Table 1

Individual Study Results

First Author/Year	Diagnosis	Outcome Measure	Result/Findings
Ågren (2010)	HF (NYHA II-IV)	Caregiver Burden Scale Short Form (SF)-36 Beck Depression Inventory Control Attitude Scale Knowledge Questionnaire Charlson Co-morbidity Index	68% of partners = low level burden 30% of partners = medium burden 2% of partners = high burden Regression analysis showed poor mental health (p=0.001) and lower perceived control (p=0.001) in partners and poor patient physical health (p=0.001) predicts higher caregiver burden
Al-Rawashdeh (2017)	HF (NYHA I-IV)	Beck Depression Inventory Minnesota Living with HF (modified for caregivers) Patient Health Questionnaire Short-Form 12 Health Survey	Patients whose spouse has higher sleep disturbance have poorer mental well-being (β = -2.19, p <0.05) Caregiver sleep disturbance significantly correlated with their own physical (β = -4.94, p< 0.001) and mental well-being scores (β = -6.62, p< 0.001)
Andersen (2015)	HF	n/a	1) Involvement, willingness to assume responsibility and desire for knowledge 2) Unclear Responsibility and Insufficient Flow of Information 3) Available and Competent Supporters
Badr (2017)	COPD	Patient Health Questionnaire COPD Severity Index Activities of Daily Living scale Lubben Social Network Scale Zarit Burden Interview Checklist created for this study re: co-morbidities (patients & caregivers) Smoking status Self-management behaviours – pts.	30% of patients and 20% of caregivers = mild depression 30% of patients and 8% of caregivers = moderate to severe depression. Depression levels of patients and caregivers were significantly correlated (r=0.28, P= 0.01)

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Bakas (2006)	HF (NYHA II-IV)	Control Attitudes Scale Oberst Caregiving Burden Scale Bakas Caregiving Outcomes Scale Medical Outcomes Study General Health	Caregivers reported their lives had changed for the worse due to providing care (M= 3.7, SD =1.5, 1 worst, 7 best Performing household tasks and managing patient behaviours were most difficult, and the caregiver's emotional and financial well-being, time for social activities, and general health had deteriorated. (ρ -0.46, p < 0.05)
Baker (2010)	HF (LVAD in situ)	n/a	1) Commitment
Bove (2016)	COPD (GOLD C&D)	n/a	1) Undefined and unpredictable responsibility
Burke (2014)	HF (NYHA II-IV)	n/a	1) Health Manager/Care Plan Enforcer 2) Advocate for Improved Quality of Life 3) Expert in the Lived Experience of HF 4) Expressions of Role Conflict and Role Strain
Chung (2016)	HF (NYHA II-IV)	Beck Depression Inventory-II Zarit Burden Interview Oberst Caregiving Burden Scale Bakas Caregiving Outcome Scale Medical Outcome Study	42% reported severe burden Caregivers of patients with depressive symptoms had a higher level of burden (25±13 vs 13.5±12 on the ZBI; p<0.001), Caregivers reported worse mental quality of life (46±10 vs 51±10 on the -12v2; p=0.026) than those of patients without depressive symptoms
Clark (2008)	HF (NYHA II – IV)	n/a	1) The sharing of caring 2) The basis of care: formal and informal forms of knowledge about CHF 3) The activities of informal care: visible and invisible
Cossette (1993)	COPD (GOLD III-V)	The SCL-90 scale The subjective Stress Scale Caregiving tasks index The family/friend support index	Nearly 40% of wives used psychotropic drugs Difficult emotional support significantly predicted somatization (β= 0.26, p ≤ 0.05), depression (β= 0.34, p ≤ 0.01), obsession compulsion (β= 0.43, p ≤ 0.01), anxiety (β= 0.26, p ≤ 0.05), and hostility (β= 0.37, p ≤ 0.01)

