Measures of Patient Activation and Social Support in a Peer-Led Support Network for Women With Cardiovascular Disease

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■ **PURPOSE:** Social support has been associated with beneficial effects on many disease states and overall health and well-being. However, there is limited research exploring the impact of peer-led support models among women living with coronary heart disease. This study describes the structure of peer-led support groups offered by WomenHeart (WH): The National Coalition for Women Living with Heart Disease, and assesses WH participants' quality of life and social, emotional, and physical health.

■ **METHODS:** Participants were recruited from 50 WH groups. A 70-item online survey was administered, and the main analytic sample included 157 women. Multivariate logistic regression was used to examine the association between patient activation levels (lower activation levels: 1, 2 vs higher activation levels: 3, 4) and social support scores (range: lowest 8 to highest 34), adjusting for age.

■ **RESULTS:** High levels of social support, patient activation, physical activity, and low levels of stress, anxiety, and depression were reported. Those who were at or above the median for the social support measures (indicating high levels of social support) had greater odds of high levels of patient activation (level 3 or 4) than individuals reporting low levels of social support (OR = 2.23; 95% CI, 1.04-4.76; P = .012).

■ **CONCLUSIONS:** Women who regularly attended a support group by a trained peer leader were highly engaged in their health care and had low levels of stress, anxiety, and depression. These findings lend credibility to the value of the peer support model and could potentially be replicated in other disease states to enhance patient care.

Social support has been recognized as having a strong impact on health and well-being and has also been shown to have protective effects in a wide variety of disease states including cancer, depression, and coronary heart disease (CHD), specifically post–myocardial infarction.[1-4] Social support has also been linked to improved functional recovery following a stroke.[5] Conversely, low perceived social support has been associated with increased mortality and morbidity in CHD populations.[6-10]

Social support can be garnered from family, friends, or peers. Peer support may include emotional, appraisal, or informational support. Emotional support refers to active listening, reflection, reassurance, and encouragement.[11] Appraisal or informational support conveys information that pertains to self-evaluation

and provides feedback on behaviors and emotions. Informational support provides the relevant knowledge needed to assist with problem solving.[11] The enhanced support structure (ie, face-to-face meetings, shared experience of a disease or condition) of peer support may improve disease self-management, such as goal setting around self-care behaviors, and increased self-efficacy.[12] Peer support can be offered in a variety of settings such as self-help groups, one-on-one sessions, or online support groups.[13,14]

Peer social support can augment the care offered in traditional health care settings by creating a personalized support structure to impact individuals where the bulk of disease management occurs—outside of the clinical environment. While there have been numerous studies exploring the effectiveness of peer-led support in populations of individuals living with diabetes,[13] there has been a limited amount of research investigating the value and impact of peer-led support models among women living with CHD.[15]

This study seeks to address this gap. First, we describe the peer-led group model of WomenHeart: The National Coalition for Women Living with Heart Disease (WH), including the selection, training, and continuing education of its peer leaders. Second, we present the baseline findings from a research study exploring the impact of a peer-led social support model among those who attend support groups sponsored by WH.

METHODS

Design

This work represents findings of a research study that used a quasi-experimental method to assess the quality of life, social support, and emotional and physical health of WH support group members. All study methods and procedures received institutional review board approval.

Setting

WH offers the nation's only peer-led support network for women living with heart disease. Each support network is led by a trained WH Support Network Coordinator who is a woman living with heart disease. WH Support Networks meet monthly and provide women with heart health educational information with an emphasis on secondary prevention. They also offer personal support as women face their journey living with various types of heart disease. WH Support Networks are generally affiliated with a hospital, clinic, cardiac rehabilitation program, community center, library, or faith-based organization.

WH recruits women living with heart disease across the country to apply for their National Science and Leadership program. Women are recruited using various marketing techniques including traditional media (press releases), social media, word of mouth through existing WH Champions, medical provider referrals, and the WH National Hospital Alliance members.

