'Who Cares?' The experiences of caregivers of adults living with heart failure, chronic obstructive pulmonary disease and coronary artery disease: a mixed methods systematic review

Miriam Catherine Noonan,1 Jennifer Wingham,2 Rod S Taylor3

ABSTRACT
Objective To assess the experiences of unpaid caregivers providing care to people with heart failure (HF) or chronic obstructive pulmonary disease (COPD) or coronary artery disease (CAD). Design Mixed methods systematic review including qualitative and quantitative studies. Data sources Databases searched: Medline Ebsco, PsycINFO, CINAHL Plus with Full Text, Embase, Web of Science. Ethos: The British Library and ProQuest. Grey literature identified using: Global Dissertations and Theses and Applied Sciences Index and hand searches and citation checking of included references. Search time frame: 1 January 1990 to 30 August 2017.

Eligibility criteria for selecting studies Inclusion was limited to English language studies in unpaid adult caregivers (>18 years), providing care for patients with HF, COPD or CAD. Studies that considered caregivers for any other diagnoses and studies undertaken in low-income and middle-income countries were excluded. Quality assessment of included studies was conducted by two authors.

Data analysis/synthesis A results-based convergent synthesis was conducted.

Results Searches returned 8026 titles and abstracts. 54 studies—21 qualitative, 32 quantitative and 1 mixed method were included. This totalled 26453 caregivers who were primarily female (63%), with median age of 62 years. Narrative synthesis yielded six concepts related to caregiver experience at single point of time and there is a discordance between paradigms regarding emerging concepts. Four concepts emerged from qualitative papers which were not compared between paradigms regarding emerging concepts. Four concepts emerged from qualitative papers which were not compared between paradigms regarding emerging concepts. Four concepts emerged from qualitative papers which were not compared between paradigms regarding emerging concepts.

Conclusion Caregiving is life altering and complex with significant health implications. Health professionals should support caregivers who in turn can facilitate the recipient to manage their long-term condition. Further longitudinal research exploring the evolution of caregiver experiences over time of patients with chronic cardiopulmonary conditions is required.

Trial registration number CRD42016053412

INTRODUCTION
A caregiver is anyone providing unpaid care, to a friend or family member who is unable to care for themselves.1 This may be emotional support; someone to talk to, or practical support; dressing wounds, mobility assistance or medication checking.2 There are 43.5 million caregivers in the USA, 2.86 million in Australia and 6.5 million in the UK.3 Between 2001 and 2011, the number of unpaid caregivers in the UK grew at a faster rate than population growth.4 The annual value of unpaid care provided to an individual with a chronic illness is estimated to be £132 billion.5

Focus groups examining a caregiver’s life conducted by ‘The Institute of Public Care’ (2017), based at Oxford Brookes University; described caregivers as the ‘Skilled Helper’ performing a series of roles.6 Seltzer and Li describe a dynamic process of transitions to being a caregiver.7 These transitions comprise participating in the role before identifying as...
a caregiver, acceptance of the role, engaging in it with awareness and sometimes moving beyond the caregiving role when the patient moving to paid care settings or bereavement occurs. This process is not linear and people move through the different transitions at varying rates. Acknowledging this, it is imperative for caregivers to receive a caregiver needs assessment as legally stipulated by the 2014 Care Act. Additionally, the National Institute for Health and Care Excellence clinical guidelines for heart failure (HF) (CG108) and chronic obstructive pulmonary disease (COPD) (CG101) both recommend that family members or caregivers are provided with support and included in discussions about care.

Cardiopulmonary disease is a primary cause of illness. Cardiovascular disease is responsible for 45% deaths in Europe and one in four deaths in the USA. By 2020, COPD is projected to be in the global top five of diagnoses causing years lost through early mortality or disability-adjusted life years. Caregivers of patients with HF have a multitude of unmet needs due to fluctuations in the trajectory of HF. COPD has frequent unplanned hospital admissions and a high morbidity rate. Caregivers experience depressed mood, greater anxiety and increased subjective burden when their support needs are not met. The unpredictability of HF and COPD leads to caregivers constantly adjusting their role, creating a need to continuously reassess what caregiver needs are. Spousal caregivers of patients with myocardial infarction experience increased levels of stress, lifestyle impact and emotional distress. Caring for coronary artery bypass graft patients in tasks such as monitoring and provision of emotional support increased caregiver burden to a level described as moderate. COPD and cardiovascular disease are both increasing in prevalence and frequently coexist. We know of no systematic review that synthesises quantitative and qualitative studies to combine caregivers’ experiences of people with HF, COPD or coronary artery disease (CAD).

Using a mixed methods systematic review methodology including both qualitative and quantitative literature, this study aims to understand the experiences of adult caregivers when supporting people with HF, COPD or CAD.

METHODS

We conducted and reported this systematic review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.

Patient and public involvement

There was no patient and/or public involvement in this systematic review.

Study design

This study employed a mixed methods systematic review assessing both qualitative and quantitative studies. The rationale for using a mixed methods review approach was multifaceted. First, to gain a qualitative assessment of the type and extent of caregiver’s experiences. Second, to assess the quantitative predictors of caregiver’s experiences. Third, to develop a holistic perspective of what caregiver experiences. Finally, we wanted to assess the degree of convergence between qualitative and quantitative experiences.

Search strategy

Our search strategy was designed in conjunction with a Health Services Librarian and Information Specialists. Search terms included condition-specific terms, that is, ‘heart failure’, ‘COPD’ and ‘coronary artery disease’, caregiver-specific, plus experience related terms, ‘experience’, ‘quality of life’ ‘activities of daily living’, ‘occupational engagement’, ‘time use’, ‘self-efficacy’, ‘coping strategies’, ‘leisure activity’, ‘information exchange’ and ‘caregiver expectation’ (see online supplementary file 1, table 1 for complete list of search terms). Databases searched included: Medline Ebsco, PsycInfo, CINAHL Plus with Full Text, Embase, Web of Science, Ethos: The British Library and ProQuest. Grey literature was identified using Global Dissertations and Theses and Applied Sciences Index and hand searches and citation checking of included references. To ensure the contemporary nature of the evidence considered, the search time frame was January 1990 to August 2017. A single researcher (MN) initially screened titles and abstracts. Selection of full papers was performed by two researchers (MN and either JW or RST) and cross-checked with the eligibility criteria.

Study selection

Studies were included if they addressed ‘caregiver experience’, which was defined as encompassing the daily activities of caregivers and the impact of these activities on their lives. These were English language studies involving unpaid adult caregivers (aged >18 years), providing care for patients with HF, COPD or CAD living in the community and not residential settings with paid care staff. Qualitative, quantitative and grey literature studies were all included in the search strategy. Conference papers were excluded. Outcomes of interest included psychological and physical outcomes reported, occupational engagement and routine. As we sought to inform the practice of the UK and other high-income countries, we excluded studies undertaken in low-income and middle-income countries.

Data extraction

Data extracted from retained studies included: study design, sample and recruitment, study description, method, findings, discussion and authors’ conclusions and limitations. Caregiver quotes were extracted from qualitative studies. For quantitative studies, data extraction also included details of attrition and data analysis.

Study quality assessment

Qualitative studies were appraised using the Critical Appraisal Tool. In absence of an existing quality tool...
that could be used to appraise quantitative studies addressing the specific question of this study, a quality assessment tool was developed by the research team based on what were deemed to be the appropriate core biases, that is, (1) was the study design longitudinal (score of 1) or cross-sectional (score of 0); (2) how was the sample recruited? Purposive (score of 1) or convenience (score of 0); (3) was the level of attrition/response rate acceptable? Attrition of 20%/lower or response rate of 80% or above (score of 1) or attrition of >20% or response rate <80% (score of 0); (4) was a validated quantitative outcome(s) used? Validated (score of 1), non-validated (score of 0); (5) were the methods of data analysis appropriate? Multivariate (score of 1) or univariate (score of 0). Based on their quality assessment, scores were totalled and studies were ranked: 1 or 2 ‘low quality’, 3 ‘medium quality’ and 4 or 5 ‘high quality’. Data extraction and quality appraisal was first conducted by a single researcher (MN) and checked by one of two researchers (JW or RST).

**Data analysis and synthesis**

The methodology of mixed methods data synthesis is an emerging one and no single approach has yet been universally accepted. In this study, a results-based convergent design was chosen. This requires transformation of one method into another. Due to the heterogeneity of the quantitative methods, a meta-analysis was not appropriate. Instead, applying a narrative profile formation, the quantitative methods, a meta-analysis was not appropriately accepted. A comprehensive outline of study results and abstracts. Of these, 242 full papers were reviewed, of which 57 papers (54 studies) were included for synthesis. A detailed summary of included studies is provided in table 1. A comprehensive overview of study results and concepts generated by each study is included in online supplementary file 2).

**Study characteristics**

Of the 54 studies, 21 were qualitative, 32 quantitative and 1 mixed methods. Thirty-four focused on HF, 14 COPD and 6 CAD. The total number of caregiver participants was 26,473. Caregivers were primarily female (63%), with a median age of 62 years. Patient median age was 69 years. A summary of study characteristics is provided in table 3.

