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Experiences of informal caregivers after cardiac surgery: a systematic integrated review of qualitative and quantitative studies

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ABSTRACT

Objectives To provide a comprehensive synthesis of informal caregivers' experiences of caring for a significant other following discharge from cardiac surgery.

Design Systematic integrated review without meta-analysis.

Data sources A bibliographic search for publications indexed in six databases (Cochrane Library, CINAHL, MEDLINE, EMBASE, AMED and PsycINFO), including a scan of grey literature sources (GreyNet International, Google Scholar, Web of Science, WorldCat and the Clinical Trials Registry) was conducted in October 2018.

Eligibility criteria for selecting studies Studies were included if they described views and perspectives of informal caregivers of cardiac surgery patients (non-intervention studies (qualitative and quantitative)), and the effectiveness of interventions to evaluate support programme for informal caregivers of cardiac surgery patients (intervention studies).

Results Of the 4912 articles identified in searches, 42 primary research studies were included in a narrative synthesis with 5292 participants, including 3231 (62%) caregivers of whom 2557 (79%) were women. The median sample size across studies was 96 (range 6–734). Three major themes emerged from the qualitative study data: (1) caregiver information needs; (2) caregiver work challenges and (3) caregivers adaption to recovery. Across the observational studies (n=22), similar themes were found. The trend across seven intervention studies focused on caregiver information needs related to patient disease management and symptom monitoring, and support for caregivers to reduce symptoms of emotional distress.

Conclusion Informal caregivers want to assist in the care of their significant others after hospital discharge postcardiac surgery. However, caregivers feel insecure and overwhelmed and they lack clear/concise discharge information and follow-up support during the early at-home recovery period. The burden of caregiving has been recognised and reported since the early 1990s, but there remains a limited number of studies that assesses the effectiveness of caregiver interventions.

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Strengths and limitations of this study

- The first integrated review of caregiver experiences after cardiac surgery.
- A comprehensive search strategy including six databases and a scan of grey literature sources.
- We included all primary research studies exploring views and perspectives of informal caregivers of cardiac surgery patients independent of study design.
- Due to heterogeneity in study outcomes, a narrative synthesis was conducted.

INTRODUCTION

Cardiac surgery is a major life event with the expectation that patients will improve both symptomatically and functionally after surgery.[1] Patients undergoing coronary artery bypass graft (CABG) surgery, heart valve surgery, or CABG plus valve surgery are discharged home approximately 1 week after surgery.[2] Postoperative sternal restrictions (eg, no driving or heavy lifting) mean patients often rely on the assistance of caregivers during recovery.[3] Cardiac rehabilitation (CR) is highly recommended and cost-effective. It can increase quality of life as well as reduce rehospitalisation and mortality after cardiac surgery.[1 4] However, CR is usually not an alternative for the first 6–8 weeks due to sternal restrictions and activity limitations, and only 20%–30% of cardiac patients attend any type of outpatient CR.[4 5] This makes the early recovery period particularly challenging for informal caregivers. Cardiac surgery patients report home recovery symptoms including pain,[6 7] anxiety, depression,[8] stress, fatigue,[3] a lack of information about prescribed cardioprotective medications, and are not sure when to contact their primary care provider (PCP).[7 9]

Postdischarge, caregivers of cardiac surgery patients experience an under-recognised burden of uncertainty. Caregivers are responsible for patients' physical and emotional well-being, yet they feel they have insufficient information about what to expect (eg, patient symptoms after cardiac surgery) and how to react in their caregiving role.[3 7] Caregivers worry about escalating patient symptoms (eg, shortness of breath, palpitations); heart failure and cardiac dysrhythmias are the main reasons for readmission during the first month after discharge from cardiac surgery.[10]

The ideal transition of care to move beyond readmission penalties presupposes key components from hospital (discharge planning) to community (outpatient follow-up) that include informal caregivers to optimise transition (eg, patient/caregiver education on self-care instructions, warning signs and symptoms, who to contact for problems and medication safety).[11] There are current gaps in care coordination between hospitals and PCPs.[12] For example, 25% of patients do not follow medication recommendations posthospital discharge[13] and require rehospitalisation due to adverse drug events.[13] Tailored education and support for patients and their caregivers has improved postdischarge recovery.[14] Moreover, caregiver education and support has also improved patient health behaviours.[8] The European Society of Cardiology recommends discharge education that is person-centred for patients and their caregivers.[15] Petrini *et al*[16] highlight the need to support female caregivers as they have a greater burden of care.[16] Higher burden of care is associated with increased indirect costs due to loss of productivity (workdays).[17]

A comprehensive integrated systematic review of the literature of caregiver burden following cardiac surgery is needed. Our overall aim is to synthesise existing qualitative and quantitative literature studies and provide recommendations for caregiver education and supports after cardiac surgery. Specific objectives include: (1) provide a comprehensive synthesis of informal caregivers' experiences of caring for a significant other postdischarge from cardiac surgery; (2) identify research gaps and provide recommendations for caregiver education and support following cardiac surgery.

