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Problems Experienced in the First Month After Discharge From a Heart Failure-Related Hospitalization

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Purpose	Heart failure is a global health concern with high morbidity and mortality rates. Individuals with heart failure commonly experience problems that impact daily life. However, little is known regarding which problems are most significant during the immediate posthospitalization period. Thus, the purpose of this study was to identify high-priority problems experienced by individuals the first month after discharge from an acute care facility with a diagnosis of heart failure.
Methods	This descriptive, exploratory study was part of a 12-week randomized controlled pilot study that examined the efficacy of a coping partnership intervention (COPE-HF Partnership) between a trained research nurse and individuals with heart failure in managing self-care and depressive symptoms. Data from participants randomized to the intervention group (N=19; 58% Caucasian, 58% male) were used in this study. Participants were provided a list of potential heart failure-related problems, from which they identified those of highest priority. Content and quantitative data analysis was conducted.
Results	Difficulty in managing heart failure symptoms, adhering to treatment plan, completing daily activities, and experiencing negative emotions and moods were the most common problems experienced by individuals with heart failure. Other less common problems for the group were inadequate resources and managing interpersonal issues.
Conclusions	Individuals with heart failure experience complex problems in the home that impact all aspects of their lives. Incorporating strategies to address these problems could assist in the development of interventions to reduce negative heart failure outcomes. (<i>J Patient Cent Res Rev.</i> 2018;5:140-148.)
Keywords	heart failure; problems; postdischarge; hospitalization; morbidity; mortality; symptoms

Heart failure (HF) is a global public health concern, affecting approximately 5.7 million individuals in the United States¹ and 26 million worldwide.² Although mortality rates have declined, approximately 50% of individuals diagnosed with HF continue to die within 5 years of diagnosis.¹ HF remains the most common reason for hospital readmissions within 30 days of discharge,³ with direct and indirect costs exceeding \$30 billion dollars annually.¹ As the general population ages, the estimated prevalence and cost of care for HF will increase substantially.⁴

HF is stressful,⁵ and individuals with heart failure (IHF) frequently experience dyspnea, edema, fatigue, sleeplessness,^{6,7} and activity intolerance that impacts their functional ability.⁸⁻¹⁰ Up to 60% of IHF reportedly forget to take their HF medications.¹¹ IHF also manage multiple medications and comorbidities and experience ineffective communication with health providers.¹² The psychological sequelae of HF are significant, and many individuals experience depression¹³ and negative emotions and mood, such as anxiety, fear, and irritability.⁶ Unmet financial needs,¹⁴ inadequate psychosocial support,^{12,15} and social isolation⁹ further compound these problems in the home.

IHF experience complex problems in the home that impact all aspects of their lives. Yet, empirical literature regarding high-priority problems in the immediate

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posthospitalization period is limited. Thus, the purpose of this study was to identify high-priority problems experienced by IHF in the first month after discharge from an acute care facility with a diagnosis of HF.

METHODS

Design, Participants, and Setting

This descriptive, exploratory study was part of a 12-week randomized controlled pilot study that examined the efficacy of a coping partnership intervention (COPE-HF Partnership), primarily delivered over the telephone, on HF self-care and depressive symptoms.¹⁶ The COPE-HF Partnership intervention trained IHF to use social problem-solving skills to manage common high-priority problems associated with HF after discharge to home. Participants (N=19) who were assigned to the intervention group participated in this study. A detailed description of the intervention and corresponding protocol is available elsewhere.¹⁶ Information relevant to the current study is provided herein.

Participants were recruited during an acute care admission for HF from two local facilities that serve a diverse population regarding gender, ethnicity, and socioeconomic status from a 4-county, predominantly rural area. Participants were included if they were 1) undergoing treatment for HF, 2) reachable by telephone, 3) able to speak English and hear well enough to engage in phone contacts, and 4) 18 years of age or older. IHF were excluded from the study if they had 1) a diagnosis of HF due to a correctable cause or condition, 2) illnesses that were associated with a reduced life expectancy of < 12 months, or 3) a history of psychoses, dementia, or cognitive impairment.

