the years 1991 and 1997, there was no significant gender difference in respect to personal stigma; however, by 2000, women expressed significantly

less public stigma than men. Conner et al. (2018), Mehra et al. (2020), Preville (2015), and Scazufca et al. (2016) found no significant differences by gender for public-stigma.

- *Education*

Three studies explored the effects of education on public-stigma, with conflicting results. Mehra et al. (2020) identified a significant correlation between education and self-reported benevolence, social restrictiveness, and community mental health ideology, suggesting lower public-stigma with greater education. However, Min (2019) identified higher education related to increased likelihood of reporting public-stigma. Scazufca et al. (2016) found no significant associations between these factors.

- *Socio-Economic Status*

Two studies investigated income and found no correlation with public-stigma (Mehra et al., 2020; Scazufca et al., 2016). One study investigated socioeconomic background and found participants from a middle socioeconomic background had more public-stigma for social restrictiveness, as compared to participants from lower socioeconomic backgrounds (Mehra et al., 2020).

- *Additional Sociodemographic Factors*

The lone study exploring relationships between marital status and public-stigma found no association (Scazufca et al., 2016). One study explored the effects of geographical area, comparing rural and urban samples in Brazil (Scazufca et al., 2016), and found no significant differences between these groups in personal or perceived public-stigma. A single study investigating religious affiliation found significant differences amongst religious groups for embarrassment/shame about mental illness, suggesting that this was least common for Christians (2.2%) and most common among Buddhists/Taoists (6.2%; Ng et al., 2011).

Public Stigma: Help-Seeking

Ten studies explored associations between active help-seeking and public-stigma. Anderson et al. (2017) reported that greater personal public-stigma was associated with a reduced likelihood that participants would seek help if experiencing mental health problems. Brenes et al. (2015) also identified perceived public-stigma related to increased practical and personal barriers to hypothetical help-seeking. Sirey et al. (2014) found that lower perceived public-stigma predicted who consented to a mental health treatment referral when depression was identified. Raue et al. (2011) found that lower levels of *personal* public-stigma were associated with a preference for active treatment; however, this relationship was not replicated for levels of *perceived* public-stigma. Min (2019) found the reverse effect: participants with a higher level of perceived public-stigma had a greater likelihood of seeking mental health support.

One study found public-stigma had a significant indirect negative effect on whether participants would, hypothetically, seek help from services; this effect was mediated by perceived need for improved mental health, such that if perceived need were greater, stigma became less influential in decision-making (Préville et al., 2015). Another study found that age mediated the association between public-stigma and the predicted use of mental health services, with older and middle-aged adults who expressed lower stigma being more likely to suggest that they would use services if needed – a relationship not observed for younger adults (Park et al., 2015).

In terms of willingness to engage with treatment, studies suggest that perceived public-stigma had more of an impact than personal public-stigma. Park et al. (2018) observed that endorsing the belief that '*depression brought shame to the family*' decreased willingness to use mental health counselling and anti-depressants by 50%, whereas perceiving '*mental illness was a personal weakness*' or '*a normal part of ageing*' were not significantly correlated. Gitlin et al. (2012) found those who reported '*feeling ok if the community knew*' about mental health problems were more willing to seek physician help, whereas viewing mental health problems as '*a sign of personal weakness*' or '*feeling scared*'

others would find out was not associated with help-seeking. They reported that public-stigma was not associated with willingness to use medication. Jang et al. (2011) found that the belief *'having depression would make family members disappointed'* was a significant predictor of negative attitudes towards mental health services but *'feeling ashamed'*, *'viewing depression as a normal part of ageing'*, and *'personal weakness'* were not. Whilst the studies by Smith (2012) and Ng (2011) reported that public-stigma did not predict willingness to seek care from mental health services.

Public Stigma: Mental and Physical Health

Most studies exploring the relationship between mental health symptoms and public-stigma found positive correlations. Brenes et al. (2015) reported that increased perceived public-stigma was associated with increased worry and Smith (2012) found a similar pattern for personal public-stigma with depressive symptoms. Older adults with depression, when compared to those without, were more likely to predict perceived discrimination and negative reactions towards someone with depression (Sczufca et al., 2016) and were more likely to endorse higher perceived public-stigma (Sirey et al., 2014). Only one study (Conner et al., 2015) found no association between depression symptoms and perceived public-stigma.

Another study suggested that positive associations between mental health problems and perceived public-stigma were mediated by race (Min, 2019). Non-Hispanic white adults (aged 55-64) with high levels of psychological distress were almost 55% more likely than those without distress to report perceived public-stigma, compared to 28% for Hispanic and non-Hispanic black adults. Another study found that mastery mediated perceived public-stigma; the relationship between perceived public-stigma and depression severity only remained significant among participants with low mastery – in those with higher mastery perceived public-stigma was unrelated to depression (Raeifar et al., 2017).

Other studies found some stigma beliefs were associated with mental health symptoms. Gitlin et al. (2012) found close to twice the number of people with depression, compared to people without, would be scared if others found out about their mental health

problems; though there was no difference in perceptions regarding mental health problems being viewed as a personal weakness. Similarly, Park et al. (2018) found that believing '*depression is a normal part of ageing*' and that it '*brings family shame*' were significantly associated with anxiety and depression symptoms, though there was no such association for the belief that mental health problems were a '*sign of personal weakness*'.

One study found that people with physical limitations were 10% more likely to perceive a person with depression in a case vignette as capable of being aggressive towards others and that people would discriminate against them (Scazufca et al., 2016).

Public Stigma: Mental Health Awareness

Mehra et al. (2020) found that participants who reported a family history of mental illness perceived less public-stigma for social restrictiveness compared with participants without a family history. There were no significant differences in expressed views regarding authoritarianism, benevolence, or community mental health ideology. In one study, by Scazufca et al. (2016), identifying an older adult in a vignette as having a 'mental disorder' increased ratings of perceived dangerousness, negative reactions from others, and discrimination.

Self-Stigma

Self -Stigma: Stereotypes (Beliefs)

Overall, fewer studies (n=6) focused on self-stigma. One study (Abo-Rass, Werner & Altman, 2021) examined the self-stigma formation process, using the model proposed by Corrigan et al. (2006). This model suggests that self-stigma develops sequentially through the stages of (1) stereotype awareness, (2) stereotype agreement, and (3) self-concurrence. Abo-Rass et al. found support for this sequence, observing the highest levels of stigma in the awareness stage (M=6.34/9, SD=1.81), followed by the stereotype agreement stage (M=4.86/9, SD=1.73), and then the self-concurrence stage (M=4.10/9, SD=1.30) in their

sample of older adults in Israel. Conner et al. (2018) found evidence for self-stigmatising beliefs with an average score of 64.38/126, where higher scores indicated more self-stigma. The qualitative study by Tzouvara et al. (2018), explored self-stigma among older adults with mental health problems and identified beliefs of being inferior to others, with negative reactions towards the idea of having mental health problems expressed.

Self-Stigma: Prejudice (Emotions)

One quantitative study investigated emotional reactions to self-stigma and found that 39.8% of older adults with generalised anxiety disorder reported feeling embarrassed and worried about what others would think (Brenes et al., 2015). Tzouvara et al. (2018) also reported strong feelings of embarrassment and shame.

Self-Stigma: Discrimination (Behaviours)

Tzouvara et al. (2018) also explored behavioural reactions, finding that people with mental health problems expressed a reluctance to communicate and interact with other residents or people in the community, due to wanting to conceal their own problems and distance from others with mental health problems.

Self-Stigma: Sociodemographic Factors

- *Age*

Studies which looked at the association between self-stigma and age varied in their findings. Abo-Rass (2021) found that older adults (>65yrs) with depression reported significantly higher levels of self-stigma than younger adults (<65yrs) in Israel. However, in America, Smilowitz et al. (2020) reported that older adults (>55yrs) with bipolar disorder had significantly lower self-stigma than younger adults (<55yrs) on four out of five subscales: alienation, stereotype endorsement, discrimination experience, and social withdrawal. Brenes et al. (2015) and Conner et al. (2018), both in America, also observed that as age increased, less self-stigma was reported.

- *Racial/ethnic backgrounds*

Only Conner et al. (2018) explored links between racial/ethnic backgrounds and self-stigma, reporting no significant association between self-stigma and race. It was noted, however, that their sample was particularly small (n=21).

- *Additional Factors*

In respect to additional factors, Abo-Rass et al. (2021) found, for older adults with depression, lower levels of self-esteem were significantly associated with higher levels of stereotype agreement and self-concurrence, yet not stereotype awareness. Brenes et al. (2015) found increased worry severity for older adults with generalised anxiety disorder was positively correlated with self-stigma, which was also associated with more perceived barriers to treatment (Brenes et al., 2015). However, Conner et al. (2015) found no association between depression severity and self-stigma.

Discussion

Overview

This systematic review aimed to understand how mental health stigma presents in older people, exploring the types of stigma experienced and the various factors associated with its expression. Results should be interpreted cautiously given the variety of stigma measures and variation in cultural backgrounds of older adults in these studies (see Table 3).

For personal mental health stigma, stigmatising *beliefs* were evident among older adults; however, there was evidence for variation between certain beliefs and not all studies reported individual beliefs, making it difficult to decipher which may be more common. Of those which did report individual beliefs, a commonly held view globally was '*depression is a*

normal part of ageing'. This seems to reflect the intersectional stigma older adults with mental health problems can face, wherein ageism also influences how older people with mental health problems are understood. This may partly explain why older adults are under-represented in mental health services, as older people with depression may not seek treatment if they view symptoms as inevitable due to age (Rapaport, 2021). Another belief among older adults was that people with mental health problems are 'dangerous'. This social misperception may be augmented by the media, which may sensationalise violent crimes committed by people with mental health problems, ignoring the fact that most violent crimes are caused by people without mental health problems (Varshney et al., 2016). One qualitative study identified beliefs that people with mental health problems did not improve due to bad will or laziness. Few studies on personal stigma looked at *emotional* and *behavioural* reactions. Of those that did, fear related to unpredictability was prominent, which also related to behavioural responses, such as a perceived need to control, coerce, and avoid people with mental health problems.

For perceived stigma, beliefs such as that people are not caring and sympathetic to people with mental illness and anticipating negative social responses from others were common (around one-third or more) among older adults. There was a lack of reporting for individual stigmatising beliefs for perceived stigma. *Emotional* reactions, such as shame and disappointment, were reported among older adults. *Behavioural* reactions, such as the need to conceal mental health problems due to others negative reactions, were also reported. Most older adults predicted that having mental health problems would affect employment.

Of the few studies which included older adults *with* mental health problems, self-stigma was identified and related to internalising negative public *beliefs* about mental health problems – supporting the self-stigma formation model (Corrigan et al., 2006). Emotional reactions, such as embarrassment and shame, were related to having mental health problems among older adults. The behavioural reaction of concealing mental health problems was also reported. This has also been identified in studies with younger people in relation to having mental health problems (e.g., Kaushik et al., 2016), and relates to

Goffman's (1963) notions of people managing 'spoiled' identities through concealment from others.

In terms of associated factors, contrary to the view that older adults have more stigmatising attitudes than younger adults, studies on personal public-stigma varied; some found more mental health stigma with age, others found less, and some found no association. Age appeared to interact with other factors, including race, ethnicity, and gender, suggesting a more complex relationship (Min, 2019; Sirey et al., 2014). An earlier review on population studies of mental health stigma found older people held more stigmatising views than younger people (Angermeyer & Dietrich, 2006); however, this more recent review suggests some older adults (particularly in Western cultures) may be less stigmatising towards mental health problems than their younger counterparts. Older adults from some cultures, such as South Korea, Israeli Arabs, and India held more stigmatising views than younger adults, which may be related to particular values, such as of traditional and Confucian values among South Korean older adults, as there are observed to have been changes to value systems for younger cohorts (Park et al., 2015). In terms of self-stigma, most of the evidence was for older age being related to lower levels of stigma.

It was difficult to draw firm conclusions regarding the specific effects of racial and/or ethnic backgrounds and minoritisation on mental health stigma among older adults, especially given the broad spectrum of participant backgrounds, variation in mental health stigma measures, and lack of reporting of racial and/or ethnic backgrounds in many studies (see Table 3). However, studies on public-stigma consistently found an association with racial and/or ethnic backgrounds. This supports the notion that mental illness stigma is socially constructed and thus differs cross-culturally (Rao *et al.*, 2007). This association was also found in an earlier review exploring the impact of cultural backgrounds on mental health stigma (Abdullah & Brown, 2011). In most studies, minority statuses related to greater mental health stigma among older adults. This may be related to the triple stigma of being old, mentally unwell, and from an ethnic minority that anticipates stigma (Alegria et al., 2008;

Jimenez et al., 2013). Only one small study looked at self-stigma and race and found no association.

