

Annotated Bibliography on Patient Support Networks

Every Heartbeat Matters 2019 Partner Summit

Introduction

Purpose and Scope

The Edwards Lifesciences Foundation commissioned this literature search to review current information on the effect of patient participation in peer support groups on their recovery from treatment for heart valve disease (HVD) and other diseases and the differences in available support and its effectiveness in developed and developing countries. Although not exhaustive, this review is intended to inform our understanding of the current landscape and key knowledge gaps regarding peer support groups.

Search Methods

A PubMed search for “peer support” AND “heart valve disease” OR “heart disease” OR “valve disease” produced no results. Therefore, a broader search using the terms “surgery” AND “peer support” OR “peer support program” OR “peer support group” OR “patient support group” OR “support group” that returned 409 results was used. The results were narrowed by manually reviewing titles and abstracts for relevance. Results that were not in English, that did not have an abstract, or that were not generally applicable to surgical patients were excluded. The articles with the greatest relevance for the research questions were included and summarized in this report. The systematic search was supplemented with a manual review of papers referencing or being cited by the identified publications.

Document Structure

This annotated bibliography is arranged by research theme beginning with heart disease and critical care. We identified seven (7) articles describing peer support programs in heart disease and critical care, seven (7) articles in various types of cancer, three (3) articles about support for burn patients, and two (2) articles for other surgical conditions. Keywords are provided for each article, along with a brief description. A complete bibliography is appended.

Next Steps and Potential Future Directions

We developed a summary presentation of the findings of this literature search and emergent knowledge gaps, discussion questions, and key opinion leaders. Future work could include a more comprehensive literature search, development of a summary paper to discuss the findings, and a systematic gap analysis to identify additional research needed. This literature review and any subsequent efforts can inform approaches to providing peer support for patients undergoing treatment for HVD.

Annotated Bibliography

Heart Disease and Critical Care (7 Articles)

1. **Heart Failure Readmission Rates Lower for Hospitals with Visiting Programs.**(Mended Hearts 2015a, 2015b)

Keywords: health outcomes

These two online documents, a press release and a fact sheet, report on a 2015 analysis of Centers for Medicare & Medicaid Services data by Mended Hearts and the American College of Cardiology. The analysis found that readmission rates for heart failure were lower at hospitals with Mended Hearts visiting programs, compared with the U.S. average or hospitals without such programs. This analysis was the first of a three-phase project assessing the value of peer support. The second phase involved a survey to understand patients' perceptions about their experiences with Mended Hearts volunteers at the health care facility. The third surveyed patients about 6 weeks after discharge to explore their sense of wellness, their attitudes about their health, their impressions of Mended Hearts, and readmission rates. At approximately 6 months, three out of four patients felt they were in good or excellent health, and fewer than one in five had been readmitted to the hospital.

2. **Reducing barriers to medication access and adherence for ACA and Medicaid Participants: a peer-to-peer, community-based approach.**(Baer and Baker 2017)

Keywords: hospital ranking, patient satisfaction

In this 2016 review promoting the value of peer-support programs in facilitating treatment adherence, Baer and Baker include two case studies involving Mended Hearts peer support for cardiac patients. At Memorial Regional Hospital in Hollywood, Florida, patients are required to attend a pre-discharge class in which a pharmacist, nutritionist, and cardiac rehabilitation specialist discuss important aspects of patients' recovery plans. Mended Hearts peer supporters talk with patients about topics such as depression, positive thinking, and the importance of treatment adherence and self care. Following discharge, the peer supporters follow up with patients, provide one-on-one support, and invite them to community events to keep them involved. This program has contributed to Memorial Regional Hospital's high rankings in all aspects of patient satisfaction. Similarly, CaroMont Regional Medical Center in Gastonia, North Carolina, works with and provides in-kind support to Mended Hearts to provide a foster peer-support network among its cardiac patients. Like Memorial Regional Hospital, CaroMont is ranked "above average" in survival and patient services.

