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# BMJ Open

## The experience of depression in older adults with and without a physical long-term condition: findings from a qualitative interview study.

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3 **The experience of depression in older adults with and without a physical long-term condition: findings from**  
4 **a qualitative interview study.**  
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7  
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**Abstract**

Objective: To understand how the lived experience of depression differs among patients with a long-term condition (LTC) compared to those without an LTC, and how the experience differs across different types of LTC.

Design: Face-to-face, semi-structured, interviews.

Setting: Primary care; GP surgeries in and around North London.

Participants: 42 primary care patients with depression were recruited. Our sample comprised participants aged 55-75 years old with depression only (n= 12), depression and coronary heart disease (n=5), depression and type 2 diabetes (n=10) and depression and arthritis (n=14).

Results: Interviews were conducted, audio-recorded, transcribed, and analysed using thematic analysis. The results revealed that the cardinal diagnostic symptoms of depression (anhedonia, sadness) were experienced by all our participants regardless of LTC. However, the LTC did interact with depression by compounding somatic, cognitive and emotional symptoms, increasing disability and reducing independence, and hindering attempts at coping with mental illness. Our findings demonstrate common experiences across patients, as well as key differences based on LTC.

Conclusions: We suggest four key implications for future care practices of these patients: (1) Not all participants with depression and LTC view their mental and physical health as interconnected; there should be allowances in care plans for separate treatment pathways; (2) Key features of depression that affect LTC management are social withdrawal and lack of motivation to self-manage or access healthcare; (3) Key features of LTCs that worsen depression are pain, the unpredictability of future health and progressive disability; (4) Positive self-management of LTC could improve self-efficacy and therefore mood, and should be encouraged.

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2  
3 *Key words: Depression; long-term conditions; co-morbidity; qualitative research; interview study; thematic*  
4  
5 *analysis.*  
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9

### 10 **Strengths and limitations of the study**

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- 12 • Participant diagnoses derived from clinical records and confirmed by self-report.
- 13
- 14 • Participants were drawn from across multiple sites across North London, with diversity in demography  
15  
16 achieved.
- 17
- 18 • Comparative thematic analysis allowing for comparisons within and between groups.
- 19
- 20
- 21 • Small sample of depression and coronary heart disease cohort.
- 22
- 23
- 24 • Majority female in the depression and arthritis cohort.
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## Introduction

Estimates from the UK Biobank study suggest the prevalence for a single episode of major depressive disorder is 6.4%, varying to 12.2% for moderate recurrent major depression and 7.2% for severe recurrent major depression (Smith et al., 2013), among British adults. Depression has been associated with increased all-cause mortality (Machado et al., 2018); however causality has not yet been determined (Roest & de Jonge, 2018). One possible explanation is that individuals with depression are more than twice as likely to have a concomitant physical long-term condition (LTC), such as diabetes and coronary heart disease.

It has been hypothesised from quantitative investigations of epidemiological and clinical cohort studies that depressive symptoms which occur in cardiac patients are distinct from those experienced in psychiatric populations based on three key differences: composition of symptoms, timeline, and treatment responsiveness (Poole et al., 2011). With regard to symptoms, the hallmarks of psychiatric depression are persistent sadness and loss of interest and pleasure in activities (anhedonia). These are often associated with cognitive changes such as a sense of worthlessness and guilt, among others. By contrast, there is growing recognition that depressive symptoms in people with physical illness are dominated by somatic symptoms, such as fatigue and loss of energy (de Miranda Azevedo et al., 2014; Poole & Jackowska, 2018). In addition, it has been suggested that the chronicity, and the timing of onset of depressive symptoms in relation to the LTC, have implications for morbidity and mortality (Dickens et al., 2008; White et al., 2016). Finally, it appears that different treatment strategies may be appropriate for those living with psychiatric depression compared to those who have comorbid depression (Gold et al., 2020), with particular benefit coming from integrative collaborative care models of healthcare (Knowles et al., 2015). Qualitative data has revealed that depression in physical illness has been shown to have been normalised by health care practitioners leading to barriers in its management (Coventry et al., 2011) and there may be resistance to antidepressant medication among some LTC patients (Simmonds et al., 2013). Given these empirical observations surrounding the differences in depression symptoms, timeline and treatment, some authors have suggested that a separate subtype of depression may exist, driven by biological (inflammatory) changes (Raison & Miller, 2011) which in turn are

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2  
3 implicated in LTCs (Poole & Steptoe, 2020). However, despite a plausible hypothesis for the existence of a  
4  
5 separate subtype of depression in those with an LTC, whether or not this translates to differences in patient  
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7 experience is unclear. Therefore, further qualitative research is warranted to examine whether the lived  
8  
9 experience of depression is similar or different in patients with depression and/or a comorbid LTC.

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11  
12 Furthermore, experiences of depression across LTCs are likely to differ. A meta-synthesis of qualitative  
13  
14 data has suggested that patients with depression and a comorbid LTC either see their mental and physical  
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16 health as either separate and independent from each other, or interrelated with one having caused or  
17  
18 worsened the other (DeJean et al., 2013). However, the similarities and/or differences in how depression is  
19  
20 experienced in different LTCs is currently not well-understood. For example, depression in diabetes has been  
21  
22 revealed to be heterogenous with aspects of diabetes-related distress and demoralisation being apparent  
23  
24 (Gask et al., 2011), while depression in CHD has been associated with loss, both in terms of interpersonal loss  
25  
26 as well as loss of health/control (Simmonds et al., 2013).

27  
28  
29 Therefore, the aim of this study was twofold. First, we aimed to examine how the lived experience of  
30  
31 depression is similar or different between those with an LTC and those without, and second, we aimed to  
32  
33 understand how experiences of depression are similar or different between types of LTC. In order to take into  
34  
35 account the correlation between age and LTC onset, we focussed on the experiences of depression in adults  
36  
37 in mid-late life.

## 42 43 **Methods**

### 44 45 ***Participant selection and recruitment***

46  
47 We recruited a total of 41 participants to this study using purposive sampling to capture a range of clinical and  
48  
49 demographic characteristics. Thirty-seven participants were recruited using mailouts from 14 UK general  
50  
51 practices in the Barnet and Enfield regions of North London; a further one participant was recruited using  
52  
53 opportunistic sampling from GP surgeries in North West London; and a final three participants were recruited  
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55 from the Camden and Islington IAPT (Improving Access to Psychological Therapy) service. Participants were  
56  
57 male and female, aged 55-75 years old and English speaking. All participants were screened for current  
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3 depression by participating GP practices via electronic and hand searches of medical records. Current  
4  
5 depression was defined as a patient who had either received a clinical code of depression by their GP and/or  
6  
7 had received a referral or prescription for depression treatment in the preceding two months. All participants  
8  
9 were medically stable outpatients living within the community. We excluded patients with a severe cognitive,  
10  
11 mental or psychological impairment that would impede their ability to provide informed consent.  
12  
13

14 To compare patients living with depression, with and without an LTC, we recruited patients to one of  
15  
16 four participant groups: depression only, depression and CHD, depression and T2D, and depression and  
17  
18 arthritis. To reduce cross-over between the groups, participants with more than one LTC of interest (i.e.  
19  
20 diabetes and arthritis) were excluded. We also excluded those with another LTC such as cancer, stroke and  
21  
22 chronic lung disease to allow us to focus our discussions more easily on our chosen LTCs. The LTCs were  
23  
24 selected based on *a priori* knowledge to elicit a variety of illness experiences: coronary heart disease can have  
25  
26 an acute, life-threatening presentation (e.g. acute coronary syndromes); T2D involves monitoring and self-  
27  
28 management of blood sugar levels and can lead to acute episodes of illness (hypoglycaemia); arthritis is  
29  
30 associated with pain and functional impairment.  
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34 Practice GPs reviewed the list of those to approach prior to mailout and removed people that met the  
35  
36 exclusion criteria or they considered inappropriate to contact. The mail-out included full details of the study  
37  
38 and interested patients were invited to contact the research team to discuss participation. Patients were  
39  
40 screened by researchers over the telephone using the same inclusion and exclusion criteria before arranging  
41  
42 a convenient time and place for the interview to take place.  
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#### 46 ***Interview data collection***

47  
48 We conducted semi-structured face-to-face interviews, mainly at participants' homes or in a meeting room at  
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50 UCL (or another convenient location if requested), lasting approximately one hour (range 42–97 minutes).  
51  
52 Interviews were carried out between May to October 2019. Interviews were conducted by HR (n = 40) or LP  
53  
54 (n = 1), both health psychology researchers. The interviews began by presenting participants with four short  
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56 vignettes for participants to read and reflect on. The vignettes contained the experiences of fictional  
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3 characters written in the third person (see Appendix 1) and were designed to encourage participants to reflect  
4  
5 on their own symptoms of depression. This method is well-established for eliciting detailed information on  
6  
7 sensitive topics in qualitative research (Hughes & Huby, 2012). The interview then covered a number of topics,  
8  
9 to explore the experience of living with depression: diagnosis, precipitating events, symptoms, change in  
10  
11 experience over time, management of depression and treatment preferences. In participants with a comorbid  
12  
13 LTC we also explored the impact of depression on their physical illness and vice versa. The topic guides (see  
14  
15 Appendix 2) were modified as interviews progressed, through team discussions. To circumvent issues  
16  
17 surrounding stigma, initial questions steered clear of clinical labels, and instead invited participants to reflect  
18  
19 on 'changes to their mood'. As each interview progressed the interviewer used the participants' own  
20  
21 terminology. After each interview, demographic data and self-reported medical information were collected.  
22  
23 Participants were provided with relevant local and national mental health service information and a £10 retail  
24  
25 voucher honorarium. Any concerns over participant safety (including suicidal ideation and self-harm) were  
26  
27 discussed with the senior researcher (LP) before contacting participants' GP with their consent. A Standard  
28  
29 Operating Procedure was in place for this. Interviews were audio-recorded, with brief field notes, transcribed  
30  
31 verbatim by an external company and anonymised and verified for accuracy by the research team (HR and LP).  
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### 39 **Data analysis**

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41 We used reflexive thematic analysis (Braun & Clarke, 2006, 2021) to analyse our data from a realist/essentialist  
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43 perspective in which a (mostly) one-way relationship is taken to operate between meaning, experience and  
44  
45 language. All transcripts were read by HR and LP; GB and RF read a subsample. Data analysis was led by LP.  
46  
47 Transcripts from each group were first read and analysed inductively, separately, to enable us to build an  
48  
49 understanding of the idiographic qualities of the dataset (Braun & Clarke, 2006); inductive analysis is a bottom-  
50  
51 up approach where the codes and themes are driven by the data and not by a theoretical framework. Each set  
52  
53 of transcripts was read repeatedly, and codes were developed by LP in conjunction with HR. Codes were then  
54  
55 grouped to construct themes; refined through team discussions and piloting. Coding of transcripts was  
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57 performed using NVivo 12 (QSR International Pty Ltd., 2018) according to the thematic framework. After  
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3 conducting the initial analysis across the entire dataset, we tabulated the themes and subthemes using Excel  
4 (Microsoft for Windows 365) to allow us to systematically explore the similarities and differences in  
5 experiences across groups. This approach was informed by Framework Analysis (Ritchie & Spencer, 2002) and  
6 has been combined with thematic analysis by previous researchers conducting comparative qualitative  
7 analysis (Marcu et al., 2017). The indexing and charting of the data enabled us to maintain rigour in the analytic  
8 process. Themes were then written out and refined with feedback from team. The study was approved by NHS  
9 London – Fulham Research Ethics Committee (reference: 18/LO/2150).

## 10 11 12 13 14 15 16 17 18 19 20 21 **Results**

### 22 23 **Participants**

24 Out of 137 patients who expressed an interest in the study, 45 were eligible and 41 completed interviews.  
25 Participants were grouped into 4 cohorts based on their medical records and verified during screening  
26 telephone calls: depression only (n = 12), depression and CHD (n = 5) and depression and type 2 diabetes  
27 (T2D) (n = 10) and depression and arthritis (n = 14). In terms of CHD, patients in this group had received a  
28 diagnosis for myocardial infarction (n = 1), angina (n=2) and heart failure (n = 2). In terms of arthritis, patients  
29 in this group included those with rheumatoid arthritis (n = 2) and osteoarthritis (n = 12). Overall, participants  
30 were aged 63.5 years (standard deviation (SD) 5.5) and we sampled roughly equal numbers of men and  
31 women. However, the majority of depression and arthritis participants were female (93%). Approximately  
32 one-third of the sample were from a non-White ethnic group and 85.4% of all participants were taking  
33 antidepressant medication(s) at the time of the interview. The characteristics of the sample are presented in  
34 Table 1.  
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### 52 53 **Thematic overview**

54 We generated five overarching themes that encompass the experience of living with depression in those with  
55 and without an LTC. In each theme we have drawn out the relationship between the experience of depression  
56 in those with and without an LTC, and where relevant, compared this across the different LTC groups (CHD,  
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3 T2D and arthritis). Across all the themes, we found that the experience of depression and LTCs acted to  
4 compound the effects of each other; this was particularly apparent for those whose illness had resulted in  
5 changes to daily living. Figure 1 presents a schematic diagram of our themes.  
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10 ***Theme 1: Shaped by the course of time***

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12 Across our sample, depression was not static; it was shaped by individuals' life histories and past events. The  
13 experience of depression also shifted over time so that as people's lives progressed, different triggers for new  
14 episodes became more apparent. In those with an LTC, hardship brought about by their LTC and a loss of  
15 health was described by some as a trigger for depression.  
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22 ***Depression onset (first-ever episode)***

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24 In participants with and without LTCs, the onset of the first-ever episode of depression occurred at different  
25 ages; many could identify roots for their depression in childhood or adolescence, while others had received a  
26 diagnosis more recently. Across the groups, most participants were able to identify a precipitating adverse life  
27 event(s) to their first-ever depressive episode such as financial insecurity, (multiple) bereavement, a  
28 relationship breakdown, children taken into care, and physical and sexual abuse. For some, seemingly smaller  
29 grievances, had accumulated over time to initiate the first-ever episode of depression.  
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39 In contrast to the depression-only participants, in participants with an LTC, life histories revealed two separate  
40 discourses relating to the onset of the initial depression diagnosis: coincidental and interconnected. As such,  
41 for some, the LTC was coincidental to the onset of the depression, with the depression and LTC diagnoses  
42 occurring at different times and in relation to different precipitating/surrounding events. This discourse was  
43 predominately discussed by those with T2D, and to a lesser extent the CHD cohort. These individuals had a  
44 clear narrative about the onset of their depression, that was related to other life pressures such as caring  
45 responsibilities, fraud allegations and work rather to their LTC:  
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55 "I don't think so. I don't really think so. I had no qualms about my health. It was the other things. The  
56 inferiority complex, the pressure of work and the unhappiness with my married life. It was those  
57 things." (P.39, depression and T2D, male).  
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3 “I honestly can’t say that [depression] is the reason of that [CHD]. But yes, when you have I suppose  
4 chest pain you think about it, you sit down, you [pause]. But I don’t think it took me into depression  
5 at that time or anxiety or something.” **(P.45, depression and CHD, male).**  
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10 The second discourse highlighted the interconnected nature of the initial depression and LTC diagnosis. For  
11 these participants, depression was a new experience, and was directly attributed to their LTC, or its  
12 implications (e.g. hospitalisations, loss of mobility, job loss). The type of LTC did not make a difference, only  
13 whether the LTC was associated with unpredictable, major, and irreversible upheaval.  
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19 “Depressed? It was when I came out of hospital after having my triple bypass because my life changed  
20 completely. I lost my job, my relationship broke up, the kids and all that and I just sort of had a sort of  
21 breakdown and that was it really.” **(P.44, depression and CHD, male).**  
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### 26 *Relapsing and episodic*

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28  
29 Across all participants, after the initial onset, the experience of depression had a varying time course. A few  
30 participants had new onset depression. However, for the majority of participants, their history of depression  
31 was chronic, with repeated episodes over time. This had led to a familiarity with when a new ‘bout’ was coming  
32 on, even if there was no discernible trigger.  
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39 Where there was a clear trigger for a new episode of depression, this was often a difficult life event, such as a  
40 child going to prison or a transition to retirement. However, for some people with chronic, pre-existing  
41 depression, the LTC had also triggered a new episode. This led to a new experience of depression for these  
42 participants, which was not centred around their earlier difficult life circumstances which had originally  
43 brought about their depression. Instead, the LTC raised fears surrounding declining health, death and frailty,  
44 which fed into the new depressive episode:  
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52 “The depression since then that was different. It was felt trapped then ... I was full of tension, full of  
53 uncomfortable feeling with him. I just couldn’t, it was like having a snake you know circling around  
54 you know... So that is thank God I don’t have that. The depression that I feel in this and that is because  
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3 of my health problems and that bothers me, that bothers me a lot.” (P.22, depression and CHD,  
4  
5 female).

## 8 **Theme 2: Somatisation**

10  
11 Somatic symptoms of depression were frequently experienced by our participants, in those with and without  
12  
13 an LTC. The experience was largely similar across our four cohorts. Differences did exist in sleep disturbance  
14  
15 and crying, with LTCs (mainly arthritis but also T2D) contributing to the experience of these somatic symptoms.

### 18 *Universal somatic symptoms*

20  
21 Somatic symptoms were discussed by all our participants, irrespective of LTC. Symptoms discussed included  
22  
23 appetite changes (including over- and under-eating), crying, and loss of intimacy. By far the most common of  
24  
25 all the somatic complaints was sleep disturbance. Some described difficulties falling asleep, restless and  
26  
27 disturbed sleep, vivid dreams and nightmares, and difficulty getting out of bed in the morning. Psychomotor  
28  
29 retardation was another common somatic complaint linked to fatigue, which was experienced across all  
30  
31 groups, irrespective of LTC.

34  
35 “Really, really very slow, very sluggish. Very physically, very physical. In fact, almost as physical as it is  
36  
37 mental.... Yeah like you’re swimming. Like you’re swimming against a sea of something coming at you.  
38  
39 And you’re trying to wade yourself through and knowing that if you, and no energy, zero physical  
40  
41 energy.” (P.13, depression only, female)

### 44 *Somatic symptoms and interactions with LTCs*

46  
47 For those with an LTC, the illness also directly contributed to the experience of somatic symptoms of  
48  
49 depression. Sleep was negatively affected by the LTC through worries about managing the condition (as with  
50  
51 P.2 with T2D) or pain. Pain was particularly associated with participants in the depression and arthritis cohort.

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54  
55 “I haven’t been a very good sleeper lately; I don’t sleep the full 8 hours that they say you should do. I  
56  
57 do think about things and one of the things obviously I do think about is make sure my diabetes is  
58  
59 correct.” (P.2, depression and T2D, male).

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3 “I can’t sleep at night because of pain... And even at night I get a lot of pain in my back and that so I  
4 am just putting my legs round 10 times this way and 10 times that way because I can’t sleep.” (P.4,  
5  
6  
7 **depression and arthritis, female**).

8  
9  
10 While crying was frequently described across all our participants, in our arthritis participants we observed a  
11 unique contribution of the LTC. Arthritis (and in particular arthritic pain) compounded the emotional and  
12 somatic experience of depression, and could prompt tears of fear and frustration.  
13  
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16  
17 “I am chopping up the onions, I have to go and sit down because the pain in my back is such that I  
18 can't, I have to sit down. And like I have cried with it, not just from the onions but real tears, through  
19 frustration I suppose and pain.” (P.41, **depression and arthritis, female**).

### 20 21 22 **Theme 3: Cognitive and emotional burden**

23  
24  
25 In this theme the participants’ lived experience of the cognitive and emotional symptoms of depression are  
26 described. These key diagnostic symptoms of depression were clearly experienced by all our participants.  
27 However, we observed compounding and indirect routes linking LTCs with the cognitive and emotional burden  
28 of depression; moreover, thoughts of death were particularly prominent within the depression and CHD  
29 group.  
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#### 39 *Universal cognitive and emotional symptoms*

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42 Participants, regardless of LTC, had an overwhelming sense of disinterest in the world around them; they  
43 described a deep-rooted sadness, hopelessness, worthlessness and low self-esteem. Some felt as though they  
44 were being punished.  
45  
46  
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48  
49 “You get what you deserve in life. And I don’t deserve nothing. You know, I wasn’t a good father when  
50 I was young. I was selfish. And it’s come back and bit me up the bum, bit me on the bum. ...” (P.12,  
51  
52  
53 **depression only, male**).

