

A systematic review and thematic synthesis of older adults' perceptions, beliefs and attitudes about depression and its treatment

Dr Pushpa Nair (PN)

Dr Cini Bhanu (CB)

Dr Rachael Frost (RF)

Dr Marta Buszewicz (MB)

Dr Kate Walters (KW)

*All authors are affiliated to the Department of Primary Care and Population Health,
University College London, London, UK

Primary author for correspondence:

Pushpa Nair

Department of Primary Care and Population Health, UCL, Royal Free Campus,
Rowland Hill Street, London, NW3 2PF

pushpa.nair@nhs.net

Tel: 0207 830 2881

Funding

This work was supported by the National Institute of Health Research School for Primary Care Research.

Acknowledgements

PN was funded by the National Institute of Health Research School for Primary Care Research. This paper presents independent research and the views expressed are those of the author(s) and not necessarily those of the NIHR, the NHS or the Department of Health. Special thanks to the Royal Free Hospital Library staff for their assistance with database searches.

Abstract

Background and Objectives: Late-life depression is a major societal concern, but older adults' attitudes towards its treatment remain complex. We aimed to explore older adults' views regarding depression and its treatment.

Research Design and Methods: We undertook a systematic review and thematic synthesis of qualitative studies that explored the views of older community-dwelling adults with depression (not engaged in treatment), about depression and its treatment. We searched seven databases (inception-November 2018) and two reviewers independently quality-appraised studies using the CASP checklist.

Results: Out of 8351 records, we included 11 studies for thematic synthesis. Depression was viewed as a *normal* reaction to life stressors and ageing. Consequently, older adults preferred self-management strategies (e.g. socialising, prayer) that aligned with their lived experiences and self-image. Professional interventions (e.g. antidepressants, psychological therapies) were sometimes considered necessary for more severe depression, but participants had mixed views. Willingness to try treatments was based on a balance of different judgements, including perceptions about potential harm and attitudes based on trust, familiarity and past experiences. Societal and structural factors, including stigma, ethnicity and ageism, also influenced treatment attitudes.

Discussion and Implications: Supporting older adults to self-manage milder depressive symptoms may be more acceptable than professional interventions. Assisting older adults with accessing professional help for more severe symptoms might be better achieved by integrating access to help within familiar, convenient

locations to reduce stigma and increase accessibility. Discussing treatment choices using narratives that engage with older adults' lived experiences of depression may lead to greater acceptability and engagement.

Keywords: Qualitative research methods, Mental health (services, therapy), Analysis - Systematic Review, Depression

Background and Objectives

Late-life depression is a major societal concern, with depression forecast to be the leading cause of disease burden in developed countries by 2030 (Rodda, Walker & Carter, 2011). It affects, on average, 7% of 60+ year olds worldwide (WHO, 2017), and is associated with increased mortality, reduced quality of life, and cognitive and functional decline in 65+ year olds (Rodda et al, 2011). Depression in this age group is also harder to detect than in younger populations, often presenting with more somatic and atypical symptoms (Katona, 1994, Meeks, Vahia, Lavretsky, Kulkarni & Jeste, 2003). Whilst there is a decline in the prevalence of major depressive disorder with increasing age (Snowden, 2001), sub-threshold depressive symptoms have a higher prevalence of up to 31.1% in 65+ year olds, and are also associated with negative health parameters (Meeks et al, 2011, White et al, 2015), despite symptoms reportedly being less severe than for clinically significant depression (Ludvigsson, Milberg, Marcusson & Wressle, 2014).

The treatment of depression in later life is complex, reflecting the heterogeneity of older populations and the multiple factors involved in experiences of ageing and the development of depression. There is evidence that both antidepressants (Kok, Nolan & Heeran, 2012) and psychological therapies (Dakin & Areán, 2013, Gould, Coulson & Howard, 2012) are effective in the general older adult population, although antidepressants appear to be preferentially offered by health professionals (Walters, Falcaro, Freemantle, King & Ben-Shlomo, 2017). Despite the fact that many older adults report a preference for psychosocial management strategies (Gum et al, 2006), there is in general poorer uptake of all mental health services amongst older adults. Up to 70% of older adults with mood disorders in the USA do not access mental health services, especially those from ethnic minority and lower socioeconomic status groups (Byers, Arean & Yaffe, 2012), and in the UK, access to

Increasing Access to Psychological Therapies services for 65+ year olds is only 5.2% - half as much as for those under 65 (Department of Health, 2013).

There is evidence that many older adults view depression as a normal part of ageing (Barg et al, 2006, Burroughs et al, 2006) and are also more likely to engage with social explanatory models of depression (Givens et al, 2006); hence formal treatments (e.g. antidepressants, psychological therapies) may not be congruent with patient beliefs. Furthermore, alternative cultural models of depression may co-exist at local levels (Holm & Severinsson, 2013, Karasz, 2005). Qualitative research **can offer rich insights** into how beliefs influence attitudes towards treatments.

Two previous meta-syntheses of qualitative studies exploring older adults' beliefs and attitudes towards depression in later-life (Corcoran et al, 2013, Holm & Severinsson, 2013) noted that depression was attributed to a range of causes, encompassing functional decline, social factors and bereavement, and was associated with stigma. Older adults reported engaging with various treatment strategies, including religion, social activities and medical treatments. These meta-syntheses have focussed on older adults' *beliefs* about the nature of depression, and our meta-synthesis aimed to build on this to further understand how these beliefs influenced attitudes toward the *treatment* of depression in later life.

Research Design and Methods

We used a thematic synthesis approach, as outlined by Thomas & Harden (2008), which is a rigorous method for integrating and analysing qualitative data. Text from primary studies is coded line-by-line and used to develop descriptive themes, from which analytical themes that aim to 'go beyond' the primary data are then generated

(Thomas & Harden, 2008). We used this approach as it preserves and demonstrates connections between the analysis and primary data. (PROSPERO ID 42017067364).

Searches

We searched Ovid MEDLINE, EMBASE, PsychINFO, CINAHL, Web of Science, ASSIA and grey literature from PsychExtra, from inception to November 2018 (see Appendix 1 for search terms). We did not limit our searches by publication date, which ranged from 1887 to 2018 (inception dates differed according to database). We also carried out citation index tracking using Scopus and hand-searched reference lists of all full-text shortlisted papers and of previous relevant systematic reviews.

Eligibility

Inclusion criteria: Studies of community-dwelling older adults (mean age 65+) with current/recent experiences of depression (diagnosed/self-reported/screened positive), using qualitative methods and reporting views about the treatment of late-life depression. We included qualitative components from mixed methods studies and had no date, country or language restrictions. We excluded studies: reporting younger people's views (participants' mean age <65 years) or depression across all age groups; samples containing depressed and non-depressed people where the results were not reported separately; studies of others' views (e.g. healthcare professionals, carers); studies focused on psychotic mental health disorders; quantitative or non-empirical papers; **studies of older adults who were explicitly reported to be engaged in ongoing mental health treatments** (e.g. psychological therapies, antidepressants or intervention trials), as it was felt that the views of depressed older adults in these studies would be different to a non-clinical sample. There is low uptake of mental health services amongst the general older adult

population and evidence that treatments are not adequately tailored to this population; hence we felt it was important to focus on papers sampling older adults who were depressed, but had reasons for not currently seeking treatment.

One reviewer (PN) assessed all titles and abstracts, with 10% screened independently by a second reviewer (CB). Due to the large volume of texts retrieved, two-thirds were screened by the first reviewer and one-third by the second reviewer, with a 10% overlap. This was an iterative process, whereby all full-text papers were discussed, and studies that were deemed a 'yes' or a 'maybe' were reviewed fully by both reviewers. There was 84% concordance at this stage and disagreements were resolved through discussion with other members of the team (KW, MB, RF).

Data extraction and synthesis

We extracted data relating to study aims, location, demographics, data collection, analysis, main findings and author implications. Two reviewers independently assessed study quality using the Critical Appraisal Skills Programme checklist (2010) and made an overall judgement of quality. We did not exclude studies or weight findings within the synthesis on the basis of quality, as the role and reliability of quality assessment within qualitative systematic reviews is somewhat debated due to its subjective and reductionist nature, with generalizability and transferability of findings often highly dependent on the context in which they are reported (Dixon-Woods, 2004). However, we decided to include quality appraisal of the studies in Appendix 2 to provide an overall indication of the quality of the current evidence base, and to demonstrate that included studies met basic quality requirements.