Prior to enrollment, participants were screened for cognitive impairment using the Six-Item Cognitive Impairment Test.¹⁷ Individuals with scores 8 or higher were excluded from participation due to the possibility of cognitive impairment.¹⁷

Instruments

Sociodemographic and clinical information were collected via self-report to assess key participant characteristics (age, gender, race, etc) using a researcher-developed survey. Clinical information included the severity of HF (ie, New York Heart Association [NYHA] classification), length of time since HF diagnosis, and comorbidities (ie, Charlson

comorbidity index).¹⁸ Data related to problems experienced by individuals with HF were recorded on a data form, which specified participant identification numbers and the intervention week (that is, 1–4).

Procedure

The appropriate institutional review boards approved the study prior to recruitment. The intervention consisted of an initial 1.5-hour home visit 1 week after discharge. During this initial session, a trained nurse interventionist provided education relative to social problem-solving and instructed IHF in using these skills to manage and cope with problems and stressors. IHF learned effective skills in which to view feelings about their HF (ie, problem orientation) and to identify and solve problems using a 4-step problem-solving process.^{16,19} To provide standardization of content, IHF practiced applying problem-solving skills to the problem of fatigue during the home visit (because about 50% of IHF experience fatigue²⁰).

After practicing social problem-solving skills during the home visit, participants were provided with a set of 7 cards representing common HF problems identified from empirical literature. These problems included HF symptoms (eg, shortness of breath [SOB], fatigue), HF-related treatment regimen (eg, adhering to fluid restriction and low-salt diet, measuring weight daily, exercise participation), interpersonal and social issues (eg, lack of social support), daily activities (eg, activity intolerance, impaired sleep), mood (eg, depressive symptoms, anxiety), resource difficulties (eg, inadequate information about HF, financial problems), and other.^{13,21} The “other” card represented problems not denoted on the previous 6 cards, but were problems identified by HF participants during contacts. Participants were asked to use these cards to identify and prioritize problems that were currently most significant.

The home visit was followed by 3 weekly telephone contacts for the first month and conducted by the trained nurse interventionist. During each follow-up phone contact, IHF were asked to identify high-priority problems they were experiencing since the last contact, using the set of 7 cards. Both current and newly identified problems were examined during the phone contacts. The nurse interventionist and a trained research assistant randomly listened to phone contacts

and compared information recorded on the data form and problems identified by IHF. To ensure credibility of data, data were collected concurrently with problem prioritization on a data form during the home visit and each phone contact by the nurse interventionist and trained research assistant. Accuracy of identified problems was confirmed at the end of each contact. Further, identified problems from previous contacts (eg, week 2) were reviewed with IHF at the beginning of subsequent phone contacts (eg, week 3) before identifying any new priority problems for the current week. Conversations were not recorded, but extensive field notes were taken during the contacts by the research assistant to confirm and add understanding to problems.

Statistical Analysis

Data analysis was conducted using SPSS Statistics Version 22.0 (IBM Corporation, Armond, NY). Demographic data were analyzed using mean and standard deviation (SD), or frequency and percentage for nominal variables. Content and quantitative data analyses were used to identify problems experienced by IHF from field notes taken during interviews. These problems were independently analyzed and coded by two content experts. Differences were discussed until consensus was achieved on the final list of problems. Two other content experts randomly analyzed problems and field notes further for accuracy.

RESULTS

Mean age of participants was 61.0 years (SD: 14.5). Most were unmarried (n=13, 68.4%), Caucasian (n=11, 57.9%), male (n=11, 57.9%), and high school educated (n=13, 68.4%). Typically, 1–2 people resided in the home with the IHF (n=11, 57.9%). Most participants had a HF diagnosis for less than 1 year (n=10, 52.6%) and were NYHA class II (n=10, 52.6%). Number of comorbidities ranged from zero to 5, with 1 (n=5, 26.3%) or 2 (n=5, 26.3%) the most common (Table 1).

Problems experienced by IHF were interrelated, influencing one or more other problems identified during each contact. Field notes made during contacts provided very rich data for understanding these problems. Table 2 summarizes the frequency of the high-priority problems.

Week 1

Difficulty in managing HF symptoms (n=13) was the highest-priority problem identified by participants.