METHODS

The protocol for this integrated review has been registered in the international prospective register of systematic review. We used conventional review strategies: sensitive searching and systematic screening, and independent quality assessment. Results are reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocol.[18]

Eligibility criteria and search strategy

The eligibility criteria were purposefully kept broad to ensure we identified and described the characteristics of the evidence base related to caregivers and cardiac surgery. The studies were selected if they included: (1) views and perspectives of informal caregivers of cardiac surgery patients (non-intervention studies (qualitative and quantitative)) and (2) the effectiveness of interventions to evaluate support programme for informal caregivers of cardiac surgery patients (intervention studies). The period between 1990 and 2018 was selected to limit the search results for the electronic databases to ensure a more similar healthcare context across studies.

The selected search strategy was developed in cooperation with a health science librarian and was conducted in October 2018 in six bibliographic databases: the Cochrane Library, CINAHL, MEDLINE (Ovid), EMBASE, AMED (Allied and Complementary Medicine) and PsycINFO. The databases were searched using keywords and MeSH headings translated to each of the databases associated thesaurus. The search also included a scan of grey literature sources including GreyNet International, Google Scholar, Web of Science and WorldCat. For recently completed clinical trials we searched the Clinical Trials Registry (ie, clinical trials.gov). Publication citations were exported from electronic search interfaces to Endnote and duplicates were removed. A full description of search terms and strategies used is shown in online supplementary table S1.

Patient and public involvement

No patients were involved in the design and conduct of the study.

Study selection and analysis method

Two reviewers independently screened the title and abstracts of citations against eligibility criteria. All potentially relevant articles were retrieved, followed by an independent assessment/screening of full-text articles before data extraction and synthesises. Studies with duplicate populations were excluded.

The data extraction and synthesises of results were performed in two steps. Synthesis 1: findings from the non-intervention studies were copied verbatim into NVivo software and guidelines for thematic analysis was followed.[19] Findings of each study were assigned codes to describe relevant sentences or paragraphs and then similarities and differences between codes to organise them into a hierarchical tree structure centred on understanding informal caregiver experiences, and the findings were synthesised following a content analysis procedure described by Vaismoradi *et al*.[19] The coding and data extraction were first performed in studies with qualitative study design, thereafter the procedure was repeated for quantitative studies as described by Whittemore and Knafl.[20] The raw data were revisited on a regular basis to ensure the codes and resulting themes were grounded in the data.

Synthesis 2: the findings from intervention studies and non-intervention studies (ie, synthesis 1) were combined using a matrix to juxtapose the caregiver experiences.

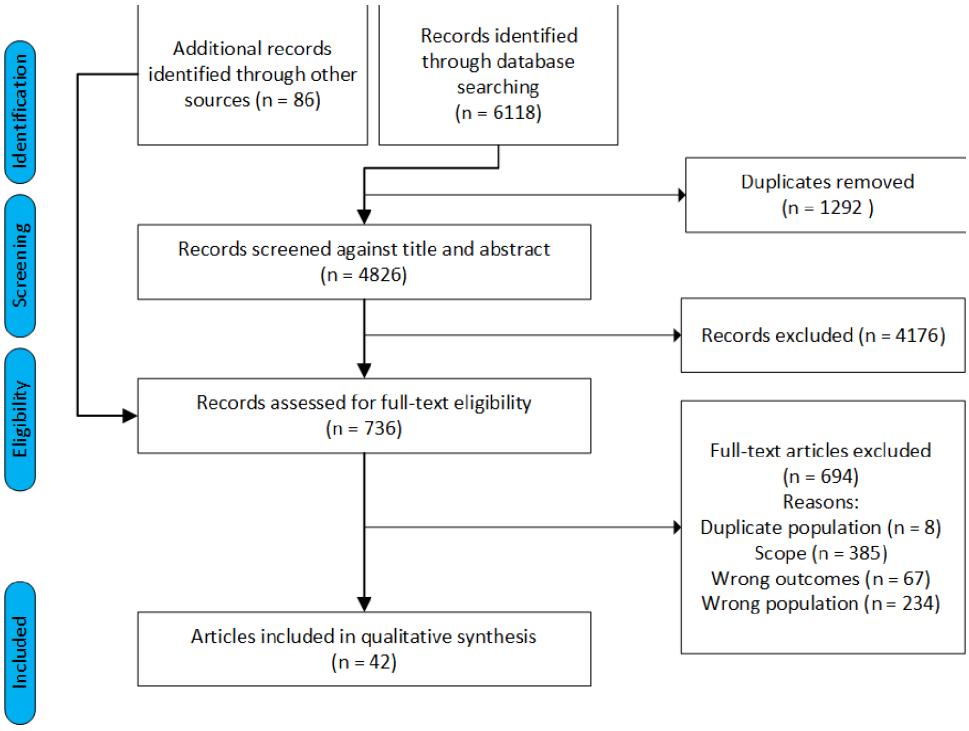

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of study selection.