Women are selected through a competitive online application process that includes a letter of recommendation and medical clearance, submission of a résumé, and a telephone interview with WH staff. Annually, women are selected for the 60 available slots based on their volunteer and professional experience, impact of heart disease on their life, ability to tell their story, their interest in providing peer education and/or support, and provider recommendation. Applications are scored and ranked because the application process is competitive.

Because the women selected are living with heart disease, they have a strong personal connection to their work for WH. The National Science and Leadership program is an annual, 4-day symposium held at the Mayo Clinic in Rochester, MN, that educates and empowers women to become peer leaders on the science and medical aspects of cardiovascular disease. This includes training on public speaking and community outreach strategies, and the provision of tools and support for women's heart health. After completing this extensive course, the women, now known as "WomenHeart Champions," return to their communities and develop a WH Support Network at their local hospital to provide peer-to-peer support and education for other women living with or at risk for heart disease.

Nearly 700 women have completed the program to become WomenHeart Champions. Seventy-five percent of WomenHeart Champions are white, non-Latina, or Hispanic. WomenHeart Champions have been trained in 49 states—every state but Hawaii. However, not all trained WomenHeart Champions are able to function as Support Network Coordinators (SNCs); some women are no longer healthy enough to be active leaders. Currently, 37% of the women who have been trained as WomenHeart Champions over the past 13 years are leading WH Support Networks in 39 states.

WH does not systematically track leadership proficiency of its SNCs. However, SNCs are required to submit a monthly report to the national office staff and district leaders. SNCs participate in quarterly calls from district leaders and meet biannually for continuing education to ensure adherence to WH's policies and the WH Support Network model. In the rare instance

that leadership abilities are not demonstrated, SNCs are encouraged to seek guidance from district leaders. They are also able to contact national office with concerns about their ability to meet the requirements.

Support Group Meeting Format

The size of the support groups varies across the country. SNCs are encouraged to limit groups to a number that allows for story sharing and bonding among attendees. Session duration is between 60 and 90 minutes. Content and delivery of sessions vary, and SNCs have latitude in developing their meeting agendas, as WH does not have fidelity agreements. However, in recent years, WH has developed 17 patient education modules and a recommended monthly schedule for their use. Examples of the modules include condition-specific topics such as atrial fibrillation, angina, anxiety, and stress and broad content areas including healthy eating, medication adherence, weight management, and health disparities. These modules provide a standardized curriculum for use across all WH Support Networks. In addition, all WH SNCs are trained in managing group dynamics, using the patient education modules, and are given facilitator's guides with objectives, discussion topics, and scripting suggestions.

Study Sample

Participants were recruited from 50 WH Support Network sites via an e-mail to the respective SNC of the groups that were selected to participate. Selection criteria for the 50 sites included being in existence for at least 1 year with a minimum of 5 support group attendees. In addition, study investigators and WH staff made an attempt to choose groups that would represent a broad geographic sample, represent groups that meet in hospitals, as well those not affiliated with hospitals (eg, community setting), and in both urban and rural locations.

It was estimated that each participating group had an average attendance of 11 participants per group. Attendance in the WH support groups is dynamic— new participants are continuously being recruited, while others move on due to a variety of reasons related to their health and life situations. For these reasons, it is difficult to estimate the exact number of women recruited to participate in the survey.

Procedures

Prior to the study launch, research staff conducted a webinar for the SNCs whose networks were selected for inclusion in the study. The webinar provided study-related information, recruitment strategies, and an opportunity for SNCs to ask questions related to the research project. Thirty SNCs participated in this webinar.

Following the webinar, the SNCs sent a recruitment e-mail with study-related details, contact information for the principal investigator, and a direct link to a unique survey URL to attendees of their respective support group members. Research staff did not have the e-mail addresses for the members of the participating groups, nor did any of these members sign a release to be contacted by a third party.