**Quality assessment**

Studies of insufficient quality were excluded, qualitative papers were appraised and only high-quality qualitative studies were included. A total of 21 out of 193 qualitative studies were classified as high quality. Quantitative studies were classified as follows: 3 high quality, 12 medium quality and 15 low quality (see table 4(a) and (b) for quality appraisal). Given the number of high-quality qualitative studies and in accord with current guidelines for the synthesis of qualitative evidence, we limited inclusion to qualitative studies of high quality only. In contrast, given the low number of high-quality quantitative studies, to ensure comprehensiveness of our review, we included all quantitative studies, regardless of quality.

**Findings**

Six concepts relating to caregiver experience were identified: (1) mental health, (2) caregiver role, (3) lifestyle change, (4) support for caregivers, (5) knowledge and (6) relationships. Four additional concepts were identified from qualitative papers only (6) expert by experience, (7) vigilance, (8) time and (9) shared-care (figure 2). The concepts are reflected in caregiver quotes in table 5.

**Mental health**

Twenty-five quantitative, and 1 mixed methods study addressed mental health. This encompassed depression and burden. Caregivers described an internal and external conflict of emotions, recognising a psychological change within themselves and the care recipient. Maintaining hope and positivity, versus managing worries, fears and anxieties was predominant. The HF study by Pressler et al identified caregivers had moderately poor health at baseline and at 8 months but they had fewer depressive symptoms over time. Burden arose due to greater responsibilities. Yeh and Bull noted the quality of relationship and lack of family support significantly predicted greater family caregiver burden. Nääström et al reported caregiver burden was concerned with the future and their fears of potential demands. Those with greater resiliency appeared to adjust and cope better with the illness trajectory. Caregivers described mental adjustment after an acute event. Living through an acute event was long lasting and some experienced post-traumatic symptoms.
| Profile | Explanation of profile | Modal narrative extracted from study | Emerging from study | Concept |
|---------|------------------------|-------------------------------------|---------------------|---------|
| Modal   | This is a narrative description of the group being studied | 102 dyads, predominantly spousal caregivers. Group is caregivers of patients with HF. Comparing depressed and non-depressed patients with HF. | This study considers whether caregiver experiences are different for caregivers when caring for depressed or non-depressed patients Spouse as a caregiver. Impact of depression on the caregiver. | |
| Average | This is a detailed narrative description based on the mean (average) attributes of the individuals/situations being studied | Caregiver mean age 56.7, 78% female, white (94%). 41% of patients New York Heart Association III-IV. 42% caregivers reported severe burden (the Zan Burden Interview (ZBI)≥17). | Caregiving resulted in burden experienced by caregivers in this study. | Mental health (burden) |
| Comparative | This is a description comparing studies and comparing individuals being studied | Caregivers who provided care for depressed patients reported higher burden than those caring for non-depressed patients. Caregivers related their burden to social life limitations, poor perceived control, stress of family obligations and patients' dependency. Caregivers of patients with depressive symptoms had a higher level of burden (25±13 vs 13.5±12 on the ZBI; p<0.001), spent more time caregiving (37±12 vs 30±11 on the Oberst Caregiving Burden Scale; p=0.004) and reported worse mental quality of life (46±10 vs 51±10 on the SF-12v2; p=0.026) than those of patients without depressive symptoms. | Patient illness severity impacts on caregiver. Lifestyle adjustment Mental health Role of caregivers |
| Normative | A comparison of the study individuals with the general population | 27% of patients in this study scored 14 or higher on Becks Depression Index (a score of 14 or higher is clinically significant for depression). Family members caring for patients with HF with depressive symptoms had significantly higher levels of caregiving burden and worse quality of life compared with those caring for patients without depressive symptoms. 'Most difficult task for both sets of caregivers—providing emotional support (M=3.3, SD=1.2). | Greater impact on caregivers' lives when patients were depressed. Mental health Role of caregivers |
| Holistic (also called inferential or summative) | A description of the overall perception of the investigator | Female, white caregivers, experienced greater levels of burden, loss of roles and greater distress when patients were depressed. This could be due to the increased need for practical and emotional support, feeling they need to be constantly present. | |

Table 1 Narrative formation (Chung, 2016)
Caregiver role
This is addressed in 18 qualitative and 14 quantitative studies. Caregiver role is complex and requires much coordination. Caregivers describe significant role change such as increasing domestic tasks. Role loss is prevalent and caregivers need to reframe their identity. Societal expectation regarding the relationship and gender influences caregivers adjusting to their roles. Caring can be positive and rewarding. Caregivers learn about themselves and strengths they have.