There was some evidence that there was lower public-stigma among older women than men, which may relate to traditional masculinity or hegemonic masculinity interacting with beliefs held by older men about mental health problems (Chatmon, 2020). Gender could also intersect with racial and/or ethnic background and age, suggesting associated factors with mental health stigma are complex and contextually-laden.

Almost all studies which looked at help-seeking found a negative association between public-stigma, particularly perceived public-stigma, and help-seeking. This mirrors the findings of an earlier all-age systematic review on mental health help-seeking, which found stigma had a small to moderate negative effect on this behaviour (Clement et al., 2014). Some studies found only some public-stigma items were correlated with help-seeking; however, it is unclear whether there may be differences in the type of help being sought. There was a lack of studies with older adults that explore self-stigma and mental health help-seeking; such studies would be particularly helpful in understanding why older people tend to be under-represented within services.

There was also an association identified between mental health symptom severity and mental health stigma, which has also been reported in a longitudinal study with adults with severe mental illness – stigma being a factor related to worsening symptoms (Oxle et al., 2018). Self-esteem was also found to mediate the extent of mental health stigma among older adults with depression (Abo-Rass et al., 2021), as identified in a review on self-stigma among younger people with mental illness, alongside other psychosocial variables such as hope and empowerment (Livingston & Boyd, 2010).

Interestingly, one study with older adults in Brazil found that merely identifying someone in a vignette as having mental health problems increased public-stigma suggesting that psychiatric labels may be loaded with negative connotations for some older adults and thus instantly increase stigmatising views (Scazufca et al., 2016).

Limitations of the evidence and further research

The literature was multicultural (see Table 3), which provides a richness in terms of identifying how stigma varies across cultures; however, it also made it difficult to compare across studies. It was, therefore, harder to draw clear conclusions about particular racial/and or ethnic groups and older adult stigma, as there were not enough studies considering each ethnic and/or racial background. Many studies did not describe the sample or report effect in terms of ethnic and/or racial backgrounds, which is problematic given that this does appear to be an implicated factor. It was also noticeable that few studies considered acculturation or assimilation of minoritised older adults and the extent of minoritisation. There is a need for more in-depth research looking at the effects of racial and/or ethnic backgrounds and minoritisation on mental health stigma among older adults. Few studies reported on the belief systems older people had in relation to their ethnic and/or racial backgrounds but it is likely that these could play a role in mental health stigma. For example, Park et al. (2018) noted that the Korean word for 'health' only relates to physical health and it is seen as a virtue of self-control to suppress psychological problems. How these cultural beliefs interact with age remains unclear.

There was a plethora of mental health stigma measures used in the studies, which made cross-study comparisons difficult, and we were thus unable to report on prevalence of stigma across studies given these variations. Wei et al. (2018) conducted a review on the quality of mental health stigma measures and identified over 100 tools, raising concerns that it was not possible to draw clear conclusions about the overall body of this research. They suggested a consensus was needed to establish what measures of stigma towards mental health problems should entail. Furthermore, considering the measures used in these studies, of those identified in this review, none were reported to be of adequate quality in the review by Wei et al. (2018) and some studies only used a single-item measure, suggesting higher-quality research with more reliable and in-depth measures could be conducted with older adults. Further qualitative research could also support a deeper understanding of experiences of mental health stigma among older adults.

Most studies relied on self-reports on measures and social desirability is a key issue when asking people to report on their own mental health stigma; it is possible that there was under-reporting, especially as social desirability may differ cross-culturally (Wei et al., 2018). People may also hold implicit mental health biases, which they are not consciously able to report. More innovative research methods may be needed to explore these forms of mental health stigma with older adults.

There were no longitudinal studies, making it harder to assess causal relationships, such as the relationship between severity of mental health symptoms and mental health stigma. Furthermore, no studies compared stigmatising views among older adults towards some specific mental health conditions (e.g., psychosis). Existing research suggests that schizophrenia is the most stigmatised mental health diagnosis (Valery & Prouteau, 2020); however, no studies identified in this review looked at this for older adults.

Limitations of this review

This review was limited to studies published in the past ten years, therefore there is a lack of understanding about how mental health stigma may have changed over time among older adults. Furthermore, it excluded studies which did not include separate data for older adults, which may have excluded important lifespan research. The cut-off age for 'older adult' in this review was adopted in line with the WHO definition; however, this may itself be considered arbitrary, as being 'old' is a subjective construct and will also be influenced by life-expectancy in various countries. It was noted that older adults were often grouped in samples despite differences in age, which does not account for cohort effects, or consider potential differences that may occur across the full spectrum of older age. It is unclear whether stigma is experienced in similar ways for the young-old, as compared to the oldest-old. Studies focusing only on mental health treatment stigma were also excluded, which are an important and related phenomenon to mental health stigma. Studies which were only published in English were included which may have excluded some interesting and important research in respect to culture.

Implications

As well as a need for further research, the evidence so far highlights that mental health stigma is prevalent among older adults internationally and manifests differently based on the views of specific cultures. An international effort to understand the mechanisms driving stigma across different nations and to explore how it manifests among groups of older adults and individuals is important.

This review has identified public mental health stigma among many older adults and thus a need to target public-stigma interventions for older adults and consider tailoring interventions to older adults from various cultural backgrounds related to specific stigmatising beliefs. Given the finding that older adults with mental health problems are aware of public-stigma and appear to internalise these negative perceptions, further highlights the importance of interventions with the overall older adult population. Peer-educators have been found to be a feasible intervention for older adults with depression to decrease self-stigma as well as severity of symptoms (Connor et al., 2015, 2018). These peer-educators should be matched by age and racial/ethnic background, and it may be important to consider ways to connect older adults living rurally or who are unable to travel, for example, through video conferencing.

Under-representation of older adults in mental health services is often attributed to unique stigma among this age group (see de Mendonça Lima & Ivbijaro, 2013). The findings from this review suggests that older age does not necessarily predict more mental health stigma; however, this relationship is complex and also related to other factors. It is important to further consider access to mental health treatments, how set up services are to support the needs of older adults, the stigma of mental health professionals around older adult mental health, and other factors which may influence help-seeking in addition to stigmatising views among older adults.

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Appendices

Appendix 1: Data extraction form

Data extraction form for systematic review

1. General Information

Study ID <i>(surname of first author and year first full report of study was published)</i>
Report IDs of other reports of this study <i>(duplicate publications, follow-up studies)</i>
Date form completed <i>(dd/mm/yyyy)</i>
Name of person extracting data
Report full reference
Report author contact details
Publication type <i>(e.g. empirical paper, abstract, dissertation, full-text)</i>
Study funding source <i>(including role of funders)</i>
Study sponsorship
Possible conflicts of interest
Notes:

2. Eligibility

Is the study empirically-based? <i>(yes/no/unclear)</i>	Location in text <i>(pg., fig, table)</i>
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Does it focus primarily on mental health stigma towards older adults? (aged 60+) (yes/no/unclear)	Location in text (pg., fig, table)

Was it published since 2011? (yes/no/unclear)

Is it available in English as a full-text article? (yes/no/unclear)

Reason for exclusion (if applicable)

Notes:

NOTE FOR ELIGIBILITY: IF 'UNCLEAR' FOR ANY ITEMS DISCUSS WITH OTHER REVIEW TEAM MEMBERS, IF ANSWERED 'NO' TO ANY DO NOT PROCEED AND EXCLUDE FROM REVIEW

3. Population and setting

Population description (from which study participants are drawn)	Location in text (pg., fig, table)

Setting (including country, area and social context)	Location in text (pg., fig, table)

Method/s of recruitment of participants	Location in text (pg., fig, table)

Studies inclusion/exclusion criteria	Location in text (pg., fig, table)

Age	Location in text (pg., fig, table)

Gender	Location in text (pg., fig, table)

Race/Ethnicity	Location in text (pg., fig, table)

Mental Health diagnosis/ severity	Location in text (<i>pg., fig, table</i>)

Co-morbidities	Location in text (<i>pg., fig, table</i>)

Other relevant demographic information	Location in text (<i>pg., fig, table</i>)

Total number of participants	Location in text (<i>pg., fig, table</i>)

Study completion rates	Location in text (<i>pg., fig, table</i>)

When was study conducted (<i>start and end dates</i>)	Location in text (<i>pg., fig, table</i>)

Duration of participation (<i>from recruitment to last follow up</i>)	Location in text (<i>pg., fig, table</i>)

Notes:

4. Comparison groups (*if relevant*)

Number in each group	Location in text (<i>pg., fig, table</i>)

Method of group allocation (<i>e.g. randomised</i>)	Location in text (<i>pg., fig, table</i>)

Description of each group (<i>group differences</i>)	Location in text (<i>pg., fig, table</i>)

Notes:

5. Methods

Aim of study	Location in text (<i>pg., fig, table</i>)
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Types of stigma included	Location in text (pg., fig, table)

Study Design (descriptive, grounded theory, cross-sectional etc.)	Location in text (pg., fig, table)

Intervention(s) and comparator(s) (if appropriate)	Location in text (pg., fig, table)

Procedure	Location in text (pg., fig, table)

6. Outcomes and analysis

Analysis method	Location in text (pg., fig, table)

Copy and paste table for each outcome (where relevant)

Outcome 1

Outcome definition/ name	Location in text (pg., fig, table)

Is outcome/tool validated? (yes/no/unclear)	Location in text (pg., fig, table)

Scales: upped and lower limits (indicate what high or low score means)	Location in text (pg., fig, table)

Results	Location in text (pg., fig, table)

Notes:

Findings (qualitative)

Themes	Location in text (pg., fig, table)

Notes:

Other information

Key conclusions of study authors	Location in text (<i>pg.</i>, <i>fig</i>, <i>table</i>)

References to other relevant studies	Location in text (<i>pg.</i>, <i>fig</i>, <i>table</i>)

Notes:

Appendix 2: Quality Assessment

AXIS quality checklist (Downes et al., 2016) for observational cross-sectional studies (n=20)

AXIS checklist (Downes et al., 2016)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20
Abo-Rass, Werner & Altman, 2021***	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y	N	NA	Y	Y	Y	Y	N	Y
Anderson, Wickramariyaratne & Blair, 2017**	Y	Y	N	Y	Y	N	N	Y	N	Y	Y	N	Y	N	Y	Y	N	Y	N	Y
Brenes et al., 2015**	Y	Y	N	Y	N	N	N	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y
Currin, Hayslip & Temple, 2011**	Y	Y	N	Y	Y	N	N	Y	N	Y	N	Y	DK	N	Y	N	Y	Y	N	DK
Gitlin et al., 2012**	Y	Y	N	Y	N	N	N	Y	N	Y	Y	Y	N	NA	Y	Y	Y	Y	N	Y
Jang et al., 2011***	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y	N	NA	Y	N	Y	Y	N	DK
Jimenez et al., 2013***	Y	Y	N	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Mehra et al., 2020**	Y	Y	Y	Y	N	N	N	Y	Y	Y	N	Y	DK	DK	Y	Y	N	Y	N	Y
Min, 2019***	Y	Y	Y	Y	Y	Y	DK	Y	Y	Y	Y	Y	DK	DK	Y	Y	Y	Y	N	DK
Ng et al., 2011***	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	N	NA	Y	Y	Y	Y	N	DK
Park et al., 2015***	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	Y	N	NA	Y	Y	Y	Y	N	DK
Park, Jang & Chiriboga, 2018***	Y	Y	N	Y	Y	N	N	Y	Y	Y	Y	Y	DK	DK	Y	Y	Y	Y	N	Y
Preville et al., 2014***	Y	Y	Y	Y	N	Y	N	Y	N	Y	Y	Y	DK	DK	Y	Y	Y	Y	N	Y
Raeifar et al., 2017**	Y	Y	N	Y	N	N	DK	Y	N	Y	Y	Y	DK	DK	Y	Y	Y	Y	N	Y
Raue et al., 2011**	Y	Y	N	Y	Y	Y	N	Y	N	N	Y	Y	N	NA	N	Y	Y	Y	N	Y
Sczufca et al., 2016***	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	DK	DK	Y	Y	Y	Y	N	Y
Sirey et al., 2014***	Y	Y	N	Y	Y	Y	DK	Y	Y	Y	Y	Y	DK	DK	Y	Y	Y	Y	N	DK
Smilowitz et al., 2020**	Y	Y	N	Y	N	N	DK	Y	Y	Y	Y	Y	DK	DK	Y	Y	Y	Y	N	DK
Smith, 2012***	Y	Y	Y	Y	Y	N	DK	Y	Y	Y	Y	Y	DK	DK	Y	Y	Y	N	N	Y
Turvey, Frolova & Jogerst, 2012**	Y	Y	N	Y	Y	N	N	N	N	Y	Y	Y	N	N	Y	Y	N	Y	N	Y