Table 1. Demographics and Descriptive Statistics (N=19)

Demographic	n (%)
Age, mean (SD)	61 years (14.5)
Gender	
Female	8 (42.1%)
Male	11 (57.9%)
Race	
African American	8 (42.1%)
Caucasian	11 (57.9%)
Marital status	
Married	6 (31.6%)
Unmarried	13 (68.4%)
Education level	
6th–9th grade	1 (5.3%)
High school graduate	13 (68.4%)
College graduate	5 (26.3%)
Number of people in house	
1–2	11 (57.9%)
3–4	7 (36.8%)
>5	1 (5.3%)
Years since HF diagnosis	
<1 year	10 (52.6%)
1–5 years	5 (26.3%)
6–10 years	1 (5.3%)
11–15 years	2 (10.5%)
>15 years	1 (5.3%)
NYHA HF class	
I	3 (15.8%)
II	10 (52.6%)
III	1 (5.3%)
IV	5 (26.3%)
Number of comorbidities*	
0	4 (21.1%)
1	5 (26.3%)
2	5 (26.3%)
3	4 (21.1%)
4	0 (0%)
5	1 (5.3%)

*Percentage is greater than 100% due to rounding.

HF, heart failure; NYHA, New York Heart Association; SD, standard deviation.

HF symptoms, such as fatigue, activity intolerance, tiredness, lightheadedness, SOB, forgetfulness, subjective memory problems, and heart palpitations, were challenging for IHF. Some individuals felt fatigued even while sitting. IHF also reported other problematic symptoms, including a consistent dry

Table 2. Frequency of Problems Reported by Week

Problems	Week 1	Week 2	Week 3	Week 4
Heart failure symptoms	13	9	9	10
Treatment regimen	12	14	12	15
Daily activities	12	6	2	5
Mood	12	7	7	5
Resources	4	4	4	3
Interpersonal/social	2	4	1	1
Other issues	1	2	1	0

cough and sleep difficulties from SOB while sleeping on their back. IHF reported sleeping in a recliner as one way to adapt to sleep difficulties. SOB was severe for some, interfering with their eating, talking, and activities. Subjective memory problems also were a challenge, with some IHF forgetting to perform self-care activities such as checking capillary blood glucose.

Managing treatment regimen, completing daily activities, and experiencing negative moods (n=12 for each of problem) were rated equally as the second-highest priority. Notably, this priority rating was almost identical to that of managing HF symptoms, emphasizing their importance to IHF. Managing their dietary regimen was the primary concern related to treatment regimen mentioned by IHF. Issues such as adhering to a healthy diet; restricting sodium, fluid, and cholesterol intake; and monitoring their weight were frequently reported. Lack of knowledge about their diet plan was a significant problem for IHF. While IHF had information from the hospital regarding their diet, they needed assistance to understand or process the information. Other IHF had difficulty reading food labels, understanding that both salt and sodium were important to restrict, and lacked knowledge related to foods and fluids that contained higher amounts of sodium. While some IHF were unsure of their sodium restriction, they reportedly knew not to use salt. Several IHF or their respective caregivers reportedly did not know how to cook without salt and requested low-salt recipes. Some IHF felt they were not eating enough due to their low-sodium diet, while others felt they needed to become accustomed to eating differently. Other issues relative to treatment plan included smoking cessation, managing multiple medications, exercising, and eliminating caffeine.

IHF reported difficulty completing daily activities. While some of these activities were instrumental activities of daily living, such as housework and shopping, others were pleasurable activities that gave significant meaning to their daily life. These activities were greatly impaired due to HF symptoms such as fatigue, low energy levels, SOB, and activity intolerance. While IHF desired to do pleasurable activities that added meaning to their life (eg, feed fish in the pond, gardening), HF symptoms prevented these activities. Although IHF disliked inactivity, several stated that they did not have the energy to participate in their usual hobbies or activities. Participating in family events also was difficult due to decreased energy or negative emotions and moods. Some IHF felt uncertainty and wanted to know recommendations regarding safe limits to their daily activities, including safe job activities if they continued to be employed.

Another major problem identified by IHF was negative emotions and moods, for example, depression, feeling down, anxiety, being grumpy, and decreased motivation and quality of life. Individuals reported mood swings similar to a roller coaster, especially when attempting to participate in pleasurable activities only to realize that they no longer had the energy to participate. IHF reported feeling depressed due to worrying about their disease and trying to manage multiple comorbidities in addition to HF. Others were anxious, worrying about new treatment regimens and whether they would be successful. A limited ability to participate in pleasurable activities (eg, working in the garden) also negatively affected their quality of life. IHF sought pleasurable moments that elevated their negative mood. For some IHF, anticipating future morbidity contributed to depression and anxiety. For those IHF returning to work, depression continued after they returned to their job.