Lifestyle changes
Fourteen quantitative and 21 qualitative studies addressed lifestyle changes. Caregivers experienced leisure, social and work-related problems. Caring interrupted and eliminated...
| First author/ref. no. | Diagnosis | Aims (as stated by authors) | Methods | Country | Data collection sampling | Participants caregiver (time caring) | Mean age (caregiver/recipient) |
|-----------------------|-----------|-----------------------------|---------|---------|-------------------------|--------------------------------------|-------------------------------|
| Ågren[37]             | HF (NYHA II–IV) | Describe the levels and identify independent predictors of caregiver burden in partners of pts with HF. | QUANT (correlational) | Sweden | Cross-sectional purposive | 135 (101 F, 34 M) (NS) | 69/71 |
| Al-Rawashdeh[38]      | HF (NYHA I–IV) | To examine whether individuals’ disturbance predicted their own and their partners’ QoL, in HF. | QUANT | USA | Cross-sectional purposive | 78 dyads (58 F, 20 M) (NS) | 62.2/59.5 |
| Andersen[63]          | HF | Obtain knowledge on experiences and views and the desire for knowledge of family caregivers of pts with HF, their competence and support required. | QUAL | Norway | Interviews convenience | 19 (17 F, 2 M) (NS) | 63/NS |
| Badr et al[39]        | COPD | Individual-level predictors of pt and cgs depression in COPD as well as how dyad members effect each other’s depression. | QUANT | USA | Cohort study purposive | 89 (68 F, 21 M) (NS) | 54.8/67 |
| Bakas et al[40]       | HF (NYHA II–IV) | Examine relationships among age, perceived control over managing HF, perceived difficulty with tasks, perceived outcomes and perceived mental and general health among cgs of persons with HF. | QUANT (descriptive correlational) | USA | Cross-sectional convenience | 21 (20 F, 1 M) (NS) | 59.6/62.7 |
| Baker et al[41]       | HF (LVAD in situ) | To describe experiences of cgs of pts who received LVAD therapy as a bridge to transplantation. | QUAL (phenomenological) | USA | Interviews convenience | 6 (5 F, 1 M) (26–372 days) | 51/NS |
| Bove et al[42]        | COPD (GOLD C&D) | Explore how spouses of pts with severe COPD experience their role | QUAL | Denmark | Focus groups purposive | 22 (13 F, 9 M) (NS) | 69.4/NS |
| Burke et al[43]       | HF (NYHA II–IV) | Understand what roles cgs perceive and desire for themselves, and to compare and contrast these roles with those they perceive to be desired by the healthcare system. | QUAL (inductive) | USA | Interviews purposive | 20 (18 F, 1 M, 1 NS) (<1 to >8 hours/week) | 59/64 |
| Chung et al[44]       | HF (NYHA II–IV) | Examine differences in cgs outcomes between cgs who care for pts with HF with and without depressive symptoms. | QUANT | USA | Cross-sectional convenience | 102 dyads (79 F, 23 M) (NS) | 56.7/61.4 |
| Clark et al[45]       | HF (NYHA II–IV) | To examine the complexity of caregiving for pts with HF. | QUAL | Scotland | Interviews convenience | 30 (23 F, 7 M) (NS) | 68 F, 67 M/NS |
| Cossette[46]          | COPD (GOLD III–V) | Examine relationship between type, number and disturbance of caregiving tasks and impact on mental health of cgs. | QUANT | Canada | Cross-sectional convenience | 89 (F) (mean=13 years) | 65/88.6 |
| Evangelista et al[47] | HF (NYHA I–IV) | Describe emotional well-being of pts with HF and cgs (correlational) Identify factors associated with emotional well-being of pts. Determine gender differences in emotional well-being of pts and cgs. | QUANT (correlational) | USA | Cross-sectional convenience | 103 dyads (73 F, 30 M) (NS) | 59.4/57.6 |
| Figueiredo et al[48]  | COPD (GOLD I–IV) | Examine coping strategies of family caregivers of pts with early and advanced COPD. To analyse subjective burden of family caregivers of pts with early and advanced COPD and its predictor variables and how these relate to their subjective health. | QUANT (correlational) | Portugal | Cross-sectional convenience | 158 (120 F, 38 M) (>4 years) | 58.4 (early COPD) 60.8 (advanced COPD)/69.4 |
| Figueiredo et al[49]  | COPD (GOLD I–IV) | To analyse subjective burden of family caregivers of pts with early and advanced COPD and its predictor variables. | QUANT (correlational) | Portugal | Cross-sectional convenience | 167 (125 F, 42 M) (>4 years) | 58.3 (early COPD) 60.5 (advanced COPD)/69.3 |
| Figueiredo et al[50]  | COPD (moderate to severe) | Obtain knowledge on experience of husbands and sons providing care to a family member. | QUAL | Portugal | Interviews purposive | 12 (M) (>4 years) | 70.9 (husbands) 43.4 (sons)/72.1 |
| Grigorovich et al[51] | HF (NYHA I–IV) | To examine changes in cgs’ well-being over time. Identify pt and cg factors associated with positive and negative outcomes. | QUANT (repeated measures) | Canada | Longitudinal convenience | 50 (31 F, 19 M) (mean=18 months) | 58/61.6 |
| First author/ref. no. | Diagnosis | Aims (as stated by authors) | Methods | Country | Data collection sampling | Participants caregiver (time caring) | Mean age (caregiver/recipient) |
|----------------------|-----------|-----------------------------|---------|---------|-------------------------|-------------------------------------|-------------------------------|
| Halm et al[14]        | CAD       | To determine cg burden after CABG surgery | QUANT   | USA     | Cross-sectional convenience | 166 (136 F, 30 M) (<12 months)  | 64.7/66.8                   |
| Halm et al[15]        | CAD       | To describe the concerns, strategies and advice of CABG cgs during the first 3 months postsurgery. To explore cg burden by age and gender | QUAL    | USA     | Interviews purposive | 32 (16 F, 16 M)(NS)  | 60.6 (M<70)/60.1 61.5 (F<70)/62.5 75.9 (M>70)/74.4 73.6 (F>70)/77.6 |
| Hess[16]              | HF        | To examine the association between cg literacy and medication administration | QUANT (correlational) | USA     | Cross-sectional convenience | 5 (F) (NS) | 65/72.8                         |
| Hooley[17]            | HF (NYHA III or IV) | To explore if greater cg burden is associated with increasing disease burden and depressive symptoms in pts and cg | QUANT    | USA     | Cross-sectional convenience | 50 (40 F, 10 M) (NS) | 61/72                        |
| Hwang et al[18]       | HF (NYHA I–IV) | To identify factors associated with the impact of caregiving | QUANT    | USA     | Cross-sectional convenience | 76 dyads (54 F, 22 M) (mean=53.4 months) | 53.4/53.8                      |
| Hynes[19]             | COPD      | To explore the experiences of cgs providing care to a family member with COPD | QUAL (phenomenological) | Ireland | Interviews convenience | 11 (9 F, 2 M) (1–15 years) | NS/NS                         |
| Imes et al[20]        | HF (NYHA III–IV) | To describe cg's experience of living with HF | QUAL (descriptive) | USA     | Interviews convenience | 14 (11 F, 3 M) (NS) | 64.8/68                      |
| Karmilovich[21]       | HF (NYHA III or IV) | To examine cg demands and components of caring. Assess stress and correlation with cg burden. | QUANT (correlational) | USA     | Descriptive survey purposive | 41 (30 F, 11 M) (NS) | 56.7/NS                      |
| Kitko[22]             | HF        | To gain a deeper understanding of the type of work in spousal caregiving | QUAL    | USA     | Interviews convenience | 20 (14 F, 6 M) (2 months–9 years) | 67/70                        |
| Kneeshaw[23]          | CAD       | To examine cg mutuality and preparedness for caring post-CABG surgery | QUANT    | USA     | Longitudinal convenience | 49 (32 F, 17 M) (NS) | 50.1/72.6                   |
| Liljeroos et al[24]   | HF        | To understand perceived caring needs in dyads and understand areas of support for cgs | QUAL    | Sweden  | Focus groups purposive | 19 dyads (NS) (7 F, 12 M) | 70/72                        |
| Lindqvist et al[25]   | COPD (mild to severe) | To describe conceptions of daily life for women caring for men with COPD | QUAL (phenomenological) | Sweden  | Interviews purposive | 21(F) (NS) | 72/NS                         |
| Loftus[26]            | HF (NYHA II–IV) | Investigate outcomes of caregiving in late-stage HF | QUANT (correlational) | UK      | Longitudinal convenience | 53 (41 F, 12 M) (6.66 hours/day) | 66.7/76.3                     |
| Lum et al[27]         | HF (NYHA II–IV) | Measure of relationship quality and cg benefit, burden and depressive | QUANT (correlational) | USA     | Cross-sectional purposive | 19 (7 F, 12 M) (<1 to >8 hours/week) | 59/69                        |
| Luttik et al[28]      | HF        | Experience and needs of cg’s well-being factors | QUAL    | The Netherlands | Interviews convenience | 13 (10 F, 3 M) (NS) | 66/88.6                      |
| Luttik et al[29]      | HF (NYHA II–IV) | Investigate QoL in cgs of pts with HF vs QoL in people with healthy partners | QUANT    | The Netherlands | Cross-sectional purposive | 303 (NS) | 67/89                        |
| Marcuccilli et al[30] | HF-LVAD in situ | Explore life adjustments of cgs caring for long-term LVAD pts. | QUAL (phenomenological) | USA     | Interviews purposive | 5 (5 F) (NS) | 56.6/NS                      |
| Marcuccilli et al[31] | HF-LVAD as DT | Explore experience of caring for family member with HF | QUAL (phenomenological) | USA     | Interviews purposive | 7 (6 F, 1 M) (18–24 hours/day) | 65/NS                        |
| First author/ref. no. | Diagnosis | Aims (as stated by authors) | Methods | Country | Data collection sampling | Participants caregiver (time caring) | Mean age (caregiver/recipient) |
|----------------------|-----------|----------------------------|---------|---------|-------------------------|---------------------------------------|-----------------------------|
| Miravitlles et al.   | COPD      | Analyse burden of cgs      | QUANT   | Spain   | Survey representative (mean=12.7 hours daily, severe COPD) | 22795                                 | 56.5/72                     |
| Nakken et al.        | COPD      | Investigate differences in male and female cgs and their perception of pts’ symptoms | QUANT (correlational) | The Netherlands | Cross-sectional convenience | 188 dyads (103 F, 85 M) (NS) | 65.4/63.3 F 65.1/68.7 M |
| Nisström et al.      | HF        | Cg’s participation and perspective of home care services | Mixed methods | Sweden | Interviews purposive | 15 (11 F, 4 M) (NS) | 77/NS                      |
| Park et al.          | CAD       | Difficulty and demands of cg tasks for older cgs of CABG pts | QUANT   | USA     | Cross-sectional convenience | 35 (29 F, 6 M) (mean=19 days) | 60/NS                      |
| Pattenden et al.     | HF        | Explore how pts and cgs cope with daily life with HF | QUAL    | UK      | Interviews purposive | 20 (18 F, 2 M) (NS) | 67.8/NS                    |
| Yeh                  | HF        | Explore burden on family cgs of older pts with HF | QUANT (correlational) | USA     | Cross-sectional purposive | 50 (35 F, 1.5M) (<8 months to >1 year) | 60.3/77.6                   |
| Pressler et al.      | HF        | Examine changes in cg burden and HRQoL. Determine different perceptions between cg’s of pts. with HF and role strain and time spent on cg tasks. | QUANT (repeated measures) | USA | Longitudinal convenience | 65 (48 F, 17 M) (mean=9.3 years) | 59.7/69                     |
| Riegner             | COPD      | To understand QoL, and its association with role strain, humour and support in cgs and pts. | QUANT (correlational) | USA     | Cross-sectional convenience | 83 dyads (50 F, 33 M) (NS) | 63.2/65.6                   |
| Rolley et al.        | CAD       | Describe experience of cgs of pts undergoing percutaneous coronary intervention | QUAL    | Australia | Focus groups convenience | 18 (F) (NS) | NS/NS                     |
| Saunders et al.      | HF        | To determine indicators of cg HRQoL | QUANT (correlational) | USA     | Cross-sectional purposive | 50 (42 F, 8 M) (mean=5.9 years) | 58.1/77.6                   |
| Saunders             | HF        | Compare employed and unemployed cgs on depression and well-being | QUANT   | USA     | Cross-sectional convenience | 41 (37 F, 4 M) (2.9–6 years) | 59 (unemployed)78 52 (employed)77 |
| Schwarz               | HF        | Evaluate support on stress for cgs | QUANT   | USA     | Cross-sectional convenience | 75 (55 F, 20 M) (mean=6 years) | 63/NS                      |
| Scott                 | HF        | HRQoL of cgs and pts receiving community-based inotropic infusions | QUANT   | USA     | Cross-sectional purposive | 18 (16 F, 2 M) | 63/69.3                   |
| Spence et al.        | COPD      | Needs and experiences of family cgs | QUAL (descriptive) | Northern Ireland | Interviews purposive | 7 (6 F, 1 M) (1–4 years) | NS/NS                     |
| Ström (2015)         | HF        | Next of kin’s experience and responsibilities when caring | QUAL    | Norway  | Interviews convenience | 19 (17 F, 2 M) (NS) | Median 63/NS |
| Takata et al.        | COPD      | Explore cg burden (long-term O2 therapy) | QUANT   | Japan   | Cross-sectional convenience | 45 dyads (37 F, 8 M (NS) | 68/75.2                   |
| Vellone et al.       | HF        | Examine cg self-efficacy and contribution to pt self-care | QUANT (correlational) | Italy | Cross-sectional convenience | 515 dyads (270 F, 245 M) | 56.6/75.6                   |
| Wallin et al.        | CAD       | To describe cg’s need for support and impact after a cardiac event | QUAL (descriptive) | Sweden  | Interviews purposive | 20 (14 F, 6 M) (NS) | 55/NS                     |
Contrastingly, Pressler et al reported caregivers’ perceptions of how their lives changed as a result of caregiving was neutral and improved from baseline to 4 and 8 months. Caregivers became adaptable in their new role. There was less personal time for leisure and hobbies either alone or with the care recipient. Caregivers described daily ‘ups and downs’ and had to adjust their routines dependent on the presentation of the care recipient.