Quality assessment

All included studies were independently assessed for quality by two reviewers using the critical appraisal tools from Joanna Briggs Institute including checklists for cross-sectional, case control, cohort, qualitative and randomised controlled trials (RCTs), studies as appropriate. Disagreement was resolved in a consensus meeting between the two reviewers.

RESULTS

After duplicates were removed, 4826 records were identified through database searching; 86 additional records were included from grey literature sources (figure 1). Following title, abstract and full text screening, 42 primary research studies (ie, RCTs (n=7), observational studies (n=22) and qualitative studies (n=13)) were included in a narrative synthesis (figure 1). Our 43 studies had an aggregate of 5292 participants, including 3231 (62%) caregivers of whom 2557 (79%) were women. Sixty-nine per cent (n=29) of the studies were conducted in North America, and 21% (n=9) in Western Europe. The median sample size across studies was 96 (range 6–734). The characteristics of all the included studies are displayed in detail in online supplementary table S2A,B and C (ie, qualitative studies), (ie, observational studies) and (ie, RCTs). The summary of findings and quality of evidence related to caregiver experiences across study design is displayed in table 1.

Findings from the qualitative studies

Thirteen qualitative research studies (n=509) explored and described the personal experiences related to caregivers and cardiac surgery patients comprising data from 328 caregivers. The majority of caregivers included were spouses (62%, n=8) of whom 84% (n=275) were women between 32 and 87 years. Most caregivers were between 50 and 70 years of age.

Across the qualitative studies, the majority of findings were related to caregivers' role and perceived responsibilities related to the cardiac surgery patient needs in the early recovery phase following discharge from hospital. Independent of the year of publication (1990–2018), three major themes emerged from the qualitative study data and included: (1) caregiver information needs; (2) caregiver work challenges; (3) caregiver adaption to recovery.

Caregiver information needs

Findings related to lack of preparedness for the caregiving role and the work associated with caregiving were evident across all studies independent of the year of publication.[3 21–30] Particularly, this included lack of verbal or written information related to how to care for the patient at home (eg, medical/nursing treatments, monitoring symptoms), what to expect (eg, physical recovery), how to deal with patients' emotional responses (eg, depression, moodiness), and lack of support/help from healthcare providers. If complications occur after surgery, lack of information and support were a great concern for the caregivers; making the rehabilitation phase lonely, burdensome and filled with insecurity that caregivers were not prepared for.[21]

Caregiver work challenges

Caregiving is associated with both direct and indirect caregiver work.[25] Findings related to caregiver work challenges were consistent within and across the included

Table 1 Summary of findings and quality of evidence related to caregiver experiences across study design (n=42)