#### 54 55 *Compounding effects of LTC on cognitive and emotional depressive symptoms*

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2  
3 For some, the combination of the LTC and the depression led to a compounding effect on the cognitive and  
4  
5 emotional depressive symptoms. In this way, the LTC directly contributed to the participants' experience of  
6  
7 depression. This was particularly observed in those with T2D and arthritis.  
8

9  
10 "I'm sitting there and taking the blood and giving myself injections and some days I just think, you  
11  
12 know, how come it's come to this? And I know how it's come to this because, you know, I'm not  
13  
14 managing my life in any sensible way, and I know that." **(P.25, depression and T2D, male).**  
15

16 For participants with severe arthritic pain, pain was seen as an all-consuming and debilitating experience,  
17  
18 which led to misery.  
19

20  
21 "I'm getting pain back in my right knee and I'm going to have to eventually have that one done. It's  
22  
23 really, oh god, what does that feel like? When I'm not feeling ... oh ... it feels like having been almost  
24  
25 injected with negativity." **(P.28, depression and arthritis, female).**  
26

27 For P.32 her depression and the functional limitations imposed by her arthritis were difficult to unravel, with  
28  
29 both acting in synergy to lead to a sense of hopelessness:  
30

31  
32 "I'm also physically unable to do as much as I would like to do in terms of just - housework and  
33  
34 shopping and it's difficult to pull it apart which is leading the sort of feelings of hopelessness and you  
35  
36 know is it worth it and I can't, I might as well just stay in bed." **(P.32, depression and arthritis, female).**  
37

38  
39 *Indirect effects of LTC upon cognitive and emotional depressive symptoms through affecting enjoyment of*  
40  
41 *activities*  
42

43  
44 For some of our LTC participants, the depression was a greater burden than their LTC, so cognitive and  
45  
46 emotional depressive symptoms were experienced regardless of their LTC. In this way, some of our LTC  
47  
48 participants experienced feelings of anhedonia, worthlessness, guilt, sadness, etc., similarly to the depression  
49  
50 only participants. However, for others, the LTC (notably T2D and arthritis) fed into the experience of cognitive  
51  
52 and emotional symptoms by removing their enjoyment of previously pleasurable activities.  
53

54  
55 An example comes from P.2, whose diabetes directly contributed to his feelings of anhedonia. This participant  
56  
57 was particularly concerned about managing his blood glucose levels during social situations.  
58  
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60



1  
2  
3 “You are part of it because you are invited, you all go out, you are all friends, you have known one  
4 another for years and everything is there, but you don’t feel as if you are really taking part if you get  
5 what I am saying. So that’s the part of the mood I have found since I have been diagnosed with  
6 diabetes and that’s the thing that holds me back from properly being 100% committed to enjoying it.”  
7  
8  
9

10  
11  
12 **(P.2, depression and T2D, male).**  
13

14 Pain also featured heavily in the descriptions of altered lifestyles recounted by our arthritis participants,  
15 perpetuating feelings of anhedonia.  
16

17  
18  
19 “That’s, and I do enjoy my food, I do enjoy cooking. I mean I haven’t had a dinner party now for over  
20 a year. I have always enjoyed doing that. But that’s, and it’s like washing up, you know I can do so  
21 much, [...] but you know like my washing up is in stages. I will do this first, then go and sit down, come  
22 back and do that lot, the next lot, then go and sit down. [...]. That is where the arthritis and depression,  
23 they are like, they join forces.” **(P.41, depression and arthritis, female).**  
24  
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30  
31 *Indirect effects of LTC on cognitive and emotional symptoms by causing a loss of control and independence*  
32

33 Financial insecurity and unequal personal relationships were experienced by many of our participants,  
34 irrespective of LTC, and had contributed to feelings of being out of control. Deteriorating physical health  
35 (particularly for those with arthritis) and increasingly frailty, had also led to feelings of loss of control for some.  
36 This was linked to feelings of loss of independence, which in turn led to feelings of depression.  
37  
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40  
41  
42 “Some of my clothes are high up, I can never reach them unless somebody is there, that makes me  
43 depressed having to rely on somebody all the time.” **(P.4, depression and arthritis, female).**  
44  
45  
46

47  
48 *Thoughts of dying*  
49

50 Suicidal ideation, thoughts of death (but not suicide) and actual suicide attempts were disclosed in participants  
51 with and without LTCs. Although the presence of an LTC did not influence suicidal thoughts, having CHD was  
52 an important leveller for these participants. These participants lived with the unpredictable nature of their  
53 illness and the threat of sudden and irreversible loss of health:  
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3 “Even now I still think about it because when I just took a deep breath here, I felt a bit of a twinge  
4 there and it’s when I got told about it, it was very disturbing because I was shown the blockage [...]  
5 and although I’ve been reassured that it won’t go up, block my heart or anything like that, but it makes  
6 you wonder because you never know what might happen.” **(P.30, depression and CHD, male).**  
7  
8  
9

10  
11  
12 For P.44 his brush with death due to having a heart attack has given him a greater acceptance of death:  
13

14 “Well I just didn’t give a shit about anything anymore, you know, apparently according to them I died  
15 twice, so I didn’t give a shit no more about it, death doesn’t scare me no more.” **(P.44, depression and**  
16  
17  
18  
19 **T2D, male).**

20  
21 For others with CHD, they were also having to confront death, but they discussed their fear surrounding a  
22 prolonged or sudden death:  
23

24  
25 “I keep saying to my sister, ‘I don’t care if I die actually in my sleep that will be fine. But if I don’t die  
26 and I can’t move, like I said to you if I can’t move and I can’t get up and can’t call that horrifies me.’  
27 That is enough to, well you know.” **(P.22, depression and CHD, female).**  
28  
29

30  
31  
32 “So, since that day, perhaps I have, it wasn’t so much when I had the heart bypass, but since the  
33 [aortic] aneurism and everything else, [...] I worry that every time I go to bed, I don’t know if I’m going  
34 to wake up. You know. So, I worry about that.” **(P.30, depression and CHD, male).**  
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#### 40 41 ***Theme 4: Depression symptoms thwart self-care***

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43  
44 In this theme we draw on the ways in which the experience of depression impeded our participants’ ability to  
45 take care of themselves; many described not washing or brushing their teeth, not wanting to cook proper  
46 meals, and retreating from their social network. This was apparent for all our participants but added an extra  
47 layer of complexity to participants with an LTC.  
48  
49  
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#### 51 52 53 ***Depression leads to lack of motivation to self-care***

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3 Depression was associated with an apathy which led to a loss of interest in behaviours that might lead to  
4 improved self-care. This was true of behaviours that might improve the depression itself such as engaging in  
5 social activities and exercising, as well as those important for managing LTCs.  
6  
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10 The impact of depression on attempts to control diabetes could lead to self-neglect, both in terms of  
11 medication adherence and adherence to medical appointments.  
12  
13  
14

15 “I suppose the most obvious impact is there are days when I just can’t be bothered to take my  
16 medication, both the medication for the depression and the insulin for my diabetes and I know it’s  
17 stupid [...]” **(P.25, depression and T2D, male).**  
18  
19  
20  
21

22 “there are times now when I wouldn’t not turn up for an appointment, absolutely, I just [...] But yes,  
23 there are times when I just think “what’s the bloody point?” in dealing with daily stuff.” **(P.25,**  
24 **depression and T2D, male).**  
25  
26  
27  
28

29 Exercise was seen as an important self-care behaviour for both mental and physical health among our  
30 participants. However, P.32 described how her lack of motivation to exercise was contributing to her physical  
31 decline, which in turn compounded her feelings of depression.  
32  
33  
34  
35

36 “As for the physical side of things, again, I suspect they would like [me] to say, I’ll lose weight, get  
37 more exercise and it’s very difficult when you don’t want to go out of the house, particularly I haven’t  
38 the confidence to go into a gym or to a swimming pool, it’s not really, you know. [...] So, and the other  
39 fear is, of course, the older I get, the general, you know, aging and infirmities, you know, yeah, it  
40 worries me greatly. You know, and it doesn’t help the depression to lift. **(P.32, depression and**  
41 **arthritis, female).**  
42  
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#### 50 *Social withdrawal prevents self-care behaviours*

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52

53 Many participants described how their attempts to cope had been thwarted by the depression itself. This was  
54 particularly true for those whose depression had led to social withdrawal. The retreat from daily life saw  
55 participants becoming withdrawn from both the outside world and their family and friends. Social withdrawal  
56  
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2  
3 impacted on participants' management of their LTC. This was observed particularly in those with T2D and  
4  
5 arthritis.

6  
7 "I did find it hard to leave the house sometimes, you know. You'd just sort of eat what was there rather  
8  
9 than go shopping, you know." (P.27, depression and T2D, female).

10  
11  
12 "Well they said because of the way, it's not helped, because I stopped, I wouldn't get out of the house,  
13  
14 I was staying in my room, that can affect arthritis because then you are letting it seize up more." (P.3,  
15  
16  
17 **depression and arthritis, female**).

18  
19  
20 As seen with those experiencing a lack of motivation, social withdrawal also negatively impacted participants'  
21  
22 willingness to engage with medical professionals (both for depression and/or the LTC).

23  
24 "I mean even the doctor, I have got to phone her tomorrow, they are going to arrange for the nurse  
25  
26 to come out because I am overdue blood tests and blood pressure and that [...]. Because she knows  
27  
28 that I just don't want to leave the house again." (P.3, depression and arthritis, female).

### 31 32 ***Theme 5: Requires wilful effort to manage***

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34  
35 The experience of depression was described as an active process, requiring an individual to find ways to cope.  
36  
37 For some with an LTC, efforts to cope with their depression were thwarted by the functional limitation  
38  
39 imposed by their illness. Controlling the LTC was also important to help manage the depression.

#### 40 41 42 *Universal coping strategies*

43  
44  
45 While many of our participants struggled to cope, nearly all engaged in some strategies to navigate their  
46  
47 current situation such as the use of alcohol and food, medical treatments, and drawing on friendships and  
48  
49 family members for support. Often this included attempts to mask feelings as a means to find comfort; alcohol  
50  
51 in particular was frequently described as a way to relax and forget.

52  
53  
54 "But what I have done, and I have been guilty of, is purchasing alcohol and trying to blot it out with  
55  
56 the alcohol." (P.23, depression and arthritis, female).

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2  
3 Many participants were engaged with healthcare professionals for depression management. For some anti-  
4  
5 depressants had been beneficial, making their symptoms less severe. However, for others, side effects or fears  
6  
7 surrounding dependency prevented their use.  
8

9  
10 “Most of us are given medication, which makes you zombie, anyway. It doesn’t help you. It just block  
11  
12 your pains, you know. You are numb. You are not sorting out. And how long are you going to use those  
13  
14 medication?” **(P.24, depression and T2D, female).**  
15

### 16 17 *LTCs impede efforts to cope with depression*

18  
19  
20 Having an LTC prevented some participants from engaging with coping strategies to help manage their  
21  
22 depression. For those with arthritis this included being unable to take part in activities that promote wellbeing,  
23  
24 including hobbies.  
25

26  
27 “But I think, yeah, so coping, well I am not walking as much as I want to, I have stopped going, I used  
28  
29 to go to water workout, water aerobics every week and I have stopped doing that, partly because of  
30  
31 the difficulty of getting into my bathers and afterwards drying myself.” **(P.1, depression and arthritis,**  
32  
33 **female).**  
34

35  
36 As P.32 described, the combination of her depression and arthritis makes coping with each insurmountable:  
37

38  
39 “You know so the depression makes you lack motivation to, perhaps, I say modify some of the effects  
40  
41 of the arthritis, but the arthritis also, in limiting you, makes the depression seem worse. Together it  
42  
43 seems like a huge, insurmountable problem because if, on their own, they might be manageable, [...].  
44  
45 So it is, yes, it impedes any kind of self-care or therapy, if you like, together.”  
46  
47

### 48 49 *Controlling the LTC improves depression*

50  
51 Interestingly across all LTC groups, those who successfully managed to engage with strategies to cope with  
52  
53 their illness, saw benefits to their mental health through feeling an increased sense of control/self-efficacy.  
54  
55 For example, failure to self-manage insulin dosages appropriately negatively impacted P.25’s mood, while  
56  
57 being in control of his T2D also helped him self-manage his depression.  
58  
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1  
2  
3 “But I carry glucose around with me. ... I think we were away somewhere and, but I was completely  
4  
5 useless for about two hours and I suppose I, you know, I had a moment of clarity about the need to  
6  
7 keep on top of it properly, because I sort of knew that if I didn’t, not only would I feel crap, physically,  
8  
9 the idea of feeling crap physically was depressing.” **(P.25, depression and T2D, male).**

10  
11  
12 Interestingly, P.30 with CHD found the unpredictable nature of his cardiac symptoms very distressing, but the  
13  
14 use of his own blood pressure monitor helped him regain a sense of control.

15  
16  
17 “this is my life saver, my BP [blood pressure] machine, I do it every day, [...] I was told 140 over 80,  
18  
19 right, yes, 140, 80, so once it’s within this, I go to sleep a bit better. If I didn’t know what my BP was,  
20  
21 I’d be worried even more.” **(P.30, depression and CHD, male).**

22  
23  
24 For some participants the physical limitations imposed by their LTC led to social isolation. This was particularly  
25  
26 apparent for those with arthritis. If participants received support with things that their arthritis prevented (for  
27  
28 example housework, food shopping), this was seen as positive for managing their depression, allowing them  
29  
30 to live well within the limits of the LTC.

31  
32  
33 “So yeah, [lady friend’s name] and [man friend’s name] took me out yesterday to go to Aldi, it’s the  
34  
35 first time since February that I have gone out to the shops.” **(P.3, depression and arthritis, female).**

## 36 37 38 39 40 **Discussion**

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42  
43 This paper explored the lived experience of depression in primary care patients with and without a comorbid  
44  
45 physical LTC (CHD, T2D and arthritis). Using thematic analysis, we generated five overarching themes. ‘Shaped  
46  
47 by the course of time’ revealed a shifting, non-linear experience of depression in which the experience was  
48  
49 defined by earlier life experiences as well as more minor, cumulative events. For some, the LTC diagnosis had  
50  
51 caused catastrophic upheaval to participants’ lives; for these individuals the LTC was capable of triggering  
52  
53 depression (both first-ever or a recurrent episode). For many, other life events were more prominent to  
54  
55 determining the course of depression; for these participants the LTC was coincidental, running alongside the  
56  
57 depression but not triggering new episodes. ‘Somatisation’ highlighted the physical experience of depression  
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2  
3 in our participants; for many, these symptoms were as dominant as the cognitive and emotional symptoms.  
4  
5 Somatic symptoms were universally experienced across all our groups, in particular feelings of tiredness and  
6  
7 fatigue and changes to eating habits. Where LTCs did interact with the somatic symptoms, this was mainly  
8  
9 driven by arthritic pain contributing to and compounding these symptoms. 'Cognitive and emotional burden'  
10  
11 explored the impact of mental symptoms, such as feelings of worthlessness, guilt, punishment, anhedonia and  
12  
13 sadness, on participants. LTCs compounded these cognitive and emotional experiences as well as indirectly  
14  
15 contributing to a worsening of these symptoms by affecting participants' enjoyment of previously pleasurable  
16  
17 activities and causing a loss of control and independence. Thoughts of dying were frequently experienced, and  
18  
19 prominent in patients with CHD where the unpredictability of future health was a psychological challenge.  
20  
21 Theme 4, 'Depression symptoms thwart self-care' examined how depression itself acts as a barrier to  
22  
23 engagement in self-care behaviours. Loss of motivation and social withdrawal and were key aspects of the  
24  
25 depressive experience which thwarted attempts for LTC self-management (particularly those with T2D).  
26  
27 Finally, 'Requires wilful effort to manage' revealed universal engagement in many coping strategies,  
28  
29 particularly attempts to mask depressive feelings such as the use of alcohol and food. However, LTCS  
30  
31 (particularly arthritis) did impede participants' ability to cope with depression, while successful management  
32  
33 of the LTC had a positive impact on mood.  
34  
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39 Findings from quantitative studies continue to make attempts to understand the relationship between  
40  
41 depression in LTCs, with the causal model thought to be bidirectional (Gold et al., 2020). Our findings  
42  
43 supported the notion that the LTC was capable of triggering depression; however, this was restricted to those  
44  
45 whose LTC has caused major life upheaval (e.g. loss of employment, relationship breakdown). It has been  
46  
47 estimated that around 80% of initial depressive episodes occur after a stressful life event (Mazure, 1998); and  
48  
49 that the severity of stressors required to precipitate recurrent depressive episodes decreases over time  
50  
51 (Tennant, 2002). None of our participants described their depression acting as a precursor to their LTC. In fact,  
52  
53 for many, the LTC was experienced as coincidental to the onset of depression; this is a view that has been  
54  
55 supported by a previous qualitative meta-synthesis (DeJean et al., 2013).  
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3 The difference in the experience of depression in those with and without an LTC has not been studied  
4 previously using qualitative research. Quantitative research has identified differences in terms of symptom  
5 presentation, chronicity and timing of symptoms, and treatment responsiveness (Poole et al., 2011). Our findings  
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7  
8 have added to this by revealing that while the symptoms of depression (somatic, cognitive, affective) were  
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The difference in the experience of depression in those with and without an LTC has not been studied previously using qualitative research. Quantitative research has identified differences in terms of symptom presentation, chronicity and timing of symptoms, and treatment responsiveness (Poole et al., 2011). Our findings have added to this by revealing that while the symptoms of depression (somatic, cognitive, affective) were universally experienced by those with and without depression, the LTC contributed to the burden of these symptoms by either directly provoking them (e.g. arthritic pain leading to tears of frustration) or by indirectly leading to negative mood by undermining the enjoyment of partaking in previously pleasurable activities as well as reducing individuals' sense of independence. T2D and arthritis were key in this regard since both illnesses were associated with lifestyle changes which negatively impacted the participants' depression, increasing feelings of anhedonia, sadness, guilt and worthlessness. Previous research has explored the impact of arthritis on leisure activities, finding that functional and physical constraints imposed by the illness can affect self-esteem (Wikström et al., 2005). Our findings extend this to the experience of those with arthritis *and* depression, suggesting that these limitations worsen the symptoms of depression. Participants with diabetes also saw a compounding effect of their physical condition on their mental health. This was particularly true for those who described being distressed by T2D and its management. Indeed, diabetes distress is now recognised as a separate disorder to major depression (Kreider, 2017) which has been linked to feelings of burden, difficulties adhering to medication regimes and depression (Tanenbaum et al., 2016).

Loss of control and lack of independence featured heavily in the accounts of our participants with arthritis; whereby functional limitations imposed by the LTC indirectly impacted depression by removing individual's sense of control and autonomy. Loss was a key theme identified in the qualitative UPBEAT-UK study of patients with depression and CHD, where patients described not only loss of health but also interpersonal loss (Simmonds et al., 2013). Health deterioration featured heavily in the accounts of all our participants with a physical LTC, and while thoughts of dying were universally experienced across groups, our CHD group revealed a strong sense of an unpredictable and uncontrollable death, which was not apparent in those with T2D and arthritis. This realistic fear underpinned the experience of depression in these participants.



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3 Our findings also observed differences in the experience of depression in participants' ability to self-care and  
4 to cope with their mental health. Social withdrawal and lack of motivation were commonly experienced in all  
5 our participants. We described how these features of depression thwart attempts to engage with self-care  
6 behaviours such as personal hygiene, meal preparation etcetera, as well as LTC (particularly T2D) specific  
7 illness-management behaviours such as adhering to medication and attending hospital appointments. While  
8 depression has been associated with poor medication adherence in previous quantitative studies of T2D and  
9 CHD patients (Carney et al., 1995; Gonzalez et al., 2007), there has been a lack of qualitative studies describing  
10 the hows and whys of this phenomenon; more research in this area is warranted.

11  
12 Findings from our study revealed the adoption of common coping behaviours across all our participants such  
13 as using alcohol and food to mask symptoms and drawing on expert sources of support; this supports findings  
14 from earlier work (Simmonds et al., 2013). However, importantly we observed that the presence of an LTC  
15 interacted with participants' attempts to manage their depression. Those with an LTC, and in particular those  
16 with increasing disability from their arthritis, were prevented from engaging with coping mechanisms they  
17 had previously adopted to promote mental wellbeing. On the upside, positive self-management of the LTC  
18 improved feelings of control and self-efficacy and in so doing improved depressed mood. Depressed patients  
19 have previously been reported to benefit most from self-efficacy gains from LTC self-management training  
20 (Jerant et al., 2008); the importance of this construct for therapeutic purposes within the modern care setting  
21 of depression and LTC patients, requires future investigation.

22  
23 Our findings have a number of important implications for care models such as the NHS' IAPT-LTC programme  
24 (NHS England, 2018). Our findings suggest that any care model of depression in LTC needs to take into account  
25 four overarching conclusions based on our data: (1) Not all participants with depression and LTC view their  
26 mental and physical health as interconnected; therefore there should be allowances in care plans for separate  
27 treatment (this is a view endorsed by Knowles et al., (2015)). (2) Key features of depression that affect LTC  
28 management and need to be considered when planning treatment and referring to psychological services are  
29 social withdrawal and lack of motivation to self-manage or access healthcare. (3) Key features of LTCs that  
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3 worsen depression that should be discussed during care planning are pain, the unpredictability of future health  
4 and progressive disability. (4) Positive self-management of LTC could improve feelings of control and self-  
5 efficacy and therefore mood, and should be encouraged.  
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10 A strength of our study was in the recruitment of participants from GP practices ensuring all our participants  
11 had received clinical diagnoses of their health conditions. To understand the differences in depression across  
12 different LTCs we excluded participants with more than one LTC of interest and with a serious or life-limiting  
13 diagnosis such as cancer, stroke or dementia. Due to the increased risk of physical illness with age, we recruited  
14 participants within an age bracket of 55 to 75 years; this enabled us to focus on the experiences of adults in  
15 mid to late life. The study was confined to North and North West London; however, we recruited from across  
16 contrasting areas to elicit a range of experiences. Despite our best efforts, unfortunately our arthritis sample  
17 was predominately female (90%); however this may partly reflect the greater incidence of osteoarthritis in  
18 women in the UK (Swain et al., 2020). Our depression and CHD group was small (n=5); therefore our findings  
19 may not reflect the diversity of views that a larger sample might have attained.  
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33 In conclusion, the results of our face-to-face interview study of depression in those with and without a physical  
34 LTC revealed that overall, key diagnostic symptoms of depression (anhedonia, sadness etc.) were experienced  
35 by all our participants regardless of LTC. However, the LTC did interact with depression by compounding  
36 somatic, cognitive, and emotional symptoms, increasing disability and reducing independence, and hindering  
37 attempts at coping with mental illness. Our findings have implications for the development and fine-tuning of  
38 mental health and LTC care programmes.  
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#### 46 **Author Contributions:**

47 LP was responsible for funding acquisition and conceived the study design. GB and RF advised on the study  
48  
49 methods. LP and HR collected the data. LP and RF led the data analysis. GB and HR contributed to the data  
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51 analysis. LP wrote the initial manuscript draft. RF, GB and HR edited the manuscript.  
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**Table 1: Characteristics of the sample, stratified by group**

	Whole sample (N= 41) <i>M±SD or N(%)</i>	Depression only (n = 12) <i>M±SD or N(%)</i>	Depression and CHD (n = 5) <i>M±SD or N(%)</i>	Depression and T2D (n = 10) <i>M±SD or N(%)</i>	Depression and arthritis (n = 14) <i>M±SD or N(%)</i>
Sex (female)	24(58.5)	6(50.0)	1(20.0)	4(40.0)	13(92.9)
Age (years)	63.5(5.5)	62.4(5.5)	66.0(4.0)	61.0(5.2)	65.1(5.9)
Married/cohabiting	17(41.5)	6(50.0)	2(40.0)	5(50.0)	4(28.6)
Ethnicity:					
White British	27(65.9)	10(83.3)	2(20.0)	6(60.0)	9(64.3)
Indian	3(7.3)			2(20.0)	1(7.1)
Pakistani	1(2.4)		1(20.0)		
Black Caribbean	1(2.4)		1(20.0)		
Other White background	7(17.1)	2(16.7)	1(20.0)	1(10.0)	3(21.4)
Other Asian background	2(4.9)			1(10.0)	1(7.0)
Employment status:					
Employed full-time	9(22.0)	3(25.0)	1(20.0)	3(30.0)	2(14.3)
Employed part-time	1(2.4)	1(8.3)			
Self-employed	7(17.1)	3(25.0)			4(28.6)
Retired	15(36.6)	4(33.3)	3(60.0)	3(30.0)	5(35.7)
Unemployed	4(9.8)	1(8.3)		3(30.0)	
Volunteer	2(4.9)		1(20.0)		1(7.1)
Disabled	3(7.3)			1(10.0)	2(14.3)
Highest educational qualification - degree or higher	15(36.6)	3(25.0)	3(60.0)	4(40.0)	5(35.7)
Antidepressant usage (yes)	35(85.4)	9(75.0)	4(80.0)	9(90.0)	13(92.9)