### Support for caregivers

Fifteen quantitative, and 1 mixed methods study examine support. This includes healthcare, family and social support. The weight of perceived external expectations, the necessity of being proactive in obtaining support and maintaining a social role was described across all diagnoses. Yeh and Bull identified lack of family support as a significant issue. Caregivers felt abandoned by healthcare teams. After hospital discharge they had to provide care without advice or medical support. Positive interactions were reported, namely access to healthcare professionals via telephone or home support.

### Knowledge

This was addressed in 17 qualitative, quantitative and 1 mixed methods study. This describes caregivers’ understanding of the diagnosis and need for knowledge throughout the duration of illness. Caregivers report information from health professionals was often inadequate. Timing and format of information was significant. Caregivers received information verbally or by leaflets in hospital but describe being left alone to provide care in the long term. Caregivers had difficulty understanding how to navigate the care system. They had to make decisions without full knowledge of the consequences of their decision making, particularly during acute exacerbations. The quantitative element of mixed methods study by Näström et al correlated with qualitative studies; receipt of sufficient information was central to managing HF and was associated with better perceived health of caregivers.

### Relationships

Twenty qualitative, quantitative and 1 mixed methods study examined relationships. In HF studies caring for individuals with more symptoms resulted in poorer perceived experiences. Higher relationship quality resulted in less burden and more benefit from the relationship. The relationship prior to diagnosis influenced the current relationship. Perspective of the relationship was either a sense of duty or this was a valuable second chance. Caregivers reported difficulty communicating about the condition leading tasks from their routine. Contrastingly, Pressler et al reported caregivers’ perceptions of how their lives changed as a result of caregiving was neutral and improved from baseline to 4 and 8 months. Caregivers became adaptable in their new role. There was less personal time for leisure and hobbies either alone or with the care recipient. Caregivers described daily ‘ups and downs’ and had to adjust their routines dependent on the presentation of the care recipient.

### Support for caregivers

Fifteen quantitative, and 1 mixed methods study examine support. This includes healthcare, family and social support. The weight of perceived external expectations, the necessity of being proactive in obtaining support and maintaining a social role was described across all diagnoses. Yeh and Bull identified lack of family support as a significant issue. Caregivers felt abandoned by healthcare teams. After hospital discharge they had to provide care without advice or medical support. Positive interactions were reported, namely access to healthcare professionals via telephone or home support.

### Knowledge

This was addressed in 17 qualitative, quantitative and 1 mixed methods study. This describes caregivers’ understanding of the diagnosis and need for knowledge throughout the duration of illness. Caregivers report information from health professionals was often inadequate. Timing and format of information was significant. Caregivers received information verbally or by leaflets in hospital but describe being left alone to provide care in the long term. Caregivers had difficulty understanding how to navigate the care system. They had to make decisions without full knowledge of the consequences of their decision making, particularly during acute exacerbations. The quantitative element of mixed methods study by Näström et al correlated with qualitative studies; receipt of sufficient information was central to managing HF and was associated with better perceived health of caregivers.

### Relationships

Twenty qualitative, quantitative and 1 mixed methods study examined relationships. In HF studies caring for individuals with more symptoms resulted in poorer perceived experiences. Higher relationship quality resulted in less burden and more benefit from the relationship. The relationship prior to diagnosis influenced the current relationship. Perspective of the relationship was either a sense of duty or this was a valuable second chance. Caregivers reported difficulty communicating about the condition leading tasks from their routine. Contrastingly, Pressler et al reported caregivers’ perceptions of how their lives changed as a result of caregiving was neutral and improved from baseline to 4 and 8 months. Caregivers became adaptable in their new role. There was less personal time for leisure and hobbies either alone or with the care recipient. Caregivers described daily ‘ups and downs’ and had to adjust their routines dependent on the presentation of the care recipient.

### Support for caregivers

Fifteen quantitative, and 1 mixed methods study examine support. This includes healthcare, family and social support. The weight of perceived external expectations, the necessity of being proactive in obtaining support and maintaining a social role was described across all diagnoses. Yeh and Bull identified lack of family support as a significant issue. Caregivers felt abandoned by healthcare teams. After hospital discharge they had to provide care without advice or medical support. Positive interactions were reported, namely access to healthcare professionals via telephone or home support.

### Knowledge

This was addressed in 17 qualitative, quantitative and 1 mixed methods study. This describes caregivers’ understanding of the diagnosis and need for knowledge throughout the duration of illness. Caregivers report information from health professionals was often inadequate. Timing and format of information was significant. Caregivers received information verbally or by leaflets in hospital but describe being left alone to provide care in the long term. Caregivers had difficulty understanding how to navigate the care system. They had to make decisions without full knowledge of the consequences of their decision making, particularly during acute exacerbations. The quantitative element of mixed methods study by Näström et al correlated with qualitative studies; receipt of sufficient information was central to managing HF and was associated with better perceived health of caregivers.

### Relationships

Twenty qualitative, quantitative and 1 mixed methods study examined relationships. In HF studies caring for individuals with more symptoms resulted in poorer perceived experiences. Higher relationship quality resulted in less burden and more benefit from the relationship. The relationship prior to diagnosis influenced the current relationship. Perspective of the relationship was either a sense of duty or this was a valuable second chance. Caregivers reported difficulty communicating about the condition leading tasks from their routine. Contrastingly, Pressler et al reported caregivers’ perceptions of how their lives changed as a result of caregiving was neutral and improved from baseline to 4 and 8 months. Caregivers became adaptable in their new role. There was less personal time for leisure and hobbies either alone or with the care recipient. Caregivers described daily ‘ups and downs’ and had to adjust their routines dependent on the presentation of the care recipient. Caregivers described daily ‘ups and downs’ and had to adjust their routines dependent on the presentation of the care recipient.
to isolation, stress and conflict between caregiver and care recipient. The relationship requires negotiation. Caregivers prioritised the care recipient over their own needs.

**Expert by experience**

Twelve qualitative studies addressed this concept. Caregivers learnt new skills. They became ‘experts by experience’ discovering through ‘doing’ and

| Study characteristics | n=54 studies |
|-----------------------|--------------|
| **Aetiology of patients** | | |
| CAD, n (%) | 6 (11) |
| HF, n (%) | 34 (63) |
| COPD, n (%) | 14 (26) |
| **Caregiver participants** | Patiens† |
| Median age (range) | 62 (43–77) | 69 (36–93) |
| Median % of female (range) | 63% (5–270) | 38% (1–229) |
| **Relationship between patient and caregiver (n=26008 caregivers)** | | |
| Spousal/partner, n (%) | 2321 (9) |
| Son/daughter, n (%) | 610 (2) |
| Sibling, n (%) | 22 (<1) |
| Parent, n (%) | 10 (<1) |
| Friend/relative, n (%) | 228 (<1) |
| Not stated | 22961 (88) |
| **Type of study** | | |
| Qualitative, n (%) | 21 (39) |
| Quantitative, n (%) | 32 (59) |
| Mixed | 1 (2) |
| **Study design** | | |
| Cross-sectional, n (%) | 24 (44) |
| Longitudinal, n (%) | 4 (7) |
| Cohort, n (%) | 2 (4) |
| Quantitative (survey), n (%) | 2 (4) |
| Qualitative (interview/focus group), n (%) | 16 (31) |
| Phenomenological, n (%) | 5 (8) |
| Inductive, n (%) | 1 (2) |
| **Continents of publication** | | |
| Europe | 22 (41) |
| North America, n (%) | 29 (54) |
| Australasia, n (%) | 3 (5) |
| **Date of publication** | n=57 publications‡ |
| 1990–1995 | 2 |
| 1996–2001 | 3 |
| 2002–2007 | 10 |
| 2008–2013 | 22 |
| 2014–2017 | 20 |

*Caregiver data based on data collected in 50 studies.
†Patient data based on data collected in 35 studies.
‡There were 57 publications, however there were 54 studies. The following studies used the same data but produced two publications: Halm, 2006 and 2007, Saunders, 2008 and 2009, Halm 2016 and 2017.
CAD, coronary artery disease; COPD, chronic obstructive pulmonary disease; HF, heart failure.
observing health professionals.66 68 83 They developed ‘proto-professional skills’; in medication administration,65 80 85 judging care recipients’ level of functioning79 and decision making in times of exacerbations.70 Caregivers observed the nuances of change in the care recipient often not perceived by healthcare teams or other family members such as skin colour or irritability.72 75 81

Vigilance
Vigilance was recurring in caregivers’ narrative across all diagnoses and was present in 19 qualitative studies.64–81 It demonstrated caregiver and care recipient working together managing the illness, jointly administering medication68 81 and attending appointments.72 The presence of illness was a process they adjusted to together.66 74 Caregivers referred to themselves and the care recipient as ‘we’, when discussing dealing with the illness.65 71 75 The mutual perspective between caregiver and care recipient served to isolate them from the world, the illness was ‘taking a life of its own…it’s like this third person’ (Hynes, 2012, p. 1071).

There were differences in caregiver experience for each of the diagnoses and these are discussed below.