Summary qualitative studies	Summary observational studies	Summary randomised controlled trials
Study characteristics	**Study characteristics**	**Study characteristics**
13 qualitative studies, n=509 (range 6–150). Caregivers n=328, 84% (n=275) women, age caregivers range 32–87 (mean not reported)	22 observational studies, n=3569 (range 34–734). Caregivers n=2148, 77% (n=1651) women, age caregivers mean=61, range 37–82	7 RCT, n=1214 (range 25–364). Caregivers n=755, 84% (n=631) women, age caregivers mean=62, range 32–76
Findings related to caregiver experiences	**Findings related to caregiver experiences**	**Findings related to caregiver experiences**
Caregiver support and information needs: ► Not prepared for the role after discharge (Halm[3]). ► Ivarsson *et al*.[21] ► Uncertainty and lack of knowledge causing physical exhaustion and emotional constraint (MacLeod[22]). ► Afraid to leave their spouse alone and uncertain about how to deal with postoperative depression (MacLeod[22]). ► Lack of information and support from healthcare providers (Karlsson *et al*[26]). ► Lack of information and follow-up postdischarge. Caregivers and patients were not prepared for recovery problems: pain, ineffective coping, activity intolerance, sleep disturbance and altered nutrition (Gillis and Belza[29]). **Caregiver work challenges** ► Learning new skills to take care of medical/nursing needs (wound care, test blood glucose). ► Check and monitor partners' progress (being sensitive to changes in patient progress, related to pain, sleeping problems and insecurity issues). ► Monitor food intake and exercise regimens, and monitor visitors. ► Coordination, keeping things on track including household tasks and finances adapting work-life balance. ► Reorganising physical environment and household task, take on new responsibilities. ► Meeting of immediate demands including assisting with physical care (personal care and applying clothes). ► Keeping the patient spirits up, deal with memory loss and confusion, and behaviour problems as moodiness and depression. Contributing studies (Halm[3]; MacLeod[22], Robley *et al*[23]; Ganske[25]; Theobald and McMurray[27]; Knoll and Johnson[28]).	**Caregiver support and information needs:** *Information* ► A need for specific instructions about how to care for the patient. Needs met less than 50% of the time: to receive information about own feelings/emotions, to be told of people/groups who can help with problems' and to talk about own anger/frustration (Carroll[38]). ► Most prevalent stressor: worries about treatment, recovery and prognosis (75%); patient moodiness (66%); worries about the patient returning to work and finances (38%); sexual concerns (36%); and helplessness/apathy on the part of the patient and increased spousal responsibility (36%) (O'Farrell *et al*[36]). ► 80% of the caregivers were not feeling prepared for patient discharge and caregivers need information and education at hospital but also after discharge (Leske and Pelczynski[41]). ► Most problematic stressors: fear of death, or that the patients would become chronical ill, finances and sleep disturbance. Needs included postsurgery support groups, referrals to community support services, preoperative and postoperative education and exercise programme (Monahan *et al*[46]). *Social support* ► The need for support highest at 6 weeks postsurgery (Robinson and Barnett[48]). ► Lower caregiver HRQoL 1-month postsurgery was associated with comorbidities, unemployment, female sex and lack of emotional support (Rantanen *et al*[50]). ► Higher caregiver burden was associated with poorer patient health status and cognitive symptoms, patient's sex (female), poorer caregiver mental HRQL, higher caregiver competence, and higher personal gain (Halm *et al*[51]). ► Caregivers experienced less social support from the social network and nurses than the patient (Rantanen *et al*[49]). ► Caregivers experienced less social support after surgery compared with before (McCoy[54]). ► Perceived availability of social support was related to better outcomes for patients and spouses for up to 1 year after CABG (King *et al*[42]). ► Social support buffered the impact of caregiving burden on mood disturbance for caregiving spouses. Caregivers received less perceived social support from network than the patients did (Rankin and Monahan[37]). **Caregiver work challenges** ► The most demanding and/or difficult caregiving tasks during first 6 months: providing social support, managing behaviour problems, taking additional households tasks, and monitoring symptoms. In early recovery providing transportation and in later recovery (3 and 6 months) managing finances were top ranked caregiver demands ([33]). ► Taking on responsibility for the outcome of their husband's recovery, his lifestyle changes, social support, health, physical health and safety, and education needs (Baird and Eliasziw[44]). ► Providing emotional support, taking over household tasks, and monitoring patients' conditions created the greatest burden (Stolarik *et al*[56]).	**Caregiver support and information needs:** ***Effect on outcome:*** Emotional support and information from healthcare providers provided through both daily telehealth follow-up (monitoring symptoms) and telephone calls over 3 weeks post discharge to reduce anxiety, depression and healthcare utilisation (Keeping-Burke *et al*[61]). Telephone support and information from healthcare providers to reduce caregiver anxiety (Hartford *et al*[60]). ***No effect on outcome:*** Education, emotional support, and exercise sessions provided in a CR programme for patients and partners to improve HRQoL (Macken *et al*[8]). Psycho-educational support sessions focusing on experiences, stress and knowledge (Ågren, 2015). Ego strengthening hypnosis session to reduce depression and profile of mood states (de Klerk *et al*[64]). Educational videotape discharge intervention for partners to improve affective states, emotional difficulties and preparedness for recovery (Mahler and Kulik[63]). Emotional support and information from healthcare providers provided through a 12 weeks psychoeducational intervention (session at discharge, and three telephone calls over 6 weeks). Outcome: physical and emotional health status (Lenz and Perkins[62]).