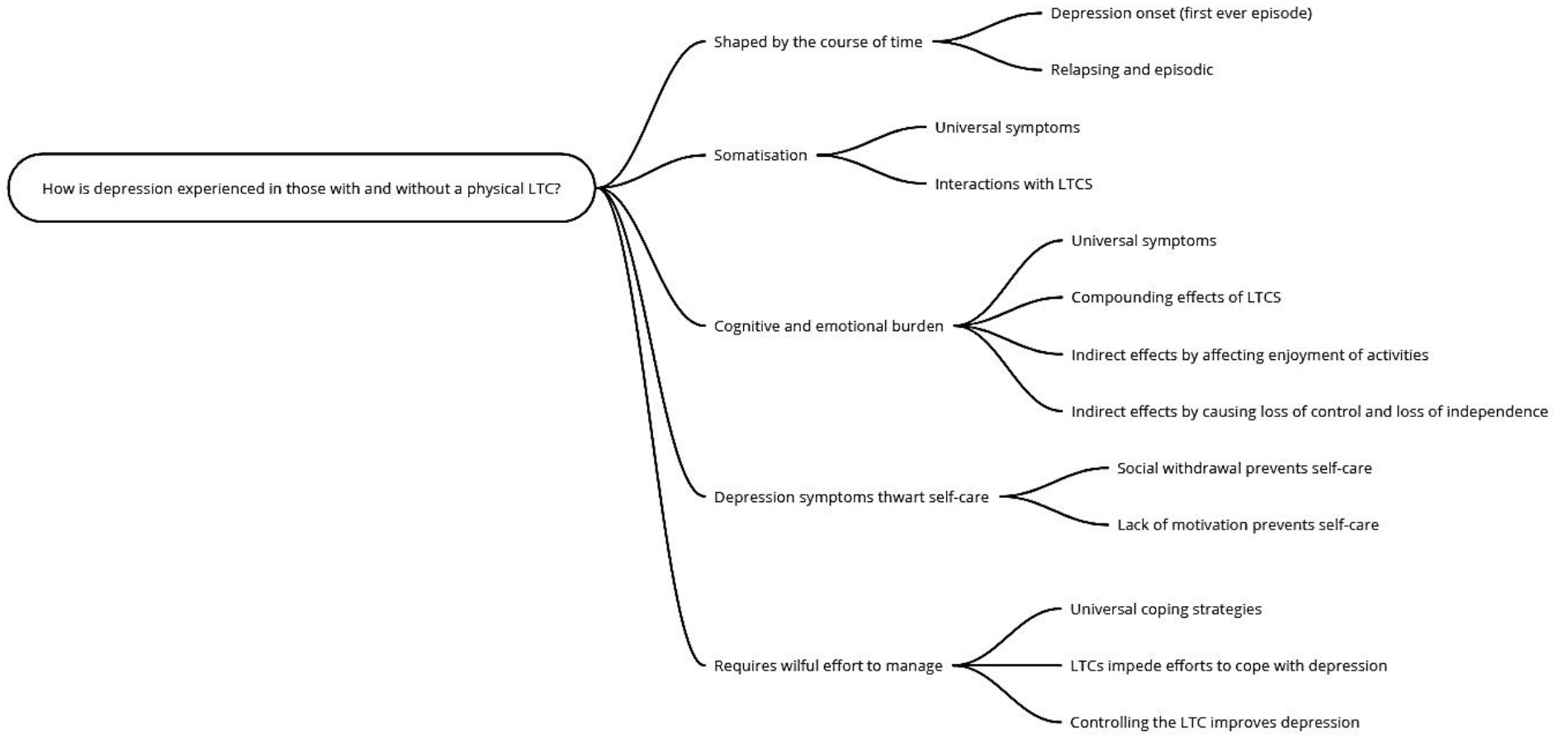


Figure 1. Schematic diagram of theme structure.

N.B. LTC: Long term condition.



Supplementary file: Appendix 1 - Vignettes

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3 **Scenario 1**  
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5 Sarah has good days and bad, but on a bad day she feels so sad and miserable that she just  
6 can't stand it. It seems to completely take over her head like she's in a fog. She feels really  
7 disappointed in herself for feeling this way, despite all the good things she has in her life.  
8 Sometimes when she's by herself she cries and even has thoughts of killing herself just to try  
9 and be anywhere but here. She feels completely worthless.  
10  
11

12 **Scenario 2**  
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14 Most days Sam wakes up and feels so tired he wishes he could just stay in bed. In fact he  
15 feels so tired most of the time that he doesn't want to do anything. He sleeps longer than he  
16 used to and doesn't have the energy to do anything. Sometimes he doesn't even feel like  
17 eating. He's even lost weight without trying to. His partner tries to show him affection and  
18 wants a kiss and a cuddle, but he just feels numb and not interested at all.  
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21 **Scenario 3**  
22

23 Jason finds it really hard to feel positive about the future at the moment, it's like he has  
24 nothing to look forward to anymore. He finds it difficult to concentrate and to make  
25 decisions these days too. He feels so frustrated and trapped by the way he feels. His friends  
26 tell him he should snap out of it, but he just can't. He wishes he didn't have to feel like this,  
27 it makes him feel like such a failure.  
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30 **Scenario 4**  
31

32 Most days Clare feels like she is being punished for something she must have done in a past  
33 life. And then she feels guilty for thinking like this. She seems to worry about her health all  
34 the time and her aches and pains get on top of her. She doesn't enjoy things the way she  
35 used to, in fact she doesn't really get any pleasure out of anything anymore. She finds it  
36 hard to leave the house some days. Everything seems a bit pointless these days, if she's  
37 being completely honest.  
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40 **Scenario 5**  
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42 Susan has always enjoyed her food, but for the past couple of months she's noticed she's  
43 been putting on some extra weight. She finds she craves her favourite foods and is comfort  
44 eating to make herself feel a bit better. She's not sure she is feeling any better though, in  
45 fact she's sleeping really badly and often wakes up several times in the night. Her sleep is  
46 restless and she wakes up tired making each day feel like it drags.  
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## The Mood and Health Study

### Interview Schedule – Depression

#### Introduction

Review of Participant Information Sheet

Consent form

Timing and confidentiality

*My name is [insert name] and I am a researcher. I'm not a doctor or a psychologist and I don't have any clinical contact with your team. I'm interested in finding out from you what your experiences have been with your mood, and there are no right answers.*

#### Vignettes

*To start I'd like you to look at what some other people have experienced, and then we'll talk about them a bit. Firstly, I'd like you to start by sorting the cards into two piles, those which you think are relevant to you and those which aren't.*

<b>Card sort</b>	<p>Can you talk me through how you have sorted the cards?</p> <p>Has anything like this ever happened to you?</p> <p>Have you ever felt these sorts of things before?</p> <p>How do you think this person's experience is different from yours?</p>
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#### Depression

<b>Precipitating events</b>	Take me back, can you tell me about when you first noticed changes to your mood?
<b>Prompts</b>	<ul style="list-style-type: none"> <li>• Can you remember feeling differently?</li> </ul>

	<ul style="list-style-type: none"> <li>• How did it feel?</li> <li>• Was there anything else you think may have contributed to your low mood?</li> <li>• How do you think that experience relates to how you feel today?</li> </ul>
<b>Diagnosis</b>	Can you talk me through the support you received during this time?
Prompts	<ul style="list-style-type: none"> <li>• E.g. family, friends, GP?</li> <li>• How did you find out you had depression? E.g. Who told you? When?</li> <li>• How did you feel when you found out it was depression?</li> </ul>
<b>Timeline</b>	How has your mood been since then?
Prompts	<ul style="list-style-type: none"> <li>• How has your mood changed over time?</li> </ul>
<b>Symptoms</b>	Can you tell me about a time when you felt your depression was at its worst?
Prompts	<ul style="list-style-type: none"> <li>• How did it feel?</li> <li>• How long did it last?</li> <li>• Can you tell me how most days are for you at the moment?</li> <li>• What's a good day for you?</li> <li>• How long have you been feeling this way?</li> <li>• Are there times when you don't feel this way? How long does this last?</li> </ul>
<b>Management of depression</b>	Are you receiving any treatment for your depression at the moment?
Prompts	<ul style="list-style-type: none"> <li>• Can you tell me about the care you have received for your depression from doctors?</li> </ul> <p>e.g. who (GP, clinic nurse/doctor)</p> <p>e.g. where (GP clinic, hospital clinic, community/third sector)</p> <p>e.g. when (routine/booked appointments, length of appointments)</p> <p>e.g. what (antidepressants, counselling)</p>

	<ul style="list-style-type: none"> <li>• Do you find it easy to talk to your doctor about your concerns?</li> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> </ul>
<b>Self-care</b>	<ul style="list-style-type: none"> <li>• Can you talk me through anything you do yourself that helps you cope better?</li> </ul>
Prompts	<ul style="list-style-type: none"> <li>• For example, exercise, eating habits, alcohol consumption, smoking, acceptance, distractions/hobbies, wallowing. Have any of these been helpful to you?</li> <li>• How do these things make you feel?</li> </ul>

### Wrapping up

Is there anything else you would like to tell me?

How have you found this interview?

Do you have any questions?

Thank you for your time.

Give sources of further support handout.

Give baseline questionnaire.

Provide participant with £10 retail voucher.



## The Mood and Health Study

### Interview Schedule – Depression and Physical Illness

#### Introduction

Review of Participant Information Sheet

Consent form

Timing and confidentiality

*My name is [insert name] and I am a researcher. I'm not a doctor or a psychologist and I don't have any clinical contact with your team. I'm interested in finding out from you what your experiences have been with your mood and health, and there are no right answers.*

#### Vignettes

*To start I'd like you to look at what some other people have experienced, and then we'll talk about them a bit. Firstly, I'd like you to start by sorting the cards into two piles, those which you think are relevant to you and those which aren't.*

<b>Card sort</b>	<p>Can you talk me through how you have sorted the cards?</p> <p>Has anything like this ever happened to you?</p> <p>Have you ever felt these sorts of things before?</p> <p>How do you think this person's experience is different from yours?</p>
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#### Depression

<b>Precipitating events</b>	Take me back, can you tell me about when you first noticed changes to your mood?
Prompts	<ul style="list-style-type: none"> <li>• Can you remember feeling differently?</li> <li>• How did you feel?</li> </ul>

	<ul style="list-style-type: none"> <li>Was there anything else you think may have contributed to your low mood?</li> <li>How do you think that experience relates to how you feel today?</li> </ul>
<b>Diagnosis</b>	Can you talk me through the support you received during this time?
Prompts	<ul style="list-style-type: none"> <li>E.g. family, friends, GP?</li> <li>How did you find out you had depression? E.g. Who told you? When?</li> <li>How did you feel when you found out it was depression?</li> </ul>
<b>Timeline</b>	How has your mood been since then?
Prompts	<ul style="list-style-type: none"> <li>How has your mood changed over time?</li> </ul>
<b>Diagnosis of physical illness (if not covered above)</b>	Can you tell me how you found out about your [arthritis/heart disease/diabetes]?
Prompts	<ul style="list-style-type: none"> <li>How long ago was this?</li> <li>Who told you? Where were you?</li> <li>How did you feel when you found out?</li> <li>Did you find out about your [arthritis/heart disease/diabetes] before or after you found out you had depression? How did you find this time?</li> </ul>
<b>Symptoms</b>	Can you tell me about a time when you felt your depression was at its worst?
Prompts	<ul style="list-style-type: none"> <li>How did it feel?</li> <li>How long did it last?</li> <li>Can you tell me how most days are for you at the moment?</li> <li>What's a good day for you?</li> <li>How long have you been feeling this way?</li> <li>Are there times when you don't feel this way? How long does this last?</li> </ul>

<p>1 2 3 4 5 6</p> <p><b>Interaction</b></p>	<p>Can you tell me about how your [arthritis/heart disease/diabetes] affects your life now?</p>
	<ul style="list-style-type: none"> <li>• How does your [arthritis/heart disease/diabetes] make you feel?</li> <li>• How do your depression and [arthritis/heart disease/diabetes] affect each other?</li> <li>• Have you ever found it difficult to cope with [arthritis/heart disease/diabetes]? e.g. coping with the symptoms, treatments?</li> </ul>
<p>19 20 21 22</p> <p><b>Management</b></p>	<p>Are you receiving any treatment for your depression at the moment?</p>
<p>23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44</p> <p>Prompts</p>	<ul style="list-style-type: none"> <li>• Can you tell me about the care you have received for your depression from doctors?  e.g. who (GP, clinic nurse/doctor) e.g. where (GP clinic, hospital clinic, community/third sector) e.g. when (routine/booked appointments, length of appointments) e.g. what (antidepressants, counselling)</li> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> <li>• How easy have you found it to get help for your depression?</li> </ul>
	<p>What treatments have you had for your [arthritis/heart disease/diabetes]?</p>
<p>46 47 48 49 50 51 52 53 54 55 56 57 58 59 60</p> <p>Prompts</p>	<p>e.g. who (GP, clinic nurse/doctor) e.g. where (GP clinic, hospital clinic) e.g. when (more than one treatment?) e.g. what (self-management courses, medication, surgery?)</p> <ul style="list-style-type: none"> <li>• Do you find it easy to talk to your doctor about your concerns?</li> <li>• How did you find the treatment?</li> </ul>

	<ul style="list-style-type: none"> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> <li>• How do you feel treatment of your [arthritis/heart disease/diabetes] has affected your depression?</li> <li>• <b>[Arthritis and angina only]</b> How have the treatments helped with your pain?</li> </ul>
<b>Self-care</b>	<ul style="list-style-type: none"> <li>• Can you talk me through anything you do yourself that helps you cope better?</li> </ul>
Prompts	<ul style="list-style-type: none"> <li>• For example, exercise, eating habits, alcohol consumption, smoking, acceptance, distractions/hobbies, wallowing. Have any of these been helpful to you?</li> <li>• How do these things make you feel?</li> </ul>

### Wrapping up

Is there anything else you would like to tell me?

How have you found this interview?

Do you have any questions?

Thank you for your time.

Give sources of further support handout.

Give baseline questionnaire.

Provide participant with £10 retail voucher.



# BMJ Open

## The experience of depression in older adults with and without a physical long-term condition: findings from a qualitative interview study.

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Manuscript ID	bmjopen-2021-056566.R1
Article Type:	Original research
Date Submitted by the Author:	13-Jan-2022
Complete List of Authors:	Poole, Lydia; UCL, Institute of Health Informatics Frost, Rachael; University College London Research Department of Primary Care and Population Health, Research Department of Primary Care and Population Health Rowlands, Hannah; King's College London Black, Georgia; University College London, Applied Health Research; Dr
<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Qualitative research, Health policy
Keywords:	Depression & mood disorders < PSYCHIATRY, QUALITATIVE RESEARCH, Coronary heart disease < CARDIOLOGY, DIABETES & ENDOCRINOLOGY, RHEUMATOLOGY

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3 **The experience of depression in older adults with and without a physical long-term condition: findings from**  
4 **a qualitative interview study.**  
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8 Lydia Poole<sup>1</sup>, Rachael Frost<sup>2</sup>, Hannah Rowlands<sup>3</sup>, Georgia Black<sup>4</sup>.  
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**Abstract**

Objective: To understand how the lived experience of depression differs among patients with a long-term condition (LTC) compared to those without an LTC, and how the experience differs across different types of LTC.

Design: Face-to-face, semi-structured, interviews.

Setting: Primary care; GP surgeries in and around North London.

Participants: 41 primary care patients with depression were recruited. Our sample comprised participants aged 55-75 years old with depression only (n= 12), depression and coronary heart disease (n=5), depression and type 2 diabetes (n=10) and depression and arthritis (n=14).

Results: Interviews were conducted, audio-recorded, transcribed, and analysed using thematic analysis. The results revealed that the cardinal diagnostic symptoms of depression (anhedonia, sadness) were experienced by all our participants regardless of LTC. However, the LTC did interact with depression by compounding somatic, cognitive and emotional symptoms, increasing disability and reducing independence, and hindering attempts at coping with mental illness. Our findings demonstrate common experiences across patients, as well as key differences based on LTC.

Conclusions: We suggest four key implications for future care practices of these patients: (1) Not all participants with depression and LTC view their mental and physical health as interconnected; there should be allowances in care plans for separate treatment pathways; (2) Key features of depression that affect LTC management are social withdrawal and lack of motivation to self-manage or access healthcare; (3) Key features of LTCs that worsen depression are pain, the unpredictability of future health and progressive disability; (4) Positive self-management of LTC could improve self-efficacy and therefore mood, and should be encouraged.

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2  
3 *Key words: Depression; long-term conditions; co-morbidity; qualitative research; interview study; thematic*  
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5 *analysis.*  
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### 10 **Strengths and limitations of the study**

- 12 • Participant diagnoses derived from clinical records and confirmed by self-report.
- 13
- 14 • Participants were drawn from across multiple sites across North London, with diversity in demography
- 15
- 16 achieved.
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- 18
- 19 • Comparative thematic analysis allowing for comparisons within and between groups.
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- 21 • Small sample of depression and coronary heart disease cohort.
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- 23
- 24 • Majority female in the depression and arthritis cohort.
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## Introduction

Estimates from the UK Biobank study suggest the prevalence for a single episode of major depressive disorder is 6.4%, varying to 12.2% for moderate recurrent major depression and 7.2% for severe recurrent major depression,[1] among British adults. Depression has been associated with increased all-cause mortality;<sup>[2]</sup> however causality has not yet been determined.<sup>[3]</sup> One possible explanation is that individuals with depression are more than twice as likely to have a concomitant physical long-term condition (LTC), such as diabetes and coronary heart disease.

It has been hypothesised from quantitative investigations of epidemiological and clinical cohort studies that depressive symptoms which occur in cardiac patients are distinct from those experienced in psychiatric populations based on three key differences: composition of symptoms, timeline, and treatment responsiveness.<sup>[4]</sup> With regard to symptoms, the hallmarks of psychiatric depression are persistent sadness and loss of interest and pleasure in activities (anhedonia). These are often associated with cognitive changes such as a sense of worthlessness and guilt, among others. By contrast, there is growing recognition that depressive symptoms in people with physical illness are dominated by somatic symptoms, such as fatigue and loss of energy.<sup>[5,6]</sup> In addition, it has been suggested that the chronicity, and the timing of onset of depressive symptoms in relation to the LTC, have implications for morbidity and mortality.<sup>[7,8]</sup> Finally, it appears that different treatment strategies may be appropriate for those living with psychiatric depression compared to those who have comorbid depression,<sup>[9]</sup> with particular benefit coming from integrative collaborative care models of healthcare.<sup>[10]</sup> Qualitative data has revealed that depression in physical illness has been shown to have been normalised by health care practitioners leading to barriers in its management <sup>[11]</sup> and there may be resistance to antidepressant medication among some LTC patients.<sup>[12]</sup> Given these empirical observations surrounding the differences in depression symptoms, timeline and treatment, some authors have suggested that a separate subtype of depression may exist, driven by biological (inflammatory) changes <sup>[13]</sup> which in turn are implicated in LTCs.<sup>[14]</sup> However, despite a plausible hypothesis for the existence of a separate subtype of depression in those with an LTC, whether or not this translates to differences in patient experience

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3 is unclear. Therefore, further qualitative research is warranted to examine whether the lived experience of  
4  
5 depression is similar or different in patients with depression and/or a comorbid LTC.  
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8 Furthermore, experiences of depression across LTCs are likely to differ. A meta-synthesis of qualitative  
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10 data has suggested that patients with depression and a comorbid LTC either see their mental and physical  
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12 health as either separate and independent from each other, or interrelated with one having caused or  
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14 worsened the other.[15] However, the similarities and/or differences in how depression is experienced in  
15  
16 different LTCs is currently not well-understood. For example, depression in diabetes has been revealed to be  
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18 heterogenous with aspects of diabetes-related distress and demoralisation being apparent,[16] while  
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20 depression in CHD has been associated with loss, both in terms of interpersonal loss as well as loss of  
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22 health/control.[12]  
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26 Therefore, the aim of this study was twofold. First, we aimed to examine how the lived experience of  
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28 depression is similar or different between those with an LTC and those without, and second, we aimed to  
29  
30 understand how experiences of depression are similar or different between types of LTC. In order to take into  
31  
32 account the correlation between age and LTC onset, we focussed on the experiences of depression in adults  
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34 in mid-late life.  
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## 39 **Methods**

### 40 ***Participant selection and recruitment***

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42 Thirty-seven participants were recruited using mailouts from 14 UK general practices in the Barnet and Enfield  
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44 regions of North London; a further one participant was recruited using opportunistic sampling from GP  
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46 surgeries in North West London; and a final three participants were recruited from the Camden and Islington  
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48 IAPT (Improving Access to Psychological Therapy) service.  
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52 **Our inclusion criteria led us to recruit participants who identified as** male and female, aged 55-75 years  
53  
54 old and English speaking. All participants were screened for current depression by participating GP practices  
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56 via electronic and hand searches of medical records. Current depression was defined as a patient who had  
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58 either received a clinical code of depression by their GP and/or had received a referral or prescription for  
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3 depression treatment in the preceding two months. All participants were medically stable outpatients living  
4 within the community. **We excluded patients** with a severe cognitive, mental or psychological impairment that  
5 would impede their ability to provide informed consent. Moreover, to compare patients living with  
6 depression, with and without an LTC, we recruited patients to one of four participant groups according to  
7 additional diagnoses identified in their medical notes: depression only, depression and CHD, depression and  
8 T2D, and depression and arthritis. To reduce cross-over between the groups, participants with more than one  
9 LTC of interest (i.e. diabetes and arthritis) in their medical notes were excluded. We also excluded those with  
10 another LTC such as cancer, stroke and chronic lung disease to allow us to focus our discussions more easily  
11 on our chosen LTCs. The LTCs were selected based on *a priori* knowledge to elicit a variety of illness  
12 experiences: coronary heart disease can have an acute, life-threatening presentation (e.g. acute coronary  
13 syndromes); T2D involves monitoring and self-management of blood sugar levels and can lead to acute  
14 episodes of illness (hypoglycaemia); arthritis is associated with pain and functional impairment.