3. **Peer support. An under-recognized resource in cardiac recovery.**(Colella and King 2004)

Keywords: CABG surgery, review

This 2004 literature review focused on social support, peer support, surgery recovery, and transitions in cardiac recovery. It highlighted three studies investigating peer-support interventions. The first was a dyadic social support program in which peer-support volunteers visited patients or their families in the hospital before, during, and after surgery. The study reported that peer support improved patients' readiness for surgery and their

motivation for cardiac rehabilitation. The second was a doctoral dissertation project exploring the effects of peer support on adherence. This project found that monthly calls from a cardiac peer over 6 months significantly increased adherence to stress modification, whereas the control group showed decreased adherence to diet, exercise, and smoking reduction. The third study, by Parent and Fortin, is summarized in this bibliography.(Parent and Fortin 2000) The authors of this literature review concluded that peer support can provide patients undergoing coronary artery bypass graft (CABG) surgery with important resources upon hospital discharge and have an impact on patient and caregiver outcomes. They also noted benefits and challenges for peer supporters, as well as challenges in conducting RCTs of peer-support interventions.

4. The effect of a peer support intervention on early recovery outcomes in men recovering from coronary bypass surgery: a randomized controlled trial.(Colella and King-Shier 2018)

Keywords: CABG surgery, RCT

This study randomized 185 men undergoing CABG surgery to a peer-support intervention (n=61) or usual care (n=124) in Ontario, Canada. To the extent possible, peers were matched with patients based on age and cultural background. Peers initially contacted patients by phone within 3 to 4 weeks following hospital discharge, then contacted them weekly for 6 weeks. Outcomes data were collected by phone at 6- and 12-weeks post-discharge. Peer volunteers received 6 hours of training to develop skills for telephone support and a training manual that included activity logs, information about recovery norms, and algorithms for referral to a nurse practitioner. No peer volunteer was paired with more than two patients. The study found no significant differences between the control group and intervention group with respect to post-surgical depression. However, it did find that patients in the control group had used significantly more health services by 12 weeks, compared with the intervention group. The authors noted the need to develop additional interventions to facilitate postoperative recovery following CABG.

5. Cardiac Home Education and Support Trial (CHEST): a pilot study.(Parry et al. 2009)

Keywords: CABG surgery, RCT, pilot study

This pilot study explored the feasibility of home-based peer support provided by telephone to 101 men and women who had had first-time, non-emergency CABG and were ready for discharge from the hospital. The pilot study was conducted in Toronto, Ontario, Canada. Patients were randomized to usual care or the peer-support group. Both groups received preoperative and postoperative education and visits from in-hospital peer volunteers. The peer-support group also received phone calls from peer volunteers for 8 weeks after discharge from the hospital. Peer volunteers received 4 hours of training on the content materials for usual care, skills for effective telephone support, and when to facilitate referrals to health professionals. Although this pilot study focused on feasibility, exploratory outcomes included health-related quality of life (QOL), pain, pain-related interference with activities, and enrollment in cardiac rehabilitation. Exploratory data were collected at 9 weeks by a research associate who was blinded to group allocation. Study results indicated that a home-based peer-support program delivered by phone was feasible, might improve recovery, and might enhance health-related QOL among patients in the first weeks

following CABG surgery. The authors called for a larger, adequately powered trial to assess the effect of such an intervention on post-CABG recovery.

6. Peer support in critical care: a systematic review.(Haines et al. 2018)

Keywords: critical illness, heart valve disease, acute myocardial infarction, systematic review

The authors reviewed eight full-text articles, most of which described studies that had been conducted in the United States or Canada. The authors noted a high risk for bias in most studies; only one of the studies was an RCT. All of the studies provided formal peer support facilitated by a professional, and almost all delivered peer support in the hospital during the acute crisis period. The review found mixed results with respect to the benefits of peer support following critical illness. However, two studies using a “buddy” peer-to-peer model that began in the hospital and extended beyond discharge found that peer support reduced anxiety and depression and increased self-efficacy and perceived social support. Two of the studies included in this review are relevant to heart valve disease. One, by Parent and Fortin, is summarized in this bibliography (Parent and Fortin 2000). The other, a 1993 prospective cohort study conducted in Sweden, reported that male patients who had experienced acute myocardial infarction increased their social networks if they participated in group-based peer support.(Fridlund, Stener-Bengtsson, and Wännman 1993) Overall, the authors called for “rigorous methodological design and reporting to advance the state of the science” in peer-support research.