After the recruitment e-mails were sent and the SNCs had communicated the study-related information to the support groups, research staff conducted a webinar for support network members in any of the participating groups that were interested in this research study. The webinar provided study-related details and described the steps they needed to take to participate. Ten support network members participated in this webinar (Figure 1).

Survey

A 70-item online survey was administered with a secure SSL encryption. Before taking the survey, participants were required to acknowledge that they had read the informed consent document and HIPAA
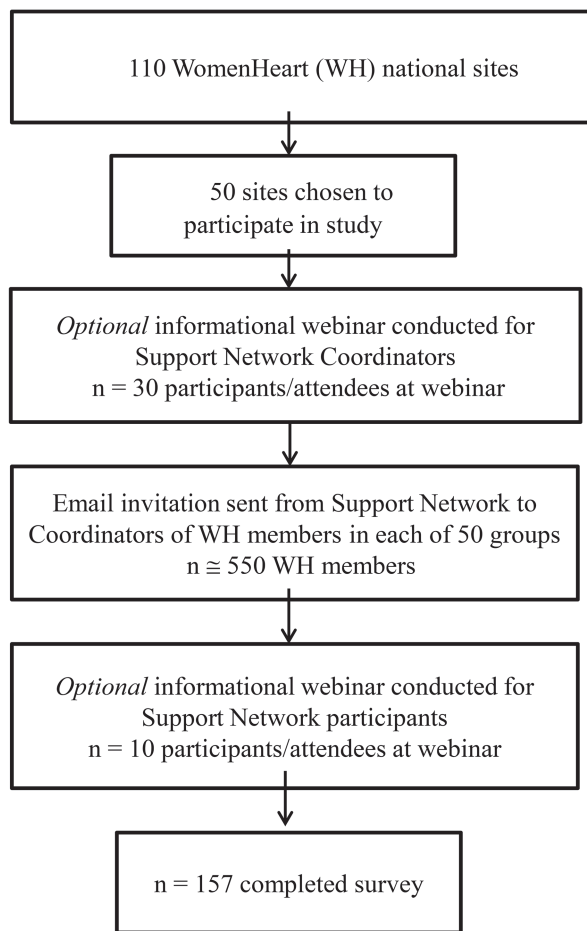

Figure 1. WomenHeart study recruitment algorithm.

authorization. The survey remained open from April 2014 through July 2014.

Measures

A 70-item online questionnaire comprising demographics and measures of social support, patient activation, stress, anxiety, and depression, physical activity, fruit and vegetable consumption, and tenure with WH was self-administered among participating support network members.

Social support

Social support was measured by the ENRICHD Social Support Inventory (ESSI). This 7-item scale measures structural, instrumental, and emotional support and has demonstrated reliability and validity.[16]

Patient activation

The 13-item Patient Activation Measure (PAM) was used to assesses the knowledge, skills, and confidence integral to managing one's own health and health care. The PAM scale is divided into 4 levels: level 1 (starting to take action) = PAM score of 47.0 or lower; level 2 (building knowledge and confidence) = PAM score of 47.1 to 55.1; level 3 (taking actions) = PAM score of 55.2 to 67.0; and level 4 (maintaining behaviors) = PAM score of 67.0 and above. The PAM has demonstrated validity and reliability.[17] A license to use PAM was obtained (Insignia Health, Portland, OR) prior to survey development.

Stress

Participants' perceptions of their stress level were measured by the Perceived Stress Scale (PSS-4). This 4-item scale has total response scores ranging from 4 to 16; the PSS-4 has firmly established validity and reliability. The PSS-4 includes 4 items that capture feelings and perceptions about the magnitude of life challenges, as well as personal stress management capabilities over the previous month.[18]

Anxiety and depression

Anxiety and depression were measured with the Patient Health Questionnaire (PHQ-4), a 4-item survey that assesses patient depressive symptoms. Items are measured on 4-point scales and summed to create a single score ranging from 0 to 12, with higher scores indicating greater depressive symptoms and a score of 10 or higher indicative of at least moderately severe depressive symptoms. This instrument is reliable and valid.[19]