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Evangelista (2002)	HF (NYHA I – IV)	SF-12 (Mental Component Summary Scale)	Caregiver emotional wellbeing associated with patient's emotional wellbeing. Caregivers' mental health score: Adjusted R2 = 0 .536, F = 40.299, p = .000. Caregivers reported higher mental wellbeing than patients (P < .001, p = 0.018 (patients), p = 0.118).
Figueiredo (2013)	COPD (GOLD I-IV)	Carers Assessment of Managing Index (Portuguese version) International Classification of Functioning Disability and Health	Better physical health perception was associated with an increasing use of problem-solving strategies (r_s = -0.313; p = 0.029)
Figueiredo (2014)	COPD (GOLD I-IV)	International Classification of Functioning Disability and Health Hospital Anxiety and Depression Scale (Portuguese version) Carers' Assessment of Difficulties Index (Portuguese version)	61.9% = caregivers of early COPD patients observed to be anxious. 70.4% = caregivers of advanced COPD patients observed to be anxious. Depression significantly more frequent in caregivers of advanced COPD patients (p = 0.030). Self-rated physical (p = 0.035) and mental health (p = 0.011) worse in caregivers of advanced COPD patients
Figueiredo (2015)	COPD (Mod – Severe)	n/a	1) Meaning 2) Challenges and constraints 3) Fears and concerns about the future 4) Needs 5) Positive aspects
Grigorovich (2017)	HF (NYHA II-IV)	Center for Epidemiological Studies-Depression (CES-D) Positive Affect Scale Caregiver Impact Scale Caregiver Assistance Scale Pearlin Mastery Scale Medical Outcomes Study Social, Support Survey, Personal Gain Scale, Brain Impairment Behaviour, MLWHFQ	Caregivers depression remained stable over1 year (mean -0.17 ± SE 0.11, p > 0.1. Caregivers depression associated with participation restriction (p< 0.05). Caregivers positive affect remained stable over 1year (0.10 ± 0.10, p > 0.1). Positive affect associated (p<0.05) with caregivers feelings of personal gain and social support

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*Halm et al. (2006)	CAD	Caregiving Burden Scale Bakas Caregiving Outcomes Scale SF-12 (spouse proxy ratings) Karnofsky Performance Scale Caregiver Competence Scale State-Trait Anxiety Inventory Center for Epidemiologic Studies Depression Scale Mutuality Scale Expressive Support Scale	Higher burden scores were associated with patient's gender (female) (β = .21, p = .02), increased personal gain (β = .29, p = .004), increased caregiver competence (β = .20, p = .05). Lower burden was associated with better health status of the patient (β= -.22, p = .02), higher caregiver mental HRQL (β = -.38, p = .01). caregiver burden was not significantly different at 3, 6, or 12 months post-surgery
*Halm et al. (2007)	CAD	(as above Halm, 2006)	Controlling for caregiver and patient characteristics, caregivers who perceived less mastery (β = 0.45, p = .001) had higher depressive symptoms
*Halm (2016)	CAD	n/a	1) Knowing what I am supposed to be doing 2) Managing multiple medications 3) Assisting with mobility 4) Dealing with unmonitorable symptoms 5) Managing poor appetite 6) Keeping spirits up 7) Navigating memory loss & confusion 8) Surviving moodiness 9) Dealing with financial matters
*Halm (2017)	CAD	n/a	1) Caregiving work – comfort, monitoring, support & functional
Hess (2009)	HF	Short-Form Test of Functional Health Literacy Self- Care Index of Heart Failure Family Caregiver Medication Administration Hassles (FCMAHS)	Analyses are the individual results for caregiver health literacy and medication medication administration hassles as the study was insufficiently powered 80% of caregivers had adequate health literacy Average FCMAHS score was 27.80 (S.D. = 14.74), with a range of 10-44. Higher scores (out of 100) indicate greater medication administration hassle.