Heart failure
HF caregivers experienced an ‘ebb and flow’ in caring, an underlying worry, fear and anxiety, which at times of life.69 70 75 76 83 The duration of caregiving and severity of illness influenced caregiver’s ability to adjust.66 73 76 Caregivers lived day by day83 and viewed the future, with hope or uncertainty about what lay ahead.65 70 72 79 82

Table 4 (a) Quality appraisal—qualitative papers

| First author/ref. no. | Design | Recruitment | Data collection | Data analysis | Findings | Total |
|-----------------------|--------|-------------|-----------------|--------------|----------|-------|
| Andersen63             | 1      | 1           | 1               | 0            | 1        | 4 (H) |
| Baker et al64          | 1      | 0           | 1               | 1            | 1        | 4 (H) |
| Bove et al65           | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Burke et al66          | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Clark et al85          | 1      | 1           | 1               | 1            | 0        | 4 (H) |
| Figueiredo et al77     | 0      | 1           | 1               | 1            | 1        | 4 (H) |
| Halm68*                | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Halm69*                | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Hynes70                | 1      | 1           | 1               | 0            | 1        | 4 (H) |
| Imes et al71           | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Kitko72                | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Liljeroos et al73      | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Lindqvist et al74      | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Luttik et al75         | 1      | 0           | 1               | 1            | 1        | 4 (H) |
| Marcuccilli76          | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Marcuccilli77          | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Nisström et al84†      | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Pattenden78            | 1      | 1           | 1               | 1            | 0        | 4 (H) |
| Rolley et al79         | 1      | 1           | 1               | 1            | 0        | 4 (H) |
| Spence et al80         | 1      | 0           | 1               | 1            | 1        | 4 (H) |
| Strom (2015)           | 1      | 1           | 1               | 1            | 1        | 5 (H) |
| Wallin et al82         | 1      | 0           | 1               | 1            | 1        | 4 (H) |
| Wingham et al83        | 1      | 1           | 1               | 1            | 1        | 5 (H) |

*Same study.
†Mixed methods study—qualitative component.
H, high quality, 4/5 out of 5 quality criteria achieved.
change or illness heightened. Lifestyle changes were long lasting and sustained. Obtaining knowledge was necessary throughout all stages of the illness. Sourcing information and communication with health professionals was often difficult.

### Table 4 (b) Quality appraisal—quantitative papers

| First author/ref. no. | Study design | Participant sampling | Participant attrition | Outcome measures | Data analysis | Overall score |
|-----------------------|--------------|-----------------------|-----------------------|-----------------|--------------|---------------|
| Ågren37               | CS           | Purp (+1)             | 0% (+1)               | Non-V           | MV (+1)      | 3 (M)         |
| Al-Rawashdeh38        | CS           | Purp (+1)             | NS                    | V (+1)          | MV (+1)      | 3 (M)         |
| Badr et al39          | CS           | Con                   | 15.5% (+1)            | Non-V           | MV (+1)      | 2 (L)         |
| Bakas et al50         | CS           | Con                   | NS                    | V (+1)          | MV (+1)      | 2 (L)         |
| Chung et al36         | CS           | Con                   | NS                    | V (+1)          | UV           | 1 (L)         |
| Cossette41            | CS           | Con                   | NS                    | V (+1)          | MV (+1)      | 2 (L)         |
| Evangelista et al42   | CS           | Con                   | 20% (+1)              | V (+1)          | MV (+1)      | 3 (M)         |
| Figueiredo et al43    | CS           | Con                   | 17% (+1)              | V (+1)          | MV (+1)      | 3 (M)         |
| Figueiredo et al44    | CS           | Con                   | 11% (+1)              | Non-V           | MV (+1)      | 2 (L)         |
| Grigorovich et al45   | LS (+1)      | Con                   | NS                    | V (+1)          | MV (+1)      | 3 (M)         |
| Halm et al46*         | CS           | Con                   | 64%                   | V (+1)          | MV (+1)      | 2 (L)         |
| Halm47                | CS           | Con                   | 64%                   | V (+1)          | MV (+1)      | 2 (L)         |
| Hess46                | CS           | Con                   | NS                    | V (+1)          | MV (+1)      | 2 (L)         |
| Hooley48              | CS           | Con                   | 0% (+1)               | V (+1)          | UV           | 2 (L)         |
| Hwang et al49         | CS           | Con                   | 35%                   | V (+1)          | MV (+1)      | 2 (L)         |
| Karmilovich50         | CS           | Purp (+1)             | 24%                   | V (+1)          | MV (+1)      | 3 (M)         |
| Kneeshaw47            | LS (+1)      | Con                   | 32.70%                | V (+1)          | MV (+1)      | 3 (M)         |
| Loftus51              | LS (+1)      | Con                   | 36%                   | V (+1)          | MV (+1)      | 3 (M)         |
| Lum et al51           | CS           | Purp (+1)             | 5% (+1)               | V (+1)          | MV (+1)      | 4 (H)         |
| Luttik et al52        | CS           | Purp (+1)             | 31%                   | Non-V           | MV (+1)      | 3 (M)         |
| Miravitles et al53    | CS           | Rand (+1)             | 0% [+1]               | Non-V           | MV (+1)      | 3 (M)         |
| Nakken et al54        | CS           | Con                   | 58%                   | Non-V           | MV (+1)      | 1 (L)         |
| Näsström et al54*     | LS (+1)      | Con                   | 7% (+1)               | V (+1)          | MV (+1)      | 5 (H)         |
| Park et al55          | CS           | Con                   | NS                    | V (+1)          | UV           | 1 (L)         |
| Yel55                 | CS           | Purp (+1)             | 39%                   | V (+1)          | MV (+1)      | 4 (H)         |
| Pressler et al54      | LS (+1)      | Con                   | 16% (+1)              | V (+1)          | MV (+1)      | 4 (H)         |
| Riegner59             | CS           | Con                   | 71.80%                | V (+1)          | MV (+1)      | 2 (L)         |
| Saunders56†           | CS           | Purp (+1)             | 36%                   | V (+1)          | MV (+1)      | 3 (M)         |
| Saunders57            | CS           | Purp (+1)             | 36%                   | V (+1)          | MV (+1)      | 3 (M)         |
| Schwarz58             | CS           | Con                   | NS                    | V (+1)          | MV (+1)      | 2 (L)         |
| Scott59               | CS           | Purp (+1)             | 10% (+1)              | Non-V           | MV (+1)      | 3 (M)         |
| Takata et al60        | CS           | Con                   | NS                    | V (+1)          | UV           | 1 (L)         |
| Vellone et al61       | CS           | Con                   | NS                    | V (+1)          | MV (+1)      | 2 (L)         |
| Woolfe57              | CS           | Con                   | 37%                   | V (+1)          | UV           | 1 (L)         |

Studt design: CS, LS.
Participant sampling: Purp, Rand, Cons, Con, NS.
Attrition: 20% or less=+1; NS.
Outcome measures: V, non-V, NS.
Data analysis: MV, UV.
*Same study.
†Mixed methods study—quantitative component.
CS, cross-sectional design; Cons, consecutive; Con, convenience; H, high quality, 4/5 out of 5 quality criteria achieved; L, low quality, 1 or 2 out of 5 quality criteria achieved; LS, longitudinal design; M, medium quality, 3 out of 5 quality criteria achieved; MV, multivariate; non-V, some or all non-validated; NS, not stated/unclear; Purp, purposive; Rand: random; V, all validated outcomes; UV, univariate.
viewed the care recipient as another child or as a ‘duty’.50 51 64 66 71 73 77 84

**Chronic obstructive pulmonary disease**
COPD caregivers experienced a prolonged impact on their mental health similar to HF caregivers.41 44 45 47 60 65 70 80 Severity of illness was influential on their experience of burden.38 45 46 49 50 Role change was long lasting and profound for many.65 67 70 80 They expressed concerns with perceived lack of knowledge.62 65 70 74 80 During exacerbations, COPD caregivers experienced anxiety and fear of their loved one dying.65 67 70 74 COPD caregivers highlighted the loss of social roles while trying to maintain the dignity of their loved ones.62 65 70 74 80 The coughing and spitting associated with COPD often left the care recipient embarrassed.65 67 80 The caregiver tried to avoid situations where this would happen. The dynamics of spousal relationships changed, caregivers described losing the intimate love they had for their partner.65 70 74 80

**Coronary artery disease**
Caregivers of patients with CAD experienced intense role change on discharge from hospital and in the acute phase of illness.47 68 70 79 82 87 88 They initially engaged with a high volume of tasks which reduced over time.46 47 68 70 79 82 87 88 CAD caregivers experienced post-traumatic symptoms if they witnessed the recipient experience an acute event.79 82 Caregivers described being unable to talk about this and reliving the event in their heads. Anxiety did ease over time for many.79 82 Caregivers felt unprepared at hospital discharge and highlighted not realising how much their routine would be disrupted.66 79 82 Caregivers reported viewing the experience as a second chance and had a renewed sense of love and appreciation for the relationship.79 82

**DISCUSSION**
This mixed methods systematic review demonstrates the similarities and differences in caregiver experiences across three common cardiorespiratory conditions. It highlighted the differences in experiences obtained from qualitative and quantitative research. Commonly occurring experiences included the exacerbation of caregiver physical and mental health due to the role. This correlates with systematic review of HF caregivers by Kang et al identifying that caregiving resulted in a multitude of changes in caregiver’s lives regardless of age, gender and ethnicity.93 Addressing both patient and caregiver needs in order to maintain well-being for both is important and recognises the value of ‘shared-care’ between patient and caregiver. The prevalence of mental health needs in this review demonstrates the need for psychosocial support for caregivers. This concurs with the studies by AasbØ et al, identifying caregivers need to be in ‘emotional control’94 and Wingham et al, describing the ‘enduring anguish’ experienced by caregivers.95 Lawton et al attribute caregiver well-being to the commitment of the caregiver to the role and dealing with competing demands, which can increase burden and negatively impact affect. Spousal caregivers may be more ready to accept the role of caregiving than adult children who may view it as an imposition on an already established lifestyle.96 In this review, societal expectations had an impact on how caregivers adjust to their role. Additionally, the quality of the relationship prior to becoming a caregiver had an influence on the caregiver subjective experience of burden.