While inadequate resources (n=4) was rated as the third-highest priority, a smaller number of IHF reported this problem, experiencing financial issues in paying for household and medical bills or healthy foods that satisfied their dietary regimen. Some IHF reportedly lost their employment because HF symptoms (eg, fatigue) interfered with their job duties. Inadequate knowledge about available resources in their local communities also was identified.

Other less common problems experienced by IHF as a group during the first week were interpersonal and social issues, which include lack of social support, transportation to health provider appointments, and impaired relationships with family members.

Week 2

Managing treatment regimen (n=14) was the main problem identified by IHF in the second week, with implementing their dietary regimen still the major concern. These concerns continued to evolve around limiting salt intake and fluids and monitoring weight. While some IHF remained overwhelmed trying to select foods to eat, others actively implemented recommended strategies such as eating small meals and utilizing community food programs. Other treatment regimen problems pertained to monitoring daily weight because some IHF did not own a personal scale.

Difficulty in managing HF symptoms (n=9) was the second-highest-priority problem, with reports of edema, fatigue, forgetfulness, SOB, nausea, lightheadedness, and cough persisting. Fatigue remained the top symptom complaint, with SOB being problematic during strenuous activity. Some IHF reported improved SOB with rest and oxygen, while others reported forgetfulness as a problem more often this week.

Negative emotions and moods (n=7) was the third-highest-priority problem reported during the second week. Depression, feeling down, anxiety, being grumpy, and decreased motivation and quality of life were common. Some IHF blamed their negative moods on a change in their active lifestyle. Others associated their negative moods with an uncertain future. Dietary regimen also contributed to anxiety in determining what to eat. Some IHF dealt with negative emotions and moods by making conscious efforts to do more enjoyable activities and visit friends and relatives.

The inability to complete daily activities (n=6) remained problematic. While fatigue was a major contributing factor in difficulty completing daily activities, participants recognized the need to implement daily activities in small increments. IHF also reported that consistent exercise provided more energy to complete these activities versus the previous week. IHF continued to report inadequate resources and interpersonal and social issues, similar to the first week. Financial resources were constrained for employed IHF due to missed work. Often, IHF were waiting for approval of governmental assistance. New interpersonal and social issues related to situations where friends and family verbally offered assistance but failed to carry through with actual physical assistance.

Week 3

Managing treatment regimen (n=12) continued to be the top problem in week 3. Although diet remained a significant issue, IHF were more active in eating small meals and trying to identify new foods and spices that added variety to their diet. IHF also actively “chose” restaurants where they could eat appropriate meals. Exercise participation and outside activities were now major issues. IHF actively attempted to do outside activities, albeit at a slower pace and with frequent rest periods. Some IHF continued to report forgetting to take scheduled medications, not weighing daily, and difficulty with smoking cessation. However, overall, the third week appeared to be a turning point for many IHF. IHF were more proactive in evaluating their problems positively and actively implementing strategies to solve those problems.

The second most common problem continued to be difficulty managing HF symptoms (n=9). Fatigue remained the most problematic symptom for most IHF, with waxing and waning of energy levels. Fatigue impacted daily activities, with some IHF still reporting SOB with activity. Yet, the majority of IHF reportedly were able to work within their limitations by interspersing activity with rest periods. Forgetfulness was a significant problem, with IHF forgetting words to use in conversations. Sleep was an issue for IHF, with some using continuous positive airway pressure (CPAP) for sleep apnea and others taking prescribed sleeping agents.

The third-highest problem reported was negative emotions and moods (n=7). Some IHF reported crying

spells. Others indicated their quality of life was poor because of fatigue. Anxiety was prevalent, as some IHF were unable to pay bills or afford prescribed heart medications. However, IHF were overall more positive regarding their mood, with most reporting less depressive symptoms and implementation of strategies to improve negative mood.