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Hooley (2005)	HF	Minnesota Living with Heat Failure Questionnaire Beck Depression Inventory II Zarit Caregiver Burden Interview	18% of caregivers had high likelihood of clinical depression Significant correlation between: caregiver burden and caregiver depression scores (r=0.61; p<0.0001), and caregiver burden and patient depression scores (r=0.28; p<0.05)
Hwang (2011)	HF (NYHA I – IV)	Dutch Objective Burden Inventory (English version) Medical Outcome Study Social Support Survey Control Attitudes Scale-Revised Caregiver Reaction Assessment Short Form 36 Health Survey Charlson Co-morbidity Index	Lack of family support for caregivers correlated with the patient's NYHA class, caregivers' relationship to the patient, p=0.003), caregivers' perceived control p <.001) and social support (p <.001) impact of caregiving on caregivers' health was associated with time since the patient's last hospital discharge, (p= .008 caregivers' perceived control, (p = .03) and social support (p <.001)
Hynes (2012)	COPD (NYHA III or IV)	n/a	1) Then and Now 2) Awareness of the disease and constant state of anxiety 3) The Caring Role 4) Perceived illness effects: striving for normalisation and symptom burden 5) Support 6) Contact with healthcare services
Imes (2011)	HF (NYHA III-IV)	n/a	1) My experience of HF in My Loved One 2) Experience with Healthcare providers 3) Patient's experience of HF as Perceived by the Partner
Karmilovich (1994)	HF (NYHA III OR IV)	Caregiver Demands Scale (physical demands/role alteration) Brief Symptom Inventory	Significant positive correlation between the number of helping behaviours and the level of stress (r = 0.32, p=0.04) Positive correlation between perceived difficulty performing caring activity and level of stress (r = 0.43, p=0.01) Burden score Mean = 15.27 (SD 11.3)

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Kitko (2010)	HF	n/a	1) The work of providing care 2) Work of living with the illness 3) The Work of navigating the system 4) The work of maintaining self 5) The work of managing the household 6) The work of vigilance 7) The work of normalcy
Kneeshaw (1999)	CAD	Mutuality Scale Preparedness for Caregiving Scale Recovery Inventory OARS activities of daily living	Significant decrease between the mutuality scale means at hospital discharge and at 3 months (p < .05) Preparedness for caring - most common concern of the caregivers was fear of the unknown, especially an emergency
Liljeroos (2014)	HF	n/a	1) Dyads perceive a need for continuous guidance throughout difference phases of the illness trajectory 2) Dyads perceive a need to share burden and support with each other and other dyads
Lindqvist (2013)	COPD (Mild to severe)	n/a	(1) Unchanged life situation where no support was needed (2) Socially restricted life and changed roles where support is needed (3) Changes in health where support is needed (4) Changes in the couple's relationship and their need for support.
Loftus (2004)	HF (NYHA II-IV)	Self-reported health status questionnaire State-Trait Anxiety Inventory Pearlin scale of Mastery Rosenberg Self-Esteem Scale Social Support Scale Dyadic Adjustment Scale Caregiver Distress Scale Sense of Competence Questionnaire Centre for Epidemiological Studies depression Scale	Severity of heart failure and level of patient disability predictive of caregiver distress (personal cost, ANCOVA, F=3.94, p<. 05; depression, ANCOVA, F=7.15, p< .05) independent of caregiver neuroticism Satisfaction with social support was a better predictor of distress than a global measure of social support

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Lum (2014)	HF (NYHA II-IV)	Zarit Burden Inventory Benefit Finding Scale Patient Health Questionnaire	Higher relationship quality associated with less caregiver burden and more caregiver benefit - (r = -0.54, 95% CI: [-0.81, -0.10], P = 0.02)
Luttik (2007)	HF	n/a	1) Changes in life 2) Anxiety 3) Changes in relationship 4) Sexuality 5) Coping/Support
Luttik (2009)	HF (NYHA II-IV)	Medical Outcome Study General Health Survey (RAND-36) Dutch Objective Burden Inventory Cantril's Ladder	Partners of people with CHF reported lower general health than partners of healthy persons (F (1,598) = 4.066, P < 0.05) Interaction effect between group (partners of people with CHF vs. individuals living with a healthy partner) and gender for general well-being, F(1,581) = 4.526, P < 0.05, and for perceived health change, F(1,604) = 4.283, P < 0.05
Marcuccilli (2011)	HF –LVAD in situ	n/a	1) Caregiving – a "24/7" Responsibility 2) Coping Strategies 3) Caregiving satisfaction
Marcuccilli (2014)	HF-LVAD	n/a	1) Advanced Heart Failure is a Life Changing Event 2) Self-doubt about LVAD Caregiving Improved with Time 3) Lifestyle Adjustments come with Time 4) Persistent Worry and Stress 5) Caregiving is not a Burden – it's part of life
Miravitlles (2015)	COPD	Survey on Disabilities, Personal Autonomy, and Dependency Situations (National Institute of Statistics in Spain)	35% of caregivers had health problems 83% of caregivers had social/leisure problems 38% of those of working age had profession related problems