Physical activity

Self-reported responses of physical activity were reported by participants utilizing the screening tool developed for the Behavioral Risk Factor Surveillance System.[20] This tool has been demonstrated to be valid and reliable. Four items indicating vigorous and moderate-intensity physical activity minutes per week were reported in moderate equivalent units; categorized as sufficient (≥150) or insufficient (<150), per national guidelines. Vigorous activity minutes were doubled to provide an estimate of moderate-intensity physical activity and added to self-reported moderate activity minutes to create a measure of total physical activity at a moderate intensity.

Fruit and vegetable consumption

Fruit and vegetable consumption was captured by a single item indicating sufficient (≥5 servings per day) or insufficient (<5 servings per day), per national guidelines.[21]

Medication adherence

Self-reported medication adherence was assessed by a 1-item question: "In a typical week, how much of the time do you take all of your medications as prescribed?" There has been no direct validity testing on this instrument.

Cardiac rehabilitation

Cardiac rehabilitation programs were assessed by the following 3 questions: (1) "Has a doctor ever recommended that you attend a cardiac rehabilitation program?"; (2) "Have you ever attended a cardiac rehabilitation program?"; and (3) "If you completed cardiac rehabilitation, how satisfied were you with the program?" Response options for "Have you ever attended a cardiac rehabilitation program?" were as follows: "No"; "Yes, I attended for part of the program"; "Yes, I attended and completed the full program"; "Not sure"; or "I choose not to answer." These questions are not associated with a validated tool.

Statistical Analysis

Total estimates are reported as means ± standard deviations for continuous variables (all continuous measures were normally distributed), or percentages for categorical measures were calculated. The PAM score was calculated on the basis of participant responses to a scale of 0 (lowest activation) to 100 (highest activation). The continuous score was converted to the ordinal 4-category variable, reflecting the 4 levels of activation (levels 1-4). The mean of the total score and the proportions of participants in each of the 4 levels are presented. The ESSI score categories ranged from 1 (none of the time) to 5 (all of the time), with item 7 (living with spouse) scored 4 for "yes" and 2 for "no."[22] Individual scores were

summed, ranging from a minimum of 8 to a maximum of 34. Description of the total score is presented as interquartile percentiles and median. In addition, participants who had a score of ≤2 on at least 2 of the 5 items[1-3,5,6] and a total score of ≤18 were grouped into the low social support category.[16]

Multivariate logistic regression was used to examine the association between PAM levels and ESSI social support scores, adjusting for age. To accomplish this, the dependent variable 4 PAM levels were collapsed into 2 groups as: levels 3 and 4 (high activation levels) with reference levels 1 and 2 (low activation levels). The independent variable ESSI score was dichotomized into a score above the median,[23] with scores at or below the median as the reference group. Analytical procedures were conducted using SPSS statistical packages version 18 (IBM, Chicago, IL).

RESULTS

A total of 157 women completed the baseline survey (Table 1). The study sample was primarily white, middle-aged, had at least some technical school or college education, was married or living with a partner, and reported a household income of more than $60 000 per year. The top conditions reported by the survey respondents were cardiovascular disease (stroke, myocardial infarction, angina, atrial fibrillation, coronary artery disease, spontaneous coronary artery dissection, or heart failure), high cholesterol, and high blood pressure. The majority of participants had attended the WH support group for ≥1 years (31.1%: 1-2 years; 43.2%: >2 years), and a high percentage (84%) reported attending the group at least once a month.