Continued

Table 1 Continued

Summary qualitative studies	Summary observational studies	Summary randomised controlled trials
Caregiver adaption to recovery *Emotional responses* ► A lonely, uncertain and burdensome phase (Ivarsson *et al*[21]; Ågren *et al*; Theobald and McMurray[24 27]). ► Difficult to ask for help from others (Ivarsson *et al*[21]). ► Exhaustion, fear, sadness, stress, worry and frustration (Ganske[25]; Karlsson *et al*[26]; Theobald and McMurray[27]). ► Caring, closeness, responsibility, and taking charge of one's health, but also control, criticism, sickness, loss, and futility (Goldsmith[29]; Gillis[31]). ► Feeling strong responsibility to fulfil commitments to the patients need, suppressing own needs (Ågren *et al*[24]; Karlsson *et al*[26]; Theobald and McMurray[27]). *Coping strategies* ► Redefining the illness, seeking spiritual support, collaborating with spouse (Whitsitt[32]; MacLeod[22]; Theobald and McMurray[27]). ► Take brakes, receive support and information from healthcare providers, and social support from family/friend to alleviate *stress* and to gain inner strength to endure (Robley *et al*[23]; Ågren *et al*[24]).	**Caregiver adaption to recovery** ► Only anxiety improved for spouses after surgery and they experienced reductions to physical health. Caregiver burden predicted decreasing social support and emotional distress (Leigh[55]). ► Highest level of anxiety symptoms at 6 weeks postsurgery (Carroll[38]). ► Patients reporting poorer physical health postoperatively were more likely to have partners with poorer preoperative physical health. Partners reporting poorer emotional, physical and social functioning postoperatively were associated with patients who had poorer preoperative mental health. Poorer postoperative HRQoL was also associated with poorer preoperative HRQoL for both patients and partners (Thomson *et al*[47]). ► Spouses with more resilience reported more social support, more positive appraisal of the surgical experience, more use of adaptive coping, and less life-change stress (Marnocha and Marnocha[43]). ► Spouses perceived their husbands' illness to be significantly more severe than did the husbands themselves. Spouses was 'taking on responsibility' for the outcome of their husband's recovery. For some spouses, taking on responsibility was embraced. For others, their feelings were mixed with anxiety, fear, and resentment (Baird and Eliasziw[44]). ► Spouses' support predicted increases in patients' mental health, whereas spouses' control predicted decreases in both patients' health behaviour and their mental health (Rantanen[49]). ► CABG surgery had a negative effect on the patients' marital satisfaction, communication, and attitudes toward the division of roles in the marriage and family. In addition to a negative influence on the emotional bonding with other members of the family. Coping strategies included seeking of spiritual support and the reframing of the problem (van der Poel and Greeff[39]). ► Careers, which experienced a heavy burden once the patient had left hospital and were less satisfied with the timing of discharge than the patients were. High levels of satisfaction with the information provided by health professionals were associated with lower depression score (Davies[35]). ► Social support, conflict, health value, and family coping did not change significantly over time. Family members reported change in low fat diet and exercise (improved) significantly(Rosenfeld[45]). ► Spouses have moderate HRQoL 1 year after surgery, lower compared with healthy sample. HRQoL inversely related to partners' physical health (Artinian[52]).	
Quality of evidence	**Quality of evidence**	**Quality of evidence**
Minor concerns about coherence → findings reasonably consistent within and across studies. **Substantial concerns about relevance** → 13 qualitative studies, n=328, 84% (n=275) women. Participants represents a selected group related to sex, age and ethnicity, majority of studies conducted in North America and Western Europe. **Minor concerns related to overall methodological quality** → minor concerns related to methodological quality of the qualitative studies: three (33%) studies with ROB >3 (range 1–8).	**Minor concerns about coherence** → findings reasonably consistent within and across studies. **Moderate concerns about relevance** → 22 observational studies, n=2148, 77% (n=1651 women. Participants represents a selected group related to sex, age and ethnicity, majority of studies conducted in North America and Western Europe. **Moderate concerns related to overall methodological quality** → moderate concerns related to methodological quality of the cohort studies: 11 (48%) studies with ROB >3 (range 1–6).	**Moderate concerns about coherence** → findings reasonably consistent within and across studies. **Substantial concerns about relevance** → seven studies, caregivers n=880, 72% (n=631) women. Participants represents a selected group related to sex, age and ethnicity, majority of studies conducted in North America and Western Europe. **Substantial concerns related to overall methodological quality** → substantial concerns related to methodological quality of the RCTs: five (71%) studies with ROB >3 (range 3–7).

CABG, Coronary Artery Bypass Graft; HRQoL, Health Related Quality of Life; RCT, randomised controlled trial; ROB, Risk of Bias, assessed with the Joanna Briggs' Checklists.

qualitative studies: caregiving requires coordination, adaption of work-life balance, reorganising/adapting physical environment in the home, and preparing and learning new skills related to medical and nursing treatments (eg, wound care, test blood glucose, assistance with personal care and dressing).[22 23 25 29 30] Most caregivers felt a strong responsibility during the recovery and were sensitive to changes in patient recovery.[27] Caregivers would check and monitor symptoms related to pain, sleeping problems, food intake and exercise regimens,[27 28] and they

would try keep things on track including household tasks and finances despite being exhausted themselves.[3 27 28]

Caregivers adaption to recovery

Disease and symptom-management tasks are burdensome and associated with stress and physical exhaustion for many caregivers.[3 27] Role reversal contributed to the stress in many cases, for example, finances were often the patient's primary responsibility.[3] We found no evidence of change in perceived caregiver burden and emotional responses over the time frame for this review (ie, 1990–2018). Feelings of loneliness, tiredness, anxiety, frustration, and insecurity continued to be frequently reported across both older and more recent studies.[3 24 26–29 31] However, caregiving was also associated with positive emotional responses (eg, caring, closeness and responsibility).[27 31 32]