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Practice GPs reviewed the list of those to approach prior to mailout and removed people that met the  
exclusion criteria or they considered inappropriate to contact. The mail-out included full details of the study  
and interested patients were invited to contact the research team to discuss participation. Patients were  
screened by researchers over the telephone using the same inclusion and exclusion criteria before arranging  
a convenient time and place for the interview to take place. **We used purposive sampling to capture a range  
of clinical and demographic characteristics within each group where possible; specifically, among those  
patients who expressed an interest in taking part we prioritised telephone screening to allow us to recruit a  
diverse sample by sex, age, ethnicity and location.**

### ***Interview data collection***

We conducted **1:1** semi-structured face-to-face interviews, mainly at participants' homes or in a meeting room  
at UCL (or another convenient location if requested), lasting approximately one hour (range 42–97 minutes).  
Interviews were carried out between May to October 2019. **Data collection continued within this time frame  
and ceased once all eligible patients at participating sites had been contacted.** Interviews were **conducted by**



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2  
3 two female researchers, HR (MSc; research assistant) (n = 40) or LP (PhD; senior research fellow) (n = 1). The  
4  
5 interviewers had received training in qualitative interviewing, and HR had prior experience of conducting  
6  
7 qualitative interviews with vulnerable groups. Neither HR or LP had any prior connection with participants,  
8  
9 other than the contact made during the recruitment process where the study objectives and procedures were  
10  
11 explained. The interviews began by presenting participants with four short vignettes for participants to read  
12  
13 and reflect on. The vignettes contained the experiences of fictional characters written in the third person (see  
14  
15 Appendix 1) and were designed to encourage participants to reflect on their own symptoms of depression.  
16  
17 This method is well-established for eliciting detailed information on sensitive topics in qualitative research.[17]  
18  
19 The interview then covered a number of topics, to explore the experience of living with depression: diagnosis,  
20  
21 precipitating events, symptoms, change in experience over time, management of depression and treatment  
22  
23 preferences. In participants with a comorbid LTC we also explored the impact of depression on their physical  
24  
25 illness and vice versa. The topic guides (see Appendix 2) were modified as interviews progressed, through  
26  
27 team discussions. To circumvent issues surrounding stigma, initial questions steered clear of clinical labels,  
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29 and instead invited participants to reflect on 'changes to their mood'. As each interview progressed the  
30  
31 interviewer used the participants' own terminology. After each interview, demographic data and self-reported  
32  
33 medical information were collected. The interviewer kept a reflective diary in order to document thoughts,  
34  
35 feelings and other interesting contextual information that occurred to her. Participants were provided with  
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37 relevant local and national mental health service information and a £10 retail voucher honorarium. Any  
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39 concerns over participant safety (including suicidal ideation and self-harm) were discussed with the senior  
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41 researcher (LP) before contacting participants' GP with their consent. A Standard Operating Procedure was in  
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43 place for this. Interviews were audio-recorded, with brief field notes, transcribed verbatim by an external  
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45 company and anonymised and verified for accuracy by the research team (HR and LP). Data for this study are  
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47 archived in a public data repository.[18]  
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### 57 ***Patient and Public Involvement***

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3 Patients and public were not involved in the development of the research question, design or study  
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5 implementation. However, the results of this study were disseminated via a large outreach and engagement  
6  
7 event through social media and podcasting platforms.  
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### 10 11 12 **Data analysis**

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14 We used reflexive thematic analysis [19,20] to analyse our data from a realist/essentialist perspective in which  
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16 a (mostly) one-way relationship is taken to operate between meaning, experience and language. According to  
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18 this approach, data saturation is not required, rather meaning is conceived as emerging from the  
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20 interpretation of the data.[21] All transcripts contained the entire interview, including the discussion that took  
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22 place regarding the material in the vignettes. The data arising from the discussion of vignettes varied across  
23  
24 participants; some participants did not engage with the vignettes and the conversation quickly flowed to the  
25  
26 semi-structured interview questions, whereas for others it prompted a divulgement of prior personal events.  
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28 As such, this data was not separated, but rather the entire transcript was treated as a single data piece.  
29  
30 Transcripts were read by HR (a health psychology researcher expertise in LTCs) and LP (a health psychology  
31  
32 researcher with an interest in depression and multimorbidity); GB (a health services researcher with expertise  
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34 in health improvement) and RF (a health services researcher with expertise in ageing and mental health) read  
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36 a subsample. Data analysis was led by LP. Transcripts from each group were first read and analysed inductively,  
37  
38 separately, to enable us to build an understanding of the idiographic qualities of the dataset;[19] inductive  
39  
40 analysis is a bottom-up approach where the codes and themes are driven by the data and not by a theoretical  
41  
42 framework. Each set of transcripts was read repeatedly, and codes were developed by LP in conjunction with  
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44 HR. HR's reflective diary was consulted to ensure no additional meaning or interpretation could be gleaned  
45  
46 from the data. Discrepancies were discussed until consensus was reached. Coding of transcripts was  
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48 performed using NVivo 12 (QSR International Pty Ltd., 2018). A codebook was kept to organise ideas and for  
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50 note keeping. For example, our coding tree included codes for the onset and timeline of depressive symptoms,  
51  
52 stressful life events, cognitive symptoms of depression, somatic symptoms of depression, past decisions, social  
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54 connections, emotional response to illness, physical illness impacting daily living, the symptoms of the physical  
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3 illness, approaching death, coping strategies and help-seeking and attitudes towards care. Codes were then  
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5 grouped to construct themes; refined through team discussions and piloting. After conducting the initial  
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7 analysis across the entire dataset, we tabulated the themes and subthemes using Excel (Microsoft for  
8  
9 Windows 365) to allow us to systematically explore the similarities and differences in experiences across  
10  
11 groups. This approach was informed by Framework Analysis [22] and has been combined with thematic  
12  
13 analysis by previous researchers conducting comparative qualitative analysis.[23] The indexing and charting  
14  
15 of the data enabled us to maintain rigour in the analytic process. Themes were then written out and refined  
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17 with feedback from team. The study was approved by NHS London – Fulham Research Ethics Committee  
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19 (reference: 18/LO/2150).  
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## 26 Results

### 27 *Participants*

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29 Out of 137 patients who expressed an interest in the study, 45 were eligible and 41 completed interviews.  
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31 Reasons for ineligibility included not meeting the clinical inclusion criteria (n = 37), non-responsive to return  
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33 phone calls (n = 26), not interested (n = 3), unavailable for interview (n =1), sample size deemed sufficient for  
34  
35 the cohort (n = 23), non-English speaker (n = 2). Participants were grouped into 4 cohorts based on their  
36  
37 medical records and verified during screening telephone calls: depression only (n = 12), depression and CHD  
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39 (n = 5) and depression and type 2 diabetes (T2D) (n = 10) and depression and arthritis (n = 14). In terms of  
40  
41 CHD, patients in this group had received a diagnosis for myocardial infarction (n = 1), angina (n=2) and heart  
42  
43 failure (n = 2). In terms of arthritis, patients in this group included those with rheumatoid arthritis (n = 2) and  
44  
45 osteoarthritis (n = 12). Overall, participants were aged 63.5 years (standard deviation (SD) 5.5) and we sampled  
46  
47 roughly equal numbers of men and women. However, the majority of depression and arthritis participants  
48  
49 were female (93%). Approximately one-third of the sample were from a non-White ethnic group and 85.4% of  
50  
51 all participants were taking antidepressant medication(s) at the time of the interview. The characteristics of  
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53 the sample are presented in Table 1.  
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## ***Thematic overview***

We generated five overarching themes that encompass the experience of living with depression in those with and without an LTC. In each theme we have drawn out the relationship between the experience of depression in those with and without an LTC, and where relevant, compared this across the different LTC groups (CHD, T2D and arthritis). Across all the themes, we found that the experience of depression and LTCs acted to compound the effects of each other; this was particularly apparent for those whose illness had resulted in changes to daily living. Figure 1 presents a schematic diagram of our themes.

### ***Theme 1: Shaped by the course of time***

Across our sample, depression was not static; it was shaped by individuals' life histories and past events. The experience of depression also shifted over time so that as people's lives progressed, different triggers for new episodes became more apparent. In those with an LTC, hardship brought about by their LTC and a loss of health was described by some as a trigger for depression.

#### ***Depression onset (first-ever episode)***

In participants with and without LTCs, the onset of the first-ever episode of depression occurred at different ages; many could identify roots for their depression in childhood or adolescence, while others had received a diagnosis more recently. Across the groups, most participants were able to identify a precipitating adverse life event(s) to their first-ever depressive episode such as financial insecurity, (multiple) bereavement, a relationship breakdown, children taken into care, and physical and sexual abuse. For some, seemingly smaller grievances, had accumulated over time to initiate the first-ever episode of depression.

In contrast to the depression-only participants, in participants with an LTC, life histories revealed two separate discourses relating to the onset of the initial depression diagnosis: coincidental and interconnected. As such, for some, the LTC was coincidental to the onset of the depression, with the depression and LTC diagnoses occurring at different times and in relation to different precipitating/surrounding events. This discourse was predominately discussed by those with T2D, and to a lesser extent the CHD cohort. These individuals had a

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2  
3 clear narrative about the onset of their depression, that was related to other life pressures such as caring  
4  
5 responsibilities, fraud allegations and work rather than to their LTC:  
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7 “I don’t think so. I don’t really think so. I had no qualms about my health. It was the other things. The  
8  
9 inferiority complex, the pressure of work and the unhappiness with my married life. It was those  
10  
11 things.” **(P.39, depression and T2D, male)**.

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13  
14 “I honestly can’t say that [depression] is the reason of that [CHD]. But yes, when you have I suppose  
15  
16 chest pain you think about it, you sit down, you [pause]. But I don’t think it took me into depression  
17  
18 at that time or anxiety or something.” **(P.45, depression and CHD, male)**.

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21 The second discourse highlighted the interconnected nature of the initial depression and LTC diagnosis. For  
22  
23 these participants, depression was a new experience, and was directly attributed to their LTC, or its  
24  
25 implications (e.g. hospitalisations, loss of mobility, job loss). The type of LTC did not make a difference, only  
26  
27 whether the LTC was associated with unpredictable, major, and irreversible upheaval.  
28

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31 “Depressed? It was when I came out of hospital after having my triple bypass because my life changed  
32  
33 completely. I lost my job, my relationship broke up, the kids and all that and I just sort of had a sort of  
34  
35 breakdown and that was it really.” **(P.44, depression and CHD, male)**.

### 36 37 38 *Relapsing and episodic*

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41 Across all participants, after the initial onset, the experience of depression had a varying time course. A few  
42  
43 participants had new onset depression. However, for the majority of participants, their history of depression  
44  
45 was chronic, with repeated episodes over time. This had led to a familiarity with when a new ‘bout’ was coming  
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47 on, even if there was no discernible trigger.  
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51 Where there was a clear trigger for a new episode of depression, this was often a difficult life event, such as a  
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53 child going to prison or a transition to retirement. However, for some people with chronic, pre-existing  
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55 depression, the LTC had also triggered a new episode. This led to a new experience of depression for these  
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57 participants, which was not centred around their earlier difficult life circumstances which had originally  
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3 brought about their depression. Instead, the LTC raised fears surrounding declining health, death and frailty,  
4  
5 which fed into the new depressive episode:  
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7 “The depression since then that was different. It was felt trapped then ... I was full of tension, full of  
8  
9 uncomfortable feeling with him. I just couldn’t, it was like having a snake you know circling around  
10  
11 you know... So that is thank God I don’t have that. The depression that I feel in this and that is because  
12  
13 of my health problems and that bothers me, that bothers me a lot.” **(P.22, depression and CHD,  
14  
15 female).**  
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## 18 19 **Theme 2: Somatisation**

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22 Somatic symptoms of depression were frequently experienced by our participants, in those with and without  
23  
24 an LTC. The experience was largely similar across our four cohorts. Differences did exist in sleep disturbance  
25  
26 and crying, with LTCs (mainly arthritis but also T2D) contributing to the experience of these somatic symptoms.  
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28

### 29 30 *Universal somatic symptoms*

31  
32 Somatic symptoms were discussed by all our participants, irrespective of LTC. Symptoms discussed included  
33  
34 appetite changes (including over- and under-eating), crying, and loss of intimacy. By far the most common of  
35  
36 all the somatic complaints was sleep disturbance. Some described difficulties falling asleep, restless and  
37  
38 disturbed sleep, vivid dreams and nightmares, and difficulty getting out of bed in the morning. Psychomotor  
39  
40 retardation was another common somatic complaint linked to fatigue, which was experienced across all  
41  
42 groups, irrespective of LTC.  
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44

45  
46 “Really, really very slow, very sluggish. Very physically, very physical. In fact, almost as physical as it is  
47  
48 mental.... Yeah like you’re swimming. Like you’re swimming against a sea of something coming at you.  
49  
50 And you’re trying to wade yourself through and knowing that if you, and no energy, zero physical  
51  
52 energy.” **(P.13, depression only, female)**  
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### 55 56 *Somatic symptoms and interactions with LTCs*

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3 For those with an LTC, the illness also directly contributed to the experience of somatic symptoms of  
4 depression. Sleep was negatively affected by the LTC through worries about managing the condition (as with  
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8 P.2 with T2D) or pain. Pain was particularly associated with participants in the depression and arthritis cohort.  
9

10 “I haven’t been a very good sleeper lately; I don’t sleep the full 8 hours that they say you should do. I  
11  
12 do think about things and one of the things obviously I do think about is make sure my diabetes is  
13  
14 correct.” **(P.2, depression and T2D, male).**

15  
16  
17 “I can’t sleep at night because of pain... And even at night I get a lot of pain in my back and that so I  
18  
19 am just putting my legs round 10 times this way and 10 times that way because I can’t sleep.” **(P.4,**  
20  
21  
22 **depression and arthritis, female).**

23  
24 While crying was frequently described across all our participants, in our arthritis participants we observed a  
25  
26 unique contribution of the LTC. Arthritis (and in particular arthritic pain) compounded the emotional and  
27  
28 somatic experience of depression, and could prompt tears of fear and frustration.  
29

30  
31 “I am chopping up the onions, I have to go and sit down because the pain in my back is such that I  
32  
33 can’t, I have to sit down. And like I have cried with it, not just from the onions but real tears, through  
34  
35 frustration I suppose and pain.” **(P.41, depression and arthritis, female).**

### 36 37 38 ***Theme 3: Cognitive and emotional burden***

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40  
41 In this theme the participants’ lived experience of the cognitive and emotional symptoms of depression are  
42  
43 described. These key diagnostic symptoms of depression were clearly experienced by all our participants.  
44  
45 However, we observed compounding and indirect routes linking LTCs with the cognitive and emotional burden  
46  
47 of depression; moreover, thoughts of death were particularly prominent within the depression and CHD  
48  
49 group.  
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#### 52 53 *Universal cognitive and emotional symptoms*

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3 Participants, regardless of LTC, had an overwhelming sense of disinterest in the world around them; they  
4  
5 described a deep-rooted sadness, hopelessness, worthlessness and low self-esteem. Some felt as though they  
6  
7 were being punished.  
8

9  
10 "You get what you deserve in life. And I don't deserve nothing. You know, I wasn't a good father when  
11  
12 I was young. I was selfish. And it's come back and bit me up the bum, bit me on the bum. ..." (P.12,  
13  
14 **depression only, male**).

### 15 16 17 *Compounding effects of LTC on cognitive and emotional depressive symptoms*

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19  
20 For some, the combination of the LTC and the depression led to a compounding effect on the cognitive and  
21  
22 emotional depressive symptoms. In this way, the LTC directly contributed to the participants' experience of  
23  
24 depression. This was particularly observed in those with T2D and arthritis.  
25

26  
27 "I'm sitting there and taking the blood and giving myself injections and some days I just think, you  
28  
29 know, how come it's come to this? And I know how it's come to this because, you know, I'm not  
30  
31 managing my life in any sensible way, and I know that." (P.25, **depression and T2D, male**).

32  
33 For participants with severe arthritic pain, pain was seen as an all-consuming and debilitating experience,  
34  
35 which led to misery.  
36

37  
38 "I'm getting pain back in my right knee and I'm going to have to eventually have that one done. It's  
39  
40 really, oh god, what does that feel like? When I'm not feeling ... oh ... it feels like having been almost  
41  
42 injected with negativity." (P.28, **depression and arthritis, female**).

43  
44 For P.32 her depression and the functional limitations imposed by her arthritis were difficult to unravel, with  
45  
46 both acting in synergy to lead to a sense of hopelessness:  
47

48  
49 "I'm also physically unable to do as much as I would like to do in terms of just - housework and  
50  
51 shopping and it's difficult to pull it apart which is leading the sort of feelings of hopelessness and you  
52  
53 know is it worth it and I can't, I might as well just stay in bed." (P.32, **depression and arthritis, female**).

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55  
56 *Indirect effects of LTC upon cognitive and emotional depressive symptoms through affecting enjoyment of*  
57  
58 *activities*  
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3 For some of our LTC participants, the depression was a greater burden than their LTC, so cognitive and  
4 emotional depressive symptoms were experienced regardless of their LTC. In this way, some of our LTC  
5 participants experienced feelings of anhedonia, worthlessness, guilt, sadness, etc., similarly to the depression  
6 only participants. However, for others, the LTC (notably T2D and arthritis) fed into the experience of cognitive  
7 and emotional symptoms by removing their enjoyment of previously pleasurable activities.  
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10 An example comes from P.2, whose diabetes directly contributed to his feelings of anhedonia. This participant  
11 was particularly concerned about managing his blood glucose levels during social situations.  
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“You are part of it because you are invited, you all go out, you are all friends, you have known one  
another for years and everything is there, but you don't feel as if you are really taking part if you get  
what I am saying. So that's the part of the mood I have found since I have been diagnosed with  
diabetes and that's the thing that holds me back from properly being 100% committed to enjoying it.”

**(P.2, depression and T2D, male).**

Pain also featured heavily in the descriptions of altered lifestyles recounted by our arthritis participants,  
perpetuating feelings of anhedonia.

“That's, and I do enjoy my food, I do enjoy cooking. I mean I haven't had a dinner party now for over  
a year. I have always enjoyed doing that. But that's, and it's like washing up, you know I can do so  
much, [...] but you know like my washing up is in stages. I will do this first, then go and sit down, come  
back and do that lot, the next lot, then go and sit down. [...]. That is where the arthritis and depression,  
they are like, they join forces.” **(P.41, depression and arthritis, female).**

#### *Indirect effects of LTC on cognitive and emotional symptoms by causing a loss of control and independence*

Financial insecurity and unequal personal relationships were experienced by many of our participants,  
irrespective of LTC, and had contributed to feelings of being out of control. Deteriorating physical health  
(particularly for those with arthritis) and increasingly frailty, had also led to feelings of loss of control for some.  
This was linked to feelings of loss of independence, which in turn led to feelings of depression.