7. A randomized, controlled trial of vicarious experience through peer support for male first-time cardiac surgery patients: impact on anxiety, self-efficacy expectation, and self-reported activity.(Parent and Fortin 2000)

Keywords: CABG surgery, RCT

This study randomized 56 male patients, aged 40 to 69 years who were preparing for CABG at the Montreal Heart Institute, to experimental (n=27) or control (n=29) groups. Both groups received information from health professionals on surgery and recovery. The experimental group received three one-on-one visits from peer-support volunteers at 24 hours before surgery, the fifth postoperative day, and 4 weeks after surgery. Peer-support volunteers were former male CABG patients in the same age group. The volunteers, who were selected based on their enthusiasm, ability to stimulate motivation, and willingness to share their stories of successful rehabilitation, underwent 6 hours of training on interaction principles and participated in role plays and practice sessions. The study reported that peer support reduces anxiety, improves self-efficacy expectation, and accelerates recovery. It also noted that anxiety at baseline was higher among the experimental group. The authors suggested replication of the study with physiological and psychological outcome variables, rather than self-report alone, as a way to overcome the limitations associated with an inability to provide double-blind conditions.

Cancer (7 Articles)

8. ProsCan for Couples: A feasibility study for evaluating peer support within a controlled research design.(Chambers et al. 2013)

Keywords: psychological recovery, social recovery, prostate cancer

This 2013 paper reported on the feasibility of a peer intervention protocol for couples in which the male partner was preparing for prostate cancer surgery. It became the first in a series of three publications, and the other two are described below. Ten prostate cancer survivors who had undergone a prostatectomy at least 12 months prior were recruited as Peer Support Volunteers and received 12 hours of multimodal training. A multi-user, web-based data management system allowed the project manager to monitor session delivery. Twenty heterosexual couples in which the man had been diagnosed with localized prostate cancer and planned to undergo radical prostatectomy received the intervention. Peer Support Volunteers called the couples twice before surgery and at scheduled times after surgery. The study found that evaluating peer support within a structured research design was feasible. It also reported that psychological distress declined among patients and their partners over time, but that unmet sexual needs increased. The authors noted the single-arm study design and referred to a larger, randomized, controlled trial (RCT) of peer-support among men undergoing prostatectomy.

9. A randomised controlled trial of a couples-based sexuality intervention for men with localised prostate cancer and their female partners. (Chambers et al. 2015)

Keywords: prostate cancer, psychological recovery, social recovery, RCT

Following the 2013 feasibility study described above, Chambers et al. conducted an RCT in Queensland, Australia, in 2015 to compare the effects of peer telephone support, nurse telephone support, and usual care (standard medical treatment and patient education materials) on sexual and psychosocial adjustment among couples after radical prostatectomy. The study randomized 189 heterosexual couples in which the man was preparing for prostatectomy or had undergone such surgery within the past 12 months. Peer Support Volunteers, selected from prostate cancer survivors who had undergone treatment more than 12 months before the study, received 12 hours of training on communication skills, adjustment to cancer, managing treatment effects, sexuality, and research procedures. Couples received two telephone calls from Peer Support Volunteers prior to surgery, then four biweekly calls after surgery, and two calls between 16 and 22 weeks later. Men who enrolled after they had had surgery received four biweekly calls from Peer Support Volunteers followed by two calls between 16 and 22 weeks after recruitment. The study found that use of medications for erectile dysfunction was higher in the peer- and nurse-support groups and that patients in the nurse-support group were more likely to use oral medications. However, there were no differences among groups in sexual adjustment or intimacy. Patients in the peer-support group noted shared personal experience, having a male support person, unique and practical coping advice, and empathy and concern as benefits of the intervention.

10. Five-year outcomes from a randomised controlled trial of a couples-based intervention for men with localised prostate cancer.(Chambers et al. 2019)

Keywords: prostate cancer, psychological recovery, social recovery, RCT

This 2019 paper is the third in the series, and it reports on an extension of the 2015 RCT conducted in Queensland, Australia. Of the 189 couples in the initial trial, 107 patients and

91 partners completed a 5-year assessment. At 5-years following surgery, men in the usual care group had greater sexual self-confidence and fewer sexual supportive care needs than those in the peer-support group. Men in the nurse-support group had higher masculine self-esteem than men in the peer-support group at 2 and 5 years after surgery. Among partners, the women in the peer-support group had greater sexual function and satisfaction than those in the nurse-support or usual-care group at 2 and 3 years after surgery. Women in the usual-care group had greater marital satisfaction and feelings of intimacy than those in the peer- or nurse-support groups. However, patients in the peer- or nurse-support group used treatments for erectile dysfunction more often than those in the usual-care group did. The peer-support and nurse-support groups did not differ in the use of these treatments at 2 to 5 years after surgery. The authors concluded that a blend of peer- and nurse-support can help couples cope with the psychosexual challenges following radical prostatectomy.

