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Using community health workers in collaboration with nurse case managers in effecting change in quality of life for heart failure patients

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Using Community Health Workers in Collaboration with Nurse Case Managers in
Effecting Change in Quality of Life for Heart Failure Patients

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Abstract

This project was designed to evaluate the effectiveness in improving the quality of life among heart failure patients with the addition of the role of Community Health Worker (CHW) to a current continuum case management model. The study also addressed the increased need for more appropriate and cost-effective chronic care management for heart failure patients. Hospitals and healthcare systems are being challenged to find innovative ways to decrease readmissions, decrease unnecessary emergency room visits, increase patient adherence, and manage chronic disease, all improving the patient's overall quality of life. Studies show that approximately 76% of heart failure patients have a relatively poor quality of life, while most factors can be modified through the use of ongoing education (Lakdizaji, Hassankhni, Agdam, Khajegodary, & Rezanieh, 2013). In a randomized trial documented by Lakdizaji et al. (2013), the control group that utilized an educational program showed significant differences in their total quality of life score as well as the individual physical and emotional dimensions. This study indicated that through ongoing education, heart failure patients' quality of life can improve.

CHW services enhanced the current Continuum Case Management (CCM) program through providing additional health education, health care system navigation, healthcare monitoring, and identification of potential barriers for patients to receive appropriate care. In addition to improving overall quality of life, patients receiving interventions from the CHW also experienced decreased readmissions and Emergency Department (ED) visits. By reducing unnecessary health care visits, there was also an associated decrease in healthcare costs.

Keywords: community health workers (CHW), heart failure, quality of life, case management, multidisciplinary, interprofessional, collaboration

Background and Significance

While approximately 45% of the total US population suffers from a chronic disease, the Patient Protection and Affordable Care Act (PPACA) emphasizes and places priorities on improving access to and the delivery of health care services to these individuals, especially among those who are low income, underserved, uninsured, living with health disparities, and/or living in rural communities (Islam et al., 2015). The use of CHWs is included in the design and implementation of programs considered to overcome these barriers. One specific need identified in the PPACA is the role of healthcare navigator in identifying and referring populations to community-based resources. Healthy People 2020 (2014) reports that while heart disease is the leading cause of death in the US, it is also among the most preventable. There are significant disparities based on gender, age, race/ethnicity, geographic area, and socioeconomic status in relation to risk factors, access to treatment, appropriate and timely treatment, treatment outcomes, and mortality (ODPHP, 2014). By improving quality of life through prevention, detection, and treatment of risk factors, outcomes can be significantly improved.

One creative approach to meet these needs is through the use of a Community Health Worker program. The work of CHWs achieves the Institute for Healthcare Improvement's Triple Aim of population health, experience of care (quality and satisfaction), and decreasing healthcare costs. These individuals are in a key position to meet increased demands for clinical services and are a key resource in providing broader population health strategies (CHWA, 2013). According to Baker, Polito, Sudders, and Bharel (2015), as part of the integrated health care team, CHWs contribute to cost-effective services through decreasing ED visits and readmissions. In addition, patients become more engaged in controlling their own chronic conditions. Patients' quality of care is improved while health care disparities are reduced when

utilizing the services of the CHW (Baker et al., 2015). As compared to other countries around the world, the US has been slower to adopt the CHW role but the popularity of this role is growing. A few states including Alaska, Minnesota, and New Mexico have realized third-party reimbursement for specific CHW services through Medicaid coverage (Miller, Bates, & Katzer, 2014). Research and practice-based evidence on CHW cost-effectiveness and improving quality of care continues to grow rapidly.

According to Brooks et al. (2014), a recent analysis of cost data from numerous studies showed that CHW programs have resulted in an average savings of \$2,245 per patient (based on 6 months to 2-years post-program relative to controls). In addition, uncompensated care charges were reduced by \$206,485 due to cost avoidance, less uncompensated care, and more primary care visits (Brooks et al., 2014). Brooks et al. (2014) also estimated that the healthcare system saves \$2.28 for every \$1 it invests in a community health worker program. According to Perry and Zullinger (2012), a CHW provides an essential link within the healthcare team and is a powerful force for promoting healthy behaviors. With a focus on collecting and reporting outcomes, optimal results can be obtained for various populations. By adding the CHW, the current case management program could potentially serve a larger population of patients and meet the needs of patients within our community who do not require the skills of a nurse.