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Nakken (2017)	COPD	Charlson comorbidity index
		Dutch relationship questionnaire
		Care dependency scale
		Utrecht Coping List
		Hospital Anxiety and Depression Scale
		EuroQol-5 Dimensions
		Medical Outcome Study Social Support
		Family Appraisal of Caregiving
			Depression levels (P=0.261) social support (P=0.222 to 0.897) and caregiver burden (P=0.410 to 0.720) were comparable for male and female caregivers
			Female caregivers had more symptoms of anxiety (P<0.0001) and worse health status (P=0.001
			   Lower levels of social support were associated with higher levels of caregiver strain
			   No differences in caregiver burden between gender (P=0.401 to 0.724)

Näsström (2017)	HF	Charlson comorbidity index Relatives' perception of quality of care Dutch Objective Burden Inventory EuroQol The Patient Health Questionnaire	1) Adapting to the caring needs and illness trajectory 2) Coping with caregiving demands 3) Interacting with healthcare providers 4) Need for knowledge to comprehend the health situation More information was associated with better perceived health (rho 0.56, P < 0
Park (2013)	CAD	Caregiving Burden Scale	Subscale scores of caregiving demand and caregiving difficulty were 31.1 and 22.9 Demanding caregiving activities perceived by caregivers were: providing transportation, additional household tasks, providing emotional support, and two tied for fourth: monitoring symptoms and additional tasks outside the home
Pattenden (2007)	HF	n/a	1) Symptoms, multiple medications, co-morbidities 2) Confusion, anxiety and depression 3) Adapting life to heart failure 4) Changing roles for carers
Pi-Ming Yeh (2012)	HF	JAREL Spiritual Well-being Scale Carers Assessments of Managing Index Care Continuity Scale Caregiver Reaction Assessment Caregivers Esteem Subscale Lack of Family Support Subscale	People expressed medium levels of ADL dependency (Mean = 9.56, SD = 3.93) Higher scores of the older people's ADL dependence (β = 0.47, P < 0.001), lower scores of quality of relationship (β = -0.39, P < 0.01) and higher scores of lack of family support (β = 0.41, P < 0.001) were found to predict significantly greater family caregiver burden