Caregivers' roles and responsibilities were influenced by coping strategies such as seeking support[22 24 27 32] and partnering (eg, marital quality, shared meaning).[22 32] Many caregivers described the importance of taking brakes (eg, get out of the house), when they received support and information from healthcare providers, and social support from family/friends all these factors were described to decrease depressive feelings, reduce social isolation, alleviate physical and emotional stress, and contribute to better adaptation for caregivers during the patients' recovery.[3 23]

Findings from the observational studies

Twenty-two (52%) studies comprising data from 3569 participants including 2148 caregivers (77%, n=1651 women) were grouped as primarily descriptive (ie, cohort (n=11), cross-sectional (n=10), case-control (n=1)). The median sample size across studies was 124 (range 34–734), and the mean age of caregivers enrolled was 61 years (range 37–82). Across the observational studies, we identified similar themes as found in the qualitative studies: caregiver work challenges (n=6)[33–37]; caregivers' adaption to recovery including emotional responses (n=9)[35 37–44]; caregiver stress (n=4),[41 43–48]; caregivers' health-related quality of life (HRQoL) (n=9).[36 45–52] Thirteen studies also explored caregiver experiences of social support.[37–39 42 43 45 46 49 51–55] Five studies[33 37 51 55 56] utilised a validated tool to assess caregiver burden: the Caregiving Burden Scale[57] and the Zarit Caregiving Burden Inventory.[58] Four other studies included a study-specific developed tool[35 40 41 48] to assess caregiver work/challenges. In the other studies, caregiver experiences were more indirectly assessed through validated measures related to family/life event stress,[39 43 54] HRQoL,[36 45–52] and functional outcome for spouses.[42]

Findings from the intervention studies

Seven RCTs assessing the effectiveness of interventions targeting caregivers were identified comprising data from 1214 participants including 755 caregivers (84% (n=631) women). The median sample size across intervention studies was 90 (range 25–364), and the mean age of caregivers enrolled was 62 years (range 32–76).

The trend across the intervention studies was predominantly to address caregiver information needs related to patient disease management and symptom monitoring,[8 59–63] and to provide support for caregivers to reduce symptoms of emotional distress.[8 59–62 64] The follow-up time ranged from four to 24 weeks, and healthcare personnel delivered the intervention in all studies. No studies used peers to deliver the intervention, and no study described the involvement of end-users (ie, patient and public involvement or patient engagement) in the development of caregiver interventions.

Support and information from healthcare providers were provided to patients and partners (n=262) through six telephone calls over 7-week postdischarge CABG surgery and was found to be more effective in reducing anxiety compared with control (usual care).[60] Similarly, a symptom-management programme[61] (n=362) provided emotional support and information from healthcare providers through daily telehealth follow-up (monitoring symptoms) and telephone calls over 3 weeks postdischarge CABG surgery. The intervention group had reduced caregiver anxiety and depressive symptoms, and healthcare utilisation compared with control. In contrast, Lenz and Perkins[62] compared emotional support and information from healthcare providers in a 12-week psycho-educational programme (session at discharge, and three telephone calls over 6 weeks) to control (usual care including a videotape with discharge instructions). However, no significant differences between groups were found related to physical and emotional health status (primary outcome). Caregivers were more depressed than patients from before surgery, a tendency that continued over the 12-week follow-up. Another study,[8] provided education, emotional support, and exercise sessions for caregivers (ie, partners) over 12 weeks in a CR programme compared with control, but no difference in HRQoL was observed. A study of 1 hour multidisciplinary psycho-educational support session at 6-week, 12-week and 24-week post discharge focusing on caregiver experiences, stress and knowledge compared with control (usual care), found no significant difference between groups related to knowledge and perceived caregiver burden in a sample (n=42) with partners of patients with postoperative heart failure after cardiac surgery.[59] Mahler and Kulik[63] assessed the effects of an educational videotape discharge intervention for partners measured over 6 months compared with control on emotional distress and preparedness for recovery. However, no significant differences were observed between groups. de Klerk *et al*[64] evaluated the use of complementary alternative medicine approach to reduce emotional distress in 25 spouses of CABG surgery patients. Four 1 hour sessions (one preoperatively) with ego strengthening hypnosis did not reduce depression at 6-week follow-up, however, spouses in the intervention group showed significantly reduced psychological morbidity levels compared with control.