Note: *** meets 15 or more criteria, ** meets 10-14 criteria, * meets 5-9 criteria – meets 4 or less criteria

Y- yes, N- no, DK- don't know, NA- not applicable

Joanna Briggs Checklist (Moola et al., 2017) for analytical cross-sectional studies (n=2)

Joanna Briggs Checklist (2017)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8
Conner et al., 2015	Y	Y	Y	Y	N	N	Y	Y
Conner et al., 2018	Y	Y	Y	Y	N	N	Y	Y

Y- yes, N-no, ?- unclear

CASP quality checklist (casp-uk.net) for qualitative studies (n=2)

CASP (2018)	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Criteria met
Bañbura & Opoczyńska-Morasiewicz, 2020	Y	Y	N	N	Y	C T	C T	N	Y	CT	4/10
Tzouvara, Papadopoulos & Randhawa, 2018	Y	Y	Y	Y	Y	C T	C T	Y	Y	Y	8/10

Y- yes, N-no, CT- can't tell

Chapter Two

Empirical Paper

Couples' lived experiences of mental health informal caregiving and care-receiving in later
life

Couples' lived experiences of mental health informal caregiving and care-receiving in later
life

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submission guidelines for this journal:

<https://journals.sagepub.com/author-instructions/JAH>

Abstract

Background: Mental health problems are common among older adults; however, there is a lack of understanding around informal caregiving in this context and uniquely caregiving within co-habiting partner/spousal relationships. This study explored experiences of caregiving and care-receiving among older adults who had encountered significant mental health problems for the first time in later life. **Methods:** Semi-structured interviews were undertaken with five people with mental health problems and, separately, with their partners (N=10). The design was informed by multi-perspectival interpretative phenomenological analysis. **Results:** Participants experienced continuity and change to their relationships. For some 'caring' was seen to be an extension of their relationship; for others, a new role which could create aloneness and defy expectations of reciprocity. Perceptions of the person with mental health problems having changed indicated that mental health stigma and ageism had permeated identities – despite efforts by couples to preserve previous identities. There was uncertainty among caregivers who had 'no roadmap' for mental health caregiving. **Conclusions:** Participants placed relationships at the heart of caregiving and care-receiving experiences in later life; they described continuity and change in a life disrupted by mental health problems. Implications for how mental health services can support and honour relationships are discussed.

Keywords: Older adults; Mental Health; Caregivers; Couples; Coping; Qualitative

Introduction

Although most older adults report good mental health, it is acknowledged that a sizeable proportion – around 15-20% – are likely to experience mental health problems at some time in later life (World Health Organization [WHO], 2017). In the context of an ageing population, it is therefore anticipated that the number of older people experiencing mental health difficulties, and requiring mental health support, will increase in coming years. Most older people with mental health problems present with anxiety and mood-related difficulties; however, significant mental health conditions traditionally associated with early-life onset (e.g., psychosis and bipolar disorder) can also be encountered for the first time in later life and can cause significant distress (Howard et al., 2000; Depp & Jeste, 2004). Older adults have the highest suicide rates of any age group, which has been related to factors such as bereavement, physical disability, loneliness, and, crucially, poor mental health (National Council on Aging, 2021). It is clearly important to gain an understanding of the experiences and support needs of older adults with mental health problems and to ensure that services are equipped to meet these needs.

Over recent years, mental health care has shifted away from hospital-based provision, with increasing focus on community-based services; in this context, it is more likely that people experiencing mental health difficulties will be supported at home, often with additional care provided by family members. Indeed, up to 90% of people with mental health problems live with relatives who provide practical and emotional support (Shah, Wadoo & Latoo 2010). Surprisingly little is known about the experience of providing this kind of informal care in later life. Research exploring informal caring in older age has largely focused on caregiving experiences in the context of dementia – which has been a key priority in health and social care policy and research internationally (Saad & Bangash, 2016). A wealth of research has examined caring experiences in this context (Gilhooly et al., 2016), yet relatively little attention has been given to caregiving in other circumstances and, particularly,

in respect to caring for somebody with mental health difficulties (McCormack & Skatvedt, 2017).

Research exploring mental health caregiving among young and middle-aged adults (<65 years) identifies a significant impact on family carers, including physical health problems (e.g., sleeplessness and headaches), psychological difficulties (e.g., depression), and socioeconomic challenges (e.g., occupational and financial costs; Fekadu et al., 2019; Zauszniewski *et al.*, 2009). Being placed in unpredictable and unfamiliar situations with a family member who has mental health problems has also been associated with significant anxiety and worry for caregivers (Shah et al., 2010). Recent research suggests there may be significant differences in caring in the context of mental health, as compared to physical health and dementia care, including there being less social support and increased stigma, increased isolation, and greater physical and mental burden for those providing care (Estrada-Fernández et al., 2021). It has been suggested that families of people with poor mental health can also experience vicarious stigma, impacting on identity and sense of self, with a propensity towards concealment of problems and avoidance that increases social seclusion for the family as a whole (Muralidharan et al., 2016).

There is limited empirical insight into the unique experiences of informal caregiving for an older adult with significant mental health difficulties. One study investigating broader family experiences of caring for an older adult with severe and persistent mental health problems in Australia found that caring could be a difficult and demanding undertaking (McCann, Bamberg & McCann, 2015). In this study, family carers reported feeling physically and emotionally drained, experiencing considerable loss alongside adverse effects on lifestyle and social relationships. There were, however, also positive aspects to caregiving: some carers developed resilience and found caring to be powerful and satisfying; others successfully harnessed social support and found ways to purposefully maintain wellbeing. The study by McCann et al. (2015) included a sample composed predominantly of adult offspring, most of whom were not co-habiting with the family member; it is understood that

co-habiting carers – especially partners – may experience higher levels of psychological distress than those who live apart from care-receivers (Pinquart & Sörensen, 2011).

It is more common when people have a partner, that they will provide informal care and it is important to consider their unique experiences, which may differ significantly from other types of familial relationships (Noël-Miller, 2011). Providing care in a child-parent context may be related to the experience of role reversal (Chappell, Dujela & Smith, 2015), whereas within partnerships there may be an expectation of mutual caregiving or a tendency to view caregiving as a duty in the relationship (Lawn & McMahon, 2014; Zegwaard et al., 2013). It has been suggested that partner caregivers may be particularly vulnerable to carer stress when they are older and concomitantly confronting age-related issues of their own (Penning & Wu, 2016; Johansson et al., 2021). It is also important to consider the specific context of partner caregiving where relationships may have been established for many years – even over entire lifetimes, which may itself influence transitions to caregiving within a dyad.

There is much to learn regarding the experiences of older caregivers in the context of mental health; however, research exploring the experiences of older people with mental health problems *receiving* informal care is equally lacking. The caring relationship, by definition, entails care being given *and* received, yet much of the caregiving literature focuses on *caregiver* experiences and outcomes (Lyons et al., 2002). It is important to consider the impact on both aspects of the relationship and the congruence, conflict, and negotiation related to the process of caring *and* being cared for. It has been suggested that care-receivers are often overlooked and treated as an objective cause of caregiving stress, rather than a contributor within a dynamic relationship (Zarit, 1994). Consideration of both perspectives is likely to be necessary to fully understand how care is provided and can be supported (Forbat & Henderson, 2003).

This study aimed to explore the experiences of caregiving and care-receiving in the context of mental health difficulties in older age, specifically, focusing on how co-habiting couples adjusted to these experiences when encountered for the first time in later life. It is intended that the results will provide insights that inform the provision of support from mental

health services for people experiencing mental health problems in later life, and for the partners who support them.

Method

Design

This exploratory cross-sectional study used semi-structured interviews to gain insight into the lived experiences of older people in relation to mental health caregiving and receiving. All aspects of study design were informed by the principals of interpretative phenomenological analysis (IPA); an approach that draws on phenomenology, hermeneutics, and idiography to systematically explore how individuals interpret and make sense of lived experiences (Smith, Flowers, & Larkin, 2009). This approach was selected to explore participants' *subjective* accounts of caregiving and care-receiving, as described in their own words. It was intended that data would be analysed to highlight features of experience important to the particular older people who took part in this study, rather than to establish an objective or generalisable account of caregiving and care-receiving in this context.

Traditionally, IPA focuses on homogenous groups; however, this approach can be limiting when the research focus has a strong relational component, as is the case in caring relationships (Larkin, Shaw & Flowers, 2019, pg. 184), as such, *multi-perspectival* IPA has been applied to understand experiences from multiple accounts of the 'lived world' (Larkin, Shaw & Flowers, 2019). In this study, it has been used to explore experiences of informal care from the perspectives of carers *and* the cared for.

Ethical Issues

Approval for this study was obtained from Bangor University, School of Human and Behavioural Sciences Ethics Committee (Ref 2021-16958), Bromley Research Ethics Committee (HRA and HCRW approval, IRAS 302703) and site-specific NHS Research and

Development approval. Research materials (e.g., written information sheets) were developed by the researchers in consultation with an Experts by Experience group (the 'People Panel') within the North Wales Clinical Psychology Programme (NWCPP) at Bangor University. This group includes older adults, people with mental health problems, and family carers.

Recruitment / Participants

A purposive sample was recruited through a secondary-care Older Adult Community Mental Health Team (OACMHT) in North Wales. Potential participants were identified by healthcare professionals within the OACMHT according to specific inclusion and exclusion criteria:

Inclusion

- Being in a couple where one member has mental health problems (of sufficient severity to require ongoing OACMHT support), with these difficulties being encountered for the first time in older age (≥ 65 years).
- Both members of the dyad being ≥ 65 years of age.
- Currently cohabiting.

Exclusion

- Insufficient English to take part in interviews.
- Dementia or cognitive impairment sufficient to prevent either member of the couple from being able to give informed consent or to participate in interviews.
- Significant clinical risk factors indicating that it was not safe or appropriate for an individual to take part.

Eligible individuals were approached by healthcare professionals in the OACMHT who were known to at least one member of the dyad. All were given a verbal overview of the research and asked to indicate whether they wanted further information. Those who expressed an interest were provided with a written information sheet (*Appendix 1*) and given

time to read and ask questions. It was made clear that ongoing care would not be affected by non-participation and that OACMHT staff would not have access to interview data. Those wishing to participate either gave verbal consent to be contacted by the first author or returned an opt-in slip (*Appendix 2*). Written and verbal consent was obtained in all cases.

Over the recruitment period, five couples, were identified as meeting the eligibility criteria. All were approached and all consented to take part ($n=10$). The five people with mental health difficulties (under the care of the OACMHT) described diagnoses of severe anxiety, depression, psychosis, or bipolar disorder. All cohabiting partners were married, with marriage duration of 35-58 years. Participants ages ranged from 68 to 91 years. All were white-British, retired and from a range of socio-economic backgrounds.

A relatively small sample size was sought in accordance with IPA tradition, focusing on quality and richness of data rather than quantity. A sample of ten individuals enabled in-depth analysis of each interview. It also facilitated the more complex *multi-perspectival* approach, which entailed analysis for each individual, within and between dyads, and across groups (Larkin, Shaw & Flowers, 2019).

Procedures

Each participant was interviewed alone. Separate interviews were used to enable each partner to tell their story from their own perspective, capturing the individual within the dyad and recognising that there may have been aspects of experience that they were reluctant to share in their partner's presence (Antoine *et al.*, 2018). All participants were interviewed by the first author, a trainee clinical psychologist, and informed that the research contributed to attainment of a professional qualification. Participants were offered interviews remotely (e.g., via telephone or video-link) or in-person. All chose to be seen in-person, with COVID-19 guidelines followed. A choice of venue – clinic or home – was offered. Where participants opted to be seen at home, discussions were held to ensure there was a confidential space for interviews to take place.

An interview schedule was used flexibly to guide interviews, with questions exploring how mental health difficulties had affected relationships, the nature of the care given/received within the dyad and from services, and the impact of giving/receiving care in the context of the dyadic relationship (*Appendix 3*). This guide was developed after review of existing caregiver research and via consultation with Experts by Experience from the NWCPP. Interviews were participant-led and non-directive, enabling participants to explore topics of personal interest and importance. Field notes, including the observations and initial thoughts and reflections, were made directly after interviews.