To conduct thematic synthesis, text from the results/findings sections of included studies was coded line-by-line by the first reviewer using NVivo 11 software (QSR International, 2015) and organised under different categories, as outlined below. 25%

of papers were independently coded by the second reviewer to ensure consistency of emergent themes, with good agreement. Codes were organised under three main headings, which were inductively derived from the data – ‘Beliefs about depression’, ‘Beliefs about whether depression should be treated’ and ‘Attitudes to treatment options/preferences’. In total, there were 29 codes under these main headings, with more than 40 further sub-codes. The team met twice to discuss and refine codes. Codes were used to generate descriptive themes that were summarised and discussed by the whole team. Analytical themes were developed by the first reviewer in order to ‘go beyond’ the original data (Thomas & Harden, 2008) and these were discussed with all authors to reach consensus. The impact of demographic data, such as ethnicity and gender, was also compared within each theme. However, it was often not possible to differentiate the views of those who self-reported depressive symptoms from those with a formal diagnosis, and it was also sometimes not clear whether those who screened positive for depressive symptoms had a diagnosis. Also, it was generally not possible to differentiate (and therefore compare) the views of older adults who had previously been treated for depression and those that had not.

Results

(Figure 1 here)

(Table 1 here)

Description of included studies

Out of 8351 unique records, we screened 156 full-texts and included 11 studies in our qualitative synthesis (Figure 1) with a total of n=258 participants, and a

publication date range of 2002-2018. Studies encompassed both publicly funded and insurance-based healthcare systems, and a range of ethnicities, with a greater number of female participants (Table 1). Most studies contained a mix of ages (total age range 60-90+) and rarely distinguished between older-old (>80) and younger-old views (65-80). All studies were rated as acceptable or good according to the CASP criteria (Appendix 2).

Factors influencing attitudes towards the treatment of depression in later life

We identified a range of factors on an individual, societal and structural level that influenced older adults' attitudes towards the treatment of depression in later life; these are outlined in more detail below.

1. Individual factors

Explanatory models of depression

Explanatory models of depression appeared to influence whether older adults felt support was required. In particular, there was a dominance of social explanatory models of depression (e.g. depression viewed as a natural consequence of adverse psychosocial factors), which appeared to contribute to a reluctance across papers to access formal mental health services, as they were perceived to be less appropriate to the causes.

"We create our own depression...You say, oh, I'm depressed, let me go see the doctor. But some things you got to deal with. You know? From your inner self, you know?.....Don't look for the Doc to find out a remedy. You got to work one out within."
(Conner et al, 2010a, p. 271)

This was further highlighted in one study, where older adults were able to correctly identify the man in the vignette they were given as being depressed, but did not view his depression as a medical illness requiring treatment (Marwaha & Livingstone, 2002). Amongst some older adults, there was a consequent desire to use non-medical vocabulary to describe their experiences of low mood in later life, with a preference for terms like 'sad' and 'nerves' and a resistance to being labelled with 'depression' (Conner et al, 2010b, Guptill, 2005, Gustavson, 2010, Van der Weele et al, 2012).

'I went to Kaiser and there you're labelled, boxed and sealed...so, once somebody says you're depressed, then the next doctor they don't even read your chart but it's got a label. I was stuck with this depression.' (Gustavson, 2010, p.56)

There was strong evidence from the majority of papers, across different contexts, to suggest that many older adults viewed depression as socially rooted – as a normal reaction to an accumulation of life stressors, such as financial problems, relationship issues and family conflict, or as a response ageing (Conner et al, 2010 a & b, Guptill, 2005, Gustavson, 2010, Lee-Tauler et al, 2016, Ward, Mengesha & Issa, 2014, Stark et al, 2018, Wilby, 2008), In several papers (Guptill, 2005, Gustavson, 2010, Ward et al, 2014, Wilby, 2008), depression was traced further back to earlier traumatic life experiences, such as abuse, or family bereavements. This included two papers focusing on the views of older women (Guptill, 2005, Ward et al, 2014), in which marital difficulties, inequality and oppression by male partners were cited as additional factors.

One of the reasons I'm depressed right now is because I have such a small income coming in....I worry and am afraid that I 'm going to be a bag lady some day, that I'll be living on the street the rest of my life.' (Guptill, 2005, p.111)

'My husband was very controlling, like emotional abuse....I often wondered that if I 'd married someone else and had a different life if I would have suffered from this much depression.' (Guptill, 2005, p.107)

Ethnic minority groups in the USA, in particular, viewed depression as socially rooted. For African-Americans, reported life-long experiences of racism, discrimination and poverty appeared to have the effect of normalising their experiences of depression and creating a shared identity of group resilience (Conner et al, 2010 a & b, Ward et al, 2014), whilst for Korean-American older adults, disappointment with immigrant life often underpinned their depressive symptoms (Lee-Tauler et al, 2016).

'It seems to me it doesn't matter how you have to be but, still if you're black, you're still looked down on. To me, that's the way that I feel.' (Conner et al, 2010a, p.271)

Although depression was usually explained in social terms, there was evidence that some older adults felt depression could be considered a medical illness requiring professional help if it was severe enough (Gustavson, 2010, Lee-Tauler et al, 2016, Marwaha & Livingstone, 2002, Van der Weele et al, 2012). It was not clear across studies whether past experiences of treatment had a bearing on this attitude.

'If you are depressed and you worry too much then it is mental illness; most of the time no, but if you don't pull yourself out of it then it becomes a mental illness'
(Marwaha & Livingstone, 2002, p.262)

However, explanatory models did not determine the *type* of professional support preferred if symptoms were severe. For example, some older women who had previously tried antidepressants still explained the root cause of their depression in social terms (Guptill, 2005).

Self-image & Lived Experience

A strong theme to emerge from all the papers in this review is that the impetus to combat depression must come from within, and older people felt that they had developed a variety of coping strategies to deal with this over the course of their lives in response to life stressors. All studies emphasised the need for inner strength, resilience and control in the face of depression, regardless of its severity, by maintaining a positive mental attitude and avoiding negative thoughts. Lived experience had also taught many older adults that depression would eventually pass with time (Conner et al, 2010 a & b, Gustavson, 2010), and that it was important to experience the feelings, especially in the context of bereavement (Gustavson, 2010).

'I don't think of myself as a delicate flower that's going to blow over. I've survived incredible stuff. So I can survive.' (Gustavson, 2010, p.51)

Seeking formal treatment was often viewed as a challenge to self-image; as a personal weakness or failure of one's coping mechanisms (Conner et al, 2010 a & b, Guptill, 2005, Marwaha & Livingstone, 2002, Stark et al, 2018), and many older adults consequently minimised or denied their depressive symptoms (Conner et al, 2010 a & b, Guptill, 2005, Lee-Tauler et al, 2016, Stark et al, 2018, Van der Weele et al, 2012, Ward et al, 2014, Wilby, 2008).

'A lot of people...like me....I wear a mask. You know, I could be depressed, but you would never know, 'cause I wouldn't tell you....that's the most depressing thing for me, just 'cause I kept hiding.' (Conner et al, 2010a, p.273)

Consequently, self-management strategies that were in line with beliefs about depression, self-image and lived experiences were generally preferred across all studies. Behavioural strategies were varied, but mainly included keeping busy, for example - by going outdoors, exercising, cleaning, engaging in hobbies, volunteering, attending day centres and seeing family and friends. Prayer and religion were also viewed as helpful across all ethnic groups, but appeared to be particularly culturally sanctioned in African-American groups (Conner et al, 2010 a & b, Guptill, 2005, Gustavson, 2010, Lee-Tauler et al, 2016, Marwaha & Livingstone, 2002, Lawrence et al, 2006, Stark et al, 2018, Ward et al, 2014, Wilby, 2008). Pets were also viewed positively in two papers as having potential therapeutic value (Guptill, 2008, Stark et al, 2018).

'I keep very busy and I do all kinds of things to improve my mood. I've discovered the joys of exercise, so I get those endorphins working and I am very involved in social things to try to keep myself busy and happy'. (Gustavson, 2010, p.60)

Potential harm

Self-management strategies were generally perceived as being associated with less potential harm than professional interventions, which were viewed as having greater potential to disrupt the status quo and to make older adults feel uncomfortable, apprehensive or out of control. For example, counselling was viewed as potentially harmful if done by someone with inadequate training (Gustavson, 2010, Lee-Tauler et al, 2016), even amongst older adults who positively endorsed it, and some feared that psychotherapists might manipulate them (Stark et al, 2018).