Study participants reported high levels of social support, low levels of stress, low levels of anxiety and depression, and high levels of patient activation (Table 2). Patient activation in individuals who score in the upper half (levels 3 and 4) have higher confidence to assume self-management behaviors and make lifestyle changes. Those who score in the lower half (levels 1 and 2) may understand that they have to be involved in their care but lack the basic knowledge about their condition or treatment that is necessary for them to take an active role.[17] Sixty-nine percent reported achieving at least ≥150 minutes of moderate physical activity per week. The majority had quit or never smoked, and less than half reported eating ≥5 servings of fruit and vegetables a day. Fifty-nine percent of study participants had been referred to cardiac rehabilitation and, of those, 98% attended at least 1 session, 89% completed the full

Table 1 • Participant Demographics and Tenure With WomenHeart (N = 157)[a]	
Age, y	63.0 ± 10.8
Age groups	
21-39 y	2.5
40-59 y	28.0
≥60 y	69.4
Race[b]	
White	92.4
Hispanic	4.5
Black	3.2
Asian	< 1
Native American	1.9
Other[c]	1.3
Education	
High school or GED	6.5
Technical or some college	41.3
College degree	29.0
Graduate degree	23.2
Marital status	
Single, never married	7.8
Living with partner or married	64.9
Divorced/widowed/separated	27.3
Household annual income	
< $30 000	9.0
$30 000-$59 000	31.0
≥$60 000	60.0
Reported conditions	
Diabetes	14.6
High blood pressure	47.8
Cardiovascular disease[d]	75.8
High cholesterol	56.1
Depression	20.4
Employment	
Full-time	26.1
Part-time	20.3
Retired	42.5
Other	11.1
Tenure with WomenHeart	
0-6 mo	16.2
7-11 mo	9.5
1-2 y	31.1
>2 y	43.2
Frequency of attendance at WomenHeart support group meetings	
Once per month	84.1
1-2 times per month	8.3
Every other month	1.9
Unspecified	5.7

Abbreviation: GED, general educational development.
[a]Categorical variables reported as percentages, and continuous variables reported as mean ± SD; percentages may not total 100.0% due to rounding.
[b]Participants may specify >1 race.
[c]Other, missing race or unspecified.
[d]Self-reported stroke, heart attack, angina, atrial fibrillation, coronary artery disease, spontaneous coronary artery dissection, or heart failure.

Table 2 • Distribution of Behaviors and Measures of Health-Related Quality of Life[a]

Smoking	
Current	0.0
Quit	43.7
Never smoked	56.3
Fruit and vegetables	
≥5 servings per day	37.1
Physical activity	
≥150 min/wk at moderate-intensity equivalent	68.7
PHQ-4	
Normal	61.8
Mild depression	25.5
Moderate depression	3.8
Severe depression	0.6
Undetermined	8.3
PAM-13, mean ± SD	60.8 ± 21.7
Level 1: Starting to take role	14.6
Level 2: Building knowledge and confidence	12.7
Level 3: Taking actions	38.9
Level 4: Maintaining behaviors	28.7
Undetermined	5.1
ESSI	
Total score, mean ± SD	24.7 ± 4.8
25th percentile	22
Median	25
75th percentile	28
Perceived low social support[b]	9
PSS-4	
Low (0-7)	76.4
High (8-16)	23.6

Abbreviation: ESSI, ENRICHD Social Support Inventory; PAM-13, 13-item Patient Activation Measure; PHQ-4, 4-item Patient Health Questionnaire; PSS-4, 4-item Perceived Stress Scale.
[a]Variables reported as percentages unless otherwise noted.
[b]To qualify for low social support, participants must have had a score of ≤2 on at least 2 of the 5 items[1-3,5,6] and a total score of ≤18.[16]

program, and 9% completed part of the program. The majority (89%) reported taking their medication "all of the time."

Multivariate logistic regression exploring the relationship between social support and patient activation showed that those who were at or above the median for the social support measures (indicating high levels of social support) were >2 times more likely to report high levels of patient activation (level 3 or 4) compared with individuals reporting low levels of social support (Table 3).