Interviews lasted between 50 to 85 minutes and were audio-recorded to enable transcription. Each participant was given a £20 gift voucher to thank them for participation. All were given a list of contacts (e.g., for voluntary helplines, community support, and the OACMHT) in case they required further support after interviews.

Data analysis

Interviews were transcribed verbatim and anonymised. Analysis – using multi-perspectival IPA – involved:

1. Reading and re-reading individual transcripts to actively engage with the data and become familiar with it.
2. Initial noting: writing detailed notes and comments on the data, including descriptive linguistic, and conceptual comments
3. Developing emergent themes: shifting from working with the transcript to working primarily with the initial notes and re-organising the data by themes.
4. Searching for connections among emergent themes: charting or mapping how themes fit together, including abstraction, subsumption, polarisation, contextualisation, numeration, and function (*see Appendix 4*).
5. Moving to the next transcript and repeating stages 1-4: as recommended for multi-perspectival IPA, the next interview analysed was the other member of the couple (Larkin, Shaw, & Flowers, 2019).

6. Looking for patterns across cases and between the groups: exploring themes across cases, dyads, and the two groups to identify the most potent themes, re-labelling, and identifying more abstract themes. A final list of themes was then created.

IPA proposes that while direct access to participants' worlds is impossible, insights can be gained by interpreting this world. Analysis within the IPA tradition recognises the researcher as engaged in a 'double hermeneutic' (Shinebourne, 2011): participants attempt to interpret and make sense of their experiences and the researcher then attempts to interpret and make sense of those reported experiences. This acknowledges that the researcher's experiences and beliefs influence their interpretation, making reflexivity throughout data collection, analysis, and interpretation vital.

All analysis was undertaken by the interviewing researcher. The third author reviewed annotated transcripts and documents of quotes/themes to support the credibility and interpretation of the data (Smith et al., 2009). This process also provided an opportunity to ensure that the study followed the four principals of quality for qualitative research outlined by Yardley (2000; 2008): *sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance*.

Themes are presented in a narrative account, with verbatim quotes embedded to promote transparency regarding the relationship between interpretations and data. Pseudonyms have been assigned for each participant and dyadic data are presented at a group level, without identifying which caregiver/care-receivers were linked, so as to maintain confidentiality.

Reflexivity Statement

I am a woman in my early 30s who was undertaking this research as a trainee clinical psychologist as partial fulfillment of my training course. My position as a trainee clinical psychologist and researcher may have influenced how participants related to me, and I to them, throughout the research process. At the time of this research, I was on an elective placement in an Older Adult Mental Health service, and I have prior experience working with

Older Adults and of conducting qualitative research with Older Adult couples living with dementia. I considered how being comparatively young to the people I was interviewing may have influenced both how the couples spoke to me and the interpretations that were made. For example, there was a sense of being 'taught' by these older adults as a younger person with less life experience and some older adults shared assumptions about how they thought I might interpret something they said, such as perceiving I might think their daily routines were 'boring'. I considered that my prior research background working with older couples might have influenced the interpretations, for example during my prior research experience I became interested in selfhood and identities. It was important to be mindful of the lens in which I interpreted data and to bracket my prior experiences to draw out the unique perspectives of these older adults. The third author, who was also involved in discussing and interpreting the data and emerging themes, is a qualified Clinical Psychologist, who was, at the time of this research, working in an Older Adult Mental Health service and had prior experience of Interpretative Phenomenological Analysis. Her experience of the method, and of working with Older Adults clinically, was also considered during data analysis.

Results

This study aimed to explore lived experiences of informal caregiving and receiving in later life within the context of experiencing significant mental health problems for the first time in later life. Although commonalities in experience were identified, it was evident that responses to the experience of mental health crises – and to the giving and receiving of care – were best understood within the unique personal context of each established dyadic relationship. Individuals were part of pre-existing relationships that were both threatened and strengthened by the change in circumstance. Analysis derived seven themes, summarised in Table 1, which capture these similarities and differences.

It is important to note that the people who took part in this study did not refer to themselves as caregivers (CG) or care-receivers (CR) – rather as partners, wives, and

husbands; however, these terms are used pragmatically to distinguish these two groups. They denote the person who has sought help for mental health difficulties (CR) and the partner who has provided them with support (CG). The complexities of such labels are considered within the analysis.

Table 1

Theme descriptors for caregivers (CG) and care-receivers (CR)

Theme	Description
Continuity and Change	<i>Captures the disruption to couples' lives as well as stability through their long-standing relationships. CR focused more on continuity and CG on change.</i>
Caring: New or Extended Roles	<i>Describes how 'caring' could be seen as an extension of relationships or a new role that could defy expectations for reciprocity.</i>
Together and Alone	<i>Explores both experiences of being 'together' more such as physically and 'alone' such as for CG in caring or CR in masking mental health problems.</i>
Not that Sort of Person	<i>Reveals how CG and CR began to see the person with mental health problems differently. CR felt viewed negatively by wider family and services.</i>
Preserving Identities	<i>Outlines how CG and CR's used strategies to preserve identities of the CR and couple such as compartmentalising difficult interactions and externalising mental health problems.</i>
Needing them now	<i>Describes how CR came to rely on CG to keep them emotionally regulated. CG also spoke about 'looking out for' partners to keep them safe. Some CR felt guilty and CG felt loss and fatigue.</i>
No roadmap	<i>Captures the uncertainty for the future and fluctuation of mental health symptoms. CG were often unsure how to support their partners.</i>

Continuity and Change

At a time of significant change, the presence of a longstanding partner – and an established relationship – became an important source of stability and continuity. There was also a profound sense of disruption to couples' shared lives when mental health crises were

encountered, with practical, social, and emotional consequences for both members of the dyad. Couples recognised attempts to incorporate new experiences into the continuing narrative of a long-standing relationship.

Care-receivers tended to focus more on continuity than change. This may have related to them 'needing' their partners more, encouraging a focus on preserving the relationships. It may also have reflected some care-receivers having fluctuating insight into the impact that mental health problems had on their shared lives. For care-receivers, there was value and a comfort in what remained the same – e.g., doing 'normal' things together. As Harry (CR) explained:

When [partner] and I came together that was it, I'm a great believer in fate... we came together and have 37 years of wonderful, wonderful times and it's now (laughs), like when little gestures, for instance, float around in the morning, what we do, we get a 'sws' and a 'cwutch', which is a 'kiss' and a 'cuddle', so we stop whatever *it* is and it puts us right for a while.

Harry expressed joy in sharing the history of his 'wonderful' relationship. Although he and his partner spent little time together since he developed mental health problems, he focused on continuity through the small moments of coming together, where intimate gestures could still 'put them right for a while'.

Caregivers appeared to emphasise more of the change and disruption in relationships. Some felt that relationships had become fragile, with caregiving coming to dominate daily life for the couple. Most described a loss of the freedom that they had expected to enjoy with their partner at this stage of life (e.g., hopes of travelling and pursuing hobbies in retirement). There was an emphasis on *discontinuation* and disruption. As Simon (CG) explained: "*We could go and spend 3 months in Paris, you know, just looking around the art galleries, it would be great, and we could just do it, but we can't because this thing is just a giant sea anchor.*" Simon lamented lost possibilities, noting the enforced restriction of the 'anchor' now in place. The metaphor of the anchor, representing his partner's mental health problems, illustrated their impact; portraying a life of restriction, unable to move forward.

Caring: New or Extended Roles

Caring could be seen as an extension of the existing relationship or a new role that developed within it. In most cases, one partner needing to provide a greater degree of care created an imbalance in roles, with the needs of the care-receiver typically taking priority.

Some caregivers and receivers saw caregiving as a continuous element of a relationship in which *'we've always been there for each other'* (Paula, CR). Caring was seen as a duty in their partnership, each were still doing what they could to support one another. For these participants, caring meant doing more of the things they had always done. As such, caregiving was not identified as a new identity or seen as different from how things were before. As Sion (CG) stated: *'I prioritise her and she'd do exactly the same for me, it's what we do'*. It was noted, however, among all caregivers and receivers that there was now less reciprocity in emotional support given whereby caregivers were doing more of this to support their partners living with mental health problems.

Other caregivers felt that caregiving defied expectations of reciprocity more broadly within the relationship, with a sense of unfairness at one partner now 'having to' support the other in new ways. This seemed to be an issue that care-receivers were sensitive to. As Nora (CR) expressed: *"I do feel sorry for him, I feel that I'm a burden because...he didn't sign up to be a carer."* For Nora, there was a perception that her partner had not 'signed up' for caregiving as part of their relationship and a sense of guilt that he now occupied this new role.

Marked role reversals, in tasks and in emotional support, often created a new 'caregiving' context. However, many participants distanced themselves from the term 'carer' and felt it took something away from other roles, such as wife, husband and partner. As Jeff (CR) explained: *"she's my wife (laughs) not a carer... but I can't get out of it that she does care for me, she does care, she looks after me, so it's hard."* For Jeff, the term 'carer' appeared almost humorous in relation to his wife. There was conflict in him wanting to see her as his wife but realising that she was also caring for him in a new way.

Together and Alone

Participants experienced both aloneness and togetherness in relationships. Most couples found themselves physically spending more time together; however, psychologically, they also described feeling that they were in different worlds. Although each person could acknowledge the subjective world of the other, it was not always felt to be understood, which for some created a ‘wall’ between them. This could lead to conflict and frustration, especially where there were unsuccessful attempts to re-establish a shared reality. Generally, caregivers reported that their partners expressed a distorted reality – changed by their experience of psychosis, low mood, or anxiety.

There was also concealment within relationships: caregivers described how partners were no longer confidantes, as they did not want to upset them by talking about their own difficulties. Care-receivers also described masking mental health problems, so as not to burden their partners, leaving them to confront their worst moments alone. Paula (CR) revealed: *“I could be having the worst day. I could be upstairs and thinking I just want to scream and scream ‘cause the feeling is so bad sometimes, but I don’t tell him.”* There was a sense of loneliness in Paula’s experience, describing the extent of her mental distress, how much she wanted to let it out, and *still* choosing not to tell her partner how she was feeling. Throughout the interview, Paula referenced not wanting to be *‘that person’*, emphasising the importance of protecting her partner’s other roles, such as husband and friend, by concealing her problems and living alone with them.

Being older in age, some care-receivers had physical health problems as well as mental health difficulties; these participants talked about caregivers being busy doing practical tasks at home, reducing time and space to be with them. For some this evoked a sense of sadness. However, for others, time alone could be valuable and important – even necessary. For Harry (CR), not being accompanied by his partner meant freedom, he explained: *“With [partner] not coming with me, it’s like, erm, a pigeon being released, I can go up, down, sideways, I can do exactly what I like without anyone telling me whatever.”*

Harry described his partner as an authoritarian figure, often leaving him feeling ‘told off’ in her attempts to monitor his behaviour and keep him safe, which encouraged him to seek escape. There was a sense that Harry wanted to be able to leave his partner behind and the couple found themselves spending decreasing amounts of time together when Harry felt well enough to go out alone.

Some couples also found themselves feeling isolated and alone *as a dyad*, with attempts to shield wider family from the reality of the situation. This was often to protect other identities of the care-receiver (e.g., as parent) or to avoid burdening others. As Jeff (CR) explained: “*Do I want to share it? Do I feel that I should burden them [family] with it? You know why should I? I don’t want to put pressure on them, me talking about how I feel mentally...*” Jeff did not want to share his mental health experiences with his adult children, even though he felt able to share this with his partner, he questioned the purpose of sharing with family, fearing that he would create stress and ‘*pressure*’ for them. This left him feeling somewhat unsupported by the wider network. Some caregivers believed that wider family (e.g., adult children) were too busy or would not be understanding. Mental health services were also often seen to be unsupportive and unavailable, leaving day-to-day support largely managed within couples – chiefly by caregivers.

Not that Sort of Person

Caregivers, to various degrees, described viewing their partner differently since mental health difficulties emerged: they were described as being transformed from strong to weak, normal to not normal, able to unable, and reliable to unreliable. Both mental health stigma and ageism appeared to permeate perceptions. Gwen (CG) reported: “*I’ve got to get him motivated because otherwise he’ll just sit there like an old man in a nursing home*”. Gwen talked about *having* to motivate her partner to do things, lest she struggle seeing him ‘*just sitting*’. This reminded her, instead of her husband, of an old man in a nursing home, someone unrecognisable to her, with negative connotations of illness and absence. Some caregivers talked about their partners ‘*not trying hard enough*’ to recover, seeing the mental

health crisis as a failure or weakness in character. Developing mental health problems for the first time in later life was also seen as transgressive, challenging caregiver's perceptions of the person they had known over a lifetime. This could be distressing, as Roger (CG) reflected: *"The main difficulty in understanding is because she's been so strong all her life and then seeing her basically crumble and become just this shadow of what she was before."* Roger spoke of a 'crumbling' of who his wife of over 50 years was to him, juxtaposing the '*strong*' character he knew with a perceived '*weakness*' related to her mental health.