Problem Statement

This project was designed to evaluate the effectiveness in improving the quality of life among heart failure patients with the addition of the role of Community Health Worker (CHW) to a current continuum case management model. The study also addressed the increased need for more skill appropriate and cost-effective chronic care management for heart failure patients.

Grant funding was secured to add Community Health Workers to Sentara RMH Medical

Center's current case management program and expand services to additional chronic heart failure patients. Services enhanced disease management through working closely with the Continuum Case Managers and providing health education, health care system navigation, healthcare monitoring, and identification of potential barriers for patients to receive appropriate care. Through additional coordination of these services, patients may experience enhanced quality of life. In addition to improving quality of life, other objectives include a decrease in hospital readmissions, avoidable Emergency Department (ED) visits, and associated healthcare costs.

Theoretical Framework

The Quality-Caring Model (Duffy and Hoskins, 2003) was used as the theoretical framework for this study. According to this model, caring professional practice requires:

- Knowledge of the caring factors and relationships among patients, caregivers, the healthcare team and the community
- Skills (both behaviors and competencies)
- Intentions which are the attitudes and beliefs that lead to choices
- Time, primarily focusing relationships

In this model, the role of the Community Health Worker is to engage in caring relationships. These relationships included caring for self, caring for patients/caregivers, and caring for the community. By feeling "cared for" patients have improved outcomes. The Quality-Caring Model consists of 8 caring factors. Relationships are developed through mutual problem solving, attentive reassurance, human respect, encouraging manner, appreciation of unique meanings, healing environment, basic human needs, and affiliation needs. This model is

applicable in the daily practice of nurses and CHWs caring for patients in the community.

(Duffy & Hoskins, 2003) Figure 1: Quality-Caring Model

The Donabedian Quality Framework (Donabedian, 1966) was used for program evaluation. Donabedian describes a model that assesses the quality of care in a manner that is flexible for multiple settings or situations. The framework demonstrates a relationship between the structures of healthcare, processes of patient care, and health outcomes (McDonald et al., 2007). Within the context of this project, health outcomes result from care delivery to the patient and the patient's underlying characteristics. According to Donabedian, care coordination is expected to be influenced by structure variables and to have causal effects on patient outcomes (McDonald et al., 2007).

Literature Synthesis

A systematic literature review evaluating the use of Community Health Workers was completed and served as the background of evidence for this project. According to Brooks, et al. (2014), the estimated number of CHWs rose from 10,000 to 120,000 between 1998 and 2010. Recognized as important members of the healthcare team, CHWs facilitate access and improve the quality of medical care with an emphasis on prevention and chronic care. Programs are demonstrating evidence of the impact of the CHW role in the prevention of health care disparities and in the management of chronic disease. While less than 18% of the population accounts for more than 70% of all healthcare spending, the need for management of chronic disease is essential (AHA, 2011). The Centers for Disease Control and Prevention (2015) shared information about states currently integrating CHW roles into patient billing. Minnesota has initiated comprehensive policies to foster increased utilization of CHWs through initiation of reimbursement of services through Medicaid (Rosenthanl et al., 2010).

According to Whitley, Everhart, & Wright (2006), a longitudinal cohort study showed evidence of increased primary care visits with decreased emergent and inpatient visits, accompanied by an overall reduction in uncompensated costs. Through comprehensive support for older patients with heart failure, quality of life can be increased without increasing cost. (Phillips et al., 2004). Using “care guides” with roles similar to the CHW, a prospective cohort study demonstrated success among patients with chronic illnesses, including heart failure (Adair et al., 2012). One year into that program, which included basic education, coaching, assistance with community resources, and prioritization of goals, failure to meet nationally recommended guidelines decreased by 28% (Adair et al., 2012). Resources for the implementation of the CHW role are increasing in availability such as the CHWN Training Manual to assist in the standardization and success of training, data collection, and evaluation (Schall, 2015). Documentation on the role of CHWs as best practice has existed for years, as evidenced by a 2006 House Document by James Madison University. However, more current recommendations still suggest the need for additional studies to evaluate the full effectiveness of CHW interventions (Alvillar, Rush, & Dudley, 2011).