DISCUSSION

These findings demonstrate that this sample of WH Support Network attendees reported high levels of physical activity and low levels of anxiety, depression, and stress. This group of women also reported high levels of medication adherence and high levels of participation in cardiac rehabilitation. The rates of medication adherence in this group are higher than the average 50% medication adherence rates shown broadly across chronic disease states.[24] In addition, rates of attendance at cardiac rehabilitation are high when compared with other groups of women who are advised to attend cardiac rehabilitation.[25]

Our participants reported high levels of patient activation, indicating they have the skills, knowledge, and confidence to manage their health. Previous studies assessing patient activation have found an association between high levels of patient activation, and high levels of patient activation have been associated with improved health outcomes.[23] Only a small number of women surveyed indicated that they have low levels of social support. These high levels of activation and social support may not be representative of the general population of women living with heart disease, but it is of interest that these groups of women are doing so well. In addition, there was a strong association between levels of social support and patient activation. While we cannot assume causality, we can possibly infer that peer support may be promoting a high level of self-care behaviors and health-related quality of life due to the high levels of support demonstrated by regular or frequent attendance at support groups (84% report monthly participation).

Previous research examining the effects of peer support on the health of participants has demonstrated mixed results. An association between peer

Table 3 • Multivariate Association Between Patient Activation and Social Support

Enhancing Recovery in CHD	OR (CI)	P Value
At or below median (≤25)	Reference	
Above median (>25)	2.23 (1.04-4.76)	.012

Abbreviation: CHD, coronary heart disease.

support interventions and a reduction in symptoms of depression was found by Pfeiffer and colleagues.[26] Lucksted et al[27] found that peer support may have lasting benefits for caregivers and family, as it relates to managing stress associated with caregiver burden in a randomized controlled trial of family members of adults with mental illnesses. While some studies have demonstrated few or unclear benefits from peer support groups beyond usual care,[13,28,29] others have demonstrated that social support impacts sustained behavior change in populations with diabetes, cancer, HIV-AIDS, and mental illness.[12,15,30] In a 6-week community-based diabetes self-management program, Lorig and colleagues[14] found that those in the intervention group (a peer-led diabetes self-management program) had significant increases in self-efficacy, patient activation, and other outcome measures of interest when compared with those receiving usual care.

Limitations

Our study population self-selected to participate in this study and may be prone to healthy volunteer response bias, as this sample of women participating in the WH Support Network may be more engaged in their health care and healthy behaviors. Our study sample also comprises those who had been members of the support group, the majority of which reported a tenure of ≥1 year. This prolonged membership may also bias our findings, as this may also indicate a healthy volunteer bias. In addition, our study may not be generalizable to the general public, due to a lack of racial/ethnic and socioeconomic status diversity. The implementation of this study was also limited to those able to participate in an online study; study investigators relied on peer leaders to assist with delivery of study, and the study investigators were not able to consent participants in person, thus making it difficult to directly address any study-related questions. Self-report was utilized for measures of medication adherence and participation in cardiac rehabilitation, and limitations of self-report are acknowledged.

Practice Implications

Peer-led support groups should be a referral consideration for providers whose patients have CHD, as our findings demonstrate positive health-related outcomes as it relates to social support, patient activation, and commitment to self-care behaviors. Peer-led support groups can provide beneficial supplementary care to usual care and create a sense of community with other individuals who share similar health concerns. Providers of patients with CHD should familiarize themselves with peer support options available in their community.

CONCLUSIONS

These study results lend credibility to the belief that peer-led support groups provide a positive impact on the lives of individuals and should be considered as an enhancement to traditional clinical care. This study contributes to a broader understanding of cardiac support groups led by trained peers and will add to the description of the social, emotional, and health outcomes of peer-led cardiac support groups. The WH curriculum could serve as a valuable model to develop standards or guidelines for training and education to peer leaders for cardiovascular disease with the potential to be replicated to other disease states.

Further research is needed to develop mechanisms to make peer-led support available to all women living with heart disease. In addition, the WH support network design, and the strength of its training and continuing education of the support network coordinators, is a valuable model that holds promise for supporting, engaging, and improving the lives of women with heart disease.

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