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2  
3 "Some of my clothes are high up, I can never reach them unless somebody is there, that makes me  
4  
5 depressed having to rely on somebody all the time." (P.4, depression and arthritis, female).  
6  
7

#### 8 *Thoughts of dying*

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10  
11 Suicidal ideation, thoughts of death (but not suicide) and actual suicide attempts were disclosed in participants  
12  
13 with and without LTCs. Although the presence of an LTC did not influence suicidal thoughts, having CHD was  
14  
15 an important leveller for these participants. These participants lived with the unpredictable nature of their  
16  
17 illness and the threat of sudden and irreversible loss of health:  
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19  
20 "Even now I still think about it because when I just took a deep breath here, I felt a bit of a twinge  
21  
22 there and it's when I got told about it, it was very disturbing because I was shown the blockage [...]  
23  
24 and although I've been reassured that it won't go up, block my heart or anything like that, but it makes  
25  
26 you wonder because you never know what might happen." (P.30, depression and CHD, male).  
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29 For P.44 his brush with death due to having a heart attack has given him a greater acceptance of death:  
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31  
32 "Well I just didn't give a shit about anything anymore, you know, apparently according to them I died  
33  
34 twice, so I didn't give a shit no more about it, death doesn't scare me no more." (P.44, depression and  
35  
36 T2D, male).  
37

38 For others with CHD, they were also having to confront death, but they discussed their fear surrounding a  
39  
40 prolonged or sudden death:  
41

42  
43 "I keep saying to my sister, 'I don't care if I die actually in my sleep that will be fine. But if I don't die  
44  
45 and I can't move, like I said to you if I can't move and I can't get up and can't call that horrifies me.'  
46  
47 That is enough to, well you know." (P.22, depression and CHD, female).  
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49  
50 "So, since that day, perhaps I have, it wasn't so much when I had the heart bypass, but since the  
51  
52 [aortic] aneurism and everything else, [...] I worry that every time I go to bed, I don't know if I'm going  
53  
54 to wake up. You know. So, I worry about that." (P.30, depression and CHD, male).  
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#### 58 ***Theme 4: Depression symptoms thwart self-care***

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3 In this theme we draw on the ways in which the experience of depression impeded our participants' ability to  
4 take care of themselves; many described not washing or brushing their teeth, not wanting to cook proper  
5 meals, and retreating from their social network. This was apparent for all our participants but added an extra  
6 layer of complexity to participants with an LTC.  
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13 *Depression leads to lack of motivation to self-care*  
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15 Depression was associated with an apathy which led to a loss of interest in behaviours that might lead to  
16 improved self-care. This was true of behaviours that might improve the depression itself such as engaging in  
17 social activities and exercising, as well as those important for managing LTCs.  
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23 The impact of depression on attempts to control diabetes could lead to self-neglect, both in terms of  
24 medication adherence and adherence to medical appointments.  
25  
26

27 "I suppose the most obvious impact is there are days when I just can't be bothered to take my  
28 medication, both the medication for the depression and the insulin for my diabetes and I know it's  
29 stupid [...]" (P.25, depression and T2D, male).  
30  
31  
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33

34 "there are times now when I wouldn't not turn up for an appointment, absolutely, I just [...] But yes,  
35 there are times when I just think "what's the bloody point?" in dealing with daily stuff." (P.25,  
36 depression and T2D, male).  
37  
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41 Exercise was seen as an important self-care behaviour for both mental and physical health among our  
42 participants. However, P.32 described how her lack of motivation to exercise was contributing to her physical  
43 decline, which in turn compounded her feelings of depression.  
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48 "As for the physical side of things, again, I suspect they would like [me] to say, I'll lose weight, get  
49 more exercise and it's very difficult when you don't want to go out of the house, particularly I haven't  
50 the confidence to go into a gym or to a swimming pool, it's not really, you know. [...] So, and the other  
51 fear is, of course, the older I get, the general, you know, aging and infirmities, you know, yeah, it  
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3 worries me greatly. You know, and it doesn't help the depression to lift. **(P.32, depression and**  
4  
5 **arthritis, female).**  
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#### 8 *Social withdrawal prevents self-care behaviours*

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10  
11 Many participants described how their attempts to cope had been thwarted by the depression itself. This was  
12  
13 particularly true for those whose depression had led to social withdrawal. The retreat from daily life saw  
14  
15 participants becoming withdrawn from both the outside world and their family and friends. Social withdrawal  
16  
17 impacted on participants' management of their LTC. This was observed particularly in those with T2D and  
18  
19 arthritis.  
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22 "I did find it hard to leave the house sometimes, you know. You'd just sort of eat what was there rather  
23  
24 than go shopping, you know." **(P.27, depression and T2D, female).**  
25  
26

27 "Well they said because of the way, it's not helped, because I stopped, I wouldn't get out of the house,  
28  
29 I was staying in my room, that can affect arthritis because then you are letting it seize up more." **(P.3,**  
30  
31 **depression and arthritis, female).**  
32  
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34  
35 As seen with those experiencing a lack of motivation, social withdrawal also negatively impacted participants'  
36  
37 willingness to engage with medical professionals (both for depression and/or the LTC).  
38

39 "I mean even the doctor, I have got to phone her tomorrow, they are going to arrange for the nurse  
40  
41 to come out because I am overdue blood tests and blood pressure and that [...]. Because she knows  
42  
43 that I just don't want to leave the house again." **(P.3, depression and arthritis, female).**  
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#### 46 **Theme 5: Requires wilful effort to manage**

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49 The experience of depression was described as an active process, requiring an individual to find ways to cope.  
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51 For some with an LTC, efforts to cope with their depression were thwarted by the functional limitation  
52  
53 imposed by their illness. Controlling the LTC was also important to help manage the depression.  
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#### 56 *Universal coping strategies*

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3 While many of our participants struggled to cope, nearly all engaged in some strategies to navigate their  
4 current situation such as the use of alcohol and food, medical treatments, and drawing on friendships and  
5 family members for support. Often this included attempts to mask feelings as a means to find comfort; alcohol  
6 in particular was frequently described as a way to relax and forget.  
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11  
12 "But what I have done, and I have been guilty of, is purchasing alcohol and trying to blot it out with  
13 the alcohol." (P.23, depression and arthritis, female).  
14  
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16 Many participants were engaged with healthcare professionals for depression management. For some anti-  
17 depressants had been beneficial, making their symptoms less severe. However, for others, side effects or fears  
18 surrounding dependency prevented their use.  
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23 "Most of us are given medication, which makes you zombie, anyway. It doesn't help you. It just block  
24 your pains, you know. You are numb. You are not sorting out. And how long are you going to use those  
25 medication?" (P.24, depression and T2D, female).  
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### 30 *LTCs impede efforts to cope with depression*

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33 Having an LTC prevented some participants from engaging with coping strategies to help manage their  
34 depression. For those with arthritis this included being unable to take part in activities that promote wellbeing,  
35 including hobbies.  
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40 "But I think, yeah, so coping, well I am not walking as much as I want to, I have stopped going, I used  
41 to go to water workout, water aerobics every week and I have stopped doing that, partly because of  
42 the difficulty of getting into my bathers and afterwards drying myself." (P.1, depression and arthritis,  
43 female).  
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50 As P.32 described, the combination of her depression and arthritis makes coping with each insurmountable:

51 "You know so the depression makes you lack motivation to, perhaps, I say modify some of the effects  
52 of the arthritis, but the arthritis also, in limiting you, makes the depression seem worse. Together it  
53 seems like a huge, insurmountable problem because if, on their own, they might be manageable, [...].  
54 So it is, yes, it impedes any kind of self-care or therapy, if you like, together."  
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### *Controlling the LTC improves depression*

Interestingly across all LTC groups, those who successfully managed to engage with strategies to cope with their illness, saw benefits to their mental health through feeling an increased sense of control/self-efficacy. For example, failure to self-manage insulin dosages appropriately negatively impacted P.25's mood, while being in control of his T2D also helped him self-manage his depression.

"But I carry glucose around with me. ... I think we were away somewhere and, but I was completely useless for about two hours and I suppose I, you know, I had a moment of clarity about the need to keep on top of it properly, because I sort of knew that if I didn't, not only would I feel crap, physically, the idea of feeling crap physically was depressing." **(P.25, depression and T2D, male).**

Interestingly, P.30 with CHD found the unpredictable nature of his cardiac symptoms very distressing, but the use of his own blood pressure monitor helped him regain a sense of control.

"this is my life saver, my BP [blood pressure] machine, I do it every day, [...] I was told 140 over 80, right, yes, 140, 80, so once it's within this, I go to sleep a bit better. If I didn't know what my BP was, I'd be worried even more." **(P.30, depression and CHD, male).**

For some participants the physical limitations imposed by their LTC led to social isolation. This was particularly apparent for those with arthritis. If participants received support with things that their arthritis prevented (for example housework, food shopping), this was seen as positive for managing their depression, allowing them to live well within the limits of the LTC.

"So yeah, [lady friend's name] and [man friend's name] took me out yesterday to go to Aldi, it's the first time since February that I have gone out to the shops." **(P.3, depression and arthritis, female).**

## **Discussion**

This paper explored the lived experience of depression in primary care patients with and without a comorbid physical LTC (CHD, T2D and arthritis). Using thematic analysis, we generated five overarching themes. 'Shaped by the course of time' revealed a shifting, non-linear experience of depression in which the experience was

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3 defined by earlier life experiences as well as more minor, cumulative events. For some, the LTC diagnosis had  
4 caused catastrophic upheaval to participants' lives; for these individuals the LTC was capable of triggering  
5 depression (both first-ever or a recurrent episode). For many, other life events were more prominent to  
6 determining the course of depression; for these participants the LTC was coincidental, running alongside the  
7 depression but not triggering new episodes. 'Somatisation' highlighted the physical experience of depression  
8 in our participants; for many, these symptoms were as dominant as the cognitive and emotional symptoms.  
9 Somatic symptoms were universally experienced across all our groups, in particular feelings of tiredness and  
10 fatigue and changes to eating habits. Where LTCs did interact with the somatic symptoms, this was mainly  
11 driven by arthritic pain contributing to and compounding these symptoms. 'Cognitive and emotional burden'  
12 explored the impact of mental symptoms, such as feelings of worthlessness, guilt, punishment, anhedonia and  
13 sadness, on participants. LTCs compounded these cognitive and emotional experiences as well as indirectly  
14 contributing to a worsening of these symptoms by affecting participants' enjoyment of previously pleasurable  
15 activities and causing a loss of control and independence. Thoughts of dying were frequently experienced, and  
16 prominent in patients with CHD where the unpredictability of future health was a psychological challenge.  
17 Theme 4, 'Depression symptoms thwart self-care' examined how depression itself acts as a barrier to  
18 engagement in self-care behaviours. Loss of motivation and social withdrawal and were key aspects of the  
19 depressive experience which thwarted attempts for LTC self-management (particularly those with T2D).  
20 Finally, 'Requires wilful effort to manage' revealed universal engagement in many coping strategies,  
21 particularly attempts to mask depressive feelings such as the use of alcohol and food. However, LTCs  
22 (particularly arthritis) did impede participants' ability to cope with depression, while successful management  
23 of the LTC had a positive impact on mood.

24 Findings from quantitative studies continue to make attempts to understand the relationship between  
25 depression in LTCs, with the causal model thought to be bidirectional.[9] Our findings supported the notion  
26 that the LTC was capable of triggering depression; however, this was restricted to those whose LTC has caused  
27 major life upheaval (e.g. loss of employment, relationship breakdown). It has been estimated that around 80%  
28 of initial depressive episodes occur after a stressful life event;[24] and that the severity of stressors required

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3 to precipitate recurrent depressive episodes decreases over time.[25] None of our participants described their  
4 depression acting as a precursor to their LTC. In fact, for many, the LTC was experienced as coincidental to the  
5 onset of depression; this is a view that has been supported by a previous qualitative meta-synthesis.[15]  
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10 The difference in the experience of depression in those with and without an LTC has not been studied  
11 previously using qualitative research. Quantitative research has identified differences in terms of symptom  
12 presentation, chronicity and timing of symptoms, and treatment responsiveness.[4] Our findings have added to  
13 this by revealing that while the symptoms of depression (somatic, cognitive, affective) were universally  
14 experienced by those with and without depression, the LTC contributed to the burden of these symptoms by  
15 either directly provoking them (e.g. arthritic pain leading to tears of frustration) or by indirectly leading to  
16 negative mood by undermining the enjoyment of partaking in previously pleasurable activities as well as  
17 reducing individuals' sense of independence. T2D and arthritis were key in this regard since both illnesses were  
18 associated with lifestyle changes which negatively impacted the participants' depression, increasing feelings  
19 of anhedonia, sadness, guilt and worthlessness. Previous research has explored the impact of arthritis on  
20 leisure activities, finding that functional and physical constraints imposed by the illness can affect self-  
21 esteem.[26] Our findings extend this to the experience of those with arthritis *and* depression, suggesting that  
22 these limitations worsen the symptoms of depression. Participants with diabetes also saw a compounding  
23 effect of their physical condition on their mental health. This was particularly true for those who described  
24 being distressed by T2D and its management. Indeed, diabetes distress is now recognised as a separate  
25 disorder to major depression [27] which has been linked to feelings of burden, difficulties adhering to  
26 medication regimes and depression.[28]  
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49 Loss of control and lack of independence featured heavily in the accounts of our participants with arthritis;  
50 whereby functional limitations imposed by the LTC indirectly impacted depression by removing individual's  
51 sense of control and autonomy. Loss was a key theme identified in the qualitative UPBEAT-UK study of  
52 patients with depression and CHD, where patients described not only loss of health but also interpersonal  
53 loss.[12] Health deterioration featured heavily in the accounts of all our participants with a physical LTC, and  
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3 while thoughts of dying were universally experienced across groups, our CHD group revealed a strong sense  
4 of an unpredictable and uncontrollable death, which was not apparent in those with T2D and arthritis. This  
5 realistic fear underpinned the experience of depression in these participants.  
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10 Our findings also observed differences in the experience of depression in participants' ability to self-care and  
11 to cope with their mental health. Social withdrawal and lack of motivation were commonly experienced in all  
12 our participants. We described how these features of depression thwart attempts to engage with self-care  
13 behaviours such as personal hygiene, meal preparation etcetera, as well as LTC (particularly T2D) specific  
14 illness-management behaviours such as adhering to medication and attending hospital appointments. While  
15 depression has been associated with poor medication adherence in previous quantitative studies of T2D and  
16 CHD patients [29,30], there has been a lack of qualitative studies describing the hows and whys of this  
17 phenomenon; more research in this area is warranted.  
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29 Findings from our study revealed the adoption of common coping behaviours across all our participants such  
30 as using alcohol and food to mask symptoms and drawing on expert sources of support; this supports findings  
31 from earlier work.[12] However, importantly we observed that the presence of an LTC interacted with  
32 participants' attempts to manage their depression. Those with an LTC, and in particular those with increasing  
33 disability from their arthritis, were prevented from engaging with coping mechanisms they had previously  
34 adopted to promote mental wellbeing. On the upside, positive self-management of the LTC improved feelings  
35 of control and self-efficacy and in so doing improved depressed mood. Depressed patients have previously  
36 been reported to benefit most from self-efficacy gains from LTC self-management training;[31] the importance  
37 of this construct for therapeutic purposes within the modern care setting of depression and LTC patients,  
38 requires future investigation.  
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51 Our findings have a number of important implications for care models such as the NHS' IAPT-LTC  
52 programme.[32] Our findings suggest that any care model of depression in LTC needs to take into account four  
53 overarching conclusions based on our data: (1) Not all participants with depression and LTC view their mental  
54 and physical health as interconnected; therefore there should be allowances in care plans for separate  
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3 treatment (this is a view endorsed by Knowles and colleagues).[10] (2) Key features of depression that affect  
4 LTC management and need to be considered when planning treatment and referring to psychological services  
5  
6 are social withdrawal and lack of motivation to self-manage or access healthcare. (3) Key features of LTCs that  
7  
8 worsen depression that should be discussed during care planning are pain, the unpredictability of future health  
9  
10 and progressive disability. (4) Positive self-management of LTC could improve feelings of control and self-  
11  
12 efficacy and therefore mood, and should be encouraged.  
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17 A strength of our study was in the recruitment of participants from GP practices ensuring all our participants  
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19 had received clinical diagnoses of their health conditions. To understand the differences in depression across  
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21 different LTCs we excluded participants with more than one LTC of interest and with a serious or life-limiting  
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23 diagnosis such as cancer, stroke or dementia. Due to the increased risk of physical illness with age, we recruited  
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25 participants within an age bracket of 55 to 75 years; this enabled us to focus on the experiences of adults in  
26  
27 mid to late life. The study was confined to North and North West London; however, we recruited from across  
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29 contrasting areas to elicit a range of experiences. Despite our best efforts, unfortunately our arthritis sample  
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31 was predominately female (90%); however this may partly reflect the greater incidence of osteoarthritis in  
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33 women in the UK.[33] Our depression and CHD group was small (n=5); therefore our findings may not reflect  
34  
35 the diversity of views that a larger sample might have attained. Also, as part of our reflexive practice, we noted  
36  
37 that as researchers our experience and identities as female academic researchers working in London, of White  
38  
39 (HR, RF, GB) and mixed (LP) ethnic background, is likely to have shaped our understanding, prioritisation, and  
40  
41 interpretation of the data. The trustworthiness of our analysis, however, has been enhanced through  
42  
43 researcher triangulation, drawing on the multiple expertise of the research team. Moreover, we used multiple  
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45 levels to the analysis process from use of the reflective diary, through to the generation of themes, and the  
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47 comparative exercise through the charting of codes. Participant checking was not undertaken which could  
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49 have added a useful check to our interpretive work.  
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56 In conclusion, the results of our face-to-face interview study of depression in those with and without a physical  
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58 LTC revealed that overall, key diagnostic symptoms of depression (anhedonia, sadness etc.) were experienced  
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3 by all our participants regardless of LTC. However, the LTC did interact with depression by compounding  
4 somatic, cognitive, and emotional symptoms, increasing disability and reducing independence, and hindering  
5 attempts at coping with mental illness. Our findings have implications for the development and fine-tuning of  
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10 mental health and LTC care programmes.  
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19 **Contributorship statement:**

20 LP was responsible for funding acquisition and conceived the study design. GB and RF advised on the study  
21 methods. LP and HR collected the data. LP and RF led the data analysis. GB and HR contributed to the data  
22 analysis. LP wrote the initial manuscript draft. RF, GB and HR edited the manuscript.  
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30 **Competing interests:**

31 The authors have no competing interests to declare.  
32  
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45 **Data sharing statement:**

46 The data for the study are archived in the UK Data Service.[18]  
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For peer review only

**Table 1: Characteristics of the sample, stratified by group**

	Whole sample (N= 41) <i>M±SD or N(%)</i>	Depression only (n = 12) <i>M±SD or N(%)</i>	Depression and CHD (n = 5) <i>M±SD or N(%)</i>	Depression and T2D (n = 10) <i>M±SD or N(%)</i>	Depression and arthritis (n = 14) <i>M±SD or N(%)</i>
Sex (female)	24(58.5)	6(50.0)	1(20.0)	4(40.0)	13(92.9)
Age (years)	63.5(5.5)	62.4(5.5)	66.0(4.0)	61.0(5.2)	65.1(5.9)
Married/cohabiting	17(41.5)	6(50.0)	2(40.0)	5(50.0)	4(28.6)
Ethnicity:					
White British	27(65.9)	10(83.3)	2(20.0)	6(60.0)	9(64.3)
Indian	3(7.3)			2(20.0)	1(7.1)
Pakistani	1(2.4)		1(20.0)		
Black Caribbean	1(2.4)		1(20.0)		
Other White background	7(17.1)	2(16.7)	1(20.0)	1(10.0)	3(21.4)
Other Asian background	2(4.9)			1(10.0)	1(7.0)
Employment status:					
Employed full-time	9(22.0)	3(25.0)	1(20.0)	3(30.0)	2(14.3)
Employed part-time	1(2.4)	1(8.3)			
Self-employed	7(17.1)	3(25.0)			4(28.6)
Retired	15(36.6)	4(33.3)	3(60.0)	3(30.0)	5(35.7)
Unemployed	4(9.8)	1(8.3)		3(30.0)	
Volunteer	2(4.9)		1(20.0)		1(7.1)
Disabled	3(7.3)			1(10.0)	2(14.3)
Highest educational qualification - degree or higher	15(36.6)	3(25.0)	3(60.0)	4(40.0)	5(35.7)
Antidepressant usage (yes)	35(85.4)	9(75.0)	4(80.0)	9(90.0)	13(92.9)

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**Figure 1 Caption** (*figure itself attached as separate .jpg file*)

**Figure 1. Schematic diagram of theme structure.**

**N.B. LTC: Long term condition.**

For peer review only



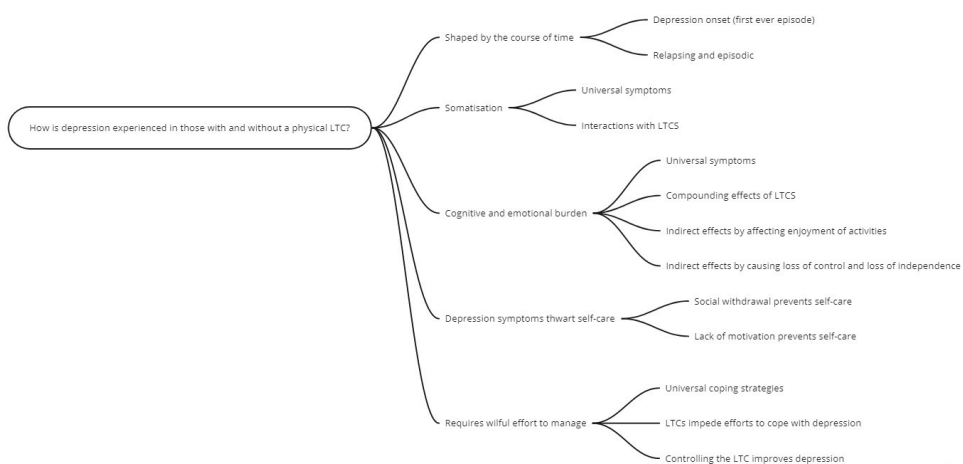


Figure 1. Schematic diagram of theme structure.  
 N.B. LTC: Long term condition.

372x187mm (96 x 96 DPI)

Supplementary file: Appendix 1 - Vignettes

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3 **Scenario 1**  
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5 Sarah has good days and bad, but on a bad day she feels so sad and miserable that she just  
6 can't stand it. It seems to completely take over her head like she's in a fog. She feels really  
7 disappointed in herself for feeling this way, despite all the good things she has in her life.  
8 Sometimes when she's by herself she cries and even has thoughts of killing herself just to try  
9 and be anywhere but here. She feels completely worthless.  
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12 **Scenario 2**  
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14 Most days Sam wakes up and feels so tired he wishes he could just stay in bed. In fact he  
15 feels so tired most of the time that he doesn't want to do anything. He sleeps longer than he  
16 used to and doesn't have the energy to do anything. Sometimes he doesn't even feel like  
17 eating. He's even lost weight without trying to. His partner tries to show him affection and  
18 wants a kiss and a cuddle, but he just feels numb and not interested at all.  
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21 **Scenario 3**  
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23 Jason finds it really hard to feel positive about the future at the moment, it's like he has  
24 nothing to look forward to anymore. He finds it difficult to concentrate and to make  
25 decisions these days too. He feels so frustrated and trapped by the way he feels. His friends  
26 tell him he should snap out of it, but he just can't. He wishes he didn't have to feel like this,  
27 it makes him feel like such a failure.  
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30 **Scenario 4**  
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32 Most days Clare feels like she is being punished for something she must have done in a past  
33 life. And then she feels guilty for thinking like this. She seems to worry about her health all  
34 the time and her aches and pains get on top of her. She doesn't enjoy things the way she  
35 used to, in fact she doesn't really get any pleasure out of anything anymore. She finds it  
36 hard to leave the house some days. Everything seems a bit pointless these days, if she's  
37 being completely honest.  
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41 **Scenario 5**  
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43 Susan has always enjoyed her food, but for the past couple of months she's noticed she's  
44 been putting on some extra weight. She finds she craves her favourite foods and is comfort  
45 eating to make herself feel a bit better. She's not sure she is feeling any better though, in  
46 fact she's sleeping really badly and often wakes up several times in the night. Her sleep is  
47 restless and she wakes up tired making each day feel like it drags.  
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## The Mood and Health Study

### Interview Schedule – Depression

#### Introduction

Review of Participant Information Sheet

Consent form

Timing and confidentiality

*My name is [insert name] and I am a researcher. I'm not a doctor or a psychologist and I don't have any clinical contact with your team. I'm interested in finding out from you what your experiences have been with your mood, and there are no right answers.*

#### Vignettes

*To start I'd like you to look at what some other people have experienced, and then we'll talk about them a bit. Firstly, I'd like you to start by sorting the cards into two piles, those which you think are relevant to you and those which aren't.*

<b>Card sort</b>	<p>Can you talk me through how you have sorted the cards?</p> <p>Has anything like this ever happened to you?</p> <p>Have you ever felt these sorts of things before?</p> <p>How do you think this person's experience is different from yours?</p>
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#### Depression

<b>Precipitating events</b>	<p>Take me back, can you tell me about when you first noticed changes to your mood?</p>
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Prompts	<ul style="list-style-type: none"> <li>• Can you remember feeling differently?</li> <li>• How did it feel?</li> <li>• Was there anything else you think may have contributed to your low mood?</li> <li>• How do you think that experience relates to how you feel today?</li> </ul>
<b>Diagnosis</b>	Can you talk me through the support you received during this time?
Prompts	<ul style="list-style-type: none"> <li>• E.g. family, friends, GP?</li> <li>• How did you find out you had depression? E.g. Who told you? When?</li> <li>• How did you feel when you found out it was depression?</li> </ul>
<b>Timeline</b>	How has your mood been since then?
Prompts	<ul style="list-style-type: none"> <li>• How has your mood changed over time?</li> </ul>
<b>Symptoms</b>	Can you tell me about a time when you felt your depression was at its worst?
Prompts	<ul style="list-style-type: none"> <li>• How did it feel?</li> <li>• How long did it last?</li> <li>• Can you tell me how most days are for you at the moment?</li> <li>• What's a good day for you?</li> <li>• How long have you been feeling this way?</li> <li>• Are there times when you don't feel this way? How long does this last?</li> </ul>
<b>Management of depression</b>	Are you receiving any treatment for your depression at the moment?
Prompts	<ul style="list-style-type: none"> <li>• Can you tell me about the care you have received for your depression from doctors?</li> </ul> <p>e.g. who (GP, clinic nurse/doctor)</p> <p>e.g. where (GP clinic, hospital clinic, community/third sector)</p> <p>e.g. when (routine/booked appointments, length of appointments)</p>

	<p>e.g. what (antidepressants, counselling)</p> <ul style="list-style-type: none"> <li>• Do you find it easy to talk to your doctor about your concerns?</li> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> </ul>
<b>Self-care</b>	<ul style="list-style-type: none"> <li>• Can you talk me through anything you do yourself that helps you cope better?</li> </ul>
<b>Prompts</b>	<ul style="list-style-type: none"> <li>• For example, exercise, eating habits, alcohol consumption, smoking, acceptance, distractions/hobbies, wallowing. Have any of these been helpful to you?</li> <li>• How do these things make you feel?</li> </ul>

### Wrapping up

Is there anything else you would like to tell me?