11. Perioperative educational interventions and contemporary sexual function outcomes of radical prostatectomy.(Faris, Montague, and Gill 2019)

Keywords: prostate cancer, psychological recovery, social recovery

This review of educational interventions for men undergoing radical prostatectomy discussed a 2004 randomized trial in which long-term survivors of prostate cancer provided one-on-one peer support. The peer-support group showed less depression, compared with the control group, during the first 4 weeks of the program, but this difference had disappeared by the completion of the study at week 8. However, patients in the peer-support group were bothered less by sexual problems, despite no differences between groups in sexual function. The review also noted a 2003 study in which patients who attended lectures and received supplemental peer discussions were bothered less by sexual problems, compared with those who had attended lectures alone or received usual care. Both intervention groups also reported improved physical activity and greater employment stability after 1 year.

12. Peer support interventions for breast cancer patients: a systematic review.(J. Hu et al. 2019)

Keywords: breast cancer, review, non-surgery

This review focused on 15 RCTs identified from English- and Chinese-language databases. A total of 1,695 patients was included in the review. The authors identified five types of peer roles: peer supporter, peer educator, peer counselor, peer facilitator, and peer case manager. They also identified six models: one-on-one face-to-face, one-on-one telephone, one-on-one internet, group face-to-face, group telephone, and group internet. Depression, QOL, emotional distress, self-efficacy, knowledge about breast cancer, and use of support services were the most common outcomes measured. As with other reviews of peer-support interventions, this one found mixed results. Interestingly, it specified that, on the basis of the evidence, internet-based group models in which peers have not received training are ineffective and even harmful to patients with breast cancer. Because of limited evidence and heterogeneity of interventions, the review made no firm recommendation in favor of peer support, and it called for more research with “rigorous methodological design and reporting.” The review did not specifically discuss surgical outcomes.

13. Belonging to a peer support group enhance [sic] the quality of life and adherence rate in patients affected by breast cancer: a non-randomized controlled clinical trial.(Tehrani et al. 2011)

Keywords: breast cancer, QOL, controlled clinical data, developing country

This study assessed the effects of a peer-support intervention on the QOL among 61 women with breast cancer in Isfahan, Iran. Four women were chosen as group leaders and given eight training sessions on coping with stress and worries, gaining self-awareness, and mindfulness. Peer support groups met twice monthly for 1.5 to 2 hours each, for a total of six session during the intervention. The control group participated in six educational sessions on breast cancer, its treatment and complications, and appropriate nutrition, among other topics. QOL was assessed by the Persian-language translation of the Short Form 36. Both groups showed statistically significant improvements in body pain, role limitation due to physical problems, role limitation due to emotional problems, and social functioning following the intervention. However, those in the peer-support group scored significantly higher on vitality and mental health. Study participants had stage II or III breast cancer and had had a mastectomy at least 6 months before. However, the study did not address surgical recovery.

14. Adjusting to life after esophagectomy: the experience of survivors and carers.(McCorry et al. 2009)

Keywords: esophageal cancer, esophagectomy, psychosocial recovery

This qualitative study involved focus groups of 12 esophageal cancer survivors and 10 caregivers recruited from the Oesophageal Patients' Association in Northern Ireland. Separate focus groups were held for survivors and caregivers. Among the three major themes arising from focus group discussions was the value of peer support, both for the survivor and the caregiver. Both survivors and caregivers reported that peer support normalized their experiences, provided "opportunities for upward social comparison," and generated hope. The authors note that peers "have the unique ability to describe and empathize about the sensory, physical, social, and emotional consequences of surgery, helping to aid post-operative recovery and well-being." However, the study also noted that most survivors did not interact with other survivors until they had contacted the support group, typically following recovery from surgery.