As one of the most widely used health-related quality of life questionnaires for heart failure patients, there is concern by some that the Minnesota Living with Heart Failure Questionnaire (MLWHFQ©) lacks a third factor representing a social dimension. In a study by Bibao, Escobar, Garcia-Perez, Navarro, & Quiros (2016), the MLWHFQ© was given to 2565 patients with heart failure to analyze the internal structure of the MLWHFQ©, the unidimensionality of the total score and to compare the different factor structures proposed. This study confirmed the adequacy of the physical and emotional scales but did recommend an additional scale for the social dimension, such as Munyombwe’s social factor (Bibao et al.,

2016). These results also supported the validity of using the MLWHFQ© physical, emotional and total scores in patients with heart failure, for clinical practice and research.

In a similar study by Gonzalez (2016), 36 patients completed the MLWHFQ© prior to and post enrollment in a 14-day student-led transitional care program. This study also evaluated the percentage of patients requiring readmission to the hospital within 30 days of initial hospitalization (Gonzalez, 2016). No statistically significant difference was noted between the total MLWHFQ scores pre- and post-survey $t(34) = 1.554, p = .13$, physical and emotional dimensions also showed no statistical significance (Gonzalez, 2016). Gonzalez (2016) states a lower rate of healthcare utilization was noted within 30 days following their initial hospitalization, which may have been in part due to the program which allowed the nurse practitioner to address status changes a timely manner.

Teaching and reinforcing self-management skills is a good method to promote quality of life. However, research focused on self-management and quality of life is limited. A study by Tung et al. (2013) examined the relationship between self-care ability and quality of life in patients with heart failure in Taiwan. The MLWHFQ© was one of 3 questionnaires used to collect data as a pre-test and at the 1 and 2 month follow-up assessments in this quasi-experimental design of 82 patients. Increased awareness of self-management skills and self-care ability for heart failure patients was achieved through individualized interventions, including a self-management patient book, self-management training, and multiple follow-up telephone calls. The results demonstrated that patients with HF who received self-management intervention experienced a better quality of life than do those who did not participate in such program (Tung et al. 2013).

The primary objective of this pilot project was to determine if the use of Community

Health Workers will increase the quality of life for those patients living with the diagnosis of heart failure. In addition to improving quality of life other objectives included a decrease in hospital readmissions, avoidable ED visits and associated healthcare costs.

Project Design

Definitions

Continuum Case Manager (CCM)-Registered Nurse (RN) responsible for the assessment, planning, and coordination of case management services

Community Health Worker (CHW)-Non-licensed provider acting under the direction of the CCM; a frontline, trusted member of the community in which she/he serves

This project was conducted as a longitudinal study designed to evaluate the effectiveness of CHW interventions on quality of life over a period of 18 months. For the purposes of this capstone project, a pilot analysis took place over the course of CHW intervention for 3 months, with pre-post data collection for 3 months before and after intervention. Based on the results of this analysis, revisions may be made to the overall study design.

Setting

This program was conducted through Sentara RMH Medical Center's case management program. Sentara RMH Medical Center is a 238-bed community hospital serving a seven-county area with a population of approximately 218,000 people. This project encompassed care provided in the community setting through the continuum case management model. This model was designed to follow the chronically ill, medically complex patient beyond the walls of the hospital. The CHW is an added member of the case management team. Patients met the designated Continuum Case Management criteria to be seen and served by the CHW to be

included in the study. Referrals were made while the patients were an inpatient or from practitioners in the community. Patients provided consent to case management services upon initiation of services. Patients were identified for case management services following the same criteria as currently utilized. This study included those patients who met inclusion criteria for initial assessment between April 2016 and June 2016. Appendix A: Continuum Case

Management Criteria

Inclusion criteria:

- Adult patients with heart failure
- Meets criteria for continuum case management services (See Appendix A)
- Need for services delivered by the community health worker (page 11)

Exclusion criteria:

- Patients <18 years of age
- Prisoners
- Pregnant Women
- Cognitively Impaired Persons
- Non-English speaking patients (to assure accurate MLWHFQ data)

(these individuals will receive services but not the MLWHFQ or be included in this study)

Method/Tools

A Community Health Worker (CHW) was paired with a CCM. After completion of the MLWHFQ© on the first visit, interprofessional collaboration occurred as the RN Continuum Case Manager and the Community Health Worker developed a plan of care with the patient based on the findings from the questionnaire. This plan was individualized based on the

patient's identified needs. The interventions and tasks were assigned based on the appropriate skill set of the healthcare provider. The plan of care was developed and directed by the CCM.