How have you found this interview?

Do you have any questions?

Thank you for your time.

Give sources of further support handout.

Give baseline questionnaire.

Provide participant with £10 retail voucher.



## The Mood and Health Study

### Interview Schedule – Depression and Physical Illness

#### Introduction

Review of Participant Information Sheet

Consent form

Timing and confidentiality

*My name is [insert name] and I am a researcher. I'm not a doctor or a psychologist and I don't have any clinical contact with your team. I'm interested in finding out from you what your experiences have been with your mood and health, and there are no right answers.*

#### Vignettes

*To start I'd like you to look at what some other people have experienced, and then we'll talk about them a bit. Firstly, I'd like you to start by sorting the cards into two piles, those which you think are relevant to you and those which aren't.*

<b>Card sort</b>	<p>Can you talk me through how you have sorted the cards?</p> <p>Has anything like this ever happened to you?</p> <p>Have you ever felt these sorts of things before?</p> <p>How do you think this person's experience is different from yours?</p>
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#### Depression

<b>Precipitating events</b>	<p>Take me back, can you tell me about when you first noticed changes to your mood?</p>
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<p>Prompts</p>	<ul style="list-style-type: none"> <li>• Can you remember feeling differently?</li> <li>• How did you feel?</li> <li>• Was there anything else you think may have contributed to your low mood?</li> <li>• How do you think that experience relates to how you feel today?</li> </ul>
<p><b>Diagnosis</b></p>	<p>Can you talk me through the support you received during this time?</p>
<p>Prompts</p>	<ul style="list-style-type: none"> <li>• E.g. family, friends, GP?</li> <li>• How did you find out you had depression? E.g. Who told you? When?</li> <li>• How did you feel when you found out it was depression?</li> </ul>
<p><b>Timeline</b></p>	<p>How has your mood been since then?</p>
<p>Prompts</p>	<ul style="list-style-type: none"> <li>• How has your mood changed over time?</li> </ul>
<p><b>Diagnosis of physical illness (if not covered above)</b></p>	<p>Can you tell me how you found out about your [arthritis/heart disease/diabetes]?</p>
<p>Prompts</p>	<ul style="list-style-type: none"> <li>• How long ago was this?</li> <li>• Who told you? Where were you?</li> <li>• How did you feel when you found out?</li> <li>• Did you find out about your [arthritis/heart disease/diabetes] before or after you found out you had depression? How did you find this time?</li> </ul>
<p><b>Symptoms</b></p>	<p>Can you tell me about a time when you felt your depression was at its worst?</p>
<p>Prompts</p>	<ul style="list-style-type: none"> <li>• How did it feel?</li> <li>• How long did it last?</li> <li>• Can you tell me how most days are for you at the moment?</li> <li>• What's a good day for you?</li> </ul>

	<ul style="list-style-type: none"> <li>• How long have you been feeling this way?</li> <li>• Are there times when you don't feel this way? How long does this last?</li> </ul>
<b>Interaction</b>	Can you tell me about how your [arthritis/heart disease/diabetes] affects your life now?
	<ul style="list-style-type: none"> <li>• How does your [arthritis/heart disease/diabetes] make you feel?</li> <li>• How do your depression and [arthritis/heart disease/diabetes] affect each other?</li> <li>• Have you ever found it difficult to cope with [arthritis/heart disease/diabetes]? e.g. coping with the symptoms, treatments?</li> </ul>
<b>Management</b>	Are you receiving any treatment for your depression at the moment?
Prompts	<ul style="list-style-type: none"> <li>• Can you tell me about the care you have received for your depression from doctors?</li> </ul> <p>e.g. who (GP, clinic nurse/doctor) e.g. where (GP clinic, hospital clinic, community/third sector) e.g. when (routine/booked appointments, length of appointments) e.g. what (antidepressants, counselling)</p> <ul style="list-style-type: none"> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> <li>• How easy have you found it to get help for your depression?</li> </ul>
	What treatments have you had for your [arthritis/heart disease/diabetes]?
Prompts	<p>e.g. who (GP, clinic nurse/doctor) e.g. where (GP clinic, hospital clinic) e.g. when (more than one treatment?) e.g. what (self-management courses, medication, surgery?)</p>



	<ul style="list-style-type: none"> <li>• Do you find it easy to talk to your doctor about your concerns?</li> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> <li>• How do you feel treatment of your [arthritis/heart disease/diabetes] has affected your depression?</li> <li>• <b>[Arthritis and angina only]</b> How have the treatments helped with your pain?</li> </ul>
<b>Self-care</b>	<ul style="list-style-type: none"> <li>• Can you talk me through anything you do yourself that helps you cope better?</li> </ul>
<b>Prompts</b>	<ul style="list-style-type: none"> <li>• For example, exercise, eating habits, alcohol consumption, smoking, acceptance, distractions/hobbies, wallowing. Have any of these been helpful to you?</li> <li>• How do these things make you feel?</li> </ul>

### Wrapping up

Is there anything else you would like to tell me?

How have you found this interview?

Do you have any questions?

Thank you for your time.

Give sources of further support handout.

Give baseline questionnaire.

Provide participant with £10 retail voucher.

## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

# BMJ Open

## The experience of depression in older adults with and without a physical long-term condition: findings from a qualitative interview study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-056566.R2
Article Type:	Original research
Date Submitted by the Author:	02-Feb-2022
Complete List of Authors:	Poole, Lydia; UCL, Institute of Health Informatics Frost, Rachael; University College London Research Department of Primary Care and Population Health, Research Department of Primary Care and Population Health Rowlands, Hannah; King's College London Black, Georgia; University College London, Applied Health Research; Dr
<b>Primary Subject Heading</b>:	Mental health
Secondary Subject Heading:	Qualitative research, Health policy
Keywords:	Depression & mood disorders < PSYCHIATRY, QUALITATIVE RESEARCH, Coronary heart disease < CARDIOLOGY, DIABETES & ENDOCRINOLOGY, RHEUMATOLOGY

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3 **The experience of depression in older adults with and without a physical long-term condition: findings from**  
4 **a qualitative interview study.**  
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**Abstract**

Objective: To understand how the lived experience of depression differs among patients with a long-term condition (LTC) compared to those without an LTC, and how the experience differs across different types of LTC.

Design: Face-to-face, semi-structured, interviews.

Setting: Primary care; GP surgeries in and around North London.

Participants: 41 primary care patients with depression were recruited. Our sample comprised participants aged 55-75 years old with depression only (n= 12), depression and coronary heart disease (n=5), depression and type 2 diabetes (n=10) and depression and arthritis (n=14).

Results: Interviews were conducted, audio-recorded, transcribed, and analysed using thematic analysis. The results revealed that the cardinal diagnostic symptoms of depression (anhedonia, sadness) were experienced by all our participants regardless of LTC. However, the LTC did interact with depression by compounding somatic, cognitive and emotional symptoms, increasing disability and reducing independence, and hindering attempts at coping with mental illness. Our findings demonstrate common experiences across patients, as well as key differences based on LTC.

Conclusions: We suggest four key implications for future care practices of these patients: (1) Not all participants with depression and LTC view their mental and physical health as interconnected; there should be allowances in care plans for separate treatment pathways; (2) Key features of depression that affect LTC management are social withdrawal and lack of motivation to self-manage or access healthcare; (3) Key features of LTCs that worsen depression are pain, the unpredictability of future health and progressive disability; (4) Positive self-management of LTC could improve self-efficacy and therefore mood, and should be encouraged.

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2  
3 *Key words: Depression; long-term conditions; co-morbidity; qualitative research; interview study; thematic*  
4  
5 *analysis.*  
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### 10 **Strengths and limitations of the study**

- 12 • Participant diagnoses derived from clinical records and confirmed by self-report.
- 13
- 14 • Participants were drawn from across multiple sites across North London, with diversity in demography
- 15
- 16 achieved.
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- 19 • Comparative thematic analysis allowing for comparisons within and between groups.
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- 21 • Small sample of depression and coronary heart disease cohort.
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- 24 • Majority female in the depression and arthritis cohort.
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## Introduction

Estimates from the UK Biobank study suggest the prevalence for a single episode of major depressive disorder is 6.4%, varying to 12.2% for moderate recurrent major depression and 7.2% for severe recurrent major depression,[1] among British adults. Depression has been associated with increased all-cause mortality;<sup>[2]</sup> however causality has not yet been determined.<sup>[3]</sup> One possible explanation is that individuals with depression are more than twice as likely to have a concomitant physical long-term condition (LTC), such as diabetes and coronary heart disease.

It has been hypothesised from quantitative investigations of epidemiological and clinical cohort studies that depressive symptoms which occur in cardiac patients are distinct from those experienced in psychiatric populations based on three key differences: composition of symptoms, timeline, and treatment responsiveness.<sup>[4]</sup> With regard to symptoms, the hallmarks of psychiatric depression are persistent sadness and loss of interest and pleasure in activities (anhedonia). These are often associated with cognitive changes such as a sense of worthlessness and guilt, among others. By contrast, there is growing recognition that depressive symptoms in people with physical illness are dominated by somatic symptoms, such as fatigue and loss of energy.<sup>[5,6]</sup> In addition, it has been suggested that the chronicity, and the timing of onset of depressive symptoms in relation to the LTC, have implications for morbidity and mortality.<sup>[7,8]</sup> Finally, it appears that different treatment strategies may be appropriate for those living with psychiatric depression compared to those who have comorbid depression,<sup>[9]</sup> with particular benefit coming from integrative collaborative care models of healthcare.<sup>[10]</sup> Qualitative data has revealed that depression in physical illness has been shown to have been normalised by health care practitioners leading to barriers in its management <sup>[11]</sup> and there may be resistance to antidepressant medication among some LTC patients.<sup>[12]</sup> Given these empirical observations surrounding the differences in depression symptoms, timeline and treatment, some authors have suggested that a separate subtype of depression may exist, driven by biological (inflammatory) changes <sup>[13]</sup> which in turn are implicated in LTCs.<sup>[14]</sup> However, despite a plausible hypothesis for the existence of a separate subtype of depression in those with an LTC, whether or not this translates to differences in patient experience

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3 is unclear. Therefore, further qualitative research is warranted to examine whether the lived experience of  
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5 depression is similar or different in patients with depression and/or a comorbid LTC.  
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8 Furthermore, experiences of depression across LTCs are likely to differ. A meta-synthesis of qualitative  
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10 data has suggested that patients with depression and a comorbid LTC either see their mental and physical  
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12 health as either separate and independent from each other, or interrelated with one having caused or  
13  
14 worsened the other.[15] However, the similarities and/or differences in how depression is experienced in  
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16 different LTCs is currently not well-understood. For example, depression in diabetes has been revealed to be  
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18 heterogenous with aspects of diabetes-related distress and demoralisation being apparent,[16] while  
19  
20 depression in CHD has been associated with loss, both in terms of interpersonal loss as well as loss of  
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22 health/control.[12]  
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25 Therefore, the aim of this study was twofold. First, we aimed to examine how the lived experience of  
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27 depression is similar or different between those with an LTC and those without, and second, we aimed to  
28  
29 understand how experiences of depression are similar or different between types of LTC. In order to take into  
30  
31 account the correlation between age and LTC onset, we focussed on the experiences of depression in adults  
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33 in mid-late life.  
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## 36 37 38 **Methods**

### 39 40 ***Participant selection and recruitment***

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42 Thirty-seven participants were recruited using mailouts from 14 UK general practices in the Barnet and Enfield  
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44 regions of North London; a further one participant was recruited using opportunistic sampling from GP  
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46 surgeries in North West London; and a final three participants were recruited from the Camden and Islington  
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48 IAPT (Improving Access to Psychological Therapy) service.  
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51 Our inclusion criteria led us to recruit participants who identified as male and female, aged 55-75 years  
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53 old and English speaking. All participants were screened for current depression by participating GP practices  
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55 via electronic and hand searches of medical records. Current depression was defined as a patient who had  
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57 either received a clinical code of depression by their GP and/or had received a referral or prescription for  
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3 depression treatment in the preceding two months. All participants were medically stable outpatients living  
4 within the community. We excluded patients with a severe cognitive, mental or psychological impairment that  
5 would impede their ability to provide informed consent. Moreover, to compare patients living with  
6 depression, with and without an LTC, we recruited patients to one of four participant groups according to  
7 additional diagnoses identified in their medical notes: depression only, depression and CHD, depression and  
8 T2D, and depression and arthritis. To reduce cross-over between the groups, participants with more than one  
9 LTC of interest (i.e. diabetes and arthritis) in their medical notes were excluded. We also excluded those with  
10 another LTC such as cancer, stroke and chronic lung disease to allow us to focus our discussions more easily  
11 on our chosen LTCs. The LTCs were selected based on *a priori* knowledge to elicit a variety of illness  
12 experiences: coronary heart disease can have an acute, life-threatening presentation (e.g. acute coronary  
13 syndromes); T2D involves monitoring and self-management of blood sugar levels and can lead to acute  
14 episodes of illness (hypoglycaemia); arthritis is associated with pain and functional impairment.

15  
16 Practice GPs reviewed the list of those to approach prior to mailout and removed people that met the  
17 exclusion criteria or they considered inappropriate to contact. The mail-out included full details of the study  
18 and interested patients were invited to contact the research team to discuss participation. Patients were  
19 screened by researchers over the telephone using the same inclusion and exclusion criteria before arranging  
20 a convenient time and place for the interview to take place. We used purposive sampling to capture a range  
21 of clinical and demographic characteristics within each group where possible; specifically, among those  
22 patients who expressed an interest in taking part we prioritised telephone screening to allow us to recruit a  
23 diverse sample by sex, age, ethnicity and location.

### 24 **Interview data collection**

25 We conducted 1:1 semi-structured face-to-face interviews, mainly at participants' homes or in a meeting room  
26 at UCL (or another convenient location if requested), lasting approximately one hour (range 42–97 minutes).  
27 Interviews were carried out between May to October 2019. Data collection continued within this time frame  
28 and ceased once all eligible patients at participating sites had been contacted. Interviews were conducted by  
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3 two female researchers, HR (MSc; research assistant) (n = 40) or LP (PhD; senior research fellow) (n = 1). The  
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5 interviewers had received training in qualitative interviewing, and HR had prior experience of conducting  
6  
7 qualitative interviews with vulnerable groups. Neither HR or LP had any prior connection with participants,  
8  
9 other than the contact made during the recruitment process where the study objectives and procedures were  
10  
11 explained. The interviews began by presenting participants with four short vignettes for participants to read  
12  
13 and reflect on. The vignettes contained the experiences of fictional characters written in the third person (see  
14  
15 Appendix 1) and were designed to encourage participants to reflect on their own symptoms of depression.  
16  
17 This method is well-established for eliciting detailed information on sensitive topics in qualitative research.[17]  
18  
19 The interview then covered a number of topics, to explore the experience of living with depression: diagnosis,  
20  
21 precipitating events, symptoms, change in experience over time, management of depression and treatment  
22  
23 preferences. In participants with a comorbid LTC we also explored the impact of depression on their physical  
24  
25 illness and vice versa. The topic guides (see Appendix 2) were modified as interviews progressed, through  
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27 team discussions. To circumvent issues surrounding stigma, initial questions steered clear of clinical labels,  
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29 and instead invited participants to reflect on 'changes to their mood'. As each interview progressed the  
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31 interviewer used the participants' own terminology. After each interview, demographic data and self-reported  
32  
33 medical information were collected. The primary interviewer (HR) kept a reflective diary in order to document  
34  
35 thoughts, feelings and other interesting contextual information that occurred to her. Participants were  
36  
37 provided with relevant local and national mental health service information and a £10 retail voucher  
38  
39 honorarium. Any concerns over participant safety (including suicidal ideation and self-harm) were discussed  
40  
41 with the senior researcher (LP) before contacting participants' GP with their consent. A Standard Operating  
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43 Procedure was in place for this. Interviews were audio-recorded, with brief field notes, transcribed verbatim  
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45 by an external company and anonymised and verified for accuracy by the research team (HR and LP). Data for  
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47 this study are archived in a public data repository.[18]  
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### 57 ***Patient and Public Involvement***

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3 Patients and public were not involved in the development of the research question, design or study  
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5 implementation. However, the results of this study were disseminated via a large outreach and engagement  
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7 event through social media and podcasting platforms.  
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### 10 11 12 **Data analysis**

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14 We used reflexive thematic analysis [19,20] to analyse our data from a realist/essentialist perspective in which  
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16 a (mostly) one-way relationship is taken to operate between meaning, experience and language. According to  
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18 this approach, data saturation is not required, rather meaning is conceived as developing from the  
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20 interpretation of the data.[21] All transcripts contained the entire interview, including the discussion that took  
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22 place regarding the material in the vignettes. The data arising from the discussion of vignettes varied across  
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24 participants; some participants did not engage with the vignettes and the conversation quickly flowed to the  
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26 semi-structured interview questions, whereas for others it prompted a divulgement of prior personal events.  
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28 As such, these data were not separated, but rather the entire transcript was treated as a single data piece.  
29  
30 Transcripts were read by HR (a health psychology researcher expertise in LTCs) and LP (a health psychology  
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32 researcher with an interest in depression and multimorbidity); GB (a health services researcher with expertise  
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34 in health improvement) and RF (a health services researcher with expertise in ageing and mental health) read  
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36 a subsample. Data analysis was led by LP. Transcripts from each group were first read and analysed inductively,  
37  
38 separately, to enable us to build an understanding of the idiographic qualities of the dataset;[19] inductive  
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40 analysis is a bottom-up approach where the codes and themes are driven by the data and not by a theoretical  
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42 framework. Each set of transcripts was read repeatedly, and codes were developed by LP in conjunction with  
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44 HR. HR's reflective diary was consulted to ensure no additional meaning or interpretation could be gleaned  
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46 from the data. Discrepancies were discussed until consensus was reached. Coding of transcripts was  
47  
48 performed using NVivo 12 (QSR International Pty Ltd., 2018). A codebook was kept to organise ideas and for  
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50 note keeping. For example, our coding tree included codes for the onset and timeline of depressive symptoms,  
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52 stressful life events, cognitive symptoms of depression, somatic symptoms of depression, past decisions, social  
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54 connections, emotional response to illness, physical illness impacting daily living, the symptoms of the physical  
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3 illness, approaching death, coping strategies and help-seeking and attitudes towards care. Codes were then  
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5 grouped to construct themes; refined through team discussions and piloting. After conducting the initial  
6  
7 analysis across the entire dataset, we tabulated the themes and subthemes using Excel (Microsoft for  
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9 Windows 365) to allow us to systematically explore the similarities and differences in experiences across  
10  
11 groups. This approach was informed by Framework Analysis [22] and has been combined with thematic  
12  
13 analysis by previous researchers conducting comparative qualitative analysis.[23] The indexing and charting  
14  
15 of the data enabled us to maintain rigour in the analytic process. Themes were then written out and refined  
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17 with feedback from team. The study was approved by NHS London – Fulham Research Ethics Committee  
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19 (reference: 18/LO/2150).  
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## 23 **Results**

### 24 ***Participants***

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26 Out of 137 patients who expressed an interest in the study, 45 were eligible and 41 completed interviews.  
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28 Reasons for ineligibility included not meeting the clinical inclusion criteria (n = 37), non-responsive to return  
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30 phone calls (n = 26), not interested (n = 3), unavailable for interview (n =1), sample size deemed sufficient for  
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32 the cohort (n = 23), non-English speaker (n = 2). Participants were grouped into 4 cohorts based on their  
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34 medical records and verified during screening telephone calls: depression only (n = 12), depression and CHD  
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36 (n = 5) and depression and type 2 diabetes (T2D) (n = 10) and depression and arthritis (n = 14). In terms of  
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38 CHD, patients in this group had received a diagnosis for myocardial infarction (n = 1), angina (n=2) and heart  
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40 failure (n = 2). In terms of arthritis, patients in this group included those with rheumatoid arthritis (n = 2) and  
41  
42 osteoarthritis (n = 12). Overall, participants were aged 63.5 years (standard deviation (SD) 5.5) and we sampled  
43  
44 roughly equal numbers of men and women. However, the majority of depression and arthritis participants  
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46 were female (93%). Approximately one-third of the sample were from a non-White ethnic group and 85.4% of  
47  
48 all participants were taking antidepressant medication(s) at the time of the interview. The characteristics of  
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50 the sample are presented in Table 1.  
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### 59 ***Thematic overview***