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Pressler (2013)	HF (NYHA I-IV)	Oberst Caregiving Burden Scale Control Attitudes Scale Patient Health Questionniare-8 Brief Symptom Inventory Anxiety Subscale Bakas Caregiving Outcomes Scale Medical Outcomes Study Short Form-12 Charlson Comorbidity Index Family Assessment Device	Caregivers perception of life changed - neutral on average and improved from baseline to 4 (P=0.054) and 8 (P= 0.030) months Poor physical and emotional HRQOL at baseline Caregivers of patients with high HF symptoms spent more time on caregiving tasks at 4mo.(P = 0.001) & 8 mo.(P=0.003), perceived greater difficulty with caregiving tasks (baseline P=0.031 & 4 mo. P <0.001) and reported higher bassline anxiety (P=0.019) and poorer physical HRQOL at baseline (P < 0.001) and 4 mo. (P=0.008)
Riegner (1996)	COPD	Caregiver Strain Index Social Support Questionnaire – Short Form Situational Humor Response Questionnaire Coping Humor Scale Life Situation Survey	Role Strain significantly associated with quality of life (β = 0.15, F=11.5, p <.001) For caregivers; social support satisfaction made a significant contribution to quality of life with β= 0.26, F=22.90, p.<.0001, and R^2 of .26
Rolley (2010)	CAD	n/a	1) A gendered approach to health, illness and caring 2) Shock, disbelief and the process of adjustment following PCI 3) Challenges and changes of the carer-patient relationship 4) The needs of the carer: support and information
*Saunders (2009)	HF	CES-D 10 Caregiver Reaction Assessment Quality of Life Index	Caregiver burden is associated with lower CG HRQOL; increased burden in support (r=–0.50, p < .01.), finances (r=–0.52 p < .01), schedule (r=–0.62, p < .01) and health (r=–.71, p < .01) = decreased HRQOL
*Saunders (2008)	HF	(as above Saunders, 2009)	76% of caregivers had health problems in past month Highest to lowest burden ranked: schedule (M = 3.20, SD = 1.09), finances (M = 2.39, SD = 1.18), family (M = 2.38, SD = 1.10), and health (M = 2.21, SD = .98).
Saunders (2010)	HF	Centre for Epidemiological Studies Short Depression Scale Quality of Life Index (QLI)	Caregiver depression not difference between employed and unemployed caregivers (t= 1.0, p < 0.05) Employed caregivers perceived higher well-being except for psychological/spiritual domain, well-being (t =-2.9, p<0.01), health/function (t =-2.3, p<0.05), socioeconomic (t = -2.7, p<0.05), family (t =-3.4, P<0.01)

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Schwarz (2003)	HF	Perceived Stress Scale Center for Epidemiological Stress Studies Depression Scale Inventory of Socially Supportive Behaviours Scale Clinical Assays Gamma Coat Cortisol	The effects model with salivary cortisol was not significant (F=1.9, p=.15). as measured by the PSS, was the only significant variable (t=5.80, p=.000) No significant associations between salivary cortisol and the PSS (F=1.059, p=.384)
Scott (2000)	HF	Caregiver Preparedness Scale Minnesota Living with Health Failure Questionnaire Caregiver Reaction Assessment The Mental Health Inventory-5 Quality of Life Index	Caregivers reported being least prepared for stress associated with role (M = 2.11) 89% of caregiver scores for mental health were less than age norm 55% of the caregivers have to eliminate things from their schedule/interrupt current activities to provide care 39% of the caregivers reported constant fatigue
Spence (2008)	COPD (Adv.)	n/a	1) Impact of family caregiving 2) Unmet Support Needs 3) Carers' perceptions of patients
Strom (2015)	HF	n/a	1) Being on the alert 2) Being a forced volunteer
Takata (2008)	COPD	Zarit Burden Interview (Japanese version) Barthel Index	53.3% of caregivers were depressed Caregivers providing longer term care were more burdened HB caregivers want to use social services such as Nursing Home 90.9% v 34.8% (p<0.05)
Vellone (2015)	HF (NYHA I-IV)	Caregiver Contribution to Self-care of heart failure Index	54.2% of caregivers were unable to recognize the signs and symptoms of a heart failure exacerbation quickly or very quickly
Wallin (2013)	CAD	n/a	1) Difficulties managing a changed life situation 2) Feeling like I come second 3) Feeling new hope for the future
Woolfe (2007)	COPD	Family Caregiver Needs Survey	Information is the most important need for caregivers (M= 6.37, SD = 0.8 Important but poorly met needs = information (27.7), psychological (26.5) and personal (25.3)

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Wingham (2015)	HF	n/a	1) Providing support
			2) Transition to becoming a caregiver
			3) Engaging help

HF = Heart Failure, COPD = Chronic Obstructive Pulmonary Disease, LVAD = Left Ventricular Assist Device, LVAD DT = Left Ventricular Assist Device Destination Therapy, CAD = Coronary Artery Disease, n/a = not applicable, PCI = Percutaneous coronary intervention, MLWHFQ = Minnesota Living with Heart Failure Questionnaire

* = same study