IHF continued to express problems as a group in completing daily activities and inadequate resources. While fatigue continued to be a major issue and IHF still had difficulty doing housework and other outside activities, the group overall was active in interspersing activity with rest. Paying bills was a major concern, but IHF were hesitant to ask for assistance from family and friends because of their independence. Others verbalized a lack of social support and had difficulty finding someone to provide transportation to their health provider.

Week 4

Understanding and managing treatment regimen (n=15) continued to be the highest-priority problem during week 4. Fluid and sodium restriction and appropriate foods to eat were major concerns. Some IHF experienced a loss of appetite, complaining that the food tasted different. However, overall, IHF as a group were more comfortable with the low-sodium diet and voiced both good and bad days regarding diet. IHF were able to note the consequences of not following their diet and fluid restrictions (ie, increased pedal edema, more SOB). Most IHF had family members that monitored what the IHF ate. Holidays were particularly problematic because some family members added salt when cooking and IHF reported lack of control of the available food.

By week 4, IHF were more proactive regarding managing their own medications. Some IHF used phone reminders and timers to reinforce medication adherence. Others wrote down medications and when they took them. Some IHF were working with physical therapy and personal trainers to develop exercise plans, while others developed their own plans through experience. A few IHF still did not own a scale due to limited finances and were not able to take a daily weight. Frequent toileting due to diuretics also was an issue, and health providers subsequently scheduled IHF to take diuretics at earlier times during the day. Smoking cessation was still a challenge for those who had smoked for many years.

The second most common problem was difficulty in managing HF symptoms (n=10). Heart palpitations and SOB were present in some IHF, interfering with sleep and activities of daily living. Fatigue was improving for the majority of IHF. Problems with sleep were still present. CPAP appeared to improve the quality but not the quantity, with IHF sleeping for short periods of time. Forgetting whether medications had been taken was still a problem. However, most IHF used pill containers, which prevented double dosing.

Negative emotions and moods (n=5) and difficulty in completing daily activities (n=5) were rated equally by IHF as the third-highest-priority problem during week 4. Negative emotions and moods continued despite antidepressants, with some still describing crying spells. Activity intolerance remained a major problem, interfering with daily activities. Some IHF reported making themselves get up and move around 4–5 times a day and participate in more outside activities. More IHF readily paced themselves, alternating activities with rest. Stamina and energy varied daily among IHF, and they were better able to mentally and physically adjust routines around the varied energy levels.

Other less common problems reported were inadequate resources and interpersonal and social issues. Negative emotions and moods, HF symptoms, inadequate resources, and interpersonal and social issues were interrelated. IHF voiced that they were unable to do daily activities with friends because of inadequate monies. IHF also feared they would experience fatigue or activity intolerance during shopping or outings if they went. Inadequate resources (eg, monies) also prevented some IHF from buying healthy foods. IHF were often waiting on governmental assistance to buy prescriptions, while others arranged a payment schedule to pay a limited amount each month on medical bills.

DISCUSSION

While empirical literature indicates IHF experience complex problems in the home, studies that identify problems viewed as high priority by IHF in the immediate posthospitalization period are limited. Our findings support those of previous studies that indicated uncertainty is prevalent in the lives of IHF,²²⁻²⁴ occurs very early in HF and includes feelings of confusion, being overwhelmed, and a loss of control.

Similar to findings of others,^{23,25} HF symptoms (eg, fatigue, activity intolerance) significantly influenced completion of daily activities, depression, and social activities the first 4 weeks postdischarge. Findings of this study agree with prior research that identified fatigue and SOB,²⁶ plus comorbidities,²⁷ as major contributors related to interference with daily activities and social activities as well as a factor related to increased reports of depression. However, while some IHF were learning to monitor their HF symptoms internally and to integrate a recommended treatment regimen into their daily lives, the first month was characterized by IHF being overwhelmed with life changes related to HF.

It is well known that subjective memory problems are common in HF;²⁸ however, our findings indicate that they may occur early in HF. Studies have suggested that calcium channel blockers and loop diuretics may be contributing factors to forgetfulness in IHF.²⁹ Although resources (financial, social) and interpersonal problems appeared to be a problem for fewer individuals the first month posthospitalization, many were waiting for governmental assistance with their finances.