'In my opinion, counselling should be done by someone with a great deal of... knowledge and experience as well as professionalism. If you were to receive counselling with just about anyone then one might actually get hurt.' (Lee-Tauler et al, 2016, p.563)

Counselling also involved disruption to weekly schedules, and access was influenced by physical health, transport issues and clashes with other healthcare appointments (Conner et al 2010b, Van der Weele et al, 2012). Group therapy was perceived as especially threatening amongst older-old adults (>80 years) in one paper (Van der Weele et al, 2012), with fears of being over-burdened by the problems of others, concerns over privacy, and the perception that it would be too difficult to engage in because of their age.

'It's like when you're in a doctor's waiting room – to put it bluntly – everyone's talking crap and making each other sick. No, I don't want to be involved in that.' (Van der Weele et al, 2012, p.273)

The majority of older adults perceived antidepressants as potentially harmful (Conner et al, 2010 a & b, Guptill, 2005, Gustavson, 2010, Lawrence et al, 2006, Lee-Tauler et al, 2016, Stark et al, 2018, Ward et al, 2014), with concerns over dependency, side effects, polypharmacy and worries over being emotionally dulled down. Some viewed them as a last resort and many felt that they were offered in place of counselling (Guptill, 2005, Gustavson, 2010, Lawrence et al, 2006, Ward et al, 2014).

'I didn't want to be chemically lobotomized...I really had to feel it and deal with it in my own way, however haltingly I did that. Everybody would like the magic pill that

makes it better, but I think, for me, the sense was that the magic pill would just make me want more magic pills.’ (Gustavson, 2010, p.53)

However, despite the perceived risks associated with antidepressants and their incongruence with social explanatory models of depression, in practice it appeared that many older adults had tried them (some with benefit), despite many holding ambivalent views about their value (Guptill, 2005, Gustavson, 2010, Lawrence et al, 2006, Stark et al, 2018).

‘One has to be very, very careful with medication. But without medication – it doesn’t work’. (Stark et al, 2018, p.6)

Trust, familiarity and past experiences

Concerns over the potential harm from treatments were balanced against the desire to be listened to. Trust and familiarity, as well as past experiences, were important in determining the form of treatment older people wanted. Despite some of the provisos mentioned above, talking to someone was generally viewed as helpful, and psychological therapies were positively endorsed in five studies (Guptill, 2005, Gustavson, 2010, Lawrence et al, 2006, Lee-Tauler et al, 2016, Stark et al, 2018), either based on past experiences or hypothetical ideas, especially if the counsellor was perceived to be professional, non-judgemental and trustworthy.

‘You’d sit there and talk to a person who was interested in what you’ve got to say and what you are going to ask and a qualified individual who knows what they are talking about psychologically. It always calmed me down, but gave me answers you know.’ (Gustavson, 2010, p.58)

However, for some older adults, past negative experiences of counselling adversely affected their willingness to try psychological therapies again (Conner et al, 2010b, Stark et al, 2018, Ward et al, 2014, Wilby, 2008).

'Yes I went to a counsellor years ago. Counselling after I had gone through a serious depression, but after a few times and having to always wake him up to tell him the time was up, I decided to not go anymore.' (Wilby, 2008, p.73)

Amongst African-American older women, there was a strong desire for African-American therapists, who they felt would understand their experiences better (Ward et al, 2014).

'If she had been African-American, I think she would've understood. I mean, some things are just understood with us. You see what I'm saying?' (Ward et al, 2014, p.54)

Consulting with primary care physicians was mentioned in five, mostly European-based, studies (Guptill, 2005, Lawrence et al, 2006, Marwaha & Livingstone, 2002, Stark et al, 2018, Van der Weele et al, 2012), although in one study, some older adults believed GPs were not specialised enough to deal with depression (Stark et al, 2018). Older adults who had good relationships with their GPs were more likely to seek help regarding depressive symptoms. Clinician interpersonal skills were viewed as very important in one paper, with older women less likely to discuss their depression with GPs who appeared judgemental or had poor listening skills (Guptill, 2005).

'I think what helped me the most was when I got a doctor that listened to me. When I found a doctor that would listen to me that's when they were able to start to help me.'
(Guptill, 2005, p.127)

Talking to others with *shared* experiences, rather than health professionals, was an attractive alternative for some, and non-depression related support groups were mentioned as useful in two studies (Conner et al, 2010a, Gustavson 2010), amongst older adults from all socioeconomic backgrounds. These support groups tended to be in the self-referral voluntary sector, face-to-face or online, and ranged from grand-parenting circles to cancer patient groups. Unlike counselling or other medical treatments, their appeal seemed to be in *'not trying to patch you up'* (Conner et al, 2010a).

"They don't wanna patch you up. They're gonna tell it like it is, you know. Whatever your problem is. Like if I tell them they'll help me with that problem. (Conner et al, 2010a, p.274)

However, it was unclear whether these studies referred to support groups led by a mental health professional or peer-led support groups. Only one study cited depression-specific self-help groups as beneficial (Stark et al, 2018).

Seeking help from familiar sources, such as family and friends, was preferred by many older adults (Guptill, 2005, Gustavson, 2010, Lawrence et al, 2006, Van der Weele et al, 2012), with family highlighted as especially important amongst the South Asian community in a UK study (Lawrence et al, 2006).

'And if it hadn't been for my son and his wife and family I don't think I would have made it. They kept me motivated more than anything. If it hadn't been for them I don't know what I would have done. They talked to me and I was able to go to their house as much as possible.' (Guptill, 2008, p.122)

However, familiarity was not always a positive thing and some older adults feared burdening those close to them or receiving negative responses, which sometimes prevented help-seeking (Conner et al, 2010b, Guptill, 2005, Stark et al, 2018).

'No, I don't talk to anyone about it, I just keep it myself, because I have children and grandchildren, but I don't tell them. Because I don't want them to worry. Because they have their own personal problems, so I keep mine to myself.' (Conner et al, 2010b, p.979)

2. Societal issues

Stigma, Ethnicity and culture

Culture and ethnicity were prominent themes across most papers, due to the high volume of studies focusing on ethnic minority groups (n=6). Help-seeking for depression in later life was strongly associated with perceived stigma across all studies and contexts, although it was particularly important in African-American communities (Conner et al, 2010 a & b, Ward et al, 2014). Most African-American older adults displayed negative views towards psychological therapy, as well as greater mistrust of the medical profession (Conner et al, 2010 a & b, Ward et al, 2014). Fewer ethnic older adults in the US sought help from their family and friends and there was a greater desire for privacy (Conner et al, 2010 a & b, Lee-Tauler et al, 2016, Ward et al, 2014). In UK studies, ethnic older adults appeared less inclined to discuss depressive symptoms with their GP, who they saw as more appropriate for

physical health problems, whilst South Asian elders expressed concerns over privacy and counselling (Lawrence et al, 2006, Marwaha & Livingstone, 2002).

'I don't think we discuss it that much, Black people. If you're depressed, nobody knows. You don't tell people, you know.' (Conner et al, 2010b, p.974)

Seeing a psychiatrist was mentioned in only four papers. Although there were a few positive comments regarding their professionalism, older people generally associated them with greater stigma than consulting with GPs, across both self-referral and secondary referral systems. They were considered to be reserved for more severe mental health problems and more likely to prescribe medication (Conner et al, 2010b Lawrence et al, 2006, Marwaha & Livingstone, 2002, Ward et al, 2014).

'I would feel that if someone was to say we are going to make an appointment for you to see a psychiatrist, straight away I would think oh I am going off me rocker kind of thing.' (Lawrence et al, 2006, p.1381)

Ageism

Nearly all studies in our review indicated that, to an extent, many older adults regarded depression as a normal part of ageing, especially if associated with loneliness, functional decline and changes in social roles, such as retirement, becoming a carer and bereavement. Consequently, many felt that treatments would make no difference because of their age (Conner et al, 2010b, Guptill, 2005, Gustavson, 2010, Stark et al, 2018, Van der Weele et al, 2012, Wilby, 2008) and, in one paper, some felt that even doctors regarded their treatment as a waste of time (Stark et al, 2018).