Quality appraisal

The overall methodological quality of the included studies was moderate (table 1). The findings were reasonably consistent within and across studies; however, there were moderate to substantial concerns about relevance (ie, partial relevance due to a homogenous sample from North America or Western Europe). For the qualitative studies, risk of bias was primarily related to lack of a statement locating the researcher culturally/theoretically (n=11, 85%), and the lack of clarity regarding the researcher's influence on the research (n=12, 92%) studies. The risk of bias for the cross-sectional studies was related to unclear or missing identification of confounding factors (n=7, 70%), and unclear descriptions of inclusion criteria/study participants (n=2, 20%). The overall quality of the cohort studies was poor, with a high risk of bias related to missing identification of the confounding factors (n=7, 64%), and incomplete follow-up (n=5, 45%). There were substantial concerns related to the methodological quality of the intervention studies. All intervention studies reported randomisation, however, the methods of randomisation were unclear (n=5, 71%) and there was lack of blinding (n=7, 100%). The overall risk of bias of the included studies is displayed in detail in online supplementary table S3.

DISCUSSION

The aim of this integrated review was to identify informal caregiver experiences following cardiac surgery. Forty-three studies met the inclusion criteria, and the results were summarised according to the methodological considerations of Whittemore and Knafl.[20]

The burden of cardiac surgery caregiving has been described since the early 1990s,[18 33 51] however, only a limited number of studies to date have assessed the effectiveness of interventions to lighten caregivers' burden. Our results indicate that caregivers want to take care of their cardiac surgery partners when they are discharged from hospital, however, they feel insecure and overwhelmed, and they lack clear and concise discharge information and follow-up support during recovery.[3 21–30]

A consistent theme across the included studies was the amount of work and challenges associated with caregiving, and the lack of preparedness, which contributed to physical, mental and emotional stress for both care recipients and caregivers.[17 65] The review findings are complementary to other research on caregiver strains across different populations.[66] Among families, there is often an expectation that those living in the same household should help each other more than those living outside it. However, the caregiver responsibility can make the care recipients feel like a burden,[21 23 28 67] and caregivers often have higher rates of elevated blood pressures, anxiety, depression and emotional distress compared with the normal population.[66] In a multicohort study (N ≈50 000),[68] providing care more than 20 hours weekly was associated with a higher risk of cardiovascular disease compared with those providing care 1–8 hours weekly (HR=2.63, 95% CI 1.20 to 5.76).

Efforts in other jurisdictions indicate that tailored education and support from healthcare providers that engage caregivers are associated with improved postdischarge recovery for the surgical patient.[14] However, there are no clear guidance or recommendations to improve the situation for caregivers after the discharge of cardiac surgery patients. Interestingly, only seven intervention studies were identified in this review. Two studies[60 61] reported that emotional support and self-management information were found to be effective in reducing caregiver anxiety compared with control up to 3 weeks and 6 weeks, respectively. The lack of intervention studies for caregivers may indicate the individualised approach to self-management support of cardiovascular disease patients, which has not included much attention to caregivers, over the last decade.[69] However, there is no doubt that informal caregivers contribute to maintain health and well-being by supporting and helping CABG surgery patients to self-manage and engage in health promotion behaviours.[70] A meta-synthesis including 27 studies (N≈500, 56% men), reported that caregivers played a significant role in recovery and promoted lifestyle changes by joining patients in exercise regimes, assisting with dietary changes, and providing motivation and encouragement. Conversely, overprotective family members can lead to frustration and tension within the family. Occasionally, lack of family support related to lifestyle changes was also associated with frustration and reduced adherence to behavioural changes.[28 31 70] Communication deficiency concerning emotions between couples following a cardiac event was also evident in a systematic review of 20 studies conducted between 1999 and 2009.[71] Most couples experienced great distress including sexual concerns following the cardiac event, however, they also reported that the disease had brought them closer together.[22 31 71]

Generally, women are more involved in caregiving than men,[66] and 84% of the caregivers across the included studies were female spouses. The higher caregiver burden among women can generate health differences both intrasex and between women and men.[16] Accordingly, Petrini *et al*[16] reported larger sex differences in depression and physical health among caregivers as compared with the general adult population. In particular, higher levels of stressors and lower levels of social resources, among women versus men, accounted for elevated sex differences.

Living with a spouse is associated with improved short and long-term outcomes after cardiac events.[72] Recently published data, obtained from a population-based register study,[73] reported that median life expectancy was 4.8 years shorter for unmarried women aged 60 years at the surgery with low income and low education, compared with married women with high income and higher education level. Similarly, regardless of age, single living and/or being unmarried increases the risk of having a heart attack and worsens its prognosis both in men and women in a study based

on the Finish ACS (acute coronary syndrome) register.[74] According to a recent observational study,[75] including 429 caregivers of surgical aortic valve replacement (SAVR) and transcatheter aortic valve replacement (TAVR) patients, results indicated that SAVR caregivers experienced the process mentally more stressful (level ≥much: 51% vs 30%, p<0.001), and time-to-recover was longer for SAVR caregivers as compared with TAVR caregivers (>3 months: 39% vs 28% for SAVR and TAVR relatives, respectively; p=0.026). These results suggest that cardiac surgery is associated with more emotional distress and a higher caregiver burden compared with less invasive procedures. Optimising communication between healthcare personnel and caregivers by offering enhanced treatment and self-management information could be in important approach to enhance transitions from hospital to home.[11]