The CHW skill set include but was not limited to:

- Health education, including chronic disease management
- Healthcare system navigation determination of need for relevant community referrals, resources, etc.
- Arranging transportation to/from healthcare appointments
- Collecting vital signs, weights
- Reviewing home environment for potential safety concerns, including the use of assistive devices and other self-care equipment
- Assistance with financial associated paperwork, forms
- No skills can be provided by a CHW that requires a licensed care provider (such as a RN, LPN, CNA, etc.).

The CHW services were explained to the patient by the CCM. The CHW was in continuous communication with the CCM as she/he was still responsible for the overall care of the patient. All care provided by the CHW was documented as directed by policy.

The CHW was oriented to their role through several avenues. The Harrisonburg-Rockingham Health Department received a multi-year planning grant to establish a Community Health Worker Network. As part of this grant, an Eastern Mennonite nursing professor was assigned as the Community Health Worker Network Coordinator. She was responsible for coordinating training and providing continuing education opportunities. The SRMH CHW also received general SRMH orientation as well as orientation with the Continuum Case Management that included completing competencies on skills and documentation tools. The length of case

management services was dependent on the patient status and the need for services. It could be one visit to visits on a regular basis for several months. There was no maximum number of visits.

All patients meeting criteria for CCM and CHW services were offered services. Data was gathered by CHW's using the Minnesota Living with Heart Failure® Questionnaire (paper). All data was maintained by SRMH, meeting HIPAA requirements. Immediately following completion, the MLWHRQ tool was stored in a locked cabinet in the continuum case management office. Access was only available to the case management staff. MLWHRQ review was completed by this writer. Paperwork will be destroyed at the conclusion of the project by shredding the completed MLWHRQ tools. IRB approval was obtained on November 10, 2015 from the Sentara RMH Medical Center Institutional Review Board.

Evaluation Plan

The Minnesota Living with Heart Failure Questionnaire (MLWHFQ) ([Appendix B&C](#)) was used by the CHW to evaluate the heart failure patients' perception of quality of life at the time of initiation of services and after 3 months for the purposes of this pilot study. The MLWHFQ was designed in 1984 to measure the effects of the disease process and treatments of heart failure on an individual's quality of life (Rector, 2015). This tool was constructed to measure the physical, emotional, social and mental components of one's quality of life. The questionnaire utilizes a 6-point Likert scale to determine how much each of 21 facets prevented them from living as they desire (Rector, 2015). Through attention to early treatment, removal of actual and/or potential barriers, and additional health education and self-management skills, the CHW can significantly impact the quality of life for patients.

The total MLWHFQ score can be highly reliable as demonstrated by estimates of the correlation between repeated baseline assessments as well as measures of internal consistency such as Cronbach's alpha coefficient ($\alpha=0.87-0.94$) (Rector, 2015). High internal consistency indicates that the total score measures the single construct of the effect of heart failure on an individual's quality of life (Rector, 2015). In addition to an overall score, patients will receive a physical dimension score (items 2,3,4,5,6,7,12,13) and an emotional dimension score (17,18,19,20,21). These are scored by simple summation. If a response is missing, that item will be eliminated and a sum of responses is used. That same subset will be used to represent that individual each time the questionnaire is completed for consistency.

"Clinically meaningful" refers to an effect that would prompt patients and physicians to make a change in care. According to Rector (2015) improvement of 5 points in one study was enough to encourage patients to take a new medication with no side effects. There is no "gold standard" to determine when quality of life has truly changed to provide a cut-off for improvement or deterioration.