Caregivers had predominantly negative experiences of support and described uncertainty of how to obtain this. Caregivers need greater support and knowledge transfer to conduct their role.93 They should be included in clinical appointments98 to ensure they are not isolated in providing care and to allow for knowledge exchange. Giacomini et al in their review of caregivers living and dying with COPD reported increasing isolation in addition to their own health issues.88 They described pressure balancing their variety of roles; similar experiences to the caregivers in this synthesis across all diagnoses. Caregivers emphasised their need to be vigilant. This falls into five categories as defined by Mahoney’s study of Alzheimer’s caregivers; ‘watchful supervision’, ‘protective intervening’, ‘anticipating’, ‘on duty’ and ‘being there’. Caregivers in this synthesis described overt vigilance, putting one’s head on the chest of the recipient to check breathing or covert vigilance; observing them throughout the day.99 Healthcare professionals must be aware of these levels of vigilance and the constant presence of them to support caregivers in their role.

Caregivers are valuable providers of care. Caregiver’s needs should be assessed systematically and in a formalised manner in healthcare settings.16 When
Table 5  Illustrative quotes of caregiver experience—by concept

| Concept          | Quote                                                                 |
|------------------|-----------------------------------------------------------------------|
| Mental health    | “The mental strain is difficult. I feel so trapped”.                 |
|                  | “You fall into a huge hole, then the world gets so tiny, it all gets so narrow that it is almost unbearable”. |
|                  | “I feel like sleeping beauty. The hawthorn hedge has closed around me, and I cannot do anything about it.” |
| Role             | “I can sum up my role in three words, I am a cheerleader, drill sergeant, and negotiator”. |
| Lifestyle change | “Our life has come down. The two of us used to go out dancing. We loved dancing and then it all stopped”. |
| Knowledge        | “I wish I had had more education on the ‘what ifs’. When I was leaving the hospital nobody really said, ‘OK now this is what’s going to happen and this is what you’re going to have to do’. If there would’ve been any kind of complications I would’ve been totally in the dark. I didn’t know all the things I needed to know” |
| Relationships    | “I just love him and I find that every day when I see him, what else could I do to try and make him a wee bit … better? It’s very satisfying to know that he appreciates what I do and it’s nice to know that you are helping someone”. |
|                  | “It’s like having another child sometimes because you are sort of responsible and I feel he is my responsibility. I feel that he is not anybody else’s responsibility” |
| Support          | “And then I really felt alone in it all. Because everybody would call and come over and ask, how is John? Hardly anyone asked ‘how are you doing’?”. |
|                  | “Doctors (do) not realize that I do your life is just normal and then this comes and smashes everything to bits, you know and there are so many questions”. |
|                  | “I would be lost without, our heart failure nurse, and, all the other input we’ve had from all the other professionals, like the podiatrist and GP… You can do it, but in partnership with everybody else”. |
| Vigilance        | “Every morning I put my ear to his chest and listen to his heart, that is how we first discovered he was in atrial fibrillation so now I do it every morning before I leave. I monitor him very closely and there are days in which I do not feel comfortable leaving for work so those days I work at home. I call everyday from work and we have our routine, if I am not aware of anything he had planned for the day, I then immediately call my neighbour to check on him”. |
| Shared care      | “There were days I thought to myself, where are we going from here? But we mastered it together and tried to do things at his pace”. |
| Time             | “At first it was overwhelming. I didn’t think I could do it. When they first told me I was like, ‘I can’t do that’, you know. And then they explained to me, like, yes you can. It’s like getting a new baby. You know, you learn how to take care of them step by step and then it’s just part of the routine. And that’s really the way it was”. |
| Expert by experience | “It’s so frustrating when she goes into hospital and the nurses and the doctors say it’s her condition, you know. I’m like I’m with her twenty-four hours a day, I know how breathless she is without infection and I know how breathless she is with an infection there’s a major difference”. |
|                  | “I see him every day, they are just little subtle changes, they are not showing up in the numbers the doctors are concerned with but I see it”. |

developing collaborative models of care the inclusion of caregivers is imperative.100

Strengths and limitations
This review demonstrates the complexity of what it means to be a caregiver and should inform clinical care development of interventions. A mixed methods review can be contentious101 due to the synthesis of differing paradigms. In this review, it required transformation of quantitative data into qualitative data.15 102 We aimed to present a convergence of caregiver experiences by conducting a mixed methods synthesis. However, it demonstrated four differing concepts between the two paradigms. This highlights the challenge of synthesising multiple methods. It is worth exploring how the four additional qualitative concepts could be captured quantitatively in order to inform healthcare intervention. This mixed methods synthesis is, to our knowledge, the first to combine caregiver experiences in HF, COPD or CAD. It examines the differences and similarities in experiences, establishing a comprehensive assessment of the knowledge base of caregiver experiences in common cardiorespiratory conditions.

There are limitations to this study; both in our review methods and the nature of included studies. First, we acknowledge that the inclusion of lower quality quantitative studies may lead to risk of bias: the majority of quantitative studies used convenience sampling, had a high attrition and low response rate. Non-validated outcome measures were used in some quantitative studies with the majority of studies conducting univariate rather than multivariate analysis. However, given the limited number of high-quality quantitative studies (four studies), we believe this broader inclusion increased the scope of our review in order to achieve a holistic understanding of
Caregiver experiences. Furthermore, we would note that the conclusions of this review were broadly the same with consideration of only the high-quality quantitative studies. Second, studies were restricted to English language only, from high-income countries and excluding caregivers of nursing home residents. This may limit the applicability of findings to other settings. Third, converting quantitative data into a qualitative data set risks the quantitative data set being oversimplified. This was managed with regular research team meetings to review each stage of this process. Fourth, qualitative synthesis is an interpretation of other researcher’s interpretations. To minimise individual interpretative bias, a second researcher was used to seek confirmation of the results. Finally, included qualitative and quantitative studies were primarily cross-sectional in design, therefore considering caregiver experience only at a single point of time.

Implications for practice and future research

There are a number implications following this review. It has demonstrated there are similarities and differences in the caregiver experience in HF, COPD or CAD. The impact on caregiver’s lives of those with HF and COPD appears longer lasting and more turbulent than caring for patients with CAD. CAD caregiver’s experience of hospital during exacerbations increased distress at discharge. This review reflects the complexity of the caregiver’s role. The mixed methods approach inditced differences in what is being investigated. This is important in demonstrating an understanding of the caregiver experience when dealing with complex conditions. Future research should focus on involving caregivers in the design and delivery of interventions for patients with cardiopulmonary disease. Best practice interventions for CAD caregivers in the discharge process from hospital to home must be formalised. There appears to be a focus on the mental health of caregivers of those with HF; however, further research is needed to explore this in COPD and CAD caregivers. Exploration of this via support groups for caregivers of cardiorespiratory conditions is merited. Clinically, the healthcare team need to identify who the caregiver is and be aware of their needs with the use of a carer’s needs assessment. There must be a greater understanding of caregiver support needs, what they avail of and are they aware of what is available to them in the community. This can be achieved in conversation between the healthcare team and caregivers and warrants further research as to how and whether caregivers avail of external supports.

Consideration needs to be given as to whether quantitative research tools to explore caregiver expertise, view of the future, experience of shared care and vigilance can be developed to capture these qualitative concepts to inform the development of self-management interventions for patients and caregivers. Repeated measures examining perceived control and caregiver needs may contribute to a greater understanding of caregiver experiences, which arose in qualitative studies. Additionally, longitudinal studies with repeated assessment need to be conducted to assess the stability of caregiver experiences and whether they are liable to much change over time. In this review, only 4 out of 32 quantitative studies examined caregiver’s experiences longitudinally. Understanding whether there are caregiver changes over time will facilitate greater understanding of caregiver needs for health professionals when working with this population. The emergence of additional concepts from qualitative studies emphasises the role of mixed methods research when examining lived experiences. The additional concepts also demonstrated the nuanced expertise of the caregiving experience. It is important for researchers to consider how to reflect this in quantitative investigation so as to inform funders in order to develop and trial interventions in HF, COPD and CAD. The quality of quantitative studies in COPD and CAD were medium or low. There is a need for more empirically robust studies examining the experiences of these caregivers. Additionally, greater understanding of caregiver’s experiences with this population will facilitate the development of robust evidence-based guidelines for health services when working with HF, COPD and CAD.

CONCLUSIONS

This mixed methods systematic review provides a holistic synthesis of caregiver experiences of people with HF, COPD or CAD. It demonstrates there are a number of implications when an individual becomes a caregiver for those with chronic cardiopulmonary disease. Caregivers reframe their identity and change their life course. Caregivers learn a multitude of skills and develop expertise in their new role. Their expertise is invaluable and should be acknowledged in healthcare interventions for these conditions. The quality of evidence was limited by assessment of caregiver experience at single time point. There is need for future studies that employ longitudinal designs examining the change in caregiver experience over time. Caregiving can be positive if caregivers have access to support, are well informed and part of the healthcare team. Understanding the experiences of caregivers for people with these conditions allows healthcare professionals and policy makers to reflect on our approach. Health services must consider caregivers in the design and delivery of interventions.