Care-receivers also came to see themselves differently, with changes in character described in ways suggestive of internalised self-stigma. Some care-receivers spoke about being perceived differently by wider family and also by mental health professionals (e.g., feeling that they were being pitied or infantilised). Some care-receivers reported that services saw them as patients rather than people; many emerged having been labelled as 'ill' and were offered only medication. As Paula (CR) recalled:

It was like the stigma of being *ill* and everything and I'm like this spoiled person, it was something she [professional] said once, she said *'Well, we've already discussed this, Paula, remember? We discussed it and it's this....'* and it was like I'm a child and that's how I felt, oh my god, I felt, being such a proud person and running my own business... and to be spoken to like that, I thought *'I don't want this anymore...'* it wasn't helping at all. I'm a grown woman, I was 68, and I've reached this stage in my life and then for her to even think I'm that sort of person, I'm not that sort of person you're making me out to be, I was struggling so much, the anxiety made me absolutely terrified but she made me feel worse.

Paula acknowledged stigma and a 'spoiled' identity, with mental health problems – and potentially age – overshadowing the person within. Paula felt that she was treated like a child, which conflicted with her self-concept of a proud woman who had run her own business. She spoke of wanting to be respected for who she was – and the age she was.

Paula appears angry that her true identity had been obscured; this felt worse than the terror of her anxiety.

Preserving Identities

Care-receivers often spoke about who they were 'before', in apparent attempts to convey a sense of the 'real' them. This was an identity that caregivers could help to maintain, as they had known them across a whole lifetime. A number of care-receivers noted that mental health professionals could not always see this part of them – they tended to see problems not people. Preserving identities sometimes involved care-receivers distancing themselves from services or mental health groups, expressing a belief that they did not really belong in those settings. This increased the need for support from caregivers.

There were lots of ways that couples attempted to protect identities as part of the sense making process. Both caregivers and care-receivers described compartmentalising difficult interactions, externalising the mental health problems or associated challenging behaviours, distancing the caregiver from a 'carer' status, minimising the impact of change, and focusing on continuity within the relationship. Julie (CG), spoke of the distressing changes in her partner due to his mental health difficulties:

You put them [things partner has said and done] in a little box at the back of your mind and you don't want to think about them to be perfectly honest with you, you know. When somebody's hurt you so much that, really, it's just, you know, you put them away and I don't think about them... because if I thought of all the things he'd said and done, well, then, I wouldn't...

Julie talked of storing all of the hurtful things that her partner had said in a mental 'box' and placing this at the back of her mind, so as not to think about it. This was important in enabling her to continue the caring role. Julie paused at the end of her comment, not even completing her thought, as if she could not go any further. She later spoke about the importance of trying to '*think they're ill*' (i.e., not really responsible) and focusing on times

that her partner had treated her well. This seemed to be part of a process of preserving the former identity; her partner's behaviours were due to an illness, not a reflection of who he really was.

Both caregivers and care-receivers concealed from partners to protect either the relationship – and role of husband, wife, or partner – or to preserve a sense of self. Care-receivers concealed mental health difficulties and caregivers concealed new tasks that they were taking on. Gwen (CG) noted that her partner had previously been responsible for tending to the garden; to avoid him feeling guilty and to preserve a sense of balance in role, she would only do tasks in the garden once her partner was occupied or distracted. She explained: *“I’ve told him to stop feeling guilty, so now I try and if he’s watching like snooker or something... and kind of when I’ve got him occupied in that, I’ll do [the garden]”* Care-receivers also talked about trying to do more for themselves or limiting the support from partners, so as to minimise the sense that they were a ‘cared for’ person.

Needing them now

The practical and emotional support provided by caregivers differed between dyads; however, all caregivers played a key role in supporting their partners emotional wellbeing. Care-receivers often described relying on and needing caregivers to keep them emotionally regulated. *‘Being there’* was the main care task identified by both caregivers and care-receivers, which represented containment, as well as reinforcing a sense of safety and stability. As Jeff (CR) expressed: *‘she’s been there all the while for me’*. For caregivers, this could be burdensome, as there was perceived to be a lack of boundaries at times where this was a supportive need without a tangible endpoint. Some care-receivers wanted partners with them *all* the time and for care-receivers there was a sense that anxious-attachments had developed. Paula (CR) explained: *‘It’s really important that [partner]’s with me, I wouldn’t cope the same.’* Although previously an independent, confident woman, Paula no longer felt that she could cope without her partner being present.

Other caregiver tasks included reassurance, assuming responsibilities to take away stresses, distraction, motivation, supporting avoidance, and encouraging participation in valued activities. There was frustration for some caregivers that they could not always change their partners emotions or make them feel better. Most did not feel that they had sufficient understanding of mental health to do this, leaving many to merely comfort rather than bring about meaningful change.

Some caregivers spoke about having responsibilities in 'looking out for' as opposed to 'after' their partners. This often involved monitoring wellbeing and anticipating risk – a task that kept some caregivers feeling unable to relax. As Gwen (CG) reflected: *'I'm panicking, I'm not relaxed'*. Although services could be contacted as needed, it was caregivers who were left with ultimate responsibility for their partner's safety, which could be daunting. Caregiving could, at times, challenge the mental health of caregivers in this way.

There was a paradox whereby being needed/needing for the emotional wellbeing of a partner could inadvertently create difficult emotions such as guilt and shame for care-receivers, and low mood, stress and anxiety in caregivers and care-receivers. As Jeff (CR) reflected: *'she's there, she's helping me, it's reassuring, sometimes I feel that should she be having to do that you know?... I find I'm suffering from the guilt side'*.

No Roadmap

Mental health problems were not static; they fluctuated in response to environmental triggers, which meant symptoms changed over time. For some, there had been improvements, which gave hope for the future, for others, there had been no change, leaving significant uncertainty. There was a sense of there being 'no roadmap' for this; experiences were individual and dynamic, which meant caregiving needed to be reactive. Situations were changeable and care was co-created between couples, almost as a dance between them. Care-receivers sometimes put boundaries in place and caregivers needed to care 'around' them – what could be done was not always clear. As Harry (CR) explained: *'I say to [partner] 'When I'm down, do nothing for me' but then I think 'What can she do?' because I don't want*

to know anyone, I don't want to be fussed around, I want to be left alone.' Harry described putting boundaries in place for his partner and explicitly negotiating with her to do 'nothing' for him. He sought to keep her out of a caring role, seeing this as being 'fussed around'. Equally his partner described needing to carefully time the support that she gave, knowing that at times stepping in would not be useful for Harry.

Caregivers were often uncertain about what their roles were and there was uncertainty among some about whether they were caring in the 'right' way. Most felt unsure about what they could possibly do to support their partner's mental health. This was often exacerbated by a lack of support and guidance from services. As Gwen (CG) reflected:

I'm trying to get him involved but I don't know whether I'm supposed to, am I making it worse... nobody rings me or tells me, nobody advised me in the beginning how to treat him, I've tried all sorts, I've tried not to, I've tried doing it, I've tried all sorts of different ways... and trying to work out what works best.

Gwen described being unsure of how she was '*supposed to*' support her partner. She had not received training and the role was not clear. She talked about using a trial-and-error approach and feeling helpless in not finding the 'right' way to help. This contrasted with experiences of supporting physical health needs, where caregivers appeared clearer about roles and more confident in their execution. Care-givers had little confidence beyond the need to care for their partners in '*just being there*'. Both caregivers and care-receivers were finding their way together and facing an uncertain future.

Discussion

This study explored the subjective experiences of mental health caregiving and care-receiving in later life. At the heart of these experiences were *relationships*: mental health problems could be incorporated into ongoing relationships or seen as a disruption to them. For these older adults, the unexpected need for additional care emerged in the context of long-standing relationship dynamics and seemed to create varying degrees of 'imbalance' in

established roles. There was as much prominent ‘care work’ to maintain the relationship identity as there were ‘care tasks’ to support the person with mental health problems.

Although couples often found that they were spending more time together physically, they also described feeling isolated: alone in the ‘hidden’ reality of having mental health problems or of being a caregiver. Couples were living with mental health problems together, yet were also ‘alone together’ in this reality – often reinforced by efforts to shield wider family, avoid burdening others, or to protect the identity of the care-receiver within social networks. There were also varying degrees of connection with formal support; mental health services were typically experienced as unreliable, amplifying the sense of aloneness – a finding observed in other research exploring caregiving in older age (Lawn & McMahon, 2014).

For older adults in this study, the identity of the person with mental health problems was often seen to be ‘spoiled’. Mental health stigma, and its interplay with ageism, permeated participants’ realities (Temple *et al.*, 2021). Developing mental health difficulties for the first time in *later* life was unexpected in most cases; many expressed surprise that such difficulties could develop so suddenly in older age. It was also felt to be untimely in this stage of life, in which many had been expecting to enjoy the freedoms of retirement. Care-receivers saw themselves through others’ disapproving eyes, which challenged their sense of self (Cooley, 1902). Both caregivers and care-receivers used strategies intended to preserve identities, as well as to protect the relationship. Some caregivers downplayed the caregiving role or dismissed partners’ challenging behaviours in attempts to restore positive identities (Moore & Gillespie, 2014). It is again important to consider these dynamics in relation to the age of participants and the duration of relationships – having spanned decades of life. It appeared that one function of caregivers within the relationship was to ‘hold’ and protect the identity, dignity, and integrity of their partner throughout the mental health crisis. Formal care from services, in contrast, appeared to further undermine the sense of self for many care-receivers – identifying instead with age or illness.

Caregivers discussed fatigue and loss of independence, whilst care-receivers were conscious of relying more on caregivers. Care-receivers described feeling guilty, useless, and like a burden to others, which has been described elsewhere by care-receivers in relation to chronic illness and disability (Nieuwenhuis, Beach, Schulz, 2018). There was a loss of perceived reciprocity and a grief for this, which has been described by other caregivers of people with mental health problems (Rahmani et al., 2018; Shah et al., 2010; O'Neill, 2020). As described by Roth et al. (2008), the onset of a chronic illness can strongly challenge the emotional and physical boundaries of couples because the illness is an uninvited guest. There was a sense, in this study, that how couples related to one another had changed with the onset of mental health problems: some caregivers and care-receivers described carers as duty-bound or captive in their roles (Pearlin et al., 1990), whereas others saw it as a choice to provide support.

An important function of community mental health services is to support informal caring relationships. Existing research suggests that carers express dissatisfaction with formal mental health support, with some services focusing narrowly on the needs of the person with mental health problems without considering carer needs (Muir-Cochrane et al., 2014). For community care to be effective, services should consider systems around the person – including the vital support of family caregivers (Zegwaard *et al.*, 2013).

In this study, mental health services were often found lacking, for caregivers *and* care-receivers. Lazarus and Folkman (1984) define stress for caregivers as a relationship between person and environment that is appraised by the person as taxing or exceeding resources. Inadequate support from services left some caregivers in this study feeling under-resourced and struggling to cope. Both caregivers and care-receivers expressed a sense of there being no 'roadmap' for the journey, which seemed to be perpetuated by poor communication from mental health services. The tasks of caregiving in a mental health context appeared nebulous. Rather than tangible 'tasks', there was a greater focus on supporting emotional wellbeing; caregivers described simply 'being there' as the most

prominent aspect of the role. Fluctuating symptoms and changing needs meant that caregivers needed to be responsive, which made it difficult to plan too far ahead.

Clinical Implications

This study highlights the important role of partners – as caregivers – where older adults encounter mental health difficulties in later life. Although caregivers in this study had a central role in helping to support their partner's wellbeing, some felt ill-equipped to do so. Services could helpfully play a greater role in supporting these relationships (Zegwaard *et al.*, 2013). Some strategies that caregivers were using (e.g. providing reassurance or enabling partners to avoid anxiety-provoking situations) may well have exacerbated or maintained mental health problems in the long-term. It is possible, therefore, that systemic interventions that provide psychoeducation and coping skills training for caregivers may be helpful, especially given that spousal caregivers typically spend significant time with their partners (Beesdo-Baum *et al.*, 2012). It may also be helpful to provide training to equip staff to work more effectively with families and the caregiving context (Stanbridge *et al.*, 2013). Family caregivers should also be recognised for the complex and emotionally challenging support they often give (Rowe & Rizzo, 2013; Chan & O'Brien, 2011).