Data related to readmissions and ED visits was tracked and retrieved from the patient's electronic medical record (Meditech and EPIC) by the Community Health Worker. Patients were also asked on each contact (visit or phone call) about any hospitalizations or ED visits in the event they were outside of our hospital system. Total charges related to readmissions and ED visits (within hospital system) were retrieved through the Finance Division. This information was captured from the financial module of the patient's electronic medical record (in Meditech and HBOC) and placed into Excel for data analysis.

Findings

The evaluation of this project followed the Donabedian Model (Donabedian, 1966) that highlights structure, process, and outcomes (McDonald et al., 2007). The table below represents the operationalization of the three aspects of the model.

Program Evaluation Model		
Structure	Process	Outcome of Service
Resources	Use of CHWs for delivery of skill appropriate services	Most appropriate use of skill mix
Education	Self-management and patient/family education	Increase patient and family knowledge and self-management skills; improve quality of life
Access	Patient/family involvement in care and evaluation	Reduction in readmissions; ED visits
Healthcare Finances	Use of available/ appropriate resources	Decrease in healthcare expenses

Resources

Through the use of the CHW role, the most appropriate skill mix was used in providing care to patients included in this study. Upon completion of the patient's individualized plan of care, the RN CCM was responsible for skills required of a RN while the CHW was able to fulfill those duties that did not require a RN license but was so important to maintain the necessary level of care for the patients.

Education

At each CHW visit, education interventions were addressed. These include education related to general heart failure, nutrition, medication adherence strategies, appointment scheduling, or other issues specific to the patient. Specific teaching is documented in the patient's medical record for each visit. In addition, all referrals are documented in the medical record. These referrals are based on findings from the MLWHFQ© and/or the individualized

plan of care. Of the 41 patients in the study, 1-6 referrals were made based on the findings of the MLWHFQ© on the first patient visit. Referral examples include:

LifeAlert	Insurance Counseling/Financial Assistance
Behavioral Health	Home Health
Free Clinic	Durable Medical Equipment
Outpatient Diabetes Education	Physical Therapy
Meals on Wheels	People Helping People (Utilities)
SNAP (Supplemental Nutrition Assistance)	Veterans Administration
Telehealth Monitoring	Advanced Care Planning

Descriptive statistics were used to characterize the data obtained from the MLWHFQ© results. A paired *t*-test was used to determine if there was a statistically significant difference between the pre and post MLWHFQ© assessments. Minnesota Living with Heart Failure Questionnaire (MLWHFQ©) data from the CHW first visit (pre) and 90 day visit (post) was entered into a software package, SPSS (Statistical Package for the Social Science). A total of 41 patients were enrolled into this study. A paired *t* Test was run with a statistical significance set at $p < .01$. Based on the Likert scale, the desired direction is a lower score. Questions 2,3,4,5,6,7,12, and 13 are compared to evaluate the physical dimension of the patients' quality of life, while questions 17,18,19,20, and 21 were compared for the emotional dimension. A total score was reviewed, looking at all questions. All outcome variables were found to be statistically significant in improving quality of life. See Table 1.

Table 1: Minnesota Living with Heart Failure Questionnaire (MLWHFQ©)

	Pre Questionnaire Mean/Std. Deviation	Post Questionnaire Mean/Std. Deviation	Paired t Test
Physical Dimension	26.3(8.2)	8.7(5.1)	13.3*
Emotional Dimension	14.4(5.8)	7.6(4.7)	7.3*
Total Score	59.7(15.8)	22.2(11.2)	15.1*

*<.01

Access

In addition, data related to readmissions and ED visits 3 months pre and post initiation of CHW services was entered into SPSS. A paired t test was run which also indicated a statistically significant reduction in avoidable hospitalizations and ED visits post CHW intervention. See Table 2.

Table 2: Admissions and ED Visits (n=41)

	Pre	Post	Paired t-test t value
Total Admissions	84	17	
Total ED visits	74	18	
Mean Admissions (SD)	2.02 (1.1)	.47(.65)	7.59*
Mean ED visits (SD)	1.75(1.3)	.50 (.77)	5.51*

*p=<.000

Healthcare Finances

Based on the reduction in readmissions and ED visits after the implementation of the CHW role, the study was able to show a decrease in total charges for all services provided at Sentara RMH Medical Center. Total charges decreased by \$846,225 or 79.2%. This savings can be linked to the improvement of overall quality of life, increased use of community resources, and/or improvement of self-management skills, all influenced by the CHW's involvement.