'I just figure at 94 you know good and well, you ain't gonna be here that much longer now....I wonder why they want to waste their time on older people when they could use younger people that have more to give.' (Conner et al, 2010b, p.977)

3. Structural issues

Access to healthcare and health education

Poorer access to mental health services was more prevalent in US studies, perhaps reflecting inequalities in insurance-based healthcare systems, and was significant in ethnic minority groups from lower socio-economic backgrounds. Poverty, lack of health insurance, transport issues, being undocumented and lack of bilingual counsellors were all cited as obstacles associated with accessing services (Conner et al, 2010b, Lee-Tauler et al, 2016), although these factors are unlikely to be limited to the older population. Long distances and poor financial resources were also cited as obstacles in a German study to accessing psychosocial treatments (Stark et al 2018). One UK study described feelings of marginalisation in the healthcare system amongst Black Caribbean older adults (Marwaha & Livingstone, 2002). In studies positively endorsing counselling, it appeared few ethnic older adults actually had direct experiences of this (Lawrence et al, 2006, Lee-Tauler et al, 2016), in contrast to White Caucasian older adults (Guptill, 2005, Gustavson, 2010), perhaps reflecting greater stigma and access barriers in these populations.

'If you become ill and your first language is not English then you're in the shit'
(Marwaha & Livingstone, 2002, p.263)

In European studies, time constraints in GP consultations and lack of continuity meant that older adults were less likely to talk to their GPs about depressive

symptoms and were more likely to prioritise physical health needs (Lawrence *et al* 2006, Marwaha & Livingstone, 2002, Stark *et al*, 2018).

'There's so much to say and so little time. So you always feel like you haven't got enough time with the doctor. Yes so then you think to yourself, ah well, the important thing, first, cure your pains and then think about the depression later on.' (Lawrence *et al*, 2006, p.1380)

African-American older adults felt that education about mental health needed to be made more relevant to them (Conner *et al*, 2010a) and there appeared to be some confusion amongst ethnic older adults about the theory behind counselling (Lawrence *et al*, 2006, Lee-Tauler *et al*, 2016, Ward *et al*, 2014), perhaps reflecting a lack of culturally appropriate education and service information, although no formal comparisons were made with non-ethnic minority older adults.

'Well, if you look at television, for instance, and they bring the advertisement on depression medicine...- I have not seen a black person. They're always um— always white.' (Conner *et al*, 2010a, p.271)

(Figure 2 here)

Discussion and Implications

In our review and synthesis of 11 qualitative studies, we found that depression was generally perceived to be a normal part of ageing or a response to psychosocial

stressors, rather than a medical illness. The context of older people's lived experiences meant that they often regarded depression as something that would pass with time, requiring self-management rather than outside interventions. There was recognition that depression could become an illness if severe enough and might then require professional help, but this boundary was often difficult to recognise on a personal level, with help-seeking associated with stigma and challenges to self-image. Consequently, the most significant finding of this review was the strong desire amongst older people for self-management of depressive symptoms using behavioural and cognitive strategies, such as keeping busy, resilience and prayer, and this reflects findings from previous qualitative meta-syntheses on the subject (Corcoran et al, 2013, Holm and Severinsson, 2013). A more recent systematic review (Kharicha, Manthorpe, Iliffe, Davies & Walters, 2018) has also found that strategies of acceptance and endurance are used by older adults to manage loneliness, with those displaying these traits being more likely to engage with community services.

Our review also found that willingness to try interventions was based on a balance of different judgements. Perceptions of potential harm and risk may influence the acceptability of certain treatments (Von Faber et al, 2013, Chew-Graham et al, 2012). Older adults are generally more risk averse than younger adults, especially when depressed (Chou, Lee & Ho, 2007), and our review found that *formal* treatments tended to be associated with greater perceptions of potential harm, compared to self-management strategies. Notions of potential harm have previously been reported in relation to antidepressants (Burroughs et al, 2006), but we found that, whilst older adults viewed antidepressants as potentially harmful, many had tried them, revealing a degree of ambivalence between opinions, attitudes and behaviours. We found that concerns about potential harm also extended to other professional interventions (e.g. psychological therapies), if they made older adults

feel uncomfortable or apprehensive. However, such judgements were balanced against a desire to be listened to, with trust, familiarity and past experiences being important factors, and talking to someone was generally viewed as helpful if that person was perceived as non-judgemental and trustworthy. Stigma was a prevalent feature across all studies, but we found that it was perceived to be higher amongst ethnic minority older adults, who also appeared to face greater structural barriers; ethnicity was therefore an influential factor affecting attitudes to treatment. Gender was highlighted in two papers as affecting older women's experiences of depression, but it did not appear to affect treatment-seeking. A summary of our results is depicted in Figure 2 above.

Strengths and limitations of the review

We systemically identified studies that involved a range of healthcare systems, ethnicities and socioeconomic settings. However, most studies were carried out in high-income Western countries, so our findings may not be transferable to other settings. Most studies did not adequately differentiate between the views of 'younger old' (< 80) and 'older old' (>80), despite reported differences in health and wellbeing between these subpopulations (Smith, Borchelt, Maier & Jopp, 2002). Where ages were stated, we looked for variations in views during our analysis, but no clearly significant differences were identified. Although within a few papers some of the sample had clearly received treatment(s) for depression in the past, most studies did not adequately differentiate between those views and the views of those who had not previously received treatments, which is likely to be an important influential factor on current perspectives and attitudes towards treatments. Furthermore, although we excluded papers where it was clear participants were receiving active treatment for depression, within a minority of studies it appeared a few participants were on antidepressants, but reasons were not explicitly stated/explored within the studies, and it was not possible to differentiate their views from the rest of the sample. We did

not exclude these studies as the overall data was valuable and we felt these findings reflect the frequent, often ambiguous use of antidepressants in this age group.

Implications for practice

Although the evidence base for psychosocial interventions, such as exercise and social activities, is fairly limited (Forsman, Schierenbeck & Wahlbeck, 2011, Holvast, Massoudi, Voshaar & Verhaak, 2017,), there is evidence that behavioural activation/pleasant activity scheduling has better and more long-lasting effects than antidepressant medication (Dimidjian et al, 2006, Dobson et al, 2008). Supporting older adults in the self-management of milder depressive symptoms may be more acceptable than **formal** treatments (Von Faber et al, 2013), as it would facilitate independence and draw on natural resilience developed over a lifetime. GPs and third sector organisations (Kingstone et al, 2017) may be best placed to signpost to local services that promote social activities. However, self-efficacy strategies are unlikely to be sufficient to manage more severe depression. Locating services within familiar, convenient and accessible venues, such as Day Centres, churches, local libraries or GP practices, might reduce stigma and increase access to support. GPs were identified as potentially valuable sources of support, being well placed to educate and deliver information about services. However, instead of preferentially offering medication alone (Walters et al, 2017), it may be more appropriate to refer alongside for psychological therapies, if these are sufficiently accessible and engaging for older adults. Some studies have demonstrated that collaborative and step-wise treatment approaches (e.g. the IMPACT program) have resulted in greater reduction of depressive symptoms, as well as reduced healthcare costs (Unutzer et al, 2008, 2002). Integrated care, whereby mental health professionals are on-site in primary care practices, may be another way of improving access to services and providing support to GPs. Enhancing the interpersonal skills of healthcare professionals and raising awareness about issues related to ageism might further

improve care for depressed older adults. A recent study (Gordon, Ling, Robinson, Hayes & Crosland, 2018) has highlighted how older adults' narratives of talking about mood with their GPs can reveal a lot about their beliefs about depression and their openness to treatment. Some studies have suggested that discussing treatment choices in terms of narratives (e.g. by eliciting older adults' views on why they are depressed, how they see themselves and what they hope to gain from treatment) may be more appropriate (Lindley et al, 2012), as older adults tend to rely on affective rather than cognitive processes in decision-making, based on the sum of their lived experience (Cartensen & Michels, 2005). Support groups, through GP practices or the voluntary sector, may also facilitate this idea of narrative sharing, although our review suggests that some older people may be reluctant to attend group interventions focused on mental health, and another study exploring loneliness showed that older adults tended to have negative views about social groups (Kharicha et al, 2017). However, in our review, it was not clear how well older adults' understood the different types of groups that might be available. This review, in concordance with the results of other studies (Memon et al, 2016), has also highlighted that more work needs to be done to improve access to mental health services amongst ethnic minority groups, as well as address perceived greater levels of stigma; there is evidence that collaborative care approaches have had good results in delivering effective care to minority populations (Arean et al, 2005), and another study has highlighted peer education strategies as an effective way of reducing stigma (Conner, McKinnon, Ward, Reynolds & Brown, 2015).