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3 We generated five overarching themes that encompass the experience of living with depression in those with  
4 and without an LTC. In each theme we have drawn out the relationship between the experience of depression  
5 in those with and without an LTC, and where relevant, compared this across the different LTC groups (CHD,  
6 T2D and arthritis). Across all the themes, we found that the experience of depression and LTCs acted to  
7 compound the effects of each other; this was particularly apparent for those whose illness had resulted in  
8 changes to daily living. Figure 1 presents a schematic diagram of our themes.  
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### 16 17 **Theme 1: Shaped by the course of time**

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19 Across our sample, depression was not static; it was shaped by individuals' life histories and past events. The  
20 experience of depression also shifted over time so that as people's lives progressed, different triggers for new  
21 episodes became more apparent. In those with an LTC, hardship brought about by their LTC and a loss of  
22 health was described by some as a trigger for depression.  
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#### 29 *Depression onset (first-ever episode)*

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31 In participants with and without LTCs, the onset of the first-ever episode of depression occurred at different  
32 ages; many could identify roots for their depression in childhood or adolescence, while others had received a  
33 diagnosis more recently. Across the groups, most participants were able to identify a precipitating adverse life  
34 event(s) to their first-ever depressive episode such as financial insecurity, (multiple) bereavement, a  
35 relationship breakdown, children taken into care, and physical and sexual abuse. For some, seemingly smaller  
36 grievances, had accumulated over time to initiate the first-ever episode of depression.  
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46 In contrast to the depression-only participants, in participants with an LTC, life histories revealed two separate  
47 discourses relating to the onset of the initial depression diagnosis: coincidental and interconnected. As such,  
48 for some, the LTC was coincidental to the onset of the depression, with the depression and LTC diagnoses  
49 occurring at different times and in relation to different precipitating/surrounding events. This discourse was  
50 predominately discussed by those with T2D, and to a lesser extent the CHD cohort. These individuals had a  
51 clear narrative about the onset of their depression, that was related to other life pressures such as caring  
52 responsibilities, fraud allegations and work rather than to their LTC:  
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3 “I don’t think so. I don’t really think so. I had no qualms about my health. It was the other things. The  
4 inferiority complex, the pressure of work and the unhappiness with my married life. It was those  
5 things.” (P.39, depression and T2D, male).  
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10 “I honestly can’t say that [depression] is the reason of that [CHD]. But yes, when you have I suppose  
11 chest pain you think about it, you sit down, you [pause]. But I don’t think it took me into depression  
12 at that time or anxiety or something.” (P.45, depression and CHD, male).  
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17 The second discourse highlighted the interconnected nature of the initial depression and LTC diagnosis. For  
18 these participants, depression was a new experience, and was directly attributed to their LTC, or its  
19 implications (e.g. hospitalisations, loss of mobility, job loss). The type of LTC did not make a difference, only  
20 whether the LTC was associated with unpredictable, major, and irreversible upheaval.  
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26 “Depressed? It was when I came out of hospital after having my triple bypass because my life changed  
27 completely. I lost my job, my relationship broke up, the kids and all that and I just sort of had a sort of  
28 breakdown and that was it really.” (P.44, depression and CHD, male).  
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### 33 *Relapsing and episodic*

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36 Across all participants, after the initial onset, the experience of depression had a varying time course. A few  
37 participants had new onset depression. However, for the majority of participants, their history of depression  
38 was chronic, with repeated episodes over time. This had led to a familiarity with when a new ‘bout’ was coming  
39 on, even if there was no discernible trigger.  
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46 Where there was a clear trigger for a new episode of depression, this was often a difficult life event, such as a  
47 child going to prison or a transition to retirement. However, for some people with chronic, pre-existing  
48 depression, the LTC had also triggered a new episode. This led to a new experience of depression for these  
49 participants, which was not centred around their earlier difficult life circumstances which had originally  
50 brought about their depression. Instead, the LTC raised fears surrounding declining health, death and frailty,  
51 which fed into the new depressive episode:  
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3 “The depression since then that was different. It was felt trapped then ... I was full of tension, full of  
4 uncomfortable feeling with him. I just couldn’t, it was like having a snake you know circling around  
5 you know... So that is thank God I don’t have that. The depression that I feel in this and that is because  
6 of my health problems and that bothers me, that bothers me a lot.” (P.22, depression and CHD,  
7 female).

## 15 **Theme 2: Somatisation**

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18 Somatic symptoms of depression were frequently experienced by our participants, in those with and without  
19 an LTC. The experience was largely similar across our four cohorts. Differences did exist in sleep disturbance  
20 and crying, with LTCs (mainly arthritis but also T2D) contributing to the experience of these somatic symptoms.

### 25 *Universal somatic symptoms*

26  
27  
28 Somatic symptoms were discussed by all our participants, irrespective of LTC. Symptoms discussed included  
29 appetite changes (including over- and under-eating), crying, and loss of intimacy. By far the most common of  
30 all the somatic complaints was sleep disturbance. Some described difficulties falling asleep, restless and  
31 disturbed sleep, vivid dreams and nightmares, and difficulty getting out of bed in the morning. Psychomotor  
32 retardation was another common somatic complaint linked to fatigue, which was experienced across all  
33 groups, irrespective of LTC.

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41 “Really, really very slow, very sluggish. Very physically, very physical. In fact, almost as physical as it is  
42 mental.... Yeah like you’re swimming. Like you’re swimming against a sea of something coming at you.  
43 And you’re trying to wade yourself through and knowing that if you, and no energy, zero physical  
44 energy.” (P.13, depression only, female)

### 51 *Somatic symptoms and interactions with LTCs*

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54 For those with an LTC, the illness also directly contributed to the experience of somatic symptoms of  
55 depression. Sleep was negatively affected by the LTC through worries about managing the condition (as with  
56 P.2 with T2D) or pain. Pain was particularly associated with participants in the depression and arthritis cohort.

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3 “I haven’t been a very good sleeper lately; I don’t sleep the full 8 hours that they say you should do. I  
4 do think about things and one of the things obviously I do think about is make sure my diabetes is  
5 correct.” (P.2, depression and T2D, male).  
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10 “I can’t sleep at night because of pain... And even at night I get a lot of pain in my back and that so I  
11 am just putting my legs round 10 times this way and 10 times that way because I can’t sleep.” (P.4,  
12 depression and arthritis, female).  
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17 While crying was frequently described across all our participants, in our arthritis participants we observed a  
18 unique contribution of the LTC. Arthritis (and in particular arthritic pain) compounded the emotional and  
19 somatic experience of depression, and could prompt tears of fear and frustration.  
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24 “I am chopping up the onions, I have to go and sit down because the pain in my back is such that I  
25 can't, I have to sit down. And like I have cried with it, not just from the onions but real tears, through  
26 frustration I suppose and pain.” (P.41, depression and arthritis, female).  
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### 30 31 **Theme 3: Cognitive and emotional burden**

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33 In this theme the participants’ lived experience of the cognitive and emotional symptoms of depression are  
34 described. These key diagnostic symptoms of depression were clearly experienced by all our participants.  
35 However, we observed compounding and indirect routes linking LTCs with the cognitive and emotional burden  
36 of depression; moreover, thoughts of death were particularly prominent within the depression and CHD  
37 group.  
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#### 45 46 *Universal cognitive and emotional symptoms*

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48 Participants, regardless of LTC, had an overwhelming sense of disinterest in the world around them; they  
49 described a deep-rooted sadness, hopelessness, worthlessness and low self-esteem. Some felt as though they  
50 were being punished.  
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3 “You get what you deserve in life. And I don’t deserve nothing. You know, I wasn’t a good father when  
4 I was young. I was selfish. And it’s come back and bit me up the bum, bit me on the bum. ...” (P.12,  
5  
6  
7 **depression only, male**).

#### 10 *Compounding effects of LTC on cognitive and emotional depressive symptoms*

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12  
13 For some, the combination of the LTC and the depression led to a compounding effect on the cognitive and  
14 emotional depressive symptoms. In this way, the LTC directly contributed to the participants’ experience of  
15 depression. This was particularly observed in those with T2D and arthritis.

16  
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19  
20 “I’m sitting there and taking the blood and giving myself injections and some days I just think, you  
21 know, how come it’s come to this? And I know how it’s come to this because, you know, I’m not  
22 managing my life in any sensible way, and I know that.” (P.25, **depression and T2D, male**).

23  
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26  
27 For participants with severe arthritic pain, pain was seen as an all-consuming and debilitating experience,  
28 which led to misery.

29  
30  
31 “I’m getting pain back in my right knee and I’m going to have to eventually have that one done. It’s  
32 really, oh god, what does that feel like? When I’m not feeling ... oh ... it feels like having been almost  
33 injected with negativity.” (P.28, **depression and arthritis, female**).

34  
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37  
38 For P.32 her depression and the functional limitations imposed by her arthritis were difficult to unravel, with  
39 both acting in synergy to lead to a sense of hopelessness:

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41  
42 “I’m also physically unable to do as much as I would like to do in terms of just - housework and  
43 shopping and it’s difficult to pull it apart which is leading the sort of feelings of hopelessness and you  
44 know is it worth it and I can’t, I might as well just stay in bed.” (P.32, **depression and arthritis, female**).

#### 45 46 47 48 49 *Indirect effects of LTC upon cognitive and emotional depressive symptoms through affecting enjoyment of* 50 51 *activities*

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54  
55 For some of our LTC participants, the depression was a greater burden than their LTC, so cognitive and  
56 emotional depressive symptoms were experienced regardless of their LTC. In this way, some of our LTC  
57 participants experienced feelings of anhedonia, worthlessness, guilt, sadness, etc., similarly to the depression  
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3 only participants. However, for others, the LTC (notably T2D and arthritis) fed into the experience of cognitive  
4 and emotional symptoms by removing their enjoyment of previously pleasurable activities.  
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8 An example comes from P.2, whose diabetes directly contributed to his feelings of anhedonia. This participant  
9 was particularly concerned about managing his blood glucose levels during social situations.  
10  
11

12  
13 “You are part of it because you are invited, you all go out, you are all friends, you have known one  
14 another for years and everything is there, but you don’t feel as if you are really taking part if you get  
15 what I am saying. So that’s the part of the mood I have found since I have been diagnosed with  
16 diabetes and that’s the thing that holds me back from properly being 100% committed to enjoying it.”  
17  
18  
19  
20

21 **(P.2, depression and T2D, male).**  
22

23  
24 Pain also featured heavily in the descriptions of altered lifestyles recounted by our arthritis participants,  
25 perpetuating feelings of anhedonia.  
26  
27

28 “That’s, and I do enjoy my food, I do enjoy cooking. I mean I haven’t had a dinner party now for over  
29 a year. I have always enjoyed doing that. But that’s, and it’s like washing up, you know I can do so  
30 much, [...] but you know like my washing up is in stages. I will do this first, then go and sit down, come  
31 back and do that lot, the next lot, then go and sit down. [...]. That is where the arthritis and depression,  
32 they are like, they join forces.” **(P.41, depression and arthritis, female).**  
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40 *Indirect effects of LTC on cognitive and emotional symptoms by causing a loss of control and independence*  
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42  
43 Financial insecurity and unequal personal relationships were experienced by many of our participants,  
44 irrespective of LTC, and had contributed to feelings of being out of control. Deteriorating physical health  
45 (particularly for those with arthritis) and increasingly frailty, had also led to feelings of loss of control for some.  
46  
47  
48 This was linked to feelings of loss of independence, which in turn led to feelings of depression.  
49  
50

51  
52 “Some of my clothes are high up, I can never reach them unless somebody is there, that makes me  
53 depressed having to rely on somebody all the time.” **(P.4, depression and arthritis, female).**  
54  
55

56  
57 *Thoughts of dying*  
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3 Suicidal ideation, thoughts of death (but not suicide) and actual suicide attempts were disclosed in participants  
4  
5 with and without LTCs. Although the presence of an LTC did not influence suicidal thoughts, having CHD was  
6  
7 an important leveller for these participants. These participants lived with the unpredictable nature of their  
8  
9 illness and the threat of sudden and irreversible loss of health:  
10  
11

12 “Even now I still think about it because when I just took a deep breath here, I felt a bit of a twinge  
13  
14 there and it’s when I got told about it, it was very disturbing because I was shown the blockage [...] and although I’ve been reassured that it won’t go up, block my heart or anything like that, but it makes  
15  
16 and although I’ve been reassured that it won’t go up, block my heart or anything like that, but it makes  
17  
18 you wonder because you never know what might happen.” (P.30, depression and CHD, male).  
19  
20

21 For P.44 his brush with death due to having a heart attack has given him a greater acceptance of death:  
22

23 “Well I just didn’t give a shit about anything anymore, you know, apparently according to them I died  
24  
25 twice, so I didn’t give a shit no more about it, death doesn’t scare me no more.” (P.44, depression and  
26  
27 T2D, male).  
28  
29

30 For others with CHD, they were also having to confront death, but they discussed their fear surrounding a  
31  
32 prolonged or sudden death:  
33

34 “I keep saying to my sister, ‘I don’t care if I die actually in my sleep that will be fine. But if I don’t die  
35  
36 and I can’t move, like I said to you if I can’t move and I can’t get up and can’t call that horrifies me.’  
37  
38 That is enough to, well you know.” (P.22, depression and CHD, female).  
39  
40

41 “So, since that day, perhaps I have, it wasn’t so much when I had the heart bypass, but since the  
42  
43 [aortic] aneurism and everything else, [...] I worry that every time I go to bed, I don’t know if I’m going  
44  
45 to wake up. You know. So, I worry about that.” (P.30, depression and CHD, male).  
46  
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#### 50 ***Theme 4: Depression symptoms thwart self-care***

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52  
53 In this theme we draw on the ways in which the experience of depression impeded our participants’ ability to  
54  
55 take care of themselves; many described not washing or brushing their teeth, not wanting to cook proper  
56  
57 meals, and retreating from their social network. This was apparent for all our participants but added an extra  
58  
59 layer of complexity to participants with an LTC.  
60

### *Depression leads to lack of motivation to self-care*

Depression was associated with an apathy which led to a loss of interest in behaviours that might lead to improved self-care. This was true of behaviours that might improve the depression itself such as engaging in social activities and exercising, as well as those important for managing LTCs.

The impact of depression on attempts to control diabetes could lead to self-neglect, both in terms of medication adherence and adherence to medical appointments.

“I suppose the most obvious impact is there are days when I just can’t be bothered to take my medication, both the medication for the depression and the insulin for my diabetes and I know it’s stupid [...]” **(P.25, depression and T2D, male).**

“there are times now when I wouldn’t not turn up for an appointment, absolutely, I just [...] But yes, there are times when I just think “what’s the bloody point?” in dealing with daily stuff.” **(P.25, depression and T2D, male).**

Exercise was seen as an important self-care behaviour for both mental and physical health among our participants. However, P.32 described how her lack of motivation to exercise was contributing to her physical decline, which in turn compounded her feelings of depression.

“As for the physical side of things, again, I suspect they would like [me] to say, I’ll lose weight, get more exercise and it’s very difficult when you don’t want to go out of the house, particularly I haven’t the confidence to go into a gym or to a swimming pool, it’s not really, you know. [...] So, and the other fear is, of course, the older I get, the general, you know, aging and infirmities, you know, yeah, it worries me greatly. You know, and it doesn’t help the depression to lift. **(P.32, depression and arthritis, female).**

### *Social withdrawal prevents self-care behaviours*

Many participants described how their attempts to cope had been thwarted by the depression itself. This was particularly true for those whose depression had led to social withdrawal. The retreat from daily life saw

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2  
3 participants becoming withdrawn from both the outside world and their family and friends. Social withdrawal  
4  
5 impacted on participants' management of their LTC. This was observed particularly in those with T2D and  
6  
7 arthritis.  
8

9  
10 "I did find it hard to leave the house sometimes, you know. You'd just sort of eat what was there rather  
11  
12 than go shopping, you know." (P.27, depression and T2D, female).  
13

14  
15 "Well they said because of the way, it's not helped, because I stopped, I wouldn't get out of the house,  
16  
17 I was staying in my room, that can affect arthritis because then you are letting it seize up more." (P.3,  
18  
19 depression and arthritis, female).  
20

21  
22 As seen with those experiencing a lack of motivation, social withdrawal also negatively impacted participants'  
23  
24 willingness to engage with medical professionals (both for depression and/or the LTC).  
25

26  
27 "I mean even the doctor, I have got to phone her tomorrow, they are going to arrange for the nurse  
28  
29 to come out because I am overdue blood tests and blood pressure and that [...]. Because she knows  
30  
31 that I just don't want to leave the house again." (P.3, depression and arthritis, female).  
32

### 33 34 ***Theme 5: Requires wilful effort to manage*** 35

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37 The experience of depression was described as an active process, requiring an individual to find ways to cope.  
38  
39 For some with an LTC, efforts to cope with their depression were thwarted by the functional limitation  
40  
41 imposed by their illness. Controlling the LTC was also important to help manage the depression.  
42

#### 43 44 *Universal coping strategies* 45

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47 While many of our participants struggled to cope, nearly all engaged in some strategies to navigate their  
48  
49 current situation such as the use of alcohol and food, medical treatments, and drawing on friendships and  
50  
51 family members for support. Often this included attempts to mask feelings as a means to find comfort; alcohol  
52  
53 in particular was frequently described as a way to relax and forget.  
54

55  
56 "But what I have done, and I have been guilty of, is purchasing alcohol and trying to blot it out with  
57  
58 the alcohol." (P.23, depression and arthritis, female).  
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3 Many participants were engaged with healthcare professionals for depression management. For some anti-  
4  
5 depressants had been beneficial, making their symptoms less severe. However, for others, side effects or fears  
6  
7 surrounding dependency prevented their use.  
8

9  
10 “Most of us are given medication, which makes you zombie, anyway. It doesn’t help you. It just block  
11  
12 your pains, you know. You are numb. You are not sorting out. And how long are you going to use those  
13  
14 medication?” **(P.24, depression and T2D, female).**  
15  
16

### 17 *LTCs impede efforts to cope with depression*

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19  
20 Having an LTC prevented some participants from engaging with coping strategies to help manage their  
21  
22 depression. For those with arthritis this included being unable to take part in activities that promote wellbeing,  
23  
24 including hobbies.  
25

26  
27 “But I think, yeah, so coping, well I am not walking as much as I want to, I have stopped going, I used  
28  
29 to go to water workout, water aerobics every week and I have stopped doing that, partly because of  
30  
31 the difficulty of getting into my bathers and afterwards drying myself.” **(P.1, depression and arthritis,**  
32  
33 **female).**  
34  
35

36 As P.32 described, the combination of her depression and arthritis makes coping with each insurmountable:

37  
38 “You know so the depression makes you lack motivation to, perhaps, I say modify some of the effects  
39  
40 of the arthritis, but the arthritis also, in limiting you, makes the depression seem worse. Together it  
41  
42 seems like a huge, insurmountable problem because if, on their own, they might be manageable, [...].  
43  
44 So it is, yes, it impedes any kind of self-care or therapy, if you like, together.”  
45  
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47

### 48 *Controlling the LTC improves depression*

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50  
51 Interestingly across all LTC groups, those who successfully managed to engage with strategies to cope with  
52  
53 their illness, saw benefits to their mental health through feeling an increased sense of control/self-efficacy.  
54  
55 For example, failure to self-manage insulin dosages appropriately negatively impacted P.25’s mood, while  
56  
57 being in control of his T2D also helped him self-manage his depression.  
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3 “But I carry glucose around with me. ... I think we were away somewhere and, but I was completely  
4  
5 useless for about two hours and I suppose I, you know, I had a moment of clarity about the need to  
6  
7 keep on top of it properly, because I sort of knew that if I didn’t, not only would I feel crap, physically,  
8  
9 the idea of feeling crap physically was depressing.” **(P.25, depression and T2D, male).**

10  
11  
12 Interestingly, P.30 with CHD found the unpredictable nature of his cardiac symptoms very distressing, but the  
13  
14 use of his own blood pressure monitor helped him regain a sense of control.

15  
16  
17 “this is my life saver, my BP [blood pressure] machine, I do it every day, [...] I was told 140 over 80,  
18  
19 right, yes, 140, 80, so once it’s within this, I go to sleep a bit better. If I didn’t know what my BP was,  
20  
21 I’d be worried even more.” **(P.30, depression and CHD, male).**

22  
23  
24 For some participants the physical limitations imposed by their LTC led to social isolation. This was particularly  
25  
26 apparent for those with arthritis. If participants received support with things that their arthritis prevented (for  
27  
28 example housework, food shopping), this was seen as positive for managing their depression, allowing them  
29  
30 to live well within the limits of the LTC.

