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ILLNESS REPRESENTATION AND CARDIAC REHABILITATION
UTILIZATION AMONG OLDER ADULTS

DISSERTATION

Presented in Partial Fulfillment of the Requirements for

the Degree Doctor of Philosophy in the Graduate

School of The Ohio State University

By

Carrie Nicole Keib, M.S.

*****

The Ohio State University
2007

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ABSTRACT

Coronary heart disease (CHD) is the number one cause of mortality and disability in the United States (U.S.). The burden of CHD disproportionately impacts the older adult population of the U.S. in relation to mortality, disability, and economic cost. Greater than 55% of acute myocardial infarction deaths and 86% of CHD deaths occur in adults who are 65 years of age or older. The estimated direct and indirect cost of CHD in the U.S. for 2007 is $151.6 billion. Research studies are needed to address the increasing burden of CHD among the older adult population.

The secondary prevention of CHD may be effectively promoted through cardiac rehabilitation utilization. Cardiac rehabilitation programs are effective and safe for older adult CHD patients. Older adult patients who participate in cardiac rehabilitation receive significant benefits such as a 15% to 28% reduction in all-cause mortality, 26% to 31% reduction in cardiac mortality, improved physical function, reduction in cardiac risk factors, and increased quality of life. Unfortunately, cardiac rehabilitation utilization rates among older adults are significantly lower than utilization rates among younger adults. Only 6.6% to 53.5% of eligible adults 65 years or older in the U.S. participate in

cardiac rehabilitation. Poor cardiac rehabilitation utilization among older adults is of great concern given the established benefits associated with cardiac rehabilitation participation.

Research efforts have identified a variety of factors that influence older adult participation in cardiac rehabilitation. Patient understanding of the purpose and benefits of cardiac rehabilitation (representation of cardiac rehabilitation) and the patient's perceived meaning of CHD (illness representation) have been recognized as important targets for interventions to improve cardiac rehabilitation utilization rates among older adults. The purpose of this dissertation was to develop, pilot test, and evaluate the effectiveness of a tailored illness representation intervention to increase cardiac rehabilitation utilization among older adults. Three manuscripts are presented in this dissertation document.

Illness representations of CHD are more likely to be inaccurate among older adults, as compared to younger adults. Medically inaccurate illness representations of CHD are concerning because they are associated with poor cardiac rehabilitation utilization and are inconsistent with the secondary prevention of CHD. The first manuscript reviews the literature related to representations of cardiac rehabilitation and CHD among older adults. From this review of literature, a preliminary self-regulatory

model of cardiac rehabilitation utilization is proposed to guide the development of tailored interventions to increase cardiac rehabilitation utilization among older adults.

Inaccuracies within illness representations of CHD have been positively modified through a three session illness representation intervention during hospitalization in adults 65 years of age or younger with an acute myocardial infarction (AMI). Positive changes in illness representations were maintained three months post hospital discharge in that study. It is unknown whether inaccuracies within illness representations of CHD might also be modifiable among older adults. If inaccuracies within illness representations of CHD among older adults are also modifiable, it is possible that cardiac rehabilitation utilization would increase in this population.

The second manuscript reports a complete, detailed description of the research design, tailored illness representation intervention, study procedures, and results of the present pilot study with implications for future research. The tailored illness representation was delivered during a single post hospital discharge home telephone session using a scripted protocol. The intervention was based upon the individual patient assessment of CHD illness representation during hospitalization for an AMI, angioplasty, stent, or coronary artery bypass graft surgery. Cardiac rehabilitation utilization rates in this pilot study were considerably higher than the national level. Sixty-seven percent of

intervention group participants and 74% of control group participants attended at least one cardiac rehabilitation session. The majority of participants in the intervention and control group completed 75% or more of their prescribed cardiac rehabilitation program. Two significant predictors of cardiac rehabilitation utilization emerged in relation to illness representations of CHD: cyclical timeline and consequence dimensions. The final logistical model included two variables, cyclical timeline and consequence, and explained 34% of the variance in cardiac rehabilitation utilization.

The third manuscript reports recruitment outcomes of the present pilot study with discussion. Strategies to improve older adult participation in research during hospitalization are provided in this brief methodological report. Ninety-four older adults with CHD were referred for eligibility screening and 72 participants were enrolled. Eighty-two percent of the older adults who were screened for eligibility were enrolled during the 15 months of recruitment. A lack of interest in completing study-related paperwork and not feeling well were the most common reasons provided for non-participation. Collaboration with the inpatient cardiac rehabilitation clinicians during the recruitment process was an important contributor to our successful recruitment efforts. This manuscript provides guidance and suggestions for consideration by researchers who are interested in recruiting older adults for studies during hospitalization.

Dedicated to the loving memory of my Grandpa, Kenneth L. Alguire,

whose life was lived with courageous strength, determination and grace.

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FIELDS OF STUDY

Major Field: Nursing

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

A SELF-REGULTATORY MODEL OF CARDIAC REHABILITATION

UTILIZATION

Cardiac rehabilitation programs are composed of multiple services designed to provide patients with instruction and training in secondary prevention and self-management of coronary heart disease (CHD) (American Association of Cardiovascular & Pulmonary Rehabilitation, 2004). Empirical evidence has repeatedly demonstrated the effectiveness of cardiac rehabilitation in secondary prevention of CHD (Clark, Hartling, Vandermeer, & McAlister, 2005; Jolliffe et al., 2000; Taylor et al., 2004; Thompson & Bowman, 1998; Wenger et al., 1995). Older adults are a population at high risk of CHD related mortality and morbidity (American Heart Association, 2007). Their cardiac rehabilitation utilization rates are poor, despite known benefits of participation (Suaya et al., 2007; Williams et al., 2002).

While many studies have examined different factors that affect cardiac rehabilitation utilization among older adults, few interventions have aimed to increase cardiac rehabilitation utilization in this population. Current literature has identified patient representations of cardiac rehabilitation and CHD as key areas for the development of interventions to increase cardiac rehabilitation utilization (A. Cooper,

Lloyd, Weinman, & Jackson, 1999; A. F. Cooper, Weinman, Hankins, Jackson, & Horne, 2007; K. J. Petrie, Weinman, Sharpe, & Buckley, 1996; Shifren, 2003; Whitmarsh, Koutantji, & Sidell, 2003; Wiles & Kinmonth, 2001). Yet, this potential has not been studied among older adults. Therefore, this paper will explore the problem of poor cardiac rehabilitation utilization among older adults and propose a preliminary self-regulatory model of cardiac rehabilitation utilization to guide the development of tailored interventions for older adults with CHD.

Background

Coronary heart disease is a chronic disease that greatly impacts older Americans. The prevalence of CHD among adults who were 65 years of age or older between 2002 and 2003 was 21.9% for White, non-Hispanics; 17.4% for Black, non-Hispanics; and 14.3% for Hispanics (Centers for Disease Control & The Merck Company Foundation, 2007). The leading cause of mortality for men and women in the United States is CHD. Nearly 83% of those who die from CHD are 65 years of age or older (American Heart Association, 2007). Increased co-morbidities, greater disability, decreased health-related quality of life, and increased health care expenditures further characterize the CHD burden among older Americans. This burden will likely increase with the anticipated demographic shifts associated with increasing numbers and proportions of older Americans (Centers for Disease Control & The Merck Company Foundation, 2007). Thus, secondary prevention of CHD among older adults is identified as a significant area for the development of tailored interventions to decrease disease related burdens.