Referring back to the Quality-Caring Model (Duffy and Hoskins, 2003) the results provide evidence of the caring relationships developed between the patients, CCMs, CHWs, and the interprofessional team. Through mutual goal setting and problem solving, respect, reassurance and encouragement provided in a healing environment, the CHW/CCM team offered individualized care with positive outcomes. (Duffy & Hoskins, 2003)

Recommendation/ Implications

One of the unintended findings of this project included the increased number of issues identified during the initial MLWHFQ©. Prior to the use of this tool, the focus had been primarily on the patient's diagnosis of heart failure and resources to address this chronic disease process. Through the use of this more comprehensive tool that gathered data on the effects of heart disease on the patient's quality of life around physical, emotional, and psychosocial, a broader view of the patient's needs were identified. Upon identification, these areas of concerns were built into the care plan and interventions and referrals were matched to address these needs. This quickly became a much more inclusive assessment. As noted, referrals to community agencies increased dramatically. By addressing these needs, that had often gone unaddressed in the past, the patient's quality of life improved which in turn improved their overall health status.

As an organization, we are looking at the opportunities of opening a Transition of Care Clinic, starting with the heart failure population. Based on the results of this project, we are planning to utilize the MLWHFQ©. Use of this tool will help identify patient needs during the initial assessment to determine appropriate community referrals and opportunities to improve overall quality of life. From this information, the CHW can then assist in the delivery of skill appropriate care in the community.

A barrier for the project that made data collection a little more difficult was the fact that our healthcare organization changed electronic health records (EHR) in the middle of the project. Our CHWs were starting at the same time of the switch so they were not able to get their documentation templates into the new system. Throughout the study, all their specific documentation was completed on paper and scanned into the EHR. We were able to gather all the necessary data but it was more complex without defined fields and computer generated reports.

An exciting opportunity from this computer conversion was the ability to work with our finance department in developing a database to capture patient specific information between the two systems. After extensive work, we were able to build a program that they feel will be useful across the organization for multiple projects. In addition to specific financial data, this gives us access to service line data, DRG information, demographics, and particular physician information. Through a deeper review of this information, we will be able to assess where we have great opportunities for improvement. All of this information provides greater chances for program revisions and developments.

Conclusion

With an increasing national focus on population health management strategies, Community Health Workers have emerged as important members of the interprofessional health care teams and are especially effective at improving health outcomes for high-risk and underserved patient populations. CHWs function primarily as health educators, patient navigators, and assist with patient monitoring. Through these services, they act as a “bridge” between the patient and other healthcare providers to improve health behaviors and outcomes. Essential in managing chronic disease, these actions work to improve the patients’ overall quality

of life. As a result of this improved quality of life, we are also able to decrease readmissions, unnecessary ED visits, and overall healthcare costs.

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Appendix

Figure 1: Quality-Caring Model



Developed by Dr. Joanne Duffy,
Depicted by MD Anderson Professional Nursing Practice Model

Appendix A: Continuum Case Management Criteria

Continuum Case Management Criteria of Population Served:

Patients must meet one or more of the following:

- Must be a Virginia resident and 18 years or older
- Multiple or chronic health conditions (including but not exclusive to Heart Failure, COPD, Chronic Renal Failure, Cancer, Dementia, Pneumonia, Sepsis)
- Readmission to the hospital or ED within the past 30 days
- Lack of social support
- Home safety concerns including fall history or fall risk
- Known financial hardship affecting procurement of medications, transportation, or other healthcare related issue
- Cultural diversity causing difficulty receiving medical services
- Frequent ED visits
- Sudden change in health condition
- Resident of a long term care facility or recent crossing of various levels of care
- Lack of consistent community follow-up

Source: Sentara RMH Medical Center (SRMH) Continuum Case Management Policy Implemented 8/14