31  
32  
33 “So yeah, [lady friend’s name] and [man friend’s name] took me out yesterday to go to Aldi, it’s the  
34  
35 first time since February that I have gone out to the shops.” **(P.3, depression and arthritis, female).**

## 36 37 38 39 40 **Discussion**

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43 This paper explored the lived experience of depression in primary care patients with and without a comorbid  
44  
45 physical LTC (CHD, T2D and arthritis). Using thematic analysis, we generated five overarching themes. ‘Shaped  
46  
47 by the course of time’ revealed a shifting, non-linear experience of depression in which the experience was  
48  
49 defined by earlier life experiences as well as more minor, cumulative events. For some, the LTC diagnosis had  
50  
51 caused catastrophic upheaval to participants’ lives; for these individuals the LTC was capable of triggering  
52  
53 depression (both first-ever or a recurrent episode). For many, other life events were more prominent to  
54  
55 determining the course of depression; for these participants the LTC was coincidental, running alongside the  
56  
57 depression but not triggering new episodes. ‘Somatisation’ highlighted the physical experience of depression  
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3 in our participants; for many, these symptoms were as dominant as the cognitive and emotional symptoms.  
4  
5 Somatic symptoms were universally experienced across all our groups, in particular feelings of tiredness and  
6  
7 fatigue and changes to eating habits. Where LTCs did interact with the somatic symptoms, this was mainly  
8  
9 driven by arthritic pain contributing to and compounding these symptoms. 'Cognitive and emotional burden'  
10  
11 explored the impact of mental symptoms, such as feelings of worthlessness, guilt, punishment, anhedonia and  
12  
13 sadness, on participants. LTCs compounded these cognitive and emotional experiences as well as indirectly  
14  
15 contributing to a worsening of these symptoms by affecting participants' enjoyment of previously pleasurable  
16  
17 activities and causing a loss of control and independence. Thoughts of dying were frequently experienced, and  
18  
19 prominent in patients with CHD where the unpredictability of future health was a psychological challenge.  
20  
21 Theme 4, 'Depression symptoms thwart self-care' examined how depression itself acts as a barrier to  
22  
23 engagement in self-care behaviours. Loss of motivation and social withdrawal and were key aspects of the  
24  
25 depressive experience which thwarted attempts for LTC self-management (particularly those with T2D).  
26  
27 Finally, 'Requires wilful effort to manage' revealed universal engagement in many coping strategies,  
28  
29 particularly attempts to mask depressive feelings such as the use of alcohol and food. However, LTCS  
30  
31 (particularly arthritis) did impede participants' ability to cope with depression, while successful management  
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33 of the LTC had a positive impact on mood.  
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40 Findings from quantitative studies continue to make attempts to understand the relationship between  
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42 depression in LTCs, with the causal model thought to be bidirectional.[9] Our findings supported the notion  
43  
44 that the LTC was capable of triggering depression; however, this was restricted to those whose LTC has caused  
45  
46 major life upheaval (e.g. loss of employment, relationship breakdown). It has been estimated that around 80%  
47  
48 of initial depressive episodes occur after a stressful life event;[24] and that the severity of stressors required  
49  
50 to precipitate recurrent depressive episodes decreases over time.[25] None of our participants described their  
51  
52 depression acting as a precursor to their LTC. In fact, for many, the LTC was experienced as coincidental to the  
53  
54 onset of depression; this is a view that has been supported by a previous qualitative meta-synthesis.[15]  
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3 The difference in the experience of depression in those with and without an LTC has not been studied  
4 previously using qualitative research. Quantitative research has identified differences in terms of symptom  
5 presentation, chronicity and timing of symptoms, and treatment responsivity.[4] Our findings have added to  
6 this by revealing that while the symptoms of depression (somatic, cognitive, affective) were universally  
7 experienced by those with and without depression, the LTC contributed to the burden of these symptoms by  
8 either directly provoking them (e.g. arthritic pain leading to tears of frustration) or by indirectly leading to  
9 negative mood by undermining the enjoyment of partaking in previously pleasurable activities as well as  
10 reducing individuals' sense of independence. T2D and arthritis were key in this regard since both illnesses were  
11 associated with lifestyle changes which negatively impacted the participants' depression, increasing feelings  
12 of anhedonia, sadness, guilt and worthlessness. Previous research has explored the impact of arthritis on  
13 leisure activities, finding that functional and physical constraints imposed by the illness can affect self-  
14 esteem.[26] Our findings extend this to the experience of those with arthritis *and* depression, suggesting that  
15 these limitations worsen the symptoms of depression. Participants with diabetes also saw a compounding  
16 effect of their physical condition on their mental health. This was particularly true for those who described  
17 being distressed by T2D and its management. Indeed, diabetes distress is now recognised as a separate  
18 disorder to major depression [27] which has been linked to feelings of burden, difficulties adhering to  
19 medication regimes and depression.[28]

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42 Loss of control and lack of independence featured heavily in the accounts of our participants with arthritis;  
43 whereby functional limitations imposed by the LTC indirectly impacted depression by removing individual's  
44 sense of control and autonomy. Loss was a key theme identified in the qualitative UPBEAT-UK study of  
45 patients with depression and CHD, where patients described not only loss of health but also interpersonal  
46 loss.[12] Health deterioration featured heavily in the accounts of all our participants with a physical LTC, and  
47 while thoughts of dying were universally experienced across groups, our CHD group revealed a strong sense  
48 of an unpredictable and uncontrollable death, which was not apparent in those with T2D and arthritis. This  
49 realistic fear underpinned the experience of depression in these participants.  
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3 Our findings also observed differences in the experience of depression in participants' ability to self-care and  
4 to cope with their mental health. Social withdrawal and lack of motivation were commonly experienced in all  
5 our participants. We described how these features of depression thwart attempts to engage with self-care  
6 behaviours such as personal hygiene, meal preparation etcetera, as well as LTC (particularly T2D) specific  
7 illness-management behaviours such as adhering to medication and attending hospital appointments. While  
8 depression has been associated with poor medication adherence in previous quantitative studies of T2D and  
9 CHD patients [29,30], there has been a lack of qualitative studies describing the hows and whys of this  
10 phenomenon; more research in this area is warranted.

11  
12 Findings from our study revealed the adoption of common coping behaviours across all our participants such  
13 as using alcohol and food to mask symptoms and drawing on expert sources of support; this supports findings  
14 from earlier work.[12] However, importantly we observed that the presence of an LTC interacted with  
15 participants' attempts to manage their depression. Those with an LTC, and in particular those with increasing  
16 disability from their arthritis, were prevented from engaging with coping mechanisms they had previously  
17 adopted to promote mental wellbeing. On the upside, positive self-management of the LTC improved feelings  
18 of control and self-efficacy and in so doing improved depressed mood. Depressed patients have previously  
19 been reported to benefit most from self-efficacy gains from LTC self-management training;[31] the importance  
20 of this construct for therapeutic purposes within the modern care setting of depression and LTC patients,  
21 requires future investigation.

22  
23 Our findings have a number of important implications for care models such as the NHS' IAPT-LTC  
24 programme.[32] Our findings suggest that any care model of depression in LTC needs to take into account four  
25 overarching conclusions based on our data: (1) Not all participants with depression and LTC view their mental  
26 and physical health as interconnected; therefore there should be allowances in care plans for separate  
27 treatment (this is a view endorsed by Knowles and colleagues).[10] (2) Key features of depression that affect  
28 LTC management and need to be considered when planning treatment and referring to psychological services  
29 are social withdrawal and lack of motivation to self-manage or access healthcare. (3) Key features of LTCs that  
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3 worsen depression that should be discussed during care planning are pain, the unpredictability of future health  
4 and progressive disability. (4) Positive self-management of LTC could improve feelings of control and self-  
5 efficacy and therefore mood, and should be encouraged.  
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10 A strength of our study was in the recruitment of participants from GP practices ensuring all our participants  
11 had received clinical diagnoses of their health conditions. To understand the differences in depression across  
12 different LTCs we excluded participants with more than one LTC of interest and with a serious or life-limiting  
13 diagnosis such as cancer, stroke or dementia. Due to the increased risk of physical illness with age, we recruited  
14 participants within an age bracket of 55 to 75 years; this enabled us to focus on the experiences of adults in  
15 mid to late life. The study was confined to North and North West London; however, we recruited from across  
16 contrasting areas to elicit a range of experiences. Despite our best efforts, unfortunately our arthritis sample  
17 was predominately female (90%); however this may partly reflect the greater incidence of osteoarthritis in  
18 women in the UK.[33] Our depression and CHD group was small (n=5); therefore our findings may not reflect  
19 the diversity of views that a larger sample might have attained. Also, as part of our reflexive practice, we noted  
20 that as researchers our experience and identities as female academic researchers working in London, of White  
21 (HR, RF, GB) and mixed (LP) ethnic background, is likely to have shaped our understanding, prioritisation, and  
22 interpretation of the data. The trustworthiness of our analysis, however, has been enhanced through  
23 researcher triangulation, drawing on the multiple expertise of the research team. Moreover, we used multiple  
24 levels to the analysis process from use of the reflective diary, through to the generation of themes, and the  
25 comparative exercise through the charting of codes. Participant checking was not undertaken which could  
26 have added a useful check to our interpretive work.  
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49 In conclusion, the results of our face-to-face interview study of depression in those with and without a physical  
50 LTC revealed that overall, key diagnostic symptoms of depression (anhedonia, sadness etc.) were experienced  
51 by all our participants regardless of LTC. However, the LTC did interact with depression by compounding  
52 somatic, cognitive, and emotional symptoms, increasing disability and reducing independence, and hindering  
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3 attempts at coping with mental illness. Our findings have implications for the development and fine-tuning of  
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5 mental health and LTC care programmes.  
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19 **Contributorship statement:**

20 LP was responsible for funding acquisition and conceived the study design. GB and RF advised on the study  
21  
22 methods. LP and HR collected the data. LP and RF led the data analysis. GB and HR contributed to the data  
23  
24 analysis. LP wrote the initial manuscript draft. RF, GB and HR edited the manuscript.  
25  
26  
27  
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29

30 **Competing interests:**

31  
32 The authors have no competing interests to declare.  
33  
34  
35  
36

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38  
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40  
41

42 **Data sharing statement:**

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44 The data for the study are archived in the UK Data Service.[18]  
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For peer review only

**Table 1: Characteristics of the sample, stratified by group**

	Whole sample (N= 41) <i>M±SD or N(%)</i>	Depression only (n = 12) <i>M±SD or N(%)</i>	Depression and CHD (n = 5) <i>M±SD or N(%)</i>	Depression and T2D (n = 10) <i>M±SD or N(%)</i>	Depression and arthritis (n = 14) <i>M±SD or N(%)</i>
Sex (female)	24(58.5)	6(50.0)	1(20.0)	4(40.0)	13(92.9)
Age (years)	63.5(5.5)	62.4(5.5)	66.0(4.0)	61.0(5.2)	65.1(5.9)
Married/cohabiting	17(41.5)	6(50.0)	2(40.0)	5(50.0)	4(28.6)
Ethnicity:					
White British	27(65.9)	10(83.3)	2(20.0)	6(60.0)	9(64.3)
Indian	3(7.3)			2(20.0)	1(7.1)
Pakistani	1(2.4)		1(20.0)		
Black Caribbean	1(2.4)		1(20.0)		
Other White background	7(17.1)	2(16.7)	1(20.0)	1(10.0)	3(21.4)
Other Asian background	2(4.9)			1(10.0)	1(7.0)
Employment status:					
Employed full-time	9(22.0)	3(25.0)	1(20.0)	3(30.0)	2(14.3)
Employed part-time	1(2.4)	1(8.3)			
Self-employed	7(17.1)	3(25.0)			4(28.6)
Retired	15(36.6)	4(33.3)	3(60.0)	3(30.0)	5(35.7)
Unemployed	4(9.8)	1(8.3)		3(30.0)	
Volunteer	2(4.9)		1(20.0)		1(7.1)
Disabled	3(7.3)			1(10.0)	2(14.3)
Highest educational qualification - degree or higher	15(36.6)	3(25.0)	3(60.0)	4(40.0)	5(35.7)
Antidepressant usage (yes)	35(85.4)	9(75.0)	4(80.0)	9(90.0)	13(92.9)

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**Figure 1 Caption** (*figure itself attached as separate .jpg file*)

**Figure 1. Schematic diagram of theme structure.**

N.B. LTC: Long term condition.

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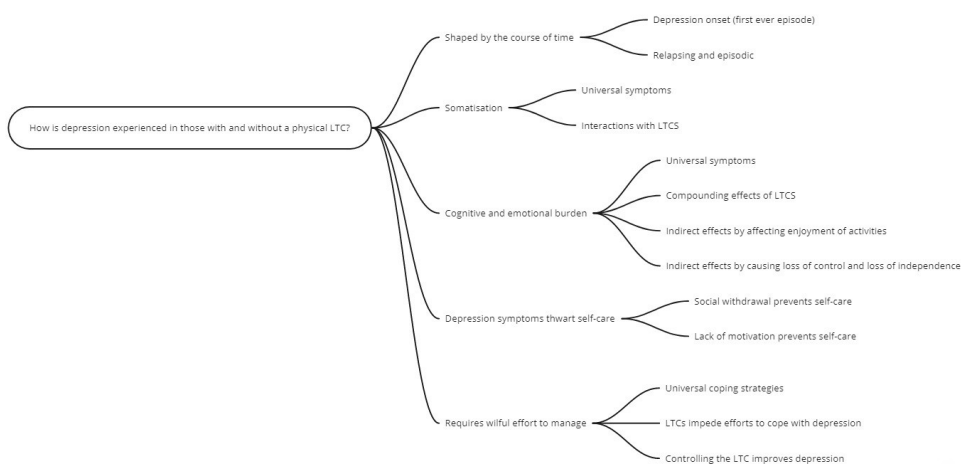


Figure 1. Schematic diagram of theme structure.  
 N.B. LTC: Long term condition.

372x187mm (96 x 96 DPI)

Supplementary file: Appendix 1 - Vignettes

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3 **Scenario 1**  
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5 Sarah has good days and bad, but on a bad day she feels so sad and miserable that she just  
6 can't stand it. It seems to completely take over her head like she's in a fog. She feels really  
7 disappointed in herself for feeling this way, despite all the good things she has in her life.  
8 Sometimes when she's by herself she cries and even has thoughts of killing herself just to try  
9 and be anywhere but here. She feels completely worthless.  
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12 **Scenario 2**  
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14 Most days Sam wakes up and feels so tired he wishes he could just stay in bed. In fact he  
15 feels so tired most of the time that he doesn't want to do anything. He sleeps longer than he  
16 used to and doesn't have the energy to do anything. Sometimes he doesn't even feel like  
17 eating. He's even lost weight without trying to. His partner tries to show him affection and  
18 wants a kiss and a cuddle, but he just feels numb and not interested at all.  
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22 **Scenario 3**  
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24 Jason finds it really hard to feel positive about the future at the moment, it's like he has  
25 nothing to look forward to anymore. He finds it difficult to concentrate and to make  
26 decisions these days too. He feels so frustrated and trapped by the way he feels. His friends  
27 tell him he should snap out of it, but he just can't. He wishes he didn't have to feel like this,  
28 it makes him feel like such a failure.  
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31 **Scenario 4**  
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33 Most days Clare feels like she is being punished for something she must have done in a past  
34 life. And then she feels guilty for thinking like this. She seems to worry about her health all  
35 the time and her aches and pains get on top of her. She doesn't enjoy things the way she  
36 used to, in fact she doesn't really get any pleasure out of anything anymore. She finds it  
37 hard to leave the house some days. Everything seems a bit pointless these days, if she's  
38 being completely honest.  
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41 **Scenario 5**  
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43 Susan has always enjoyed her food, but for the past couple of months she's noticed she's  
44 been putting on some extra weight. She finds she craves her favourite foods and is comfort  
45 eating to make herself feel a bit better. She's not sure she is feeling any better though, in  
46 fact she's sleeping really badly and often wakes up several times in the night. Her sleep is  
47 restless and she wakes up tired making each day feel like it drags.  
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## The Mood and Health Study

### Interview Schedule – Depression

#### Introduction

Review of Participant Information Sheet

Consent form

Timing and confidentiality

*My name is [insert name] and I am a researcher. I'm not a doctor or a psychologist and I don't have any clinical contact with your team. I'm interested in finding out from you what your experiences have been with your mood, and there are no right answers.*

#### Vignettes

*To start I'd like you to look at what some other people have experienced, and then we'll talk about them a bit. Firstly, I'd like you to start by sorting the cards into two piles, those which you think are relevant to you and those which aren't.*

<b>Card sort</b>	<p>Can you talk me through how you have sorted the cards?</p> <p>Has anything like this ever happened to you?</p> <p>Have you ever felt these sorts of things before?</p> <p>How do you think this person's experience is different from yours?</p>
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#### Depression

<b>Precipitating events</b>	<p>Take me back, can you tell me about when you first noticed changes to your mood?</p>
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Prompts	<ul style="list-style-type: none"> <li>• Can you remember feeling differently?</li> <li>• How did it feel?</li> <li>• Was there anything else you think may have contributed to your low mood?</li> <li>• How do you think that experience relates to how you feel today?</li> </ul>
<b>Diagnosis</b>	Can you talk me through the support you received during this time?
Prompts	<ul style="list-style-type: none"> <li>• E.g. family, friends, GP?</li> <li>• How did you find out you had depression? E.g. Who told you? When?</li> <li>• How did you feel when you found out it was depression?</li> </ul>
<b>Timeline</b>	How has your mood been since then?
Prompts	<ul style="list-style-type: none"> <li>• How has your mood changed over time?</li> </ul>
<b>Symptoms</b>	Can you tell me about a time when you felt your depression was at its worst?
Prompts	<ul style="list-style-type: none"> <li>• How did it feel?</li> <li>• How long did it last?</li> <li>• Can you tell me how most days are for you at the moment?</li> <li>• What's a good day for you?</li> <li>• How long have you been feeling this way?</li> <li>• Are there times when you don't feel this way? How long does this last?</li> </ul>
<b>Management of depression</b>	Are you receiving any treatment for your depression at the moment?
Prompts	<ul style="list-style-type: none"> <li>• Can you tell me about the care you have received for your depression from doctors?</li> </ul> <p>e.g. who (GP, clinic nurse/doctor)</p> <p>e.g. where (GP clinic, hospital clinic, community/third sector)</p> <p>e.g. when (routine/booked appointments, length of appointments)</p>

	<p>e.g. what (antidepressants, counselling)</p> <ul style="list-style-type: none"> <li>• Do you find it easy to talk to your doctor about your concerns?</li> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> </ul>
<b>Self-care</b>	<ul style="list-style-type: none"> <li>• Can you talk me through anything you do yourself that helps you cope better?</li> </ul>
<b>Prompts</b>	<ul style="list-style-type: none"> <li>• For example, exercise, eating habits, alcohol consumption, smoking, acceptance, distractions/hobbies, wallowing. Have any of these been helpful to you?</li> <li>• How do these things make you feel?</li> </ul>

### Wrapping up

Is there anything else you would like to tell me?

How have you found this interview?

Do you have any questions?

Thank you for your time.

Give sources of further support handout.

Give baseline questionnaire.

Provide participant with £10 retail voucher.





## The Mood and Health Study

### Interview Schedule – Depression and Physical Illness

#### Introduction

Review of Participant Information Sheet

Consent form

Timing and confidentiality

*My name is [insert name] and I am a researcher. I'm not a doctor or a psychologist and I don't have any clinical contact with your team. I'm interested in finding out from you what your experiences have been with your mood and health, and there are no right answers.*

#### Vignettes

*To start I'd like you to look at what some other people have experienced, and then we'll talk about them a bit. Firstly, I'd like you to start by sorting the cards into two piles, those which you think are relevant to you and those which aren't.*

<b>Card sort</b>	<p>Can you talk me through how you have sorted the cards?</p> <p>Has anything like this ever happened to you?</p> <p>Have you ever felt these sorts of things before?</p> <p>How do you think this person's experience is different from yours?</p>
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#### Depression

<b>Precipitating events</b>	<p>Take me back, can you tell me about when you first noticed changes to your mood?</p>
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Prompts	<ul style="list-style-type: none"> <li>• Can you remember feeling differently?</li> <li>• How did you feel?</li> <li>• Was there anything else you think may have contributed to your low mood?</li> <li>• How do you think that experience relates to how you feel today?</li> </ul>
<b>Diagnosis</b>	Can you talk me through the support you received during this time?
Prompts	<ul style="list-style-type: none"> <li>• E.g. family, friends, GP?</li> <li>• How did you find out you had depression? E.g. Who told you? When?</li> <li>• How did you feel when you found out it was depression?</li> </ul>
<b>Timeline</b>	How has your mood been since then?
Prompts	<ul style="list-style-type: none"> <li>• How has your mood changed over time?</li> </ul>
<b>Diagnosis of physical illness (if not covered above)</b>	Can you tell me how you found out about your [arthritis/heart disease/diabetes]?
Prompts	<ul style="list-style-type: none"> <li>• How long ago was this?</li> <li>• Who told you? Where were you?</li> <li>• How did you feel when you found out?</li> <li>• Did you find out about your [arthritis/heart disease/diabetes] before or after you found out you had depression? How did you find this time?</li> </ul>
<b>Symptoms</b>	Can you tell me about a time when you felt your depression was at its worst?
Prompts	<ul style="list-style-type: none"> <li>• How did it feel?</li> <li>• How long did it last?</li> <li>• Can you tell me how most days are for you at the moment?</li> <li>• What's a good day for you?</li> </ul>

	<ul style="list-style-type: none"> <li>• How long have you been feeling this way?</li> <li>• Are there times when you don't feel this way? How long does this last?</li> </ul>
<b>Interaction</b>	Can you tell me about how your [arthritis/heart disease/diabetes] affects your life now?
	<ul style="list-style-type: none"> <li>• How does your [arthritis/heart disease/diabetes] make you feel?</li> <li>• How do your depression and [arthritis/heart disease/diabetes] affect each other?</li> <li>• Have you ever found it difficult to cope with [arthritis/heart disease/diabetes]? e.g. coping with the symptoms, treatments?</li> </ul>
<b>Management</b>	Are you receiving any treatment for your depression at the moment?
Prompts	<ul style="list-style-type: none"> <li>• Can you tell me about the care you have received for your depression from doctors?</li> </ul> <p>e.g. who (GP, clinic nurse/doctor) e.g. where (GP clinic, hospital clinic, community/third sector) e.g. when (routine/booked appointments, length of appointments) e.g. what (antidepressants, counselling)</p> <ul style="list-style-type: none"> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> <li>• How easy have you found it to get help for your depression?</li> </ul>
	What treatments have you had for your [arthritis/heart disease/diabetes]?
Prompts	<p>e.g. who (GP, clinic nurse/doctor) e.g. where (GP clinic, hospital clinic) e.g. when (more than one treatment?) e.g. what (self-management courses, medication, surgery?)</p>

	<ul style="list-style-type: none"> <li>• Do you find it easy to talk to your doctor about your concerns?</li> <li>• How did you find the treatment?</li> <li>• How helpful has this treatment been? E.g. what was most helpful and least helpful?</li> <li>• How do you feel treatment of your [arthritis/heart disease/diabetes] has affected your depression?</li> <li>• <b>[Arthritis and angina only]</b> How have the treatments helped with your pain?</li> </ul>
<b>Self-care</b>	<ul style="list-style-type: none"> <li>• Can you talk me through anything you do yourself that helps you cope better?</li> </ul>
<b>Prompts</b>	<ul style="list-style-type: none"> <li>• For example, exercise, eating habits, alcohol consumption, smoking, acceptance, distractions/hobbies, wallowing. Have any of these been helpful to you?</li> <li>• How do these things make you feel?</li> </ul>

### Wrapping up

Is there anything else you would like to tell me?

How have you found this interview?

Do you have any questions?

Thank you for your time.

Give sources of further support handout.

Give baseline questionnaire.

Provide participant with £10 retail voucher.

## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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