According to the work by Rayan and Sawin,[76] self-management outcomes improve when the healthcare provider simultaneously maintain a focus on the individual while taking into account the family, friendship network and community relationships. Ryan and Sawin's[76] individual and family self-management theory, proposes that self-management is a dynamic interaction between factors related to the context (ie, risk and protective factors), the process (ie, knowledge and beliefs, self-regulation skills and abilities, and social facilitation), and outcomes. Despite the focus on self-management for CVD (cardiovascular disease) patients, according to a systematic review[77] and a meta-summary[78] reviewing 92 studies including approximately 14 000 participants, the physiological and social environment context was only briefly mentioned in three out of 57 RCTs, and in seven out of 35 qualitative studies, focusing on self-management of cardiac pain in women. The importance of including resources related to the care recipients context to support caregivers are also supported in a recent systematic review of 44 studies representing 17 different countries,[79] suggesting the need for developing easy and comprehensive access to information, support services, and adequate financial compensations for caregivers in outpatient care.

In a cross-sectional study (n=506),[80] preparedness for caregiving at home was positively associated with collaboration with nurses, living with the partner, higher level of education, and caregivers' health status. Preparedness was inversely associated with caregivers older age, not having paid work, and not having a professional background in healthcare. Involving caregivers in cardiac surgery care, including discharge planning, is presumed to be beneficial for the patients. However, in a cross-sectional study[69] including 425 cardiac nurses, only 35% of nurse indicated that they would invite a family for discussion at the start of the care period, 32% at the end of the care period, and 19% would invite family when planning care. Accordingly, considering family as a burden to practice was more common among nurses with lower educational levels and younger age. Nurses having their main practice role in clinical practice were more likely to have negative attitudes towards family involvement in cardiovascular patient care.[69] This confirms the need for a greater focus on education on the importance of family engagement and collaboration for healthcare personnel. A recent topical review,[14] introduced and elucidated important key steps to a successful surgical discharge, emphasising patient and caregiver collaboration, communication and teamwork, goal-setting, coordination, and education.[14] Providing enhanced information may lead to higher satisfaction and knowledge about post-surgery self-management strategies.

Findings of this review also suggest positive effects of informal caregiving. Task shifting can be liberating; patients and informal caregivers have to think differently and change perception regarding tasks that have been ascribed to men or women (eg, household chores, lawn maintenance).[67] Kepic *et al*[66] suggests that caregiving is associated with positive attributes such as feeling appreciated, needed, useful and confident, as well as having the opportunity to learn new skills. Given some positive outcomes, efforts should be made to support educational strategies that focus on trust, mutual understanding, social support and self-efficacy that foster positive expectations about the recovery processes for both caregivers and patients/care recipients. However, our review highlights the lack of effective interventions currently available for use by healthcare personnel to support caregivers after cardiac surgery. Most evidence identified relates to short-term outcomes, and further research is needed to evaluate longer-term outcomes related to health, resources and organisation of care.

Limitations

Our results indicate that studies on caregivers have small sample sizes, a diversity of measure times and outcomes, and interventions tested were without significant impact on caregiver burden. Moreover, no study included collaboration with caregivers in setting research priorities or developing caregiver interventions. There are only a few validated tools to assess cardiac surgery patient caregiver experiences. The methodological quality was moderate across the included studies; however, the risk of bias was high, particularly for the intervention studies. Most study samples included female Caucasian caregivers (ie, spouses), and the majority of studies were conducted in North America or Europe, which limits the relevance of results for other caregiver groups. The review findings were consistent and coherent across study design and year of publication. The search strategy was extensive, and it is highly likely[81] that the review finding is a reasonable representation of cardiac surgery caregiver experiences over the last decades.

CONCLUSION

Informal caregivers lack clear and concise discharge information and follow-up support. Although there exists considerable knowledge of caregivers' experiences after cardiac surgery, only a limited number of studies to date assessed the effectiveness of caregiver interventions.

Review findings indicate that various opportunities exists that could prevent or minimise the occurrence of the caregiver burden, such as tailored interventions providing emotional support, self-management education, and optimising communication and collaboration between healthcare personnel, patients and caregivers; however, more research is needed on the application of this knowledge in clinical setting.

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Contributors AKB formulated the research question. AKB devised the search strategy in consultation with an experienced health science librarian and IL at Oslo University Hospital, Norway. AKB conducted the searches. AKB and IL screened all titles, abstracts and full-text articles. AKB extracted the data in consultation with IL. AKB and IL co-wrote the manuscript. PM, MP, SH and TT critically reviewed the manuscript and made revisions prior to submission.

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