****For this study, patients must have a diagnosis of heart failure****

Appendix B: Minnesota Living with Heart Failure Questionnaire©

The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by -	No	Very Little				Very Much
1. causing swelling in your ankles or legs?	0	1	2	3	4	5
2. making you sit or lie down to rest during the day?	0	1	2	3	4	5
3. making your walking about or climbing stairs difficult?	0	1	2	3	4	5
4. making your working around the house or yard difficult?	0	1	2	3	4	5
5. making your going places away from home difficult?	0	1	2	3	4	5
6. making your sleeping well at night difficult?	0	1	2	3	4	5
7. making your relating to or doing things with your friends or family difficult?	0	1	2	3	4	5
8. making your working to earn a living difficult?	0	1	2	3	4	5
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4	5
10. making your sexual activities difficult?	0	1	2	3	4	5
11. making you eat less of the foods you like?	0	1	2	3	4	5
12. making you short of breath?	0	1	2	3	4	5
13. making you tired, fatigued, or low on energy?	0	1	2	3	4	5
14. making you stay in a hospital?	0	1	2	3	4	5
15. costing you money for medical care?	0	1	2	3	4	5
16. giving you side effects from treatments?	0	1	2	3	4	5
17. making you feel you are a burden to your family or friends?	0	1	2	3	4	5
18. making you feel a loss of self-control in your life?	0	1	2	3	4	5
19. making you worry?	0	1	2	3	4	5
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4	5
21. making you feel depressed?	0	1	2	3	4	5

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Appendix C: MLWHFQ© Instructions for Data Collection and Scoring

1. Patients should respond to the questionnaire prior to other assessments and interactions that may bias their responses. You might tell the patient that you would like to get his or her opinion before doing your medical assessment.
2. Ample, uninterrupted time should be provided for the patient to complete the questionnaire. We recommend that the patient answer the questions without being influenced by others such as their spouse or family members. Studies show that patient proxies often have different perspectives.
3. We recommend that you use the first question to give the respondent more detailed instructions as follows.
 - a. Read the introductory paragraph at the top of the questionnaire.
 - b. Read the first question with the respondent – “Did your heart failure prevent you living as you wanted during the last month (4 weeks) by causing swelling in your ankles or legs?” Then tell the respondent –
 - If you did not have any ankle or leg swelling during the past month (4 weeks) you should circle the zero (0) after this question.
 - If you did have swelling that was caused by a sprained ankle or some other cause that you are sure was not related to heart failure, you should circle the zero (0) after this question.
 - If you had swelling that might be related to your heart condition, then rate how much the swelling prevented you from doing things you wanted to do or feeling the way you would like to feel. In other words, how much did the swelling affect your life? Circle either the 0, 1, 2, 3, 4 or 5 to indicate how much the swelling affected your life during the past month – zero (0) means not at all, one (1) means very little and five (5) very much.
4. Ask the patient read and respond to all 21 questions. The entire questionnaire may be read directly to the patient if one is careful not to influence responses by verbal or physical cues.
5. Check to make sure the patient has responded to each question. If a question does not apply to the patient they should circle the zero (0). Make sure there is only one answer clearly marked for each question.

Instructions for Data Collection and Scoring (cont'd)

6. Score the questionnaire by summing the responses to all 21 questions. In addition, a physical dimension score (items 2, 3, 4, 5, 6, 7, 12, 13 on the version sent with these instructions) and emotional dimension score (items 17, 18, 19, 20, 21) have been identified by factor analysis and may be scored by simple summation to further characterize the effect of heart failure on a patient's life.
7. Partially complete questionnaires do occur despite best efforts to minimize missing data. However, missing data can greatly bias the data and complicate analysis. To reiterate, you need to make sure the respondents understand to mark zero for any items that do not apply to them, rather than leave a blank. Whenever possible review the questionnaire before the respondent leaves to make sure there are no unanswered questions or questions with more than one answer.
8. Several methods to impute missing data are discussed in the literature.^{1, 2} Multiple imputation using completed questions and perhaps other study variables to predict missing responses should be considered.³ If a missing response is not imputed, the item will be eliminated from that person's score (the sum of responses). Since intermittently missing data can greatly affect within-person changes in scores, you might want to use the same subset of questions to represent a person at all times by omitting questions that have missing data at any point in time. We do not have any recommendations about when missing data become too extensive to render the information being collected useless.