2

Cardiac rehabilitation is an effective secondary prevention measure for CHD among older adults (American Association of Cardiovascular & Pulmonary Rehabilitation, 2004; Williams et al., 2002). Benefits of cardiac rehabilitation participation for older adults include a 26-31% reduction in cardiac mortality risk (Suaya et al., 2007), cardiac risk factor modification (Ades, 2001; Leon et al., 2005; Pasquali, Alexander, & Peterson, 2001), improved quality of life and psychosocial well-being (Milani & Lavie, 1998; Pasquali, Alexander, & Peterson, 2001), improved physical function (Dolansky & Moore, 2004; Lavie, Milani, & Littman, 1993; Pasquali, Alexander, & Peterson, 2001), and decreased health care expenditures due to lower rates of CHD related re-hospitalizations (Ades, Huang, & Weaver, 1992). Older adults, however, are between 1.5 and 2.0 times less likely to complete a cardiac rehabilitation program, as compared to younger adults (Lavie et al., 1993). Only 13% of eligible patients 80 years of age or older (Evenson, Rosamond, & Luepker, 1998), 13.9% of acute myocardial infarction (AMI) patients and 31% of coronary artery bypass graft (CABG) surgery patients who are 65 years of age or older participate in a cardiac rehabilitation program (Suaya et al., 2007). Poor utilization of cardiac rehabilitation among older adults is concerning because they are at higher risk of CHD related mortality and morbidity; therefore, cardiac rehabilitation benefits may be of even greater importance in this population (Lavie et al., 1993; Wenger, 1997; Williams et al., 2002).

There is a substantial body of research investigating the problem of poor cardiac rehabilitation utilization among adults. Research findings have identified a variety of factors that are associated with or predictive of cardiac rehabilitation utilization, not

limited to the following: age, gender, race and ethnicity, social support, socioeconomic

status, insurance status, depression, anxiety, role responsibilities, transportation issues,

physician referral, and the strength of the provider's recommendation for the cardiac

rehabilitation program (Ades, Waldmann, McCann, & Weaver, 1992; Caulin-Glaser et

al., 2001; A. F. Cooper, Jackson, Weinman, & Horne, 2002; Evenson & Fleury, 2000).

An older adult's decision whether or not to participate in a cardiac rehabilitation program

is quite complex. Self-regulation theory provides a useful framework for conceptualizing

the complex problem of poor cardiac rehabilitation utilization among older adults. The

proposed self-regulatory model of cardiac rehabilitation utilization is presented in

Figure 1.1.
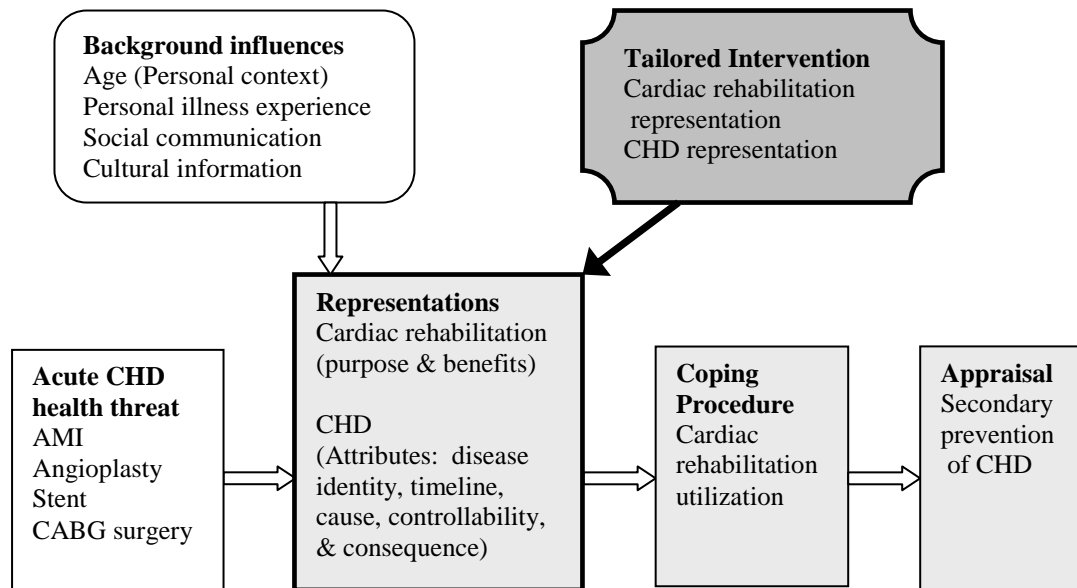
Figure 1.1. Self-regulatory model of cardiac rehabilitation utilization

Self-regulation theory applied to older adults and cardiac rehabilitation utilization

Older adults with CHD often experience acute CHD health threats along the chronic illness trajectory (Strauss, 1984). Acute myocardial infarction, angioplasty, stent, and CABG surgery are examples of acute CHD health threats that provide an opportunity for older adults to re-focus their attention on secondary prevention of CHD. In the *Self-Regulation Model*, Leventhal and colleagues (L. D. Cameron & Leventhal, 2003; Diefenbach & Leventhal, 1996; H. Leventhal, Meyer, & Nerenz, 1980; H. Leventhal, Nerenz, & Steele, 1984; H. Leventhal et al., 1997) suggest older adults progress through a series of sequential stages (representation, coping procedures, and appraisal) when confronted with an acute CHD health threat, in an effort to understand and manage their CHD experience. Older adults construct two types of representations that influence their cardiac rehabilitation utilization decision: the representation of cardiac rehabilitation, and the representation of CHD. The representation of cardiac rehabilitation includes the perceived purpose and personal benefits of cardiac rehabilitation (A. F. Cooper, Jackson, Weinman, & Horne, 2005). The representation of CHD includes five distinct, inter-related attributes and their accompanying emotional responses: 1) *disease identity*, perceived symptoms and labels for CHD; 2) *timeline*, perceived course of CHD as acute, chronic, or cyclical in nature; 3) *cause*, perceived risk factors for CHD; 4) *controllability*, perceived controllability or cure of CHD through personal or treatment efforts; and 5) *consequence,* perceived effects of CHD (Diefenbach & Leventhal, 1996; Lau & Hartman, 1983; H. Leventhal et al., 1997; Meyer, Leventhal, & Gutmann, 1985). The construction of representations is a dynamic process that is influenced within the older adult's

5

personal, social, and cultural context (Diefenbach & Leventhal, 1996; H. Leventhal et al., 1984; H. Leventhal, Diefenbach, & Leventhal, 1992). In the proposed model, cardiac rehabilitation utilization is conceptualized as a coping procedure (or responsive behavior) that is directed by the older adult's representations of cardiac rehabilitation and CHD. Appraisal, the final stage of the model, is based upon the success of coping procedures to control the CHD health threat, as defined by the representations of cardiac rehabilitation and CHD.

Representations of cardiac rehabilitation

The accuracy or inaccuracy of patient representations of cardiac rehabilitation influence whether or not an older adult will participate in a cardiac rehabilitation program (A. F. Cooper et al., 2007). Representations of cardiac rehabilitation are comprised of information related to program content, the purpose of aerobic exercise, personalized benefits associated with participation, explicit barriers to attendance, and personal CHD knowledge (A. F. Cooper et al., 2005). When older CHD patients understand the role of cardiac rehabilitation and perceive it as being personally necessary, they are more likely to participate. Conversely, cardiac rehabilitation participation is less likely when older adults perceive cardiac rehabilitation as more appropriate for younger patients, report practical barriers to participation, or express concerns about the exercise component of the program (A. F. Cooper et al., 2007).

Cardiac rehabilitation representations appear to be associated and logically correlated with representations of CHD (A. F. Cooper et al., 2007). For example, patients with CHD who perceive cardiac rehabilitation as necessary often demonstrate greater

medical accuracy in their understanding of CHD, and perceive stronger personal and treatment controllability of their CHD (A. F. Cooper et al., 2007). Unfortunately, an inaccuracy within the CHD representation may promote further inaccuracy within the cardiac rehabilitation representation. Patients with CHD who perceive less personal cardiac rehabilitation benefits often perceive fewer causal attributions for their disease. (A. F. Cooper et al., 2005). Cardiac rehabilitation representations among older adults should be assessed in order to identify potential inaccuracies that could be targeted through a tailored intervention to promote cardiac rehabilitation utilization.