This study revealed an imperative for services to recognise and respect personhood. Participants wanted to be understood as having identity beyond being a 'patient' and for their long-standing relationships to be acknowledged (Lawn & McMahon, 2014). Although the importance of person-centred care is well-versed in NHS principles and policies (e.g., Health and Care Standards; Welsh Government, 2015), in practice, it appeared lacking for some participants in this study. Systemic issues, such as a lack of resources, may have meant that health professionals were not always able to provide collaborative, holistic, and humanistic services and keep the 'person' or couple at the centre of care (McKay *et al.*, 2012). Some care-receivers spoke about feeling infantilised by services. It may also be important to consider interventions that address stigma within care contexts (Vistorte *et al.*, 2018; Bodner, Palgi & Wyman, 2018).

Care-receivers were also affected by needing more support from partners, which resulted in them feeling anxiety, guilt, and shame; therapeutic interventions which empower them to support and regulate their own emotional wellbeing may be helpful here. Increasing self-efficacy may enable them to avoid feeling that they need to rely on partners, enabling couples to work together to support mental health.

Limitations and future research

This study was the first known qualitative study to explore caregiving in the context of mental health problems among older adults. A strength of this research is that it involved caregivers *and* receivers, acknowledging that caregiving relationships are made up of two people and that both perspectives are important (Lyons, 2002). However, this study did not interview dyads together and largely focused on experiences individually. Future research could consider interviewing dyads together and linking their experiences to consider how they converge and diverge. It would be important to further consider the ethical issues around interviewing couples separately, where they reveal hidden truths, regarding how data can be presented at the dyad-level in ways that also protects the anonymity and avoid potential harm.

This study focused on older adults who were experiencing significant mental health problems for the first time in later life and did not include those who had had enduring mental health problems throughout their lives. Further research could explore how caregiving within couples made sense of experiences in these contexts. There were also a range of mental health difficulties encountered – anxiety, depression, bipolar disorder, and psychosis. It may be the case that different mental health difficulties present different challenges to caregivers and care-receivers. Future research could also usefully explore this issue further.

Participants were recruited from a secondary community mental health service. This excludes older adults who do not access services: many people who are older (Reynolds et al., 2020) and from minoritised groups in respect to race, ethnicity, gender, and sexuality, experience greater barriers to accessing mental health services (Solway, 2010). All

participants in this study were white, in heterosexual married relationships, and spoke English. Further research including people from diverse backgrounds could help to provide more socio-culturally-attuned perspectives on caregiving among older adult couples with mental health problems.

A prominent finding in this study was the importance of the pre-existing relationship, which in most cases had been presented as positive and stable. It must be acknowledged that partners can sometimes be called upon to provide care in relationships that are less cohesive, more fractious, and in which there are longstanding tensions. There are also instances in which partners decide that they do not want to, or feel able to, provide care. This study was not able to reflect on how the emergence of mental health difficulties would be experienced in these relationships, which may be important to understand.

Future research could usefully explore mental health caregiving for older adult dyads in relation to gender differences, age differences, and within other family networks, such as with adult children, and with non-married couples. This study has provided a useful starting point from which greater knowledge and understanding can grow.

Summary

Couples who encountered significant mental health problems for the first-time in later life navigated this experience in relation to their existing 'real and genuine relationships' (Lawn & McMahon, 2014). They made sense of how 'caring' became part of their interactions and what this meant in the context of established relationships. A new caring context impacted on how care-receivers perceived themselves and how caregivers perceived their partners; with mental health stigma and ageism permeating these perceptions. Couples worked to sustain 'selves' and couplehood with on-going changes. There was uncertainty in caring for mental health problems with no perceived 'roadmap' for how to provide support. This study emphasises the importance of mental health services 'seeing' the person with mental health problems and honouring identities as well as

designing and delivering services that provide a supportive function for caregivers as well as care-receivers.

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Appendices

Appendix 1: Participant Information Sheet



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PARTICIPANT INFORMATION SHEET

Research Study Title: Couples lived experiences of mental health caregiving and care-receiving in later life

Research Team

Rachel Woodbridge, Trainee Clinical Psychologist

Dr Lucy Piggan, Clinical Psychologist

Dr Mike Jackson, Research Director at North Wales Clinical Psychology Programme

I (Rachel) am a Trainee Clinical Psychologist. I am undertaking a research study as part of my doctoral training at Bangor University. The study focuses on couples' experiences of giving and receiving support or care when one member of the couple is being seen in secondary care mental health services for the first time in later life (over 65 years of age).

I would like to invite you and your partner to take part in this research study.

Before you decide if you would like to take part, it is important for you to understand why this research is being done and what it would involve for you. Please read the following information carefully and take as much time as you need to consider it. You are also welcome to share this information with anyone else who might help you to reach a decision (e.g. family or friends). However, it is up to you to decide whether or not you would like to take part. You can contact us if there is anything that is not clear, or if you would like further information.

What is the purpose of the study?

The purpose of the study is to try to better understand the experiences of couples over 65 years of age, when one member of the couple has mental health problems.

The study focus is on 'caring' (caregiving and care-receiving) or 'support' meaning both the practical and emotional support you or your partner provides when living with mental health problems.

This will be done by asking you questions about your experiences of care or support and listening to your thoughts, feelings, and reflections. **You and your partner would be interviewed individually in two separate interviews.** No previous studies have looked at the experiences of caring from the perspective of older people (over 65 years) with mental health problems. We hope that this research will help a range of people – from healthcare professionals to policy makers - better understand these caring experiences.

The project is being supervised by Dr Lucy Piggin (Clinical Psychologist) and Dr Mike Jackson (Research Director in the North Wales Clinical Psychology Programme). The study is sponsored by the School of Human and Behavioural Sciences at Bangor University.

Why have I been invited?

You have been invited because you – or your partner – are currently being supported by an Older Person's Community Mental Health Team (OPCMHT) in Betsi Cadwaladr University Health Board (BCUHB). Specifically, you – or your partner – have been accepted into a secondary care mental health service for the first time as an older adult (over the age of 65 years). We are seeking couples to take part in this study.

Although all information about the study is available in Welsh and English, we are, unfortunately, only able to conduct interviews in English. This is due to the lead researcher (Rachel Woodbridge) only speaking beginners level Welsh.

What would taking part involve?

If you and your partner agree to participate in this study, you will each be asked to take part in a single, separate interview. You will be offered a choice of being interviewed face-to-face, over the telephone, or via video conferencing depending on your preference. The interview will be organised at a time and date convenient to you, within the researcher's availability. It is important that you have a private, quiet space to complete the interview in. You may find that being interviewed at home is most suitable, however, if you feel that you would be more comfortable in a hospital clinic room, this could be arranged. You will be asked to sign a consent form if you decide to take part.

We will interview you and your partner individually. We estimate that each interview will last around 1-2 hours. You will be asked to fill out a form with some basic demographic questions to begin with. The interview will then be semi-structured which means that the researcher will ask you some questions about your experiences of caregiving or care-receiving but you will have space to talk in-depth about what you think is most relevant and important. You do not have to answer any questions you don't want to or share any information you are not comfortable sharing. You are welcome to have breaks during the interview. The interviews will be audio recorded to allow the researchers to listen to it later and identify the key points you have made.

You can withdraw from this study at any time until the research is written up, without giving a reason. Your care or support from any services would not be affected by your decision about whether to take part in this study or if you decide to withdraw.

If you are interested in taking part, please fill in the opt-in slip at the end of this sheet and return it to Rachel Woodbridge, lead researcher (contact details at the end of this sheet). Rachel will then telephone you to tell you more about the study, answer any questions you may have and make an appointment for an interview with you if you decide to take part. As this study is looking at the experiences of couples, both

members of the couple need to be willing to take part to participate in this study. Both you and your partner would be paid £20 each for taking part. Any travel expenses would also be reimbursed.

How will we use information about you?

Each interview will be strictly confidential. This means the researcher cannot talk to you about any information that your partner shared in their interview and will not share what you have talked about in your interview. The audio recordings will be written up in a word-by-word account (a 'transcript'). During this process the researcher will take out any identifying information, such as your name and personal information. Each participant will be given a fake name (pseudonym) and a unique number that will be used in the write up.

The audio recordings will be destroyed immediately after they have been written up in an anonymised transcript.

After transcribing all the interviews, we will summarise into 'themes' to describe your experiences of care-giving and care-receiving or support in the context of mental health problems. We will use direct quotes (i.e. things that people have said in the interviews) to illustrate these themes and we may use your words for this purpose. However, we will follow strict guidelines to ensure that it is not possible to identify you through your words; we will not include any names or personal details, and will replace specific terms with more general ones to ensure your anonymity. We will also only use your quotes to illustrate themes by groups of caregivers and care-receivers and will not link your quotes or pseudonym to your partners quotes or pseudonym. This is to protect you and your partner from identifying each other's quotes to ensure your information remains confidential.

Electronic data such as interview transcripts will be stored securely on an NHS secure computer which can only be accessed by the lead researcher and research supervisor. Signed consent forms with your details on will be kept at the Older Adult

Community Mental health service in XX where they will be kept locked away safely. Interview transcripts will be stored securely on the research supervisors NHS system and all study information will be destroyed after 10 years.

The results of this study may be published in academic journals, conference proceedings and as a piece of work for a doctoral qualification in Clinical Psychology. Any published information will also be anonymised, in line with the Data Protection Act (2018). Some direct quotes from your interview may be included in these reports/publications, however all information will be anonymised and it will not be possible to personally identify you from this information. The results of the study will be shared with Older Adult Community Mental Health teams across North Wales and may be used to inform the development of services. We would be happy to provide a written summary of our main findings if you would like this, once the study is complete.

If, during the interview, you say something which makes us concerned about your safety or the safety of others, we may have to break confidentiality and share this information with other people, in line with our duty of care. We would make all efforts to discuss this with you beforehand if we did think we needed to share any information with anyone.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason. Should you wish to withdraw we will discard any information that we have about you and we will not include these details in the analysis and write up.

Where can you find out more about how your information is used?

You can ask one of the research team (contact details below) any further questions or clarification about how your information is used.

What are the possible benefits of taking part?

It is hoped that you would benefit from having the opportunity to talk about your experiences. You will also contribute to research in this area which may help people and professionals such as clinicians, researchers and policy makers to understand experiences of caring among couples in the context of mental health problems. Your participation has the potential to benefit people in the future by helping us to understand informal caring experiences.

What are the possible disadvantages and risks of taking part?

There is a risk that talking about experiences of giving or receiving care or support may be personally distressing. Whether you are taking part remotely or in person, should you become upset during the interview you will be offered the following:

- You can stop the interview should you wish to at any time.
- You can take a break or decide not to continue with the study.
- You can also choose not to answer any of the questions you are asked.

You would also be given opportunity to talk to Rachel about how you are feeling; she is a trainee clinical psychologist and may advise you on ways to manage difficult emotions. There is also a list of helpful contacts provided at the end of this participant information sheet; you can get in touch with these contacts freely for further support. We would suggest contacting your care co-ordinator (e.g. your community nurse) in the first instance should you feel upset or distressed following the interview.

Additional information

The findings of this research study will be written up in a thesis as part of Rachel Woodbridge's Doctorate in Clinical Psychology course, which will be finalised in June 2022. It is also possible that in the future they will be included in a research paper for publication and/or presented at a conference.

The project has been ethically approved by Bangor University School of Ethics and by the NHS research ethics committee.

If you have any concerns regarding any aspect of the research process you can contact me directly. Additionally, if you would like to make a formal complaint at any point you can contact my research supervisor (please see below for contact details).

The project is organised and funded by the North Wales Clinical Psychology Programme, at Bangor University, in partnership with Betsi Cadwaladr University Health Board.

If you have any concerns about this study, please contact a member of the research team (contact details at the end of this information sheet).

If you are still not happy and would like to raise a formal complaint about any aspect of the study, including the way that you have been approached or treated during the course of the study, you can do this by contacting Huw Roberts, who is the Bangor University contact for complaints regarding research. His contact details are as follows:

Huw Roberts, School of Human and Behavioural Sciences Manager,
School of Human and Behavioural Sciences,
Brigantia Building,
Penrallt Road,
Bangor,
Gwynedd,
LL57 2DG.

Telephone: 01248 383229

Email: huw.roberts@bangor.ac.uk

You can also contact staff at the North Wales Clinical Psychology Programme (NWCPP) directly. Their contact details can be found at the end of this information sheet.