¹Fayers PM et al. Incomplete quality of life data in randomized trials: missing items. *Statistics in Medicine* 1998;17:679-696.

²Schaffer JL and Graham JW. Missing data: our view of the state of the art. *Psychological Methods* 2002;7:147-177.

³Raghunathan TE, et al. A multivariate technique for multiply imputing missing values using a sequence of regression models. *Survey Methodology* 2001;27:85-95.

Appendix D: Cover Letter and Consent to Participate



Dear *(Insert Potential Research Participant's Name)*

You are being invited to participate in a project designed to evaluate the effectiveness of using Community Health Workers to improve the quality of life for patients with heart failure. All patients will also be followed by a Continuum Case Manager.

Community Health Workers are an additional member of your healthcare team who can assist with

- Teaching you about your heart failure
- Assisting you to obtain needed community referrals and/or resources
- Arranging transportation to/from healthcare appointments
- Monitoring your blood pressure, weights
- Reviewing your home environment for potential safety concerns
- Helping you with financial associated paperwork, forms

For this study, you will be asked to participate by completing a short questionnaire up to 3 times over several months. The questionnaire will take 5-10 minutes to complete. The questions will ask you how heart failure affects how you live your life on a daily basis.

There are no anticipated risks related to this research. By participating in this research, you will benefit yourself and others by helping to determine the effect that Community Health Workers have on your overall quality of life.

The questionnaire will have your name included but will be stored in a locked filing cabinet at Sentara RMH Medical Center. Only case management staff and the researchers will have access to the information. All information will be destroyed after the study.

Your participation in this research is completely voluntary. If you decide not to participate, you will continue to receive the same level of services.

The results from this study will be presented to other nursing professionals in conferences and journals. At no time, however, will your name be used or any identifying information revealed. If you wish to receive a copy of the results from this study, you may contact one of the researchers at the telephone number given below.

If you would like additional information about this study, please contact me.

Patra H. Reed MSN, RN, CNML
Sentara RMH Medical Center
540-689-1170

Identification of Project	Using Community Health Workers in Collaboration with Nurse Care Managers in Effecting Change in Quality of Life for Heart Failure Patients
Statement of Age of Subject	I state that I am over 18 years of age and wish to participate in this program of research being conducted by Patra H. Reed. I have been provided satisfactory answers to my questions.
Purpose	The purpose of this study is to determine if using Community Health Workers is beneficial for heart failure patients. This project will measure quality of life, hospital admissions and ED visits related to heart failure.
Procedures	This study consists of a survey that will be administered in your home. You will be asked to provide answers to a series of questions related to the effects of your heart failure and treatment on your quality of life.
Confidentiality	All the information collected in this study is confidential to the extent permitted by law. Any identifying information will be kept in a password protected file that meets SRMH security requirements and is accessible only to the research staff. I understand that the data I provide may be grouped with data others provide for reporting and presentation and that my name will not be used.
Risks	The investigator does not perceive more than minimal risks from your involvement in this study (that is, no risks beyond the risks associated with everyday life).
Benefits	Potential benefits from participation in this study include <ul style="list-style-type: none"> • Improved quality of life • Decreased hospital readmissions • Reduced avoidable ED visits • Reduce healthcare costs • Increased self-care and knowledge of heart failure
Freedom to withdraw or ask questions	I understand that I am free to ask questions or withdraw from participation at any time and without penalty.
Medical Care	Sentara RMH Medical Center does not provide any medical or hospitalization insurance for participants in this research or any compensation for any injury sustained as a result of my participation in this research.
Contact Information	If you have any questions about your rights as a research subject or wish to report a research related injury, contact: Stewart Pollock, MD, Chairman Sentara RMH Medical Center Institutional Review Board 2010 Health Campus Drive Harrisonburg, VA 22801 540-689-1000 If you have questions about this particular study, contact: Patra H. Reed MSN, RN, CNML 2010 Health Campus Drive Harrisonburg, VA 22801 540-689-1170
Subject Information	Subject Name: _____ Subject signature: _____ Date signed: _____