Representations of coronary heart disease

A recent meta-analysis indicates several CHD illness representation attributes such as disease identity, consequence, and controllability predict cardiac rehabilitation utilization (D. P. French, Cooper, & Weinman, 2006). Medically inaccurate CHD representations have been identified as a potential target for the development of interventions to promote cardiac rehabilitation utilization (A. Cooper et al., 1999; K. J. Petrie et al., 1996; Shifren, 2003; Whitmarsh et al., 2003; Wiles & Kinmonth, 2001). Potential medical inaccuracies within the attributes of CHD disease identity, timeline, cause, controllability, and consequence are discussed in relation to cardiac rehabilitation utilization among older adults.

Disease identity attribute

An older adult's perception of CHD associated symptoms and the label for illness has significant implications for cardiac rehabilitation utilization. Older adults are more likely to participate in a cardiac rehabilitation program when they have a medically

accurate disease identity attribute and perceive greater numbers of CHD associated symptoms (Whitmarsh et al., 2003). Unfortunately, symptom interpretation can be a challenging task for older adults.

Older adults may inaccurately attribute CHD associated symptoms to the discomfort of normal aging, as they are more likely to experience an increased number of symptoms from age-related changes in the biological self, and a milder, atypical CHD symptom presentation (Aalto, Heijmans, Weinman, & Aro, 2005; E. A. Leventhal & Crouch, 1997; Prohaska, Keller, Leventhal, & Leventhal, 1987). Chronic disease burdens among older adults also complicate symptom interpretation through increased symptom experience (E. A. Leventhal & Crouch, 1997). For example, when an older adult has known chronic disease, such as gastroesophageal reflux disease, the experience of CHD associated "chest pain" may be inaccurately attributed to the older adult's occasional "heart burn". Symptom interpretation may also be potentially inaccurate for older adults who have experienced a prior AMI, as they may not have increased knowledge of typical or atypical AMI symptom presentations (Tullmann & Dracup, 2005). The potential for erroneous symptom interpretation during an acute CHD health threat is great among older adults. Older adults who inaccurately attribute their CHD associated symptoms to normal aging or other chronic disease processes are less likely to participate in cardiac rehabilitation. Therefore, the disease identity attribute is a strategic target for intervention as medically accurate disease identity attributes promote cardiac rehabilitation utilization among older adults (Whitmarsh et al., 2003).

Timeline attribute

Cardiac rehabilitation programs emphasize the chronic nature of CHD, and the need for continued secondary prevention efforts throughout the life-course (American Association of Cardiovascular & Pulmonary Rehabilitation, 2004). A medically accurate chronic disease timeline is consistent with the focus and mission of cardiac rehabilitation. Older adults, however, are more likely to perceive a medically inaccurate acute timeline for their CHD illness trajectory, as compared to younger adults (Aalto et al., 2005). The perception of only an acute CHD trajectory timeline among older adults is more likely among those who are experiencing an initial AMI event or a CABG surgery (Brink, Karlson, & Hallberg, 2006; Gump et al., 2001; Lau-Walker, 2004). Older adults may inaccurately perceive an initial AMI as a short-term problem that will be resolved following recovery rather than a symptom of a chronic condition (CHD) (Brink et al., 2006; Lau-Walker, 2004), and CABG surgery as a mechanism to "fix" CHD (Keller, 1991). When older adults inaccurately perceive CHD solely as acute, their attention is focused on immediate recovery from the acute CHD health threat. The need for secondary prevention of CHD through cardiac risk factor management and lifestyle modifications is often dismissed or minimized, as the CHD problem is perceived to be eradicated with interventional or surgical treatment. The medically accurate chronic timeline contributes to cardiac rehabilitation utilization among older adults, because it is consistent with a personal need for secondary prevention throughout the life-course.

9

Cause attribute

Patients who identify more lifestyle causal attributions for CHD are more likely to attend a cardiac rehabilitation program (Mitoff, Wesolowski, Abramson, & Grace, 2005). Older adults, however, are more prone to identify aging and less apt to identify stress or other lifestyle causal behaviors as causative factors for their acute CHD health threat, as compared to younger adults (Aalto et al., 2005). Hypertension, hyperlipidemia, and smoking are three main modifiable risk factors for CHD often unrecognized as causes of an acute CHD event by older and younger patients with these documented risks (Murphy et al., 2005; Zerwic, King, & Wlasowicz, 1997). Patient causal attributions are often inconsistent with documented personal cardiac risk factors (L. D. Cameron, Petrie, Ellis, Buick, & Weinman, 2005; A. F. Cooper et al., 2005; Fukuoka et al., 2004; Murphy et al., 2005; Zerwic et al., 1997). Furthermore, CHD patients may not be certain of any cause for their disease or recognize the underlying, progressive nature of the CHD process (A. F. Cooper et al., 2005; Fukuoka et al., 2004; Martin et al., 2005; Murphy et al., 2005; Zerwic et al., 1997). These factors contribute to the potential for older adult CHD patients to have medically inaccurate causal attributions for CHD that are inconsistent with a perceived need for cardiac rehabilitation utilization. When an acute CHD event is perceived by an older adult as an isolated episode, instead of a progressive, chronic disease, the older adult may search for a "trigger" or single cause (e.g. aging) and not consider the cumulative effect of multiple cardiac risk factors on the development of CHD over the life-course (A. F. Cooper et al., 2005; D. French, Maissi, & Marteau,

10

2005). Cardiac rehabilitation utilization may be perceived as unnecessary when older

adults do not perceive an accurate and complete personal cardiac risk factor profile.

Controllability attribute

Older adults are more likely to perceive CHD as less controllable, as compared to

younger adults. (Aalto et al., 2005; Grace et al., 2005; Gump et al., 2001). Patients with

CHD who perceive stronger personal and treatment controllability are more likely to

participate in cardiac rehabilitation (A. F. Cooper et al., 2007; K. J. Petrie et al., 1996);

CHD patients who perceive less personal and treatment controllability are less likely to

participate (A. Cooper et al., 1999; A. F. Cooper et al., 2002; Mitoff et al., 2005;

Whitmarsh et al., 2003). The perceived controllability of CHD may be influenced by the

patient's causal attribution (K. J. Petrie & Weinman, 1997) and create a personal

circumstance where a perceived need for cardiac rehabilitation is unlikely.

Consequence attribute

Patients with CHD who perceive less disease severity and fewer severe

consequences are less likely to attend cardiac rehabilitation (A. F. Cooper et al., 2002;

Mitoff et al., 2005). Older adults who denied the severity of their CHD during

hospitalization for an AMI or CABG surgery were less likely to attend cardiac

rehabilitation (Ades, Waldmann et al., 1992). Patients who minimize CHD related

consequences are more likely to only make moderate changes in daily activities and

lifestyle after the acute CHD event (Brink et al., 2006).   A perception of less disease

11

severity and fewer severe consequences may assist CHD patients in emotional coping, but it may also result in the lack of cardiac rehabilitation participation and secondary prevention efforts.

CHD representations among older adults

When older adults experience acute CHD health threats, there is a great potential for the construction of medically inaccurate CHD representations. Older adults may have inaccurate perceptions within the five attributes of CHD representations: 1) *disease identity*: erroneous symptom interpretation; 2) *timeline*: only acute in nature; 3) *cause*: inaccurate and incomplete CHD attributions: 4) *controllability*: perceptions of less controllability; and 5) *consequences*: perceptions of less disease severity and fewer consequences of CHD. These potential CHD representation inaccuracies influence cardiac rehabilitation representations and may promote poor cardiac rehabilitation utilization among older adults. For example, during hospitalization for an acute CHD event, an older adult CHD patient may inaccurately attribute CHD associated symptoms to normal aging or known chronic disease (disease identity), instead of recognizing them as part of the progression of CHD. The experience of percutaneous coronary intervention with stent placement or CABG surgery may be perceived as a treatment that "fixed" the CHD (timeline) so that it is no longer a concern. When the inpatient cardiac rehabilitation clinician discusses the benefits of outpatient cardiac rehabilitation programs with the older adult, the older adult may not perceive cardiac rehabilitation as being personally necessary. Because the CHD is perceived as an isolated event that has been "fixed", the older adult may not identify any modifiable cardiac risk factors to address

12

(causal attribution). The older adult perceives the CHD problem as having been resolved, and therefore, cardiac rehabilitation seems unnecessary as there is no perceived chronic disease to manage (controllability). The potential negative consequences of CHD have been avoided, because the stent or CABG surgery was successful. The CHD problem was caught in time (consequences). Potential CHD representation inaccuracies influence cardiac rehabilitation representations and may promote poor cardiac rehabilitation utilization among older adults.

Interventions guided by cardiac rehabilitation and CHD representations

Medically inaccurate representations of cardiac rehabilitation and CHD are strategic targets for the development of interventions to promote cardiac rehabilitation utilization and secondary prevention of CHD (A. Cooper et al., 1999; A. F. Cooper et al., 2007; King, Humen, Smith, Phan, & Teo, 2001; K. J. Petrie et al., 1996; Shifren, 2003; Whitmarsh et al., 2003; Wiles & Kinmonth, 2001). Medically inaccurate representations of cardiac rehabilitation and CHD are inconsistent with secondary prevention efforts and self-management of CHD throughout the chronic illness trajectory (Strauss, 1984). Therefore, the proposed self-regulatory model of cardiac rehabilitation utilization (Figure 1.1) recommends a tailored interventional approach to address medically inaccurate representations of cardiac rehabilitation and CHD among older adults.

The recommended tailored approach to intervention suggests the intervention should be personalized, and based upon prior assessments of the older adult's representations of cardiac rehabilitation and CHD. A tailored approach with personalized advice for cardiac risk factor modification is warranted as many older adult CHD patients

13

frequently have a lack of correspondence between their perceived and actual cardiac risk factor profiles (Murphy et al., 2005). Follow-up telephone contact with CHD patients after discharge to encourage cardiac rehabilitation utilization, answer patient questions, and clarify any misconceptions of the purpose and benefits of cardiac rehabilitation programs may be beneficial in promoting cardiac rehabilitation enrollment (Heid & Schmelzer, 2004). Pasquali and colleagues (Pasquali, Alexander, Lytle, Coombs, & Peterson, 2001) found a brief post-discharge patient education and cardiac rehabilitation referral intervention was helpful in increasing cardiac rehabilitation utilization among CABG surgery patients.

Keib and colleagues are currently conducting a pilot study using a two group experimental design to examine the effectiveness of a tailored representational intervention to optimize illness representations of CHD and promote cardiac rehabilitation utilization among older adults. This pilot study is employing the proposed self-regulatory model of cardiac rehabilitation utilization and the Revised Illness Perception Questionnaire (Moss-Morris et al., 2002) to elicit older adult representations of CHD from which to design and deliver a tailored, post-discharge telephone intervention. This pilot study is investigating whether or not baseline representations of CHD among older adults are amenable to intervention. Age-related effective interventions to promote cardiac rehabilitation utilization and prevent cardiac disease related disability among an increasing older adult population are critically needed.

14

Summary

Self-regulation theory provides a useful framework for understanding the problem of poor cardiac rehabilitation utilization among older adults. This paper presented a preliminary self-regulatory model of cardiac rehabilitation utilization to guide the development of tailored representational interventions. Representations of cardiac rehabilitation and CHD are often inaccurate among older adults, and may provide a key target for tailored interventions. Determining whether or not an older adult's cardiac rehabilitation and CHD representations are inaccurate is an important nursing assessment. Research is needed to determine whether inaccuracies in older adult representations of cardiac rehabilitation and CHD can be modified to promote cardiac rehabilitation in this at risk population. The proposed model attempts to provide a guide for the development of tailored representational interventions to promote cardiac rehabilitation utilization among older adult CHD patients.

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CHAPTER 2

A SELF-REGULATORY INTERVENTION TO INCREASE OLDER ADULT

PARTICIPATION IN CARDIAC REHABILITATION

Introduction

The primary cause of mortality in the United States is coronary heart disease

(CHD). Approximately 83% of CHD related deaths occur in adults 65 years of age or

older (American Heart Association, 2007). Older adults with CHD have increased risk for

physical disability (Ades, 2001). To reduce CHD associated risks of mortality and

disability among older adults and to enhance quality of life in this population, investment

in secondary prevention of CHD must be a priority.

Cardiac rehabilitation is beneficial and appropriate for the secondary prevention

of CHD among older adults (Ades, Waldmann, Polk, & Coflesky, 1992; Lavie, Milani, &

Littman, 1993; Milani & Lavie, 1998; Pasquali, Alexander, & Peterson, 2001; Williams

et al., 2002). Compelling benefits of cardiac rehabilitation utilization for older adults

include 15% to 28% reduction in all-cause mortality risk, 26% to 31% reduction in

cardiac mortality risk, reduction in cardiac risk factors, improved functional outcomes,

improved psychosocial well-being, and lower CHD related re-hospitalization costs (Ades,

Huang, & Weaver, 1992; Ades, 2001; Dolansky & Moore, 2004; Lavie & Milani, 2001; Milani & Lavie, 1998; Pasquali et al., 2001; Pasquali, Alexander, Coombs, Lytle, & Peterson 2003; Suaya et al., 2007; Wenger et al., 1995). Despite known cardiac rehabilitation benefits, utilization among adults 65 years of age or older is poor with only 13.9% of acute myocardial infarction (AMI) patients and 31% of CHD patients participating (Suaya et al., 2007). Cardiac rehabilitation utilization further declines with increasing age, as only 13% of adults 80 years of age or older participate (Evenson, Rosamond, & Luepker, 1998).

Poor cardiac rehabilitation utilization among older adults is related to many complex factors including but not limited to the following: low rates of referral to rehabilitation; the patient's perception of the provider's recommendation to attend rehabilitation; gender; race and ethnicity; lower income and greater deprivation; depression; social support; health status; and patient perceptions of illness (Caulin-Glaser et al., 2001; A. Cooper, Lloyd, Weinman, & Jackson, 1999; A. F. Cooper, Jackson, Weinman, & Horne, 2002; Suaya et al., 2007). Importantly, patient perceptions of illness represent a potentially modifiable personal influencing factor for cardiac rehabilitation utilization among older adults. Patient perceptions of illness are disease meanings which guide illness behavior. Research has demonstrated that illness perceptions of CHD are more likely to be medically inaccurate among older adults, as compared to younger adults (Aalto, Heijmans, Weinman, & Aro, 2005; Grace et al., 2005; Gump et al., 2001). For example, older adults are more likely to believe an interventional or surgical procedure has "fixed" their CHD. Medically inaccurate illness perceptions of CHD are inconsistent

with cardiac rehabilitation and secondary prevention of CHD. There is a critical need to develop and evaluate the effectiveness of interventions to address medically inaccurate illness perceptions of CHD (A. Cooper et al., 1999; K. J. Petrie & Weinman, 1997; K. J. Petrie, Weinman, Sharpe, & Buckley, 1996; Shifren, 2003; Whitmarsh, Koutantji, & Sidell, 2003).

The Self-Regulation Model

Leventhal and colleagues' Self-Regulation Model of Illness Representation is a potentially useful theoretical framework to guide the investigation of CHD illness perceptions among older adults (Cameron & Leventhal, 2003; Diefenbach & Leventhal, 1996; Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997). Self-regulation theory recognizes patients as active problem solvers who develop illness representations (cognitive perceptions) and emotional responses to actual or perceived health threats (e.g. CHD). Illness representations are developed in a dynamic process, influenced by internal and external stimuli (personal contextual factors, previous personal illness experiences, social communication, and cultural information). Illness representations are composed of five theoretical dimensions: 1) *disease identity* (personal understanding of symptoms and label for illness); 2) *timeline* (acute, chronic, or cyclical nature and duration of illness); 3) *cause* (beliefs about why one is experiencing illness); 4) *controllability* (personal or treatment control over illness); and 5) *consequences* (possible outcomes related to illness) (Diefenbach & Leventhal, 1996; Lau & Hartman, 1983; Leventhal et al., 1997; Meyer, Leventhal, & Gutmann, 1985).

24

Illness representations and emotional responses guide patient coping behaviors such as cardiac rehabilitation utilization, for the purpose of controlling health threats.

Petrie and colleagues evaluated the effectiveness of an inpatient illness representation intervention to facilitate better recovery and reduce disability in acute myocardial infarction (AMI) patients (n= 65) less than 65 years of age. Significant positive changes in illness representations of CHD among intervention group participants were evident before hospital discharge and sustained three months following discharge (K. J. Petrie, Cameron, Ellis, Buick, & Weinman, 2002). If inaccurate illness representations of CHD among older adults are also amenable to intervention and are positively modifiable to more accurate illness representations of CHD, it is probable cardiac rehabilitation among older adults would increase. Therefore, guided by a self-regulation model (See Figure 2.1), this study aimed to (1) develop, pilot test, and evaluate the effectiveness of a tailored illness representation intervention to increase cardiac rehabilitation utilization among older adults; and (2) examine changes in illness representations of CHD and identify predictors of cardiac rehabilitation utilization. We hypothesized that intervention participants would have greater rates of cardiac rehabilitation utilization compared to control group participants and positive changes in illness representations would predict cardiac rehabilitation utilization.

<div align="center">Method</div>

Participants

This two-group randomized controlled trial was conducted at the heart hospital of an urban, academic, tertiary care medical center. The research protocol was approved by

<div align="center">25</div>

the Ohio State University Institutional Review Board. Participants were men and women, 50 years of age or older, who were hospitalized for an initial acute CHD event (AMI, angioplasty, stent, or coronary artery bypass graft (CABG) surgery), English speaking, able and willing to provide written informed consent, and available to participate in a four month study follow-up. Persons were excluded from participation if they were co-enrolled in another research study with CHD risk factor or cardiac rehabilitation education. Exclusion criteria also included planned discharge to an extended care facility or a Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975) score indicative of impaired cognitive functioning, adjusted for age and educational level as suggested by Crum and others (Crum, Anthony, Bassett, & Folstein, 1993).

Ninety-four CHD patients expressed interest in the pilot study (See Figure 2.2). Six potential participants were determined to be ineligible for participation and 16 refused to participate after learning more about the study. Reasons for non-participation included: not wanting to fill out paperwork (n= 9), feeling poor physically (n= 5), feeling overwhelmed (n= 3), not wanting personal health information used in research (n=1), and wanting to "work on problems myself" (n=1). Seventy-two older adults were enrolled into the study and randomized to the intervention or control group. At one month 60 participants provided outcome data by mail. During the course of the study, five participants (3 intervention and 2 control group participants) indicated that they did not wish to complete the study based upon the following reasons: post-operative complications following CABG surgery (n=2), care giving role (n=1), bereavement

26

(n=1), and no longer interested (n=1). Cardiac rehabilitation utilization was verified with appropriate cardiac rehabilitation facilities for 65 participants at the conclusion of the study. This represents 13% and 7% attrition for the intervention and control group, respectively.

Procedure

Participants were enrolled after eligibility was determined and written informed consent was provided. Demographic data and baseline measures were collected during hospitalization. Participants were randomly assigned to study groups using a random numbers table with even numbers indicating intervention group membership (n=31) and odd numbers indicating control group membership (n=41). A tailored illness representation intervention was delivered to intervention group participants during a post-discharge telephone session using a scripted intervention protocol to help ensure consistency of the intervention implementation. The intervention phone call was scheduled within two weeks following the participant's hospital discharge date and delivered prior to cardiac rehabilitation participation eligibility. All intervention phone calls were delivered by the same individual. The average length of the intervention phone calls was 25 minutes, with a range of 10 minutes to 45 minutes. All participants were contacted at one month post-discharge by mail and asked to complete follow-up measures which were the same as baseline measures.

Measures

Cardiac rehabilitation utilization and illness representations of CHD were the outcomes evaluated in this pilot study. Cardiac rehabilitation utilization was defined as

27

attendance at one or more cardiac rehabilitation sessions. Cardiac rehabilitation utilization was self-reported and verified with the appropriate cardiac rehabilitation facility (with written informed consent by the participant at enrollment).

Illness representations of CHD were measured with the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002), a well-established, expanded measure of illness representations as conceptualized in Leventhal and colleagues' Self-Regulatory Model of Illness Representation. The IPQ-R has been utilized in research examining illness representations within CHD populations (Aalto et al., 2005; A. F. Cooper, Weinman, Hankins, Jackson, & Horne, 2007; French, Cooper, & Weinman, 2006; Grace et al., 2005). Sufficient internal reliability is reported for the IPQ-R, with estimates of Cronbach alpha coefficients ranging from 0.79 to 0.89. Strong discriminant, predictive and known groups validity of the IPQ-R is also reported (Moss-Morris et al., 2002).

There are 8 subscales in the IPQ-R: 1) *disease identity* (14 items); 2) *acute/chronic timeline* (6 items); 3) *cyclical timeline* (4 items); 4) *personal controllability* (6 items); 5) *treatment controllability* (5 items); 6) *consequence* (6 items); 7) *illness coherence* (5 items); and 8) *emotional representation* (6 items). The *disease identity* subscale is measured with dichotomous (yes/no) responses, asking respondents to indicate if they have experienced each symptom and whether they believe each symptom is related to their CHD. The total number of symptoms related to their CHD is the disease identity score. A higher *disease identity* score indicates a greater number of symptoms attributed to CHD.

The *acute/chronic* and *cyclical timeline*, *personal* and *treatment controllability, consequence, illness coherence*, and *emotional representation* subscales utilize a 5-point Likert type response scale (strongly disagree to strongly agree). Response items are scored from 1 to 5 with reverse scoring as appropriate. Higher scores on the *acute/chronic timeline, cyclical timeline*, and *consequence* subscales represent stronger beliefs concerning the chronic and cyclical nature of the illness, and a stronger perception that CHD has serious consequences. Higher scores on the *personal and treatment controllability* subscales, and the *illness coherence* subscale represent positive beliefs that personal and treatment actions can be taken to effectively manage CHD, and a stronger personal understanding of CHD. The *emotional representation* subscale provides an assessment of possible emotional responses generated by an illness experience such as feeling depressed, upset, angry, worried, anxious, or afraid. A higher score on the *emotional representation* subscale indicates a stronger emotional response to illness.

The *causal* dimension includes 18 items that are evaluated using the same 5-point Likert type response scale. Causal items are not summed as a subscale. Each item is evaluated as a specific causal attribution for CHD. Respondents rate their level of agreement with each item as an individual cause of CHD. This dimension also provides an opportunity for respondents to identify the three most important causes of their CHD using any of the listed items or providing additional causes.

The Brief Geriatric Depression Scale (GDS) (Yesavage et al., 1982), Interpersonal Support Evaluation List Short Form (ISEL-SF) (Cohen, Mermelstein, Kamarck, & Hoberman, 1985) and Medical Outcomes Survey Short Form- 36 v 2

(SF-36 v2) (Ware, Kosinski, & Dewey, 2000) were included in this pilot study at baseline

for the purpose of identifying potential covariates. The GDS is a widely used brief

screening tool for depression. Respondents provide "yes" or "no" answers to 15

questions about how they have felt over the past week. Scores greater than five are

suggestive of depression, while scores greater than 10 are almost always depression.

This scale has a high degree of internal consistency with an estimated Cronbach alpha

coefficient of 0.94 (Yesavage et al., 1982).

      The 16-item ISEL-SF measures four different types of functional support:

appraisal, the perceived availability of someone with whom to discuss one's problems;

belonging, the perceived availability of people with whom one can do things; *tangible*,

perceived availability of material aid; and *self-esteem*, the perceived availability of a

positive comparison when comparing self with others. "Mostly true" or "mostly false"

are the answer choices selected by respondents. Estimated Cronbach alpha coefficients

are acceptable, ranging from 0.59 to 0.76. The four functional support subscales are

summed for a total score. A higher total score indicates greater perception of the

availability of functional support and is also associated with decreases in psychological

symptomatology (Cohen et al., 1985).

      The SF-36 v2 measures nine dimensions of health-related quality of life: *physical*

functioning, *role physical*, *bodily pain*, *general health*, *vitality*, *social functioning*, *role*

emotional, *mental health*, and *health transition*. Higher scores on the *physical*

functioning, role physical, general health, vitality, social functioning, role emotional, and

mental health subscales indicate better levels of function in these areas. A higher score

on the *bodily pain* subscale indicates a lack of bodily pain and a higher score on the

health transition subscale indicates a perception of worse health now as compared to one

year ago. Internal reliability alpha coefficients are sufficient for all nine health-related

quality of life dimension subscales, exceeding 0.80 (Ware et al., 2000).

Intervention description

The intervention protocol was structured to provide a consistent format with

tailored content for each participant, derived from the baseline measure of illness

representation completed during hospitalization with the IPQ-R (Moss-Morris et al.,

2002). The intervention content specifically targeted the participant's five illness

representation dimensions, as described by Leventhal and colleagues, to affect the

responsive coping behavior of cardiac rehabilitation utilization. Prior to the delivery of

the telephone intervention, the participant's baseline IPQ-R responses were reviewed and

identified as medically accurate or inaccurate. During the intervention, medically

accurate CHD illness dimensions were reinforced through specific content review.

Medically inaccurate dimensions were challenged and participants were asked to consider

the merit of medically accurate alternative belief content. Alternative belief content was

presented specific to the participant's CHD event circumstance and medical history.

Disease identity dimension content explored the participant's beliefs about the

reason for hospitalization, symptom experience, and purpose of medical, interventional,

or surgical treatment received. A brief explanation of the pathophysiology of the

participant's CHD event, differences between typical and atypical CHD symptom

presentations, and possible gender differences were included in the intervention.

31

Timeline dimension content was addressed by discussing how long CHD would be a concern (lifetime, through short-term recovery, or not a concern) and why.

An open-ended question was used to elicit participant *causal attributions* for CHD. Participant ideas about CHD risk factors were compared to their medically documented cardiac risk factor profile. Personal, medically documented risk factors for CHD that were recognized by participants were positively reinforced through a supportive discussion reviewing specific content for each CHD risk factor. Participants were then asked about any unrecognized yet medically documented personal cardiac risk factors. Additional personal, medically documented risk factors for CHD that were recognized by participants with prompting were also positively reinforced.

The *controllability* dimension was targeted by asking participants to describe strategies they had employed to address their recognized cardiac risk factors. Participants were also asked if they had considered other personally unidentified, yet recommended strategies for cardiac risk factor management. Recommended strategies, including personal and treatment control strategies were reviewed for each cardiac risk factor with explanations why a particular strategy would help control CHD progression.

Consequences of CHD were examined by asking participants to consider their cardiac rehabilitation utilization decision. Benefits of cardiac rehabilitation were presented specific to each participant's CHD circumstance and cardiac risk factor profile. Cardiac rehabilitation utilization was discussed as a secondary prevention method to decrease possible CHD related consequences through attaining specific cardiac rehabilitation benefits associated with participation. Participants were encouraged to

complete a cardiac rehabilitation program and were reminded of the name, location, and phone number for the outpatient cardiac rehabilitation facility to which they had been referred.

Standard care

Intervention and control group participants received inpatient cardiac rehabilitation during hospitalization. An education booklet examining CHD disease processes, coronary intervention procedures, pathophysiology, cardiovascular risk factors, home-exercise program guidelines, diet, smoking cessation and medications (as needed) was provided to all patients. The educational material was not related to the individual patient's CHD illness perception. All patients were referred to a geographically accessible cardiac rehabilitation program near their home community.

Data analysis

Data were analyzed with the SPSS for Windows 15.0 statistical software package. Descriptive statistics were used to characterize the sample. Chi-square was used to determine if there were significant differences between the intervention and control groups in nominal demographic or clinical data at baseline. T-tests were used to examine the intervention and control groups for significant differences in the IPQ-R, GDS, ISEL-SF, and the SF-36 v2 scores at baseline. Differences in cardiac rehabilitation utilization rates at 4 months post hospital discharge between the intervention and control groups of the first aim were analyzed using chi-square. The second aim was addressed by using the forward stepwise method to build a logistic regression prediction model to determine if changes in illness representations of CHD were associated with cardiac rehabilitation

utilization. The Hosmer-Lemeshow goodness-of-fit statistic (Hosmer & Lemeshow, 2000) was used to assess model fit. Observations with missing data were excluded from the analysis. An *a priori* level of significance of .05 was established for all statistical analyses.

<div align="center">Results</div>

Demographic and clinical characteristics of participants are presented in Table 2.1 with similar data in the intervention and control groups. Chi-square analyses revealed no statistically significant differences between the study groups. The sample was predominately male, 65 years of age or older, and White, non-Hispanic. Stent placement was the most common CHD event experienced. Most had a high school education or higher. Greater than 90% had a support person living with them and the majority was retired.

Baseline IPQ-R, GDS, ISEL-SF, SF-36 v2 scores were evaluated using t-tests to identify any significant differences between study groups (See Table 2.2). No significant differences in IPQ-R, GDS, or ISEL-SF scores were found between the intervention and control groups at baseline. A significant difference between groups was found on the health transition score of the SF-36 v2 measure (t = -1.999, df = 70, p <.05). The health transition score reflects participant rating of general health status now compared to one year ago. Intervention group participants perceived a poorer general health status now (higher score) compared to control group participants. The health transition SF-36 v2 subscale score was therefore entered as a possible predictor in the logistic regression model.

An exploratory analysis was conducted to further consider the significant

difference between groups in the health transition score at baseline. The baseline health

transition score was tested for correlation with the baseline measures of GDS, the

emotional representation subscale score of the IPQ-R, the role emotional and mental

health subscale scores of the SF-36 v2, and cardiac rehabilitation utilization using point

biserial correlations. No significant correlations were found between the baseline health

transition scores and any of these variables.

Cardiac Rehabilitation Utilization

Cardiac rehabilitation utilization rates were verified with appropriate cardiac

rehabilitation centers for 65 participants (87% of the intervention group (n= 27) and 93%

of the control group (n=38)). To address the primary study aim, evaluating the

effectiveness of a tailored illness representation intervention to increase cardiac

rehabilitation utilization, chi-square was applied to evaluate treatment group differences

in cardiac rehabilitation utilization rates at four months post hospital discharge. Cardiac

rehabilitation utilization rates in this study were high, as 67% of the intervention and 74%

of the control group participants attended at least one cardiac rehabilitation session post

hospital discharge. Unexpectedly, the control group demonstrated slightly higher rates of

cardiac rehabilitation participation than the intervention group. The difference in cardiac

rehabilitation participation rates between study groups was not significant (χ^2 =.376, df =

1, p < .59). Overall percentages of cardiac rehabilitation utilization by group are

illustrated by bar graph in Figure 2.3. Fifty-two percent of intervention group

participants and 50% of control group participants who attended cardiac rehabilitation

programs completed 75% or more of their prescribed cardiac rehabilitation sessions. A typical cardiac rehabilitation program is 36 sessions, 3 sessions per week for 12 weeks. The range of cardiac rehabilitation utilization for both groups was between 0% and 100% attendance. The distribution of the cardiac rehabilitation utilization data violated the assumption of normality.

Illness Representations of CHD

Descriptive data for the IPQ-R subscales by group at baseline and 1 month post hospital discharge are presented in Table 2.3. A change score was created for each IPQ-R subscale by subtracting each individual participant's baseline IPQ-R subscale score from the appropriate 1 month IPQ-R subscale score. The IPQ-R change scores reflect changes in illness representation dimensions from hospitalization to pre-cardiac rehabilitation utilization post discharge. This change score also reflects pre to post intervention changes in IPQ-R dimensions for the intervention group. A one sample t-test was performed for each study group to determine if the mean IPQ-R change scores were significantly different from zero. IPQ-R change scores for the intervention and control groups are presented in Table 2.3. The *cyclical timeline* change score was significantly different from zero in the control group ($t = -2.653$, $df = 33$, $p < .012$) and the intervention group ($t = -2.342$, $df = 25$, $p < .027$).

A forward stepwise logistic regression was performed on the dependent variable of cardiac rehabilitation utilization, dichotomized as zero attendance or attendance at one or more cardiac rehabilitation sessions. The IPQ-R change scores and the baseline health transition measure of the SF-36 v2 were identified and entered as possible predictor

36

variables. Two independent variables emerged as significant covariates for cardiac

rehabilitation utilization, the *cyclical timeline* and *consequence* change scores of the IPQ-

R (See Table 2.4). For a 1-unit increase in *cyclical timeline* change score, the odds of

cardiac rehabilitation utilization are increased by a factor of 1.545 when all other

independent variables are held constant. In other words, a 1-unit increase in *cyclical*

timeline change is associated with an increase of 54.5% in the odds of cardiac

rehabilitation utilization. This suggests that when a person's cyclical timeline score at 1

month post discharge is 1 point higher than it was at baseline, that person has 54.5%

higher odds of participating in cardiac rehabilitation than someone whose cyclical

timeline score did not change. A stronger cyclical timeline perception is associated with

increased odds of cardiac rehabilitation utilization. Additionally, for a 1-unit increase in

consequence change score, the odds of cardiac rehabilitation utilization are increased by a

factor of .726 when all other independent variables are held constant. In other words, a

1-unit increase in *consequence* change score is associated with a decrease of 27.4% in the

odds of cardiac rehabilitation utilization. This indicates that when a person's

consequence score at 1 month post discharge is 1 point higher than it was at baseline, that

person has 27.4% lower odds of participating in cardiac rehabilitation than someone

whose consequence score did not change. A stronger perception of serious CHD

consequences is associated with decreased odds of cardiac rehabilitation utilization. The

final logistic model including the two significant covariates, *cyclical timeline* and

consequences, explained 34% of the variance in cardiac rehabilitation utilization and demonstrated a good fit to the data as evidenced by the Hosmer-Lemeshow goodness-of-fit statistic ($p = .87$).

Discussion

This pilot study tested the feasibility of a tailored illness representation intervention to increase cardiac rehabilitation utilization among older adults following AMI, angioplasty, stent, or CABG surgery. The illness representation intervention was delivered during a single post hospital discharge telephone session using a scripted protocol, tailored to the participant's baseline IPQ-R responses. Participants in this pilot study demonstrated strong rates of cardiac rehabilitation participation with 74% cardiac rehabilitation attendance in the control group and 67% cardiac rehabilitation attendance in the intervention group. Two IPQ-R attributes, *cyclical timeline* and *consequences*, emerged as significant predictors of cardiac rehabilitation utilization.

Among adults 65 years of age or older, cardiac rehabilitation utilization rates range from 6.6% to 53.5% throughout the United States with the greatest utilization concentrated throughout the north central states. The 67% to 74% cardiac rehabilitation utilization range in this pilot study exceeds the national range of participation for this population and is also significantly greater than the 13.3% to 17.8% state cardiac rehabilitation utilization range for Ohio (Suaya et al., 2007). The impressive cardiac rehabilitation utilization rates in this pilot study are an encouraging finding with significant clinical implications for the participants.

38

A significant difference in cardiac rehabilitation utilization rates between the intervention and control groups was not observed in this pilot study. A possible explanation for this is a "ceiling effect". For the tailored illness representation intervention to significantly improve cardiac rehabilitation utilization rates, it would require overcoming exceptionally high rates of cardiac rehabilitation utilization among the participants. A "ceiling effect" may have been fostered through the automatic cardiac rehabilitation referral process used in the heart hospital and the selection of cardiac rehabilitation facilities for referral that were geographically accessible to the patient's residence. Automatic cardiac rehabilitation referral has been highly recommended as a strategy to increase cardiac rehabilitation utilization (Suaya et al., 2007). Research findings also indicate that cardiac rehabilitation utilization is strongly deterred when the facility location is a great distance from the patient's home (Suaya et al., 2007). The heart hospital that served as the recruitment setting for this pilot study eliminated the potential barriers to cardiac rehabilitation utilization associated with the referral process and geographical concerns related to cardiac rehabilitation accessibility.

The *cyclical timeline* and *consequence* change scores were significant independent variables that predicted cardiac rehabilitation utilization. To our knowledge, this pilot study was the first to identify a significant association between the *cyclical timeline* illness representation attribute and cardiac rehabilitation utilization rates. The cyclical timeline illness representation attribute is assessed by the IPQ-R with 4 statements: 1) "The symptoms of my CHD change a great deal from day to day"; 2) "My CHD symptoms come and go in cycles"; 3) "My CHD is very unpredictable"; and 4) "I

39

go through cycles in which my CHD gets better and worse" (Moss-Morris et al., 2002). A higher score on the cyclical timeline subscale suggests stronger perceptions that CHD is cyclical or unpredictable in nature. In this pilot study, increased odds of cardiac rehabilitation utilization were associated with an increase in the cyclical timeline score from baseline (hospitalization) to 1 month post discharge (pre-cardiac rehabilitation). The cyclical timeline illness representation attribute may be important for cardiac rehabilitation utilization because it reflects patient perception of the expected pattern of CHD presentation. Persons who have an increase in their perception that CHD is unpredictable from the onset of the initial acute CHD event to the time at which they become eligible for cardiac rehabilitation may be more likely to participate because the perception that CHD is unpredictable has become stronger. Cardiac rehabilitation may be identified as a strategy to help extend the timeframe between acute manifestations of the disease and to break the cycle of unpredictability. The importance of the cyclical timeline illness representation attribute for cardiac rehabilitation utilization warrants further investigation.

Previous research has identified an association between a stronger perception that CHD has serious consequences and greater cardiac rehabilitation utilization rates (Whitmarsh et al., 2003). Results from this pilot study are inconsistent with the previous finding. In this pilot study, an increase in the *consequence* score from baseline (during hospitalization) to 1 month post discharge (pre-cardiac rehabilitation utilization) was associated with a decrease in the odds of cardiac rehabilitation utilization. There is an important methodological difference between the current study and this previous study.

The previous study assessed illness perceptions in AMI patients after hospital discharge, prior to the time when the patients were scheduled to attend a cardiac rehabilitation program. The current study assessed illness perceptions in AMI, angioplasty, stent, and CABG surgery patients at two time points: during hospitalization and post hospital discharge, prior to cardiac rehabilitation eligibility. The current study method is more rigorous because it evaluated the influence of change in CHD illness perceptions on cardiac rehabilitation utilization. A stronger perception that CHD has serious consequences from hospitalization to pre-cardiac rehabilitation eligibility was associated with decreased odds of cardiac rehabilitation utilization. The significance of this finding is unclear and warrants further exploration.

Additional CHD illness representation attributes have been found to be associated with cardiac rehabilitation utilization. A greater number of symptoms attributed to CHD (disease identity) and positive beliefs that personal and treatment actions can be taken to effectively manage CHD (personal and treatment controllability), have also been found to be associated with greater cardiac rehabilitation utilization rates (A. F. Cooper et al., 2007; Mitoff, Wesolowski, Abramson, & Grace, 2005; K. J. Petrie et al., 1996; Whitmarsh et al., 2003). Findings from this pilot study were not consistent with previous research that indicated an association between disease identity, personal and treatment controllability, and cardiac rehabilitation utilization rates.

The tailored illness representation intervention in this pilot study incorporated several recent recommendations from the literature. During the intervention, illness representations of CHD were assessed for medical inaccuracies and misconceptions

41

related to cardiac rehabilitation benefits. These inaccuracies or misconceptions were challenged with specific content for each individual (A. F. Cooper et al., 2007; King, Humen, Smith, Phan, & Teo, 2001; Whitmarsh et al., 2003). Intervention participants were contacted during a post hospital discharge telephone call to clarify questions or misconceptions and encourage cardiac rehabilitation utilization (Heid & Schmelzer, 2004). Personalized advice for cardiac risk factor management was offered related to the frequent lack of congruence between perceived and actual cardiac risk factors (Murphy et al., 2005). Results from this pilot study did not reflect a significant intervention effect on cardiac rehabilitation utilization rates, despite the incorporation of these recommended strategies. However, as previously discussed, a "ceiling effect" is suspected.

Findings from this pilot study have limited generalizability related to the small sample size and lack of diversity within the sample. Uneven random assignment of participants to the intervention or control group was another study limitation. Self-reported data was used for the assessment of CHD illness representations.

The aims of this study focused on cardiac rehabilitation utilization and illness representations of CHD among older adults. This study measured illness representations of CHD at two time points and assessed the influence of changes in illness representations on cardiac rehabilitation utilization. The construction of illness representations is a dynamic process. Additional research is needed to explore change in dimensions of CHD illness representations at different time points, such as during hospitalization, prior to cardiac rehabilitation participation, and throughout cardiac rehabilitation utilization. A clearer understanding of the role of CHD illness

representations in cardiac rehabilitation participation is needed to develop effective illness representation interventions to improve cardiac rehabilitation utilization rates. Multiple intervention doses and the inclusion of the CHD patient's primary support person may be useful methods to improve the illness representation intervention. The role of CHD illness representations in adherence to cardiac rehabilitation is also an area of needed investigation.

Background influences
Age (Personal context)
Personal illness experience
Social communication
Cultural information

Tailored Intervention
Cardiac rehabilitation
 representation
CHD representation

Acute CHD health threat
AMI
Angioplasty
Stent
CABG surgery

Representations
Cardiac rehabilitation
(purpose & benefits)

CHD
(Attributes: disease
identity, timeline,
cause, controllability,
 & consequence)

Coping Procedure
Cardiac
rehabilitation
utilization

Appraisal
Secondary
prevention
 of CHD

Figure 2.1. Self-regulatory model of cardiac rehabilitation utilization
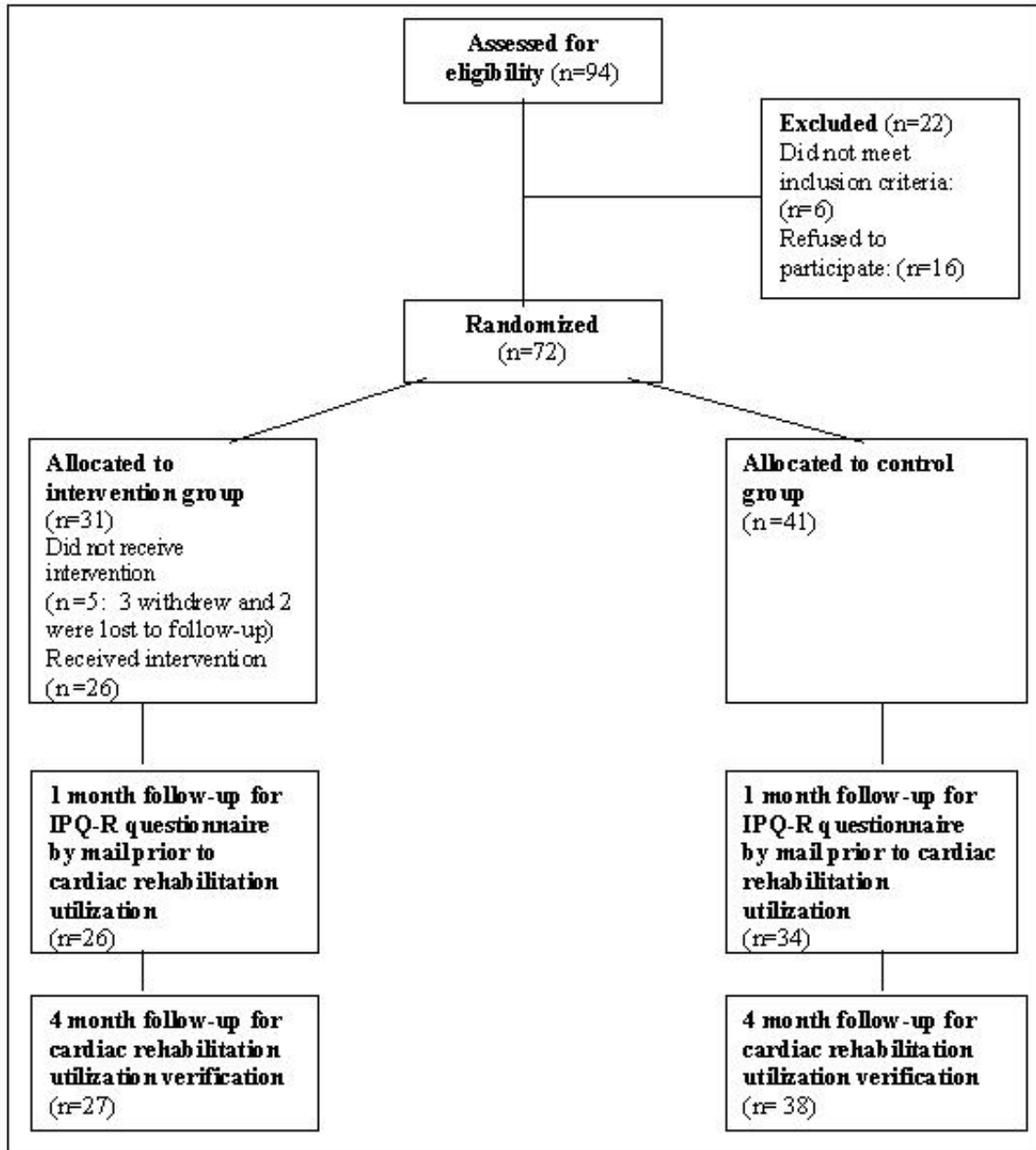
Figure 2.2. Flow Chart of the recruitment and retention of participants