You can also contact the Patient Advice and Liaison Support Officers (PALS) located in Betsi Cadwaladr University Health Board (BCUHB). They are independent from the research team. Their contact details are:

Telephone: 03000851234

Email: BCU.PALS@wales.nhs.uk

What next?

If you and your partner decide that you would like to take part in this study, please each return the 'Research Opt-in Slip' that accompanies this sheet. A pre-paid envelope is provided so that you can either post this to us or hand it to staff in the community mental health team - they will ensure it reaches us. **Alternatively, you can contact Rachel Woodbridge using the contact details below.** If you opt-in to the study, we will contact you and your partner directly using the contact details you have provided.

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

Further information and contact details

If you have any further questions or wish to take part, **please contact Rachel Woodbridge by email: rcw19szc@bangor.ac.uk or call your community mental health team and ask Rachel to call you back.**

Lead researcher:

Rachel Woodbridge, Trainee Clinical Psychologist
North Wales Clinical Psychology Programme
Brigantia Building
Penrallt Road
Bangor
Gwynedd
LL57 2DG

Research supervisor:

Dr Lucy Piggin, Clinical Psychologist
Older Person's CMHT
Wepre House
Wepre Drive
Connah's Quay
Deeside
CH5 4HA

Academic supervisor:

Dr Mike Jackson, Research Director
North Wales Clinical Psychology Programme
Brigantia Building
Penrallt Road
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LL57 2DG

Appendix 2: Opt-in slip



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Research Opt-In Slip

Couples lived experiences of mental health caregiving and care-receiving in later life

Thank you for reading the information sheet and completing this opt-in slip. Returning this slip indicates that you and your partner are interested in taking part in the research. Please include both of your details in this form. We would like to remind you that you can still change your mind about taking part at any time.

We have read the information sheet and have decided that we are interested in taking part in this research study.

Me/Partner details

My name is: _____

Signed: _____

Telephone:  _____

Preferred days/times to be contacted: _____

My first language is: English ☐ Welsh ☐

Me/Partner details

My name is: _____

Signed: _____

Telephone:  _____

Preferred days/times to be contacted: _____

My first language is: English ☐ Welsh ☐

(Please note that all interviews will be conducted in English).

Thank you/Diolch!

Appendix 3: Interview Schedules

Interview Schedule for person with mental health problems

Thank you for taking part in this interview. The purpose of the interview is to explore with you your experiences of having mental health problems and specifically about your experiences of receiving support from your partner.

1. Can you tell me about the nature of the mental health difficulties you have been experiencing and how that has impacted on your lives
Possible prompts: daily functioning, social relationships, self and identity, at this time in life
2. Can you tell me whether these problems have affected your relationship and in what ways?
3. Can you tell me about the support you have received from services?
Possible prompts: CMHT, care co-ordinator, financial, social services, positive and negative aspects of this support
4. Could you tell me about the ways in which your partner supports you?
Possible prompts: emotionally, physically, socially
5. How has this been to receive support from your partner in this way?
Possible prompts: for you, for them, at this time in life, positive/negative aspects
6. What does it mean to you/your relationship that your partner provides this support?
Possible prompts: feelings about the word 'carer' and do you perceive them as a carer to you, how has it affected your relationship/ roles, at this time in life
7. Is there anything that you would like to say more about or that I haven't asked you that you would like to talk about?

Interview Schedule for partner of person with mental health problems

Thank you for taking part in this interview. The purpose of the interview is to explore with you your experiences of having a partner with mental health problems and specifically about your experiences of providing support for your partner.

1. Can you tell me about the nature of the mental health difficulties that your partner has been experiencing and how that has impacted on your lives?

Possible prompts: daily functioning, social relationships, self and identity, at this time in life

2. Can you tell me whether these problems have affected your relationship and in what ways?

3. Can you tell me about the support you/ your partner has received from services?

Possible prompts: CMHT, care co-ordinator, financial, social services, positive and negative aspects of this support

4. Could you tell me about the ways in which you support your partner?

Possible prompts: emotionally, physically, socially

5. How has this been to provide support for your partner in this way?

Possible prompts: for you, for them, at this time in life, positive/negative aspects

6. What does it mean to you/your relationship that you provide this support?

Possible prompts: feelings about the word 'carer' and do you perceive yourself as a carer, how has it affected your relationship/ roles, at this time in life

7. Is there anything that you would like to say more about or that I haven't asked you that you would like to talk about?

Appendix 4: Examples of analysis process

Initial codes and emergent themes in extract from interview transcript

Emergent themes	Paula, Care-receiver, 01.17	Initial notes
	I: the purpose is to explore your experiences of having mental health problems and specifically about the experiences of receiving any support from your partner, so if you could tell me about the nature of the mental health problems and how it's impacted on your and Paul's lives	
Making sense of onset	P: ok erm well it started erm I had, well they said I had a psychotic episode and I don't know... I can, I've talked with Paul and then it brings things up and I remember things that have happened but I'd lost erm, I feel like, I feel like, my brain just exploded and it went into millions of pieces and it's all, it's all, it's not me, it wasn't me and I've been through so much, absolutely so much, and I've always been really <u>really</u> strong, always, I've been really <u>really</u> incredibly strong all my life and got through so much, and achieved so much and then this happened to me	'they said I had' a psychotic episode, unsure about this Forgetting psychotic episode
Loss of self		'my brain just exploded', not them
Extent of mental health problems		'It wasn't me' not connecting self with this time
Separating self from mental health breakdown		Really strong person vs. mental health breakdown, stigma
Seeing mental health problem as 'weakness'		
Shock of onset of mental health problems due to being a strong person	I: yes <u>so</u> it's a surprise it happened to you	
	P: yes, absolutely, it's such a shock, because never ever did I think that anything like this would happen to me, out of all the family, out of, I've always been strong, even though Paul is really <u>really</u> strong in character he's, he's very forceful, he's very powerful, I've always been the peacemaker, always been... but I feel I was always the strongest really because I was the one to, I was always the one to carry on calm... but we've been good together but I've always, I always feel like it's cos of my strength and understanding of people that I was able, able to make things calm again and calm things down, cos Paul and Harriet were always head to head you know	Shock of having mental health breakdown Shock that it happened to them as opposed to someone else in the family Strongest person in the family= shock it happened to them <u>Usually</u> one to be calm in family
Shock of onset of mental health problems due to being a strong person		
Seeing self as strong person in relation to others in the family, unable to make sense of why them		

Example superordinate themes for one participant

LB, carer

IDENTITIES/LOSS

Loss of who they were

Loss of partner
Contrasting partner with 'normal' behaviour
Contrast with partner participation before and now x4
Partner retreating from hobbies used to enjoy
Personality roles of each of them before vs. now
Talking about who partner was before this happened x3
Lost life narrative x2
Difficulty seeing that they've changed|

Loss of shared life together

Loss of activities used to enjoy just incase something happens x2
Loss of things used to enjoy together
Upset of loss of life thought would have at this time
Relationship has changed x2

Vs. sharing relationship moments together

Trying to laugh with partner as they used to with them

Shared impact of MH problems

Partner's cancelling finances so carer unable to access money, shared impact of MH problems

Long marriage to get through this

Due to length of marriage hasn't ruined that

Extension of previous roles

Extension of previous roles

Example grouping superordinate themes for caregiver group

List of themes for caregivers

RELATIONSHIPS

Identities

Enduring

- Lasting relationship to endure mental health problems
- Importance of sharing who they were as couple
- Importance of sharing who partner was
- Not wanting to give up on relationship
- Duty to care for one another
- Loyalty to them
- Extension of who we were
- Valuing doing 'normal' relationship activities together
- Relationship has not changed
- Oneness
- Home as safe base
- Grateful for times had with partner

Changed /threatened

- Loss of who partner was
- Partner lost life narrative
- Mental health problems becoming priority
- Partner vs. ~~carer~~
- Partner as selfish
- ~~Attributing~~ problems to partner
- Threat to identity of partner as strong
- I'm a ~~carer~~ (alone) not partner (together)
- Not getting anything out of relationship
- Loss of belongingness in own space
- Mental health problems as sign of weakness
- Stigma of ageing image
- Partner offended at idea of needing support
- Partner 'not normal' anymore
- Partner lost sense of who they were

Protecting identities

- Making sense of onset of mental health problems
- Not wanting caring to be acknowledged as highlights this new role identity
- Both trying their best
- Attributing to mental health problems to protect relationship
- Shared decision making
- Holding onto times partner treated them well
- I'm a caring person
- Loyalty to one another, not talking about them
- Putting boundaries in with how treated
- Not sharing with wider family how partner treats them to protect image of couple
- Partner not belonging in group with others with mental health problems

Chapter Three

Contributions to Theory and Clinical Practice

Contributions to Theory and Clinical Practice

This research project sought to understand experiences of mental health problems among older adults. The first chapter consists of a narrative review of the literature around older adult public- and self-stigma towards mental health problems. The second chapter consists of a qualitative empirical study to understand experiences of caregiving within older adult couples when living with mental health problems. This chapter considers the contributions of the literature review and empirical study as they relate to theory and clinical practice.

Implications for future research and theory development

The systematic review was the first known narrative synthesis of mental health stigma research with older adults. Although there were limited studies on self-stigma, the available evidence supported the self-stigma formation model (Corrigan et al., 2006), which suggests that older adults with mental health problems move sequentially through stages of (1) being *aware* of stereotypes about mental health problems, (2) *endorsing* the same stereotypes, and (3) *concurring* with stereotypes and internalising them in relation to the self. Concurring with stereotypes affected self-esteem and self-efficacy of older people with mental health problems. This suggests public mental health stigma permeates self-experiences of mental health problems among older adults and affects concepts of self. However, only one study explored the self-stigma formation process among older adults. There is a need for further research to examine this process cross-culturally and to further understand how other stigmatised attributes, such as age and minoritisation, may affect self-stigma formation in mental health.

In the empirical study on caregiving and care-receiving, the identities of older couples – both individual and shared – appeared threatened by the onset of mental health difficulties. There was evidence to suggest that mental health stigma (public and self) influenced how

participants viewed themselves. The intersectionality framework (Crenshaw, 1989) can support understanding here; it suggests that mental health stigma interacts with ageism, affecting how older adults understand the onset of mental health problems alongside being older. In the systematic review, it appeared that public mental health stigma also interacted with race and/or ethnicity, with mental health stigma seemingly socio-culturally defined. These intersecting layers of different forms of oppression and stigmatisation relate to unique experiences of being ‘othered’ and ‘othering’ when living with mental health problems and being older (Collins, 1986).

A limitation of the empirical study was that the sample was not culturally diverse, highlighting the need for further qualitative research to understand stigma processes within couples living with mental health problems across cultures. In both papers, stereotypical beliefs, such as *‘mental health problems are a sign of weakness’*, and emotional reactions, such as embarrassment and shame, related to concealment of mental health problems. It may be helpful to consider this within Corrigan et al.’s (2005) model of mental health public and self-stigma occurring at three interconnected levels of: (1) *stereotypes* or negative beliefs, (2) *prejudice* or emotional reactions relating to negative beliefs, and (3) *discrimination* or behavioural manifestations of prejudice. Further research could examine *how* these levels of public and self-stigma intersect among older adults. There is also a need for more research on emotional reactions related to mental health problems among older adults, which may be supported by research methods that seek to capture implicit emotional processing as opposed to self-report methods.

Concealment has been suggested by Goffman (1963) as a way of managing ‘spoiled identities’, suggesting people with concealable stigmatising attributes, such as mental health problems, escape considerable prejudice and discrimination by hiding these attributes. Pachankis (2007) expands on Goffman’s (1963) notions, recognising that there may be considerable stressors when concealing a stigmatising attribute. Pachankis proposed a model describing the psychological consequences of this type of concealment: in this cognitive-affective-behavioural process model, he suggests that features of situations, such

as the salience of stigma and the threat of discovery, activate cognitive and affective responses, such as preoccupation, vigilance, guilt, shame, anxiety, and depression. This then triggers behavioural reactions, such as social avoidance and isolation, which increases the importance of feedback and impairs close relationship functioning. This appears relevant to the empirical study, wherein mental health problems were perceived to come between couples partly due to concealment and a sense of separateness in experiences due to hidden attributes. Participants with mental health problems also evaluated themselves in relation to feedback from partners and others, for example, some people saw themselves as 'lazy', 'a burden' and being 'tolerated'. Caregivers also saw themselves as having a key role in supporting the social identity of their partners. Pachankis suggests that people may experience a detachment from their true self as a result of concealment; another feature of experience within the empirical study, where care-receivers experienced loss in respect to sense of self. In the literature review, more severe mental health symptoms were related to increased mental health stigma, which may be related to the affective implications proposed in Pachankis' model (e.g., anxiety and depression). Further qualitative research that focuses on stigma could be useful to better understand processes of concealment and the psychological impact this has among older adults.