Dietary regimen was a significant part of patients' treatment plan, which many IHF initially failed to understand and found confusing. Similar to other studies,³⁰ many IHF did not realize the importance of reading food labels for sodium and salt content. Some participants did not purchase a home scale for 3 to 4 weeks, emphasizing the importance of providing additional education regarding the significance of monitoring daily weight and inquiring whether the IHF has a scale prior to discharge. However, while empirical data indicate IHF assigned to an intervention group often weigh themselves more,³¹ daily weight may not improve rehospitalization or mortality.³² Although exercising appeared to be challenging initially due to HF symptoms, its implementation improved over 4 weeks.

Managing symptoms was higher priority in week 1, whereas managing treatment regimen was the highest priority during weeks 2–4. However, managing HF symptoms was rated very closely to that of managing treatment regimen, completing daily activities, and experiencing negative moods during the first week, indicating IHF viewed all of these problems with high importance immediately after discharge. Other research

indicates hospital discharge following a chronic illness is overwhelming and full of challenges, with attempts by IHF to transition from an illness-defined experience to a “normal” life as quickly as possible.³³ Consistent with previous research, IHF viewed many problems as high priority during the transition from hospital to home yet gave priority to managing HF symptoms during the first week.^{13,34} During weeks 2–4, IHF were better able to prioritize their problems on treatment regimens that potentially would improve their HF symptoms and quality of life.

Limitations

While this study provides insight into problems deemed highest priority by IHF in the immediate posthospitalization period, limitations exist that impact generalizability of study findings. Study design resulted in a small sample size of patients recently discharged from the hospital, thereby limiting generalizability. Further, patients were excluded if they had difficulty hearing on the phone. This criterion may have inadvertently excluded patients who were experiencing depression or nonadherence due to hearing loss.

Although a strong methodology was used for the intervention component, the actual experience of participating in the COPE-HF Partnership intervention may have influenced the high-priority problems reported by IHF. While the range of years since diagnosis of HF was broad (<1 to >15), the duration for most participants was less than 1 year and may have influenced the types of problems experienced by IHF. Additionally, most participants had NYHA class II HF, which may have influenced the severity and characteristics of the reported problems the first month postdischarge. Thus, more research investigating problems experienced by a more diverse group of IHF are needed.

Relevance to Practice

Consistent with other literature,^{8–15} IHF experience both cardiac (eg, difficulty in managing HF symptoms) and noncardiac (eg, inadequate resources and managing interpersonal issues) high-priority problems after discharge from the hospital to home. Many of these problems are interrelated. Initially, IHF and their families should be given discharge instructions and literature regarding HF symptoms, their treatment regimen, daily activities, and mood and emotions experienced after HF.

However, information regarding these problems and their interrelationship to each other (eg, how fatigue affects self-care activities and possible adaptations) may be best processed later (ie, weeks 2-4). This information could be offered through home visits, phone contacts, email messages, and internet resources.³⁵ Online education and coaching programs promoting HF self-care also appear promising.³⁶ Mobile phone applications (HeartMapp), which include daily alerts (eg, check weight, medication), assessment (eg, HF symptoms), audio and visual feedback, and patient education (eg, diet, self-care, activities) designed to promote self-care and improve long-term outcomes, are now available.³⁷

CONCLUSIONS

This study indicates individuals with heart failure experience complex problems in the home that can impact all aspects of their lives, with some problems deemed more significant than others. HF symptoms, treatment regimen, and negative emotions and moods were consistently reported as high-priority problems in the immediate posthospitalization period. Moreover, negative emotions and moods, HF symptoms, inadequate resources, and interpersonal and social issues were found to be interrelated problems. More research on posthospitalization problems experienced by individuals with HF is needed to support findings of this study and influence the development of interventions to reduce negative outcomes.

Patient-Friendly Recap

- Individuals diagnosed with heart failure experience complex problems in the home that impact aspects of their daily lives.
- A group of these patients was asked to prioritize the problems they encountered within a month of being discharged from the hospital.
- The authors found that individuals with heart failure have difficulty managing symptoms, adhering to their treatment plan, and performing daily activities. They also experience negative emotions and moods.
- Future interventions designed to improve health outcomes in patients with heart failure — and reduce readmissions to the hospital — should account for high-priority home-based issues.

Author Contributions

Study design: Grant, Graven. Data acquisition and/or analysis: all authors. Manuscript drafting: Grant, Graven. Critical revision: Grant, Graven.

Conflicts of Interest

None.

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