Acknowledgements. The authors would like to thank the PenCLARHC Evidence Synthesis Team at University of Exeter Medical School. Katy Oakes and Catriona Organ, Librarians at Royal Cornwall Hospital Library, Knowledge Spa, Truro, Dr Ruth Garside, Senior Lecturer in Evidence Synthesis, European Centre for Environment and Human Health for their assistance throughout the process of this review.

Contributors. MN, JW, RST: conceived and designed the review and quality appraised the included studies. MN wrote the initial draft of the manuscript. JW and RST provided feedback and edits to manuscript drafts.

Funding. This study was supported by a University of Exeter Postgraduate Studentship Grant.

Competing interests. None declared.

Patient consent. Not required.

Provenance and peer review. Not commissioned; externally peer reviewed.
REFERENCES
1. . Carers Trust (2015) https://carers.org/what-carer (accessed 26 June 2017).
2. Wolff JL, Spillman BC, Freedman VA, et al. A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med* 2016;176:372–9.
3. International Alliance of Carer Organizations. Global carer facts. 2017 http://www.carersuk.org/carer-facts/global-carer-stats/ (accessed 1 Oct 2017).
4. White C. Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001. Office of National Statistics, 2013 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcareyestimates/articles/2011censusanalysisisonunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15 (accessed 10 Oct 2017).
5. Buckner L, Yeandle S, Carers V, Carers UK. The rising value of carers’ support. 2015 http://www.carersuk.org/for-professionals/policy-policy-library/valuing-carers-2015 (accessed July 2017).
6. The Institute of Public Care. A Carer’s Life: Implications and Considerations for Commissioning, 2017 http://ipc.brookes.ac.uk/publications/A_carers_life.html (accessed 30 Sep 2017).
7. Sizzler MM, Li LW. The dynamics of caregiving: transitions during a three-year prospective study. *Gerontologist* 2000;40:165–78.
8. The Care Act. Chapter 23. The Care Act UK: The Stationery Office, 2014. http://www.legislation.gov.uk/ukpga/2014/23/contents.enacted/data.html. (accessed 11 Oct 2016).
9. National Institute for Health and Clinical Excellence. Chronic heart failure in adults: management. NICE guideline (CG108), 2010.
10. National Institute for Health and Clinical Excellence. Chronic obstructive pulmonary disease in over 16s: diagnosis and management. NICE guideline (CG101), 2010.
11. Hocking E, Wicks L, Wickramasinghe K, et al. European Cardiovascular Disease Statistics 2017. Brussels: European Heart Network. http://www.ehnnheart.org/images/CVD-statistics-report-August-2017.pdf. (accessed 25 Aug 2017).
12. Center for Disease Control and Prevention. Heart Disease and Stroke. www.cdc.gov (accessed 9 Nov 2016).
13. Raherison C, Girotet P-O. Epidemiology of COPD, *European Respiratory Review* 2009;18:213–21.
14. Nicholas Dionne-Odom J, Hooker SA, Bekelman D, et al. Heart Fail Rev 2017;22:508–15.
15. Foster F, Pippott R, Teese L, et al. Patients with COPD tell their stories about living with the long-term condition: an innovative and powerful way to impact primary health care professionals’ attitudes and behaviour? *Educ Prim Care* 2016;27:314–9.
16. Farquhar M. Assessing carer needs in chronic obstructive pulmonary disease. *Chronic Respir Dis* 2018;15:1–10.
17. Mansfield E, Bryant J, Regan T, et al. Burden and Unmet Needs of Caregivers of Chronic Obstructive Pulmonary Disease Patients: A Systematic Review of the Volume and Focus of Research Output. *COPD* 2016;13:660–72.
18. Giacomini M, DeJean D, Simeonov D, et al. Experiences of living and dying with COPD: a systematic review and synthesis of the qualitative empirical literature. *Ont Health Technol Assess Ser* 2012;12:1–47.
19. Doherty LC, Fitzsimons D, McIlfatrick SJ. Caregivers’ needs in advanced heart failure: A systematic narrative review. *Eur J Cardiovasc Nurs* 2016;15:203–12.
20. Stewart M, Davidson K, Meade D, et al. Myocardial infarction: survivors’ and spouses’ stress, coping, and support. *J Adv Nurs* 2001;31:190–8.
21. Stolarik A, Lindsay P, Sherrard H, et al. Determination of the burden of care in families of cardiac surgery patients. *Prog Cardiovasc Nurs* 2000;15:4–10.
22. Falk JA, Kadiev S, Criner GJ, et al. Cardiac Disease in Chronic Obstructive Pulmonary Disease. *Proc Am Thorac Soc* 2008;5:543–8.
23. Müllerova H, Mapel DW. Cardiovascular comorbidity in COPD: systematic literature review. *CHEST* 2013;144:1163–78.
24. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med* 2009;6:e297.
25. Johnson RB, Onwegbuizue AJ, Turner LA. Toward a Definition of Mixed Methods Research. *J Mix Methods Res* 2007;1:112–33.
26. . World Bank Data: http://www.worldbank.org/ (accessed 10 Jun 2017).
27. Critical Appraisal Skills Programme. Qualitative research checklist. http://docs.wixexample.com/ugd/ddd87_25656815020e427a19432ae773d42.pdf (accessed 10 Dec 2016).
28. Sandelowski M, Voisli C, Barroso J. Defining and Designing Mixed Research Synthesis Studies. *Res Sch* 2006;13:1–15.
29. Pruyne P, Hong QN. Annual Review of Public Health. 2014. www.annualreviews.org (accessed 27 Sep 2016).
30. Hong QN, Pruyne P, Bujold M, et al. Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Syst Rev* 2017;6:81.
31. Tashakkori A, Teddie C. Mixed Methodology: Combining Qualitative and Quantitative Approaches. In: *Applied Social Research Methodology*. Series. Thousand Oaks, CA: SAGE Publications, 1998:46.
32. Noblit GW, Hare RD. Meta-ethnography: synthesizing qualitative studies. Thousand Oaks, CA: SAGE Publications, 1988.
33. Tashakkori A, Teddie C. Foundations of Mixed Methods Research: integrating qualitative and quantitative approaches in the social and behavioural sciences. Thousand Oaks, CA: SAGE Publications, 2009.
34. Frantzen KK, Fetters MD. Meta-integration for synthesizing data in a systematic mixed studies review: insights from research on autism spectrum disorder. *Qual Quant* 2016;50:2521–77.
35. Dixon-Woods M, Fitzpatrick R, Roberts K. Including qualitative research in systematic reviews: opportunities and problems. *J Eval Clin Pract* 2001;7:125–33.
36. Chung ML, Lennie TA, Mudd-Martin G, et al. Depressive symptoms in patients with heart failure negatively affect family caregiver outcomes and quality of life. *Eur J Cardiovasc Nurs* 2016;15:30–8.
37. Agren S, Evangelista L, Strömberg A. Do partners of patients with chronic heart failure experience caregiver burden? *Eur J Cardiovasc Nurs* 2010;9:254–62.
38. Al-Rawashdeh SY, Lennie TA, Chung ML. The Association of Sleep Disturbances With Quality of Life in Heart Failure Patient–Caregiver Dyads. *West J Nurs Res* 2017;39:492–506.
39. Badr H, Federman AD, Wolf M, et al. Depression in individuals with chronic obstructive pulmonary disease and their informal caregivers. *Aging Ment Health* 2017;21:975–82.
40. Bakas T, Pressler SJ, Johnson EA, et al. Family caregiving in heart failure. *Nurs Res* 2006;55:180–8.
41. Cossette S, Lévesque L. Caregiving tasks as predictors of mental health of wife caregivers of men with chronic obstructive pulmonary disease. *Res Nurs Health* 1993:16:251–62.
42. Evangelista LS, Dracup K, Doering L, et al. Emotional well-being of heart failure patients and their caregivers. *J Card Fail* 2002;8:300–5.
43. Figureiro D, Gabriel R, Jácome C, et al. Caring for people with early and advanced chronic obstructive pulmonary disease: how do family caregivers cope? *J Clin Nurs* 2013;23:211–20.
44. Figureiro D, Gabriel R, Jácome C, et al. Caring for relatives with chronic obstructive pulmonary disease: how does the disease severity impact on family caregivers? *Aging Ment Health* 2014:18:385–93.
45. Grigorova V, Lee A, Ross H, et al. A longitudinal view of factors that influence the emotional well-being of family caregivers to individuals with heart failure. *Aging Ment Health* 2017:21:844–50.
46. Halm MA, Treut-Jacobson D, Lindquist R, et al. Correlates of caregiver burden after coronary artery bypass surgery. *Nurs Res* 2002;51:426–36.
47. Halm MA, Bakas T. Factors associated with caregiver depressive symptoms, outcomes, and perceived physical health after coronary artery bypass surgery. *J Cardiovasc Nurs* 2007;22:508–15.
48. Hooley PJ, Butler G, Howlett JG. The relationship of quality of life, depression, and caregiver burden in outpatients with congestive heart failure. *Congest Heart Fail* 2005;11:303–10.
49. Hwang B, Fleischmann KE, Howie-Esquivel J, et al. Caregiving for patients with heart failure: impact on patients’ families. *Am J Crit Care* 2011;20:431–42.