Burns (3 Articles)

15. Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi.(Barnett et al. 2017)

Keywords: burns, psychological recovery, social recovery, developing countries

Burns are common in sub-Saharan Africa, and psychological distress following a burn injury is associated with longer hospitalizations and delayed recovery. Despite advances in surgical and resuscitative techniques, however, few efforts have aimed to help patients with the psychological effects of burns. This paper reports on the establishment of a support group by trauma surgeons, a psychiatry resident, and a Malawian counselor at the Kamuzu Central Hospital in Lilongwe, Malawi. The support group allowed patients and caregivers to discuss

emotions and challenges. Discussions were held in the primary language of the region. The counselor began each session by introducing a discussion topic, speaking about it for a few minutes, then opening the session to unstructured, general discussion. The paper reported the themes of caregiver and patient concerns. Group members noted increased comfort in talking about their injuries and the value of social support. However, the paper did not explore the impact on hospital stay and recovery from injury. In addition, the group could not continue past the study period because of funding constraints.

16. Long-term social reintegration outcomes for burn survivors with and without peer support attendance: a Life Impact Burn Recovery Evaluation (LIBRE) study.(Grieve et al. 2017)

Keywords: burns, psychological recovery, social recovery

This secondary analysis of a cross-sectional study used the LIBRE instrument to explore associations between peer-group attendance and societal reintegration among burn survivors. Study participants completed the 192-item LIBRE instrument, which included two questions in its screening module concerning peer support. Of 601 burn survivors, 330 reported participating in peer support. Attendance to peer-support programs was associated with higher scores on the social interactions scale, particularly with respect to making friends, dressing to avoid stares, and attending community events. Future research questions suggested by the authors included when it is optimal to engage survivors in peer support, whether the impact of peer support differs based on the type of support, and how to refer burn survivors to peer support.

17. Inpatient peer support for adult burn survivors—a valuable resource: a phenomenological analysis of the Australian experience.(Kornhaber et al. 2015)

Keywords: burns, psychological recovery, qualitative research

This qualitative study interviewed 21 severe-burn survivors (20 men, 1 woman) from burn units across Australia. Phenomenological analysis of the survivors' "lived experience" identified the following five themes: (a) Encouragement, Inspiration, and Hope—the interaction between a burn survivor and a new patient was seen as a significant moment that motivated the patient's commitment to rehabilitation; (b) Reassurance—contact with burn survivors often provided patients with the comfort of knowing they were not alone in their recovery; (c) Timing—peer-support initiatives must consider the timing at which a patient might be most receptive to peer support; (d) Credibility—the shared experience between patient and survivor; and (e) Appropriate Matching—matching peer supporters and patients with substantial differences in burn severity could be harmful to the supporter or patient. In their discussion, the authors emphasized the need to consider the appropriateness of the supporter-patient match, the patient's readiness to receive peer support, and the physical and psychosocial status of the peer supporter.

Renal Transplant and Otolaryngology (2 Articles)

18. The effects of an empowerment intervention on renal transplant recipients: a randomized controlled trial.(Hsiao et al. 2016)

Keywords: renal transplant, RCT, empowerment, self care

This RCT randomized 130 renal transplant patients in southern Taiwan to an empowerment support group intervention or a comparison group; 122 (56 in the empowerment group, 66 in the comparison group) completed the pretest, intervention, and posttest. The empowerment group was defined as “a group of patients who have the same disease or similar health conditions.” The comparison group was not defined. The empowerment intervention comprised six biweekly 2-hour sessions. The first four sessions were led by professional staff; the last two were led by patients. Participation in the empowerment group significantly increased empowerment and self-care behaviors (defined as following the directions of their physicians or nurses), compared with the comparison group. The improvement in self-care was particularly marked among older participants, who tended to start with lower scores on the self-care pretest. The authors reported that participants in the empowerment group “gained strength from each other when they realized they shared a common experience” and “had opportunities to ... and increase their ability to care for themselves by learning from other participants.”

19. Reflections: the value of patient support groups.(A. Hu 2017)

Keywords: otolaryngology, review/commentary, no surgical references

This commentary focused on otolaryngology patients, including those with head and neck cancer, and did not discuss surgical outcomes. It noted that two otolaryngology studies reported that participation in support groups improved psychiatric morbidity, social and emotional functioning, and QOL. However, the commentary also noted another study that found that participation in support groups did not improve QOL. Despite the potential benefits of patient support groups, the commentary pointed out, participation in these groups is low. Lack of awareness, lack of time, and “confrontation with negative aspects of the condition” were cited as barriers.

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