The empirical study identified the importance of 'relationships' when adjusting to caregiving within the context of mental health problems. These findings are supported by Lawn and McMahon's (2014) *relationship theory*, which found 'real and genuine' relationships to be central to caregiving/care-receiving experiences when living with mental health problems, with caregivers often distancing themselves from the term 'carer' because it threatened other roles, such as wife, husband, friend, or partner. *Positioning theory* (Harré, 2012) may also support understanding of how couples made sense of the term 'carer'. Where *role theory* suggests that roles are relatively fixed, normative, and socio-culturally defined (Jackson, 1998), *positioning theory*, as an individual cognitive model, suggests a more fluid, situational view of roles, which individuals continually construct through language and interactions with others. In the empirical study, participants were actively making sense

of the role of 'carer' within interviews, exploring how this complemented or undermined other roles (e.g., husband, wife, or partner). The carer identity appeared to be a 'cognitive construction' that served as an *"interpretive frame and sets of standards used by individuals to make sense of personal experiences, actions, and emotions"* (Funk, 2019) (p. 14). For some, the word 'carer' contradicted spousal roles, whilst for others being a 'carer' was part of *being* a couple. Future longitudinal research could look at how older couples living with mental health problems make sense of caring relationships over time.

Identity theory, focusing on the roles people occupy as the basis for identities, may also support understanding of how couples made sense of caregiving roles in their relationships (Stryker & Burke, 2000; Hughes, Locock & Ziebland, 2013). In a study by Hughes et al. (2013), this theory was used to understand how some partners of people with multiple sclerosis described themselves engaging in caregiving acts but situated this behaviour in a role identity that was different from 'carer'. They discussed the use of 'therapeutic plotlines', whereby some caregivers emphasised the marital identity, stressing the things partners could do for themselves and underplaying situations of dependency, so as to preserve a 'persistent present' identity. This observation seems to mirror reflections from the empirical study, where couples worked to preserve identities of both the couple and the person with mental health problems. This theory may be particularly relevant to older adults who were experiencing significant mental health problems for the first time in later life, which may have challenged a well-established, life-long, view of the self. Future research to focus specifically on the role of 'carer' and what this label means among a larger sample of older adults with mental health problems would be useful to understand these role identities further.

Implications for clinical practice

The literature review identified public stigma among some older adults towards mental health problems and self-stigma within populations of older adults with mental health

problems. Public stigma reduction campaigns may be important to support more accurate awareness of mental health problems and to increase mental health literacy among older adults. A common social misconception was of people with mental health problems being 'dangerous', which may be related to sensationalised media representations of people with mental health problems as 'violent' or 'unpredictable'. Mental health professionals also have a role in educating the public about mental health problems, to ensure more accurate conceptions.

Common stereotypes which interact with ageism, such as depression being a '*normal part of ageing*', should also be considered among mental health professionals specialising in working with older people. For example, should older adults dismiss symptoms of depression, it may be important to further explore their reasoning and offer education about rates of depression in older age, as well as availability of evidence-based treatments. It is also important for mental health professionals to consider their own biases and how they influence their understanding of mental health problems among older adults, as well as the treatment options they consider with older people (Murray et al., 2006). There was some evidence of higher stigma among older men and older people from minoritised and Eastern cultures. Therefore, there may be a need for targeted public health interventions which address stigma within specific groups of older adults and that consider views within these groups, such as how traditional masculinity may affect conceptions of mental health problems. Primary care mental health services and access points should also be culturally attuned and aware of mental health stigma as a potential barrier to help-seeking or offering treatments. Mental health stigma appears to correlate with more severe mental health symptoms, impacting on self-esteem, therefore assessments to identify mental health stigma (and therapeutic interventions to target stigma) may be useful for some older adults with high internalised self-stigma. One example of an intervention is 'peer educators', where older adults with depression can be given contact with an older adult who had recently recovered, matched on gender and race. In the systematic review, there was evidence that this was an effective and feasible intervention to reduce self-stigma (Conner et al., 2015).

Findings from the empirical study indicate that participants wanted to be understood and for their long-standing relationships to be acknowledged (Lawn & McMahon, 2014). It is important for mental health professionals to consider engaging and working with couples and individuals and to provide truly person-centred services. Worryingly, some participants felt that they were stigmatised within mental health services for their age and/or mental health problems and thus it is important that services and teams who specialise in older adult care develop knowledge and expertise to avoid discrimination (Royal College of Psychiatrists, 2018). Specific training in humanistic and person-centred approaches may be useful for mental health staff.

In recent years, health and social care policies have increasingly promoted carer self-identification as the best way to target and support people in caring roles (Morgan et al., 2021). However, many partners of older adults with mental health problems did not identify as carers and some explicitly rejected this identity despite undertaking caregiving tasks. It is important that couple's support needs are met irrespective of whether either member of a dyad identifies caregivers as a carer and for health professionals not to impose this label on people but to use the language the dyad uses for the caregiving relationship.

In the empirical study, partners of people with mental health problems provided significant support for their partners and often perceived themselves to be doing this alone. The Strategy for Older People in Wales (Welsh Government, 2013) recognises that informal caregiving can have a detrimental impact on the physical, emotional, and mental health of older carers in particular; it also highlights the importance of having access to information at the right time, alongside opportunities for social participation. Many caregivers in the empirical study did not feel that they were given support or understanding about their partner's mental health problem. Furthermore, caring in the context of mental health problems appeared unique; situations were dynamic and individual experiences varied. It may be important that informal caregivers are given tailored information from healthcare professionals on how to support their partners with the specific mental health problems they

are living with and that couples are offered systemic interventions together to support mental health problems, where this is appropriate.

In the empirical study, most mental health services were experienced as not adequately meeting people's needs; most older adults were not engaged in any therapeutic interventions aside from medication. The effectiveness of psychological (and pharmacological) treatments for older people are well known, yet frequently not provided (Saunders et al., 2021). Nationally, older people's services may be underfunded by as much as £2.3 billion compared with services for younger adults (Royal College of Psychiatrists, 2013). Bucci et al. (2015) discusses the importance of mental health services meeting people's attachment needs through being a secure base, for example, providing at least one stable relationship with a staff member, providing continuity in care, availability, and flexibility. However, most older adults who took part in this study spoke of feeling abandoned by services. Partners were often seen as the secure base, yet partners were also feeling uncontained in these roles due to not receiving adequate support. There is a case to be made for more funding and resources for services to provide good quality, holistic, person-centred care for older people with mental health problems.

Personal reflections

The assessment of quality in interpretive qualitative research requires researchers to position themselves in relation to their work, so that readers can more fully interpret the research process, particularly as the researcher's perspective plays a crucial role in analysis and interpretation (Finlay, 2002). A 'sensitivity to context' is important when assessing the quality of research, which includes an awareness of the socio-cultural context (Yardley, 2000)

Interviews took place when social distancing measures were still in place and after a period of two years of numerous lockdowns in the UK due to the COVID-19 pandemic. Some of the couples who were interviewed had been shielding due to ill health and thus had

endured long periods of social isolation. The sense of aloneness and loneliness, which was shared in interviews, may be particularly relevant to this specific point in time (e.g., Bailey et al., 2021). Experiences of older adult mental health care service delivery may also have been affected by the pandemic (Bhome et al., 2021). Furthermore, following social distancing measures, interviews were conducted two meters apart, with both interviewer and interviewees wearing masks, which may have affected rapport-building with participants. However, as a trainee clinical psychologist working within the pandemic, I have developed skills in building relationships people with these measures in place.

It is acknowledged that the empirical study lacked cultural diversity as all participants were White-British/Welsh and first-language English speaking. I unfortunately only speak beginner-level Welsh and thus was unable to offer potential participants interviews in Welsh, which may have precluded some Welsh voices in the study. This is problematic as it complicitly perpetuates a system of not meeting basic Welsh language needs (Welsh Government, 2019); therefore, more research is needed to offer interviews through the medium of Welsh. More generally, understanding caregiving among older adults living with mental health problems from various cultural backgrounds would help to identify culturally distinct aspects of experience, which may support mental health services to become more culturally attuned.

Labels of being 'older' were placed on participants both by the mental health services they were recruited from (*Older Adult Mental Health service*) and in the participant information sheets for this study - recruiting people over 65 years of age in 'later life'. Some of the participants were three decades apart in age, belonging to different generations (cohorts), and did not necessarily perceive themselves as fitting into this category. Labelling 'older people' in research as over a certain age can be problematic, as experiences of 'being old' are subjective and can include a wide age range of people (Degnen, 2007). It is important to consider how participants may have experienced this labelling, how it may have impacted on the power differential in services as well as in this research, and how this may have created a distance from being interviewed by a categorically 'younger' person.

Age-based interview dynamics are important to consider where ‘older’ people are being interviewed by a ‘younger’ trainee psychologist in their early 30s. Partly, I felt that my being positioned as ‘young’ in the interviews supported power relations, as interviewees could educate me on their experiences from a position in which they were older and more experienced. This has been described elsewhere by a younger researcher interviewing older people, where they felt they were “*eagerly listening to a teacher who would educate me on their experience*” (p. 993, Jen, Zhou, & Jeong, 2020). Cross-generational interviewing carries potential for connection and learning and participants in this study seemed keen to share their stories. I felt myself privileged to learn from their life experiences. As well as this, some interviewees at times positioned their stories in relation to how they perhaps perceived I was experiencing them as a ‘young’ person. For example, saying ‘this sounds silly’ when talking about the importance of everyday routines, such as watching TV together, perhaps thinking it sounded boring to someone younger who they supposed did ‘more exciting things’. Two of the interviewees brought up how mental health problems had affected their sex lives. Interestingly, this had not been a question or prompt I had considered asking in the interview schedules and this left me wondering why I had not considered asking this when discussing how mental health problems impacted relationships. Perhaps there was an ageist assumption that I was unaware I was carrying around older age intimacy or an assumption that older people would not be comfortable sharing this with me as a younger person, perhaps transferring views of the older people I knew (my grandparents) to these individuals, where my grandparents would think it was ‘very cheeky’ to ask. This is an issue I often consider on my clinical placement with older adults, where perhaps younger healthcare professionals do not ask about intimacy as much as we should, being an important aspect of romantic relationships at any age.

I approached the topic of caregiving among older adults with mental health problems largely naively, I had not personally experienced being an ‘older person’ nor been in a relationship for the length of time these couples had been together. I also have not personally experienced being a primary caregiver for a family member or experienced

significant mental health problems. I have professional experience in working with older adults as an assistant and trainee psychologist and previously conducting qualitative research for a PhD with older couples (living with dementia) in social gerontology (Woodbridge, 2018). I felt comfortable sitting with and exploring older adults' experiences given this prior experience of interviewing spousal older adult couples. It was also important for me to 'bracket off' assumptions about 'caregiving' given my previous experience of conducting research with spousal couples in relation to dementia and to focus upon these individual experiences in relation to *mental health* caregiving. It is important to acknowledge that the analysis is bound to interpretations influenced by my experiences and to make explicit that this will have impacted the analysis. During my PhD, I became interested in selfhood and how people made sense of identities when experiencing a life-changing condition and these have been important elements to the themes identified in this study. In-depth ideographic analysis before moving to the next case for each participant has been important in staying close to participant's own experiences, as well as research supervision to support self-awareness, bracketing, and reflexivity within the double hermeneutic stance in interpretative phenomenological analysis (Smith, Flowers & Larkin, 2009).

At times, I felt a conflict in my role as researcher and professional role as a trainee clinical psychologist. During the interview stage, I was also on placement within a different older adults' community mental health team as a trainee. It was difficult for me to step into the researcher role at times and not intervene or offer support during interviews. It was also important to focus on experiences, rather than developing individual psychological formulations and thinking about how to support them psychologically. It was important for me to bracket these elements of my clinical role and stay close to people's stories. There were also advantages to being a trainee clinical psychologist, for example, qualitative interviewing includes using skills such as validating experiences, a sensitivity and person-centred approach, and putting participants at ease (Smith, Flowers & Larkin, 2009), which are skills I have developed during my clinical training. I could also provide containing endings to interviews and signposted people to other services if they required additional support. This

research has also helped me to develop in my role as a trainee clinical psychologist, I have come to recognise the importance of working systemically with couples and caring contexts and to consider in psychological formulations people's beliefs about what having '*mental health problems*' means and being sensitive to the potential role of mental health stigma.

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