50. Karmilovich SE. Burden and stress associated with spousal caregiving for individuals with heart failure. *Progress in Cardiovascular Nursing* 1994;9:33–8.
51. Loftus L. The influence of illness and psychological factors on patient and caregiver outcomes in heart failure. PhD. University of Liverpool: Liverpool, 2004.
52. Nakken N, Janssen DJ, van Vliet M, et al. Gender differences in partners of patients with COPD and their perceptions about the patients. *Int J Chron Obstruct Pulmon Dis* 2017;12:95–104.
53. Yeh PM, Bull M. Use of the resiliency model of family stress, adjustment and adaptation in the analysis of family caregiver reaction among families of older people with congestive heart failure. *Int J Older People Nurs* 2012;7:117–26.
54. Plessler SJ, Gradus-Pizlo I, Chubinski SD, et al. Family caregivers of patients with heart failure: a longitudinal study. *J Cardiovasc Nurs* 2013;28:417–28.
55. Saunders MM. Factors Associated with Caregiver Burden in Heart Failure Family Caregivers. *West J Nurs Res* 2008;30:343–59.
56. Saunders MM. Indicators of health-related quality of life in heart failure family caregivers. *J Community Health Nurs* 2010;26:173–82.
57. Saunders MM. Working and caregiving a comparison of employed and unemployed caregivers of older heart failure patients. *Holistic Nursing Practice* 2010;24:16–24.
58. Schwarz KA, Dunphy G. An examination of perceived stress in family caregivers of older adults with heart failure. *Exp Aging Res* 2003;29:221–35.
59. Scott LD, Caring and care receiving among a technologically dependent heart failure population. *ANN Adv Nurs Sci* 2000;23:82–97.
60. Takata S, Washio M, Moriwaki A, et al. Burden among caregivers of patients with chronic obstructive pulmonary disease with long-term oxygen therapy. *Int J Palliat Nurs* 2016;22:1–10.
61. Vellone E, D’Agostino F, Buck HG, et al. The key role of caregiver confidence in the caregiver’s contribution to self-care in adults with heart failure. *European Journal of Cardiovascular Nursing* 2015;14:372–81.
62. Wolffe P, McIntosh M, Conway J. The needs of caregivers of people with COPD: a study. *Australian Journal of Primary Health* 2007;13:28–35.
63. Andersen KL, Kornelussen K, Fagermoen MS. Family caregivers to a patient with chronic heart failure living at home: «co-workers» in a blunted care system. *Journal of Cardiovascular Nursing* 2015;20:162–9.
64. Baker K, Flattery M, Salyer J, et al. Caregiving for patients requiring left ventricular assistance device support. *Heart Lung* 2010;39:196–200.
65. Bove DG, Zakkrosson A-B, Midgtaard J, et al. Undefended and unpredictable responsibility: a focus group study of the experiences of informal caregiver spouses of patients with severe COPD. *J Clin Nurs* 2016;25:483–93.
66. Burke RE, Jones J, Ho PM, et al. Caregivers’ perceived roles in caring for patients with heart failure: what do clinicians need to know? *J Card Fail* 2014;20:731–8.
67. Figueiredo D, Jacone C, Gabriel R, et al. Family care in chronic obstructive pulmonary disease: what happens when the carer is a man? *Scand J Caring Sci* 2016;30:71–30.
68. Halm MA. Specific needs, concerns, strategies and advice of caregivers after coronary artery bypass surgery. *Heart Lung* 2016;45:416–22.
69. Halm MA. Age and gender influences on the needs, concerns and strategies of CABG caregivers. *Heart Lung* 2017;46:159–65.
70. Hynes G, Stokes A, McCarron M. Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience. *J Clin Nurs* 2012;21:1068–77.
71. Imes C, Dougherty CM, Pyper G, et al. Care of Patients with Heart Failure Descriptive study of partners’ experiences of living with severe heart failure. *Heart & Lung* 2011;40:208–16.
72. Kitko LA. The work of spousal caregiving in heart failure. *State College, PA: Pennsylvania State University, 2010.*
73. Liljeroos M, Ågren S, Jaarsma T, et al. Perceived caring needs in patient-partner dyads affected by heart failure: A qualitative study. *J Clin Nurs* 2014;23:2928–38.
74. Lindqvist G, Albin B, Heikkilä K, et al. Conceptions of daily life in women living with a man suffering from chronic obstructive pulmonary disease. *Prim Health Care Res Dev* 2013;14:40–51.
75. Luttik ML, Blaauwbroek A, Dijkers A, et al. Living with heart failure: partner perspectives. *J Cardiovasc Nurs* 2007;22:131–7.
76. Marcucilli L, Casida JJ, Bakas T, et al. Family caregivers’ inside perspectives: caring for an adult with a left ventricular assist device as a destination therapy. *Prog Transplant* 2014;24:332–40.
77. Pattenden JF, Roberts H, Lewin RJ. Living with heart failure: patient and carer perspectives. *Eur J Cardiovasc Nurs* 2007;6:273–9.
78. Rolley J, Smith J, DiGiacomo M, et al. The caregiving role following percutaneous coronary intervention. *J Clin Nurs* 2011;20:227–35.
79. Spence A, Hasson F, Waldron M, et al. Active carers: living with chronic obstructive pulmonary disease. *Int J Palliat Nurs* 2008;14:368–72.
80. Strom A, Andersen KL, Kornelussen K, et al. Being “on the alert” and “a forced volunteer”: a qualitative study of the invisible care provided by the next of kin of patients with chronic heart failure. *J Multidiscip Healthc* 2015;8:271–7.
81. Wällin E, Larsson M, Pehrsson F, et al. Relatives’ experiences of everyday life six months after hypothermia treatment of a significant other’s cardiac arrest. *J Clin Nurs* 2013;22:1639–46.
82. Wingham J, Frost J, Britten N, et al. Needs of caregivers in heart failure management: A qualitative study. *Chronic Illn* 2015;11:304–19.
83. Nässström L, Luttik ML, Idvalle E, et al. Exploring partners’ perspectives on participation in heart failure home care: a mixed-method design. *J Adv Nurs* 2017;73:1208–19.
84. Powell RE, Reid ME, Morrison CE, et al. The complex nature of informal care in home-based heart failure management. *J Adv Nurs* 2008;61:373–83.
85. Hess AM. The health literacy, self-care, and medication hassles of patients with heart failure and their caregivers. Masters West Lafayette, IN: Purdue University, 2009.
86. Kneeshaw MF, Considine RM, Jennings J. Mutuality and preparedness of family caregivers for elderly women after bypass surgery. *Applied Nursing Research* 1999;12:128–35.
87. Park EO, Yates BC, Schumacher KL, et al. Caregiving demand and difficulty in older adult spouses caregivers after coronary artery bypass surgery, *Geriatr Nurs* 2013;34:383–7.
88. Rieger J. The relationship of role strain, perceived social support, and humor to quality of life among couples experiencing the life-limiting illness of chronic obstructive pulmonary disease. PhD. Tallahassee, Florida State University, 1996.
89. Miravitles M, Peña-Longobardo LM, Oliva-Moreno J, et al. Caregivers’ burden in patients with COPD. *Int J Chron Obstruct Pulmon Dis* 2015;10:347–56.
90. Lum HD, Lo D, Hoekstra G. Caregiving in heart failure: relationship quality is associated with caregiver benefit finding and caregiver burden. *Heart Lung* 2014;43:306–10.
91. Kang X, Li Z, Nolan MT. Informal caregivers’ experiences of caring for patients with chronic heart failure Systematic review and meta-synthesis of qualitative studies. 2011;26:386–94.
92. Asabo S, Solbraekek KN, Kristvik E, et al. Between disruption and continuity: challenges in maintaining the “biographical we” when caring for a partner with a severe, chronic illness. *Social Health Illn* 2018;13:782–96.
93. Wingham J, Frost J, Britten N. Behind the smile: qualitative study of caregivers’ anguish and management responses while caring for someone living with heart failure. *BMJ Open* 2017;7:e014126.
94. Lawton MP, Moss M, Kleban MH, et al. A two-factor model of caregiving appraisal and psychological well-being. *J Gerontol* 1991;46:P181–P189.
95. Lee CS, Bidwell JT, Paturzo M, Alvaro M, et al. Patterns of self-care and clinical events in a cohort of adults with heart failure: 1 year follow-up. *Heart Lung* 2018;47:40–6.
96. Nakken N, Janssen DJA, van den Bogaart EHA, et al. European Respiratory Review 2015;24:498–504.
97. Mahoney DF. Vigilance. Evolution and definition for caregivers of family members with Alzheimer’s disease. *J Gerontol Nurs* 2015;11:304–19 https://doi.org/.
98. Antonakis L, Willever K, Mair M, et al. Caregivers’ contributions to heart failure self-care: A systematic review. *European Journal of Cardiovascular Nursing* 2015;14:76–89.
99. Dixon-Woods M, Agarwal S, Jones D, et al. Synthesising qualitative and quantitative evidence: A review of possible methods. *J Health Serv Res Policy* 2005;10:45–53.
100. Bazely P. Integrating analyses in mixed methods research. *SAGE Publications London* 2018.