Conclusion

Older adults' attitudes towards the treatment of late-life depression are complex, with a strong desire for self-management. However, when there is a need for professional support, there is often difficulty accessing help, with stigma still a prominent factor. Notions of potential harm, trust and past experiences seem to underpin decisions

about the acceptability of professional interventions, which currently do not appear to adequately meet older people' needs. Future policy should focus on making services more accessible and acceptable to older adults, by taking into account their lived experiences, self-image and explanatory models of depression.

Description of Authors' roles

PN, RF, MB and KW designed the review concept and protocol. PN ran the searches, screened references, undertook coding, thematic synthesis and analysis, and drafted the manuscript. CB screened 10% of titles/abstracts and one third of full-texts, coded 25% of studies, and reviewed the thematic framework. RF, MB and KW provided feedback throughout the review process, were third reviewers for resolving any inclusion disagreements and provided feedback on manuscript drafts. All authors have read and approved the final manuscript.

Conflict of interest Declaration

We have no conflict of interest to declare.

References

- Areán, P. A., Avalon, L., Hunkeler, E., Lin, E. H., Tang, L., Harpole, L..... Unützer, J. (2005). Improving depression care for older, minority patients in primary care. *Medical Care*, *43*(4), 381-390. doi:10.1097/01.mlr.0000156852.09920.b1
- Barg, F. K., Huss-Ashmore, R., Wittink, M. N., Murray, G. F., Bogner, H. R., & Gallo, J. J. (2006). A mixed-methods approach to understanding loneliness and depression in older adults. *Journal of Gerontology*, *61*, 329-339. doi:10.1093/geronb/61.6.S329

- Burroughs, H., Lovell, K., Morley, M., Baldwin, R., Burns, A., & Chew-Graham, C. (2006). 'Justifiable depression': How primary care professionals and patients view late-life depression? A qualitative study. *Family Practice*, *23*, 369–77. doi:10.1093/fampra/cmi115. doi:10.1093/fampra/cmi115
- Byers, A, Arean, P., & Yaffe, K. (2012). Low Use of Mental Health Services among Older Americans with Mood and Anxiety Disorders. *Psychiatric Services*, *63*, 66–72. doi:10.1038/jid.2014.371
- Carstensen, I. & Mikels, J. A. (2005). At the intersection of emotion and cognition aging and the positivity effect. *Current Directions in Psychological Science*, *14*, 117–21. doi:10.1111/j.0963-7214.2005.00348.x
- Chew-Graham, C., Kovandžić, K., Gask, L., Burroughs, H., Clarke, P. Sanderson, H., & Dowrick, C. (2012) Why may older people with depression not present to primary care? Messages from secondary analysis of qualitative data. *Health and Social care in the Community*, *20(1)*, 52-60. doi:10.1111/j.1365-2524.2011.01015.x
- Chou, K. I., Lee, T. M. C., & Ho, A. H. Y. (2007) Does mood state change risk taking tendency in older adults? *Journal of Psychology and Aging*, *22*, 310–18. doi:10.1037/0882-7974.22.2.310
- Conner, K. O., McKinnon, S. A., Ward, C. J., Reynolds, C. F., & Brown, C. (2015). Peer Education as a Strategy for Reducing Internalized Stigma Among Depressed Older Adults. *Psychiatric Rehabilitation Journal*, *38(2)*, 186-193. doi:10.1037/prj0000109
- Conner, K. O., Lee, B., Mayers, V., Robinson, D., Reynolds, C. F., Albert, S., & Brown, C. (2010a). Attitudes and beliefs about mental health among African American older adults suffering from depression. *Journal of Aging Studies*, *24*, 266-277. doi:10.1016/j.jaging.2010.05.007
- Conner, K. O., Copeland, V. C., Grote, N. K., Rosen, D., Albert, S., McMurray, M. L...Koeske, G. (2010b): Barriers to Treatment and culturally endorsed coping

- strategies among depressed African-American older adults. *Aging & Mental Health*. 14(8), 971-983. doi:10.1080/13607863.2010.501061
- Corcoran, J., Brown, E., Davis, M., Pineda, M., Kadolph, J., & Bell, H. (2013). Depression in Older Adults: A Meta-synthesis. *Journal of Gerontological Social Work*. 56(6), 509-534. doi:10.1080/01634372.2013.811144
- Critical Appraisal Skills Program (2010). Making sense of evidence about clinical effectiveness: 10 questions to help you make sense of qualitative research. Oxford: Public Health Resource Unit. Retrieved from: http://www.casp-uk.net/wpcontent/uploads/2011/11/CASP_Qualitative_Appraisal_Checklist_14oct10.pdf
- Dakin, E.K. & Areán, P. (2013). Patient perspectives on the benefits of psychotherapy for late-life depression. *American Journal of Geriatric Psychiatry*, 21, 155–63. doi:10.1016/j.jagp.2012.10.016
- Department of Health (2013). How to make IAPT more accessible to Older People. Retrieved from: <https://www.uea.ac.uk/documents/246046/11919343/older-peoples-compendium.pdf/c4b23dad-a332-47d5-b7af-6be290222737>
- Dimidjian, S., Hollon, S. D., Dobson, K. S., Schmaling, K. B., Kohlenberg, R. J., Addis, M. E....Jacobson, N. S. (2006). Randomized trial of behavioural activation, cognitive therapy, and antidepressant medication in the acute treatment of adults with major depression. *Journal of Consulting and Clinical Psychology*, 74(4), 658-70. doi:10.1037/0022-006X.74.4.658
- Dixon-Woods, M. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care*, 13, 223–225. doi:10.1136/qshc.2003.008714
- Dobson, K. S., Hollon, S. D., Dimidjian, S., Schmaling, K. B., Kohlenberg, R. J., Gallop, R.....Jacobson, N. S. (2008). Randomized trial of behavioural activation, cognitive therapy and antidepressant medication in the prevention of relapse and recurrence in major depression. *Journal of Consulting and Clinical Psychology*, 76(3), 468-77. doi:10.1037/0022-006X.76.3.468

- Forsman, A., Schierenbeck, I. J., & Wahlbeck, K. (2011). Psychosocial interventions for the prevention of depression in older adults: Systematic review and meta-analysis. *Journal of Aging and Health, 23*(3), 387-416.
doi:10.1177/0898264310378041
- Givens, J., Datto, C. J., Ruckdeschel, K., Knott, K., Zubritsky, C., Oslin, D. W....Barg, F. K. (2006). Older patients' aversion to antidepressants: A Qualitative study. *Journal of General Internal Medicine, 21*, 146-151. doi:10.1007/s11606-006-0249-y
- Gordon, I., Ling, J., Robinson, L., Hayes, C., & Crosland, A. (2018). Talking about depression during interactions with GPs: a qualitative study exploring older people's accounts of their depression narratives. *BMC Family Practice, 19*(1), doi:10.1186/s12875-018-0857-8
- Gould, R., Coulson, M. and Howard, R. (2012). Cognitive behavioral therapy for depression in older people: A meta-analysis and meta-regression of randomized controlled trials. *Journal of the American Geriatric Society, 60*, 817–30. doi:10.1111/j.1532-5415.2012.04166.x
- Gum, A., Hunkeler, E., Tang, L., Katon, W., Hitchcock, P., Steffens, D. C....Unützer, J. (2006). Depression treatment preferences in older primary care patients. *The Gerontologist, 46*,14–22. doi:10.1093/geront/46.1.14
- Guptill, A. M (2005), *Understanding Depression in Older Women: A Qualitative Study*. The University of New Brunswick
- Gustavson, K. A. (2010). *Late Life Depressed Mood: Crafting Meaning from Experience and Knowledge*. UC Berkeley
- Holm, A. L. & Severinsson, E. (2013). Surviving depressive ill-health: a qualitative systematic review of older persons' narratives. *Nursing and Health Sciences, 16*(1). doi:10.1111/nhs.12071

- Holvast, F., Massoudi, B., Voshaar, R. C. O., & Verhaak, P. F. M. (2017). Non-pharmacological treatment for depressed older patients in primary care: A systematic review and meta-analysis. *PLoS ONE*, *12*(9). doi:10.1371/journal.pone.0184666
- Karasz, A. (2005). Cultural differences in conceptual models of depression. *Social Science & Medicine*, *60*, 1625-1635. doi:10.1016/j.socscimed.2004.08.011
- Katona, C. L. E. (1994). Approaches to the Management of Depression in Old Age. *Gerontology*, *40*(1), 5–9. doi:10.1159/000213613
- Kharicha, K., Manthorpe, J., Iliffe, S., Davies, N., & Walters, K. (2018). Strategies employed by older people to manage loneliness: Systematic review of qualitative studies and model development. *International Psychogeriatrics*, 1-15. doi:10.1017/S1041610218000339
- Kharicha, K., Iliffe, S., Manthorpe, J., Chew-Graham, C. A., Cattan, M., Goodman, C....Walters, K. (2017). What do older people experiencing loneliness think about primary care or community based interventions to reduce loneliness?: a qualitative study in England. *Health and Social Care in the Community*, *25*(6), 1733-1742. doi:10.1111/hsc.12438
- Kingstone, T, Burroughs, H., Bartlam, B., Ray, M., Proctor, J., Shepherd, T...Chew-Graham, C. A. (2017). Developing a community-based psycho-social intervention with older people and third sector workers for anxiety and depression: a qualitative study. *BMC Family Practice*, *18*, 77. doi:10.1186/s12875-017-0648-7
- Kok, R.M., Nolen, W.A., & Heeren, T.J. (2012). Efficacy of treatment in older depressed patients: A systematic review and meta-analysis of double-blind randomized controlled trials with antidepressants. *Journal of Affective Disorders*, *141*, 103–15. doi:10.1016/j.jad.2012.02.036
- Lawrence, V., Banerjee, S., Bhugra, D., Sangha, K., Turner, S., & Murray, J. (2006). Coping with depression in later life: a qualitative study of help-seeking in

three ethnic groups. *Psychological Medicine*, 36(10), 1375-83.

doi:10.1017/S0033291706008117

Lee-Tauler, S.Y., Lee-Kwan, S. H., Han, H., Lee, H. B., Gallo, J. J., & Joo, J. H.

(2016). What does Depression Mean for Korean American Elderly? A Qualitative Follow-up Study. *Psychiatry Investigation*, 13 (5), 558-565.

doi:10.4306/pi.2016.13.5.558

Li, C., Friedman, B., Conwell, Y., & Fiscella, K. (2007). Validity of the Patient Health Questionnaire 2 (PHQ-2) in identifying major depression in older people. *Journal of the American Geriatrics Society*, 55(4), 596–602.

Lindley, E. et al. (2012). Improving decision-making in the care of older people.

Exploring the decision ecology. *RSA Action and Research Centre*. Retrieved from: <https://www.jrf.org.uk/report/improving-decision-making-care-and-support-older-people>

Ludvigsson, M., Milberg, A., Marcusson, J., & Wressle, W. (2014). Normal Aging or Depression: A Qualitative Study on the differences between subsyndromal depression and depression in very old people. *The Gerontologist*, 55(5), 760-769. doi:10.1093/geront/gnt162

Marwaha, S. & Livingstone, G. (2002). Stigma, racism or choice. Why do depressed ethnic elders avoid psychiatrists? *Journal of Affective Disorders*, 72 (3), 257-265. doi:10.1016/S0165-0327(01)00470-0

Meeks, T. W., Vahia, I. V., Lavretsky, H., Kulkarni, G., & Jeste, D. V. (2011). A Tune in 'A Minor' Can 'B Major': A Review of Epidemiology, Illness Course, and Public Health Implications of Subthreshold Depression in Older Adults. *Journal of Affective Disorders*, 129, 126–42. doi:10.1016/j.jad.2010.09.015

Memon A., Taylor, K., Mohebbati, L. M., Sundin, J., Cooper, M., Scanlon, T., & de Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in

Southeast England. *BMJ Open*, 6(11). doi:10.1136/bmjopen-2016-012337

Moher, D., Liberati, A., Tetzlaff, J. & Altman, D.G., The PRISMA Group

(2009). Preferred Reporting Items for Systematic Reviews and Meta-

Analyses: The PRISMA Statement. *BMJ Open*, 339, 2535. doi:

10.1136/bmj.b2535

QSR International Pty Ltd (2015). *NVivo qualitative data analysis Software*. Version

11.

Rodda, J., Walker, Z., & Carter, J. (2011). Depression in older adults. *British Medical*

Journal, 343, d5219. doi:10.1136/bmj.d5219

Singh, A & Misra, M. (2009). Loneliness, depression and sociability in old age.

Industrial Psychiatry Journal. 18(1), 51-55. doi:10.4103/0972-6748.57861

Smith, J., Borchelt, M., Maier, H., & Jopp, D. (2002). Health and Well-Being in the

Young Old and Oldest Old. *Journal of Social Issues*, 58, 715–732.

doi:10.1111/1540-4560.00286

Snowdon, J. (2001). Is depression more prevalent in old age? *Australian and New*

Zealand Journal of Psychiatry, 35, 782-787. doi:10.1046/j.1440-

1614.2001.00968.x

Stark, A., Kaduszkiewicz, Stein, J., Maier, W., Hesel, K., Weyerer, S....Scherer, M.

(2018). A Qualitative study on older primary care patients' perspectives on

depression and its treatment – potential barriers to and opportunities for

managing depression. *BMC Family Practice*, 19(2). doi:10.1186/s12875-017-

0684-3

Thomas, J. & Harden, A. (2008). Methods for the thematic synthesis of qualitative

research in systematic reviews. *BMC Medical Research Methodology*, 8, 45.

doi:10.1186/1471-2288-8-45

- Unutzer, J., Katon, W., Callahan, C. M., Williams, J. W., Hunkeler, E., Harpole, L., et al (2002). Collaborative care management of late-life depression in the primary care setting: a randomized controlled trial. *JAMA*, *288*(22), 2836-45. doi:10.1001/jama.288.22.2836
- Unutzer, J, Katon, W. J., Fan, M. Y., Schoenbaum, M. C., Lin, E. H., Della Penna, R. D., & Powers, D. (2008). Long-term cost effects of collaborative care for late-life depression. *The American Journal of Managed Care*, *14*(2), 95-100.
- Van der Weele, G. M., de Jong, R., de Waal, M. W., Spinhoven, P., Rooze, H. A., Reis, R....van der Mast, R. C. (2012). Response to an unsolicited intervention offer to persons aged >75 years after screening positive for depressive symptoms: a qualitative study. *International Psychogeriatrics*, *24*(2), 270-277. doi:10.1017/S1041610211001530
- Von Faber, M., Van der Geest, G., Van der Weele, G. M., Blom, J. W., Van der Mast, R. C., Reis, R., & Gussekloo, J. (2016). Older People coping with low mood: a qualitative study. *International Psychogeriatrics*. *28*(4), 603-612. doi:10.1017/S1041610215002264
- Walker, R., Bisset, P., & Adam, J. (2007) Managing risk: risk perception, trust and control in a primary care partnership, *Social Science & Medicine*, *64*(4), 911–23. doi:10.1016/j.socscimed.2006.10.034
- Walters, K., Falcaro, M., Freemantle, N., King, M., & Ben-Shlomo, Y. (2017). Sociodemographic inequalities in the management of depression in adults aged 55 and over: an analysis of English primary care data. *Psychological Medicine*, *48*(9), 1504-1513 doi:10.1017/S0033291717003014
- Ward, E. C., Mengesha, M., & Issa, F. (2014): Older African American women's lived experiences with depression and coping behaviours. *Journal of Psychiatric and Mental Health Nursing*, *21*(1), 46-59. doi:10.1111/jpm.12046
- White, J., Zaninotto, P., Walters, K., Kivimäki, M., Demakakos, P., Shankar, A....Batty, G. D. (2015). Severity of depressive symptoms as a predictor of

mortality: the English longitudinal study of ageing. *Psychological Medicine*, 45 (13), 2771-2779. doi:10.1017/S0033291715000732

WHO (2017). Fact Sheet 'Mental Health of Older Adults'. Retrieved from:

<http://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults>

Wilby, F. E. (2008). *Coping and Depression in Community-Dwelling Elders*.

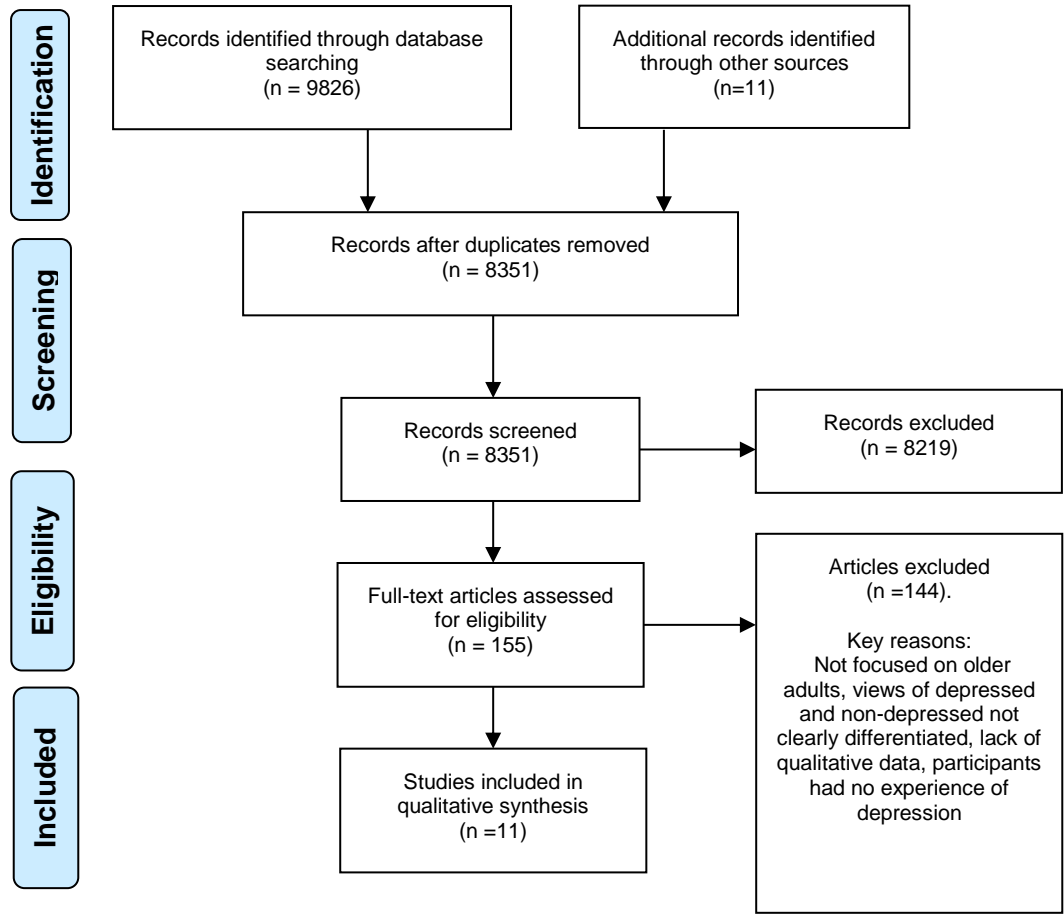
University of Utah

Tables and Figures

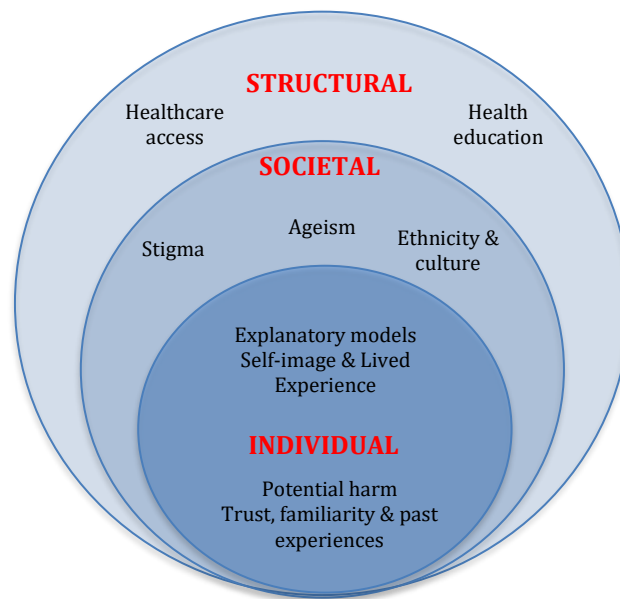
- i. Table 1 outlining included study characteristics (see Appendix 2 for more details)
- ii. Figure 1 PRISMA flowchart of screening process and selected studies (PRISMA, 2015)
- iii. Figure 2 Summary of factors influencing older adults' views on the treatment of late-life depression

i. Table 1 outlining included study characteristics (see Appendix 2 for more details)

Study	Methods	Ethnicity	Participant characteristics
Conner <i>et al</i> 2010a USA	Focus groups	African-American, lower SES	Mixed gender (80%F) Mean age 65 N=42
Conner <i>et al</i> 2010b USA	Interviews	African-American, lower SES	Mixed gender (84% F) Mean age not stated (majority 60-80) N=37
Ward <i>et al</i> 2014 USA	Interviews	African-American, lower SES	Female only Mean age 71 (60-78) N=13
Wilby 2008 USA	Mixed methods including interviews	Predominantly White Caucasian, higher SES	Mixed gender Mean age not stated (65-90+, majority 65-79) N=25 (depressed group – qualitative interviews)
Lee-Tauler <i>et al</i> 2016 USA	Interviews, case vignettes	Korean-American, lower SES	Mixed gender Mean age 67.4 (60-73) N=8
Gustavson 2010 USA	Interviews	Predominantly White Caucasian, higher SES	Mixed gender Median age 80.28 (all 75+ older-old) N=30 (depressed sample)
Guptill 2005 Canada	Interviews	White Caucasian	Female Mean Age 69.8 (64-79) N=11
Marwaha & Livingstone 2002 UK	Interviews, case vignettes	Black-Caribbean, White Caucasian	Mixed gender Age 67-93 (mean age not stated) N=20 (depressed sample)
Lawrence <i>et al</i> 2006 UK	Interviews	Afro-Caribbean, White Caucasian, South Asian	Mixed gender Age 65-90+ (mean age not stated) majority 65-80) N=37 (depressed, not treated sample)
Van der Weele <i>et al</i> 2012 Netherlands	Interviews	Ethnicities not stated	Mixed gender Mean age 82 (79-85 older-old) N=23
Stark <i>et al</i> 2018 Germany	Interviews	Ethnicities not stated	Mixed gender Median age 81 (77-91 older-old) N=12



ii. FIGURE 1 PRISMA FLOWCHART OF SCREENING PROCESS AND SELECTED STUDIES (The PRISMA Group, 2009)



iii. FIGURE 2 SUMMARY OF FACTORS INFLUENCING OLDER ADULTS' VIEWS ON THE TREATMENT OF LATE-LIFE DEPRESSION

SUPPLEMENTARY MATERIAL

Appendix 1 – Search Strategy Example

Medline:

QUALITATIVE FILTER

(http://libguides.sph.uth.tmc.edu/search_filters/ovid_medline_filters):

((("semi--structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnography* or fieldwork or "field work" or "key informant")).ti,ab. or interviews as topic/ or focus groups/ or narration/ or qualitative research/

1. AGE TERMS (OR):

older adult*.ti,ab,kw.
 oldest old.ti,ab,kw.
 elder*.ti,ab,kw.
 old age.ti,ab,kw.
 ageing.ti,ab,kw.
 geriatr*.ti,ab,kw.
 later life.ti,ab,kw.
 late life.ti,ab,kw.
 oldest-old.ti,ab,kw.
 aged over 80.ti,ab,kw.
 "Aging"/px [Psychology]

"Health Services for the Aged"/
older people.ti,ab,kw.

2. DEPRESSION/ANXIETY TERMS (OR):

Depress*.ti, ab,kw.

Anxi* .ti,ab,kw.

bereave*.ti,ab,kw.

depression/

affective symptoms/

stress, psychological/

depressive disorder/

mental health/

exp anxiety disorders/

mood adj (low or disorder)

stress adj1 (emotional or psychological)

3. ATTITUDES/FEELINGS KEYWORD TERMS (OR):

Attitud*

Belie*

Feel*

Experience*

Understand*

Idea*

View*

Perspective*

SEARCH: *1 and 2 and 3 and Qualitative filter*

APPENDIX 2: Study Characteristics

Author, Title & Country	Purpose	Design	Data Analysis	Sample	Major findings
<p>Marwaha and Livingston (2002): Stigma, racism or choice. Why do depressed ethnic elders avoid psychiatrists</p> <p>UK (London)</p>	<p>Explore and compare the views of British Caucasian and Afro-Caribbean older people on depression, treatment seeking and mental health services</p>	<p>Semi-structured interviews & case vignettes</p>	<p>Content analysis</p>	<p>Nⁱ =20 (total 40, but only depressed sample used for SR. Depressed 20, Non-depressed 20)</p> <p>Socio-demographic: Age range: 67-93 years (mean age not stated) Gender: 20 Mⁱⁱ, 20 Fⁱⁱⁱ Ethnicity: Afro-Caribbean, White, Caucasian</p> <p>Other: GP involved in recruitment No information RE socioeconomic status</p>	<p>Most people felt depression was not an illness Ethnicity rather than presence of depression affected belief of aetiology of depression Mental health services viewed as more for psychosis Stigma prevalent</p> <p><u>Limitations</u>– unclear how depression assessed <u>Quality</u>: Acceptable (CASP^{iv} 10/10)</p>
<p>Lee-Tauler et al (2016): What does Depression Mean for Korean American Elderly? A</p>	<p>Explore meaning of depression and help-seeking amongst Korean-American</p>	<p>Semi-structured interviews + case vignettes</p>	<p>Thematic analysis</p>	<p>N=8 All mod-severe depression</p> <p>Socio-demographic: Age 63-73,</p>	<p>Denial of Depression diagnosis despite screening positive Depression associated with social discrimination, immigrant experiences and family issues</p>

Qualitative Follow-up Study USA	Elderly who have depression			mean 67 Gender: 4 M, 4 F Ethnicity: Korean-American (mean time in US 24 years) Education: mean 12 yrs Other: Recruited from lager MASK study	Attempted to self-manage distress –lack of other options, fear of judgement in KAE communities Desire for culturally appropriate services Issues with access – language, health insurance, finances <u>Quality:</u> Good (CASP 10/10)
Conner et al (2010b): Barriers to Treatment and culturally endorsed coping strategies among depressed African-American older adults USA (Pennsylvania)	Explore experiences of depression, barriers to treatment and coping strategies in African-American elderly who have depression	Semi-structured interviews	Thematic analysis	N=37 Depressed sample (mild-moderate) Socio-demographic: Age: 60 + years, majority 60-80, 24% 81+ Gender: 31 F, 6 M Ethnicity: African-American Low-income area	Culturally endorsed coping strategies – resilience, faith, “frontin”, denial, self-reliance, language Barriers to treatment included access, ageism, recognising, mistrust, stigma African-American context – stigma++, privacy, history <u>Quality:</u> Good (CASP 10/10)
Guptill (2005): Understanding Depression in Older Women: A Qualitative Study Canada	Explore older women’s experiences of depression	Semi-structured interviews PHD dissertation	Thematic analysis	N=11 Depressed sample (self-identified) Socio-demographic: Age: 64-79 (mean 69.8) Gender: All female Ethnicity: Predominantly White-Caucasian Urban	Depression as loneliness Sexist discourse and gender-related experiences Ageism Finances important factor <u>Quality:</u> Good (CASP 10/10)
Conner et al (2010a): Attitudes and beliefs about mental health among African American older adults suffering from depression USA	Explore attitudes and beliefs about depression and mental health utilisation in depressed African-Americans	Focus Groups Recruited from single primary care centre	Thematic analysis	N=42 recent depressive episode (self-identified) Socio-demographic: Mean age = 65 (60-93) Gender: 84% F, 16% M Ethnicity: African-American Majority low-income Urban Other: recruited from single primary care centre	Depression normalised The African-American experience Seeking treatment as a last resort – depression as weakness, mistrust Myths about treatment Stigma Culturally appropriate coping strategies – faith, ‘frontin’, activities, support groups <u>Quality:</u> Good (CASP 10/10)
Gustavson (2010): Late Life Depressed Mood: Crafting Meaning from	Explore older adults’ knowledge about depression	In-depth interviews PhD dissertation	Thematic analysis – phenomenological approach	N=30 Depression diagnosis or self-identified	Life course perspective of depression Resilience Recovery takes time

Experience and Knowledge USA – San Francisco	and experiences			Socio-demographic: Age: 75+ (median age 80) Gender: 44% M, 56% F Ethnicity: 80.6% White Caucasian Education: 42% had graduate degrees, majority affluent	Self-management strategies, keeping busy, prayer, volunteering Talking to someone important Relationship to antidepressants complex – <u>Quality:</u> Good (CASP 10/10)
Lawrence et al (2006): Coping with depression in later life: a qualitative study of help-seeking in three ethnic groups UK (London)	Explore older adults' attitudes and beliefs regarding what would help someone with depression. Comparison of 3 ethnic groups	Semi-structured interviews	Thematic analysis	N=67 (depressed, not treated sample). Socio-demographic: Age: 65-90+ (mean age not stated, majority 65-80) Gender: mixed Ethnicity: Black Caribbean, S. Asian, White British Urban Range of socio-economic diversity	Individual responsibility for combatting depression Prayer important, especially in Black Caribbean group Family as important source of help, especially for S Asian <u>Limitations:</u> Unclear regarding strength of findings in depressed group <u>Quality:</u> Acceptable (CASP 10/10)
Ward et al (2014): Older African American women's lived experiences with depression and coping Behaviours USA	Explore elderly African-American women's experience with depression and how they deal with it	Semi-structured interviews	Transcendental phenomenological research analysis	N=13 Depressed sample Socio-demographic: Age: 60-78 (Mean age 71) Gender: all female Ethnicity: African-American Education: Highest level 8 th grade, lower SES	Depression as normal reaction to difficult life situations Did not see need for professional help Stigma Culturally sanctioned coping mechanisms - religion, resilience, activities <u>Quality:</u> Good (CASP 10/10)
Van der Weele et al (2012): Response to an unsolicited intervention offer to persons aged >75 years after screening positive for depressive symptoms: a qualitative study	Explore limiting and motivating factors in accepting or refusing an offer to join a 'coping with depression course', and perceived needs among >75 year olds who screen positive for depressive symptoms in	In-depth interviews of people recruited from a RCT who screened positive for depression (GDS >/5) and offered 'coping with depression course'	Thematic analysis – unclear RE methods	N=23 (5 accepted course, 18 refused) Socio-demographic: Age: 79-85 (mean 82) Gender: 17 F, 6 M 5 accepted course (22%), 18 refused Majority middle or high income	Denial of depressive symptoms, concerns over group participation Access issues – transport, physical health, multiple health appointments Depression seen as more severe mental state than they were experiencing. Different vocabulary to describe depression <u>Limitations:</u> Not clear where study was carried out, little demographic information

Netherlands (not explicitly stated)	General Practice			18% living independently	<u>Quality</u> : Acceptable (CASP 10/10)
Wilby (2008) : Coping and Depression in Community Dwelling Elders USA (Salt Lake County)	Explore coping strategies of older people with depression and their perceived effectiveness	Mixed methods (including in-depth interviews) PhD dissertation	Regression analysis Thematic analysis (research Qs 4 and 5)	N=21 (depressed group used for SR, though total participants 91) Socio-demographic : Age: 65+ (72% <80 yrs old) Gender: mixed Ethnicity: 95% White Caucasian Higher socioeconomic status	Self-management preferred Lack of confidence in mental health treatment Barriers to seeking treatment – influenced by previous negative experiences <u>Limitations</u> – no idea of demographics of depressed sample <u>Quality</u> : Acceptable (CASP 10/10)
Stark et al (2018) : A Qualitative study on older primary care patients' perspectives on depression and its treatments – potential barriers to and opportunities for managing depression Germany (Hamburg, Mannheim, Bonn)	Explore older people's perspectives on depression and its treatment	Semi-structured interviews	Qualitative content analysis	N=12 Depressed sample on screening Socio-demographic : Age: 75+ (median 81) Gender: mixed No other demographic data provided	Variance in views regarding the treatment of depression (both positive and negative) and about the GP's role in managing depression Stigma and fear of negative reactions <u>Limitations</u> : no demographic data provided <u>Quality</u> : Good (CASP 10/10)

List of abbreviations used

ⁱ N = number of participants in study

ⁱⁱ M = male

ⁱⁱⁱ F = female

^{iv} CASP = Critical Appraisal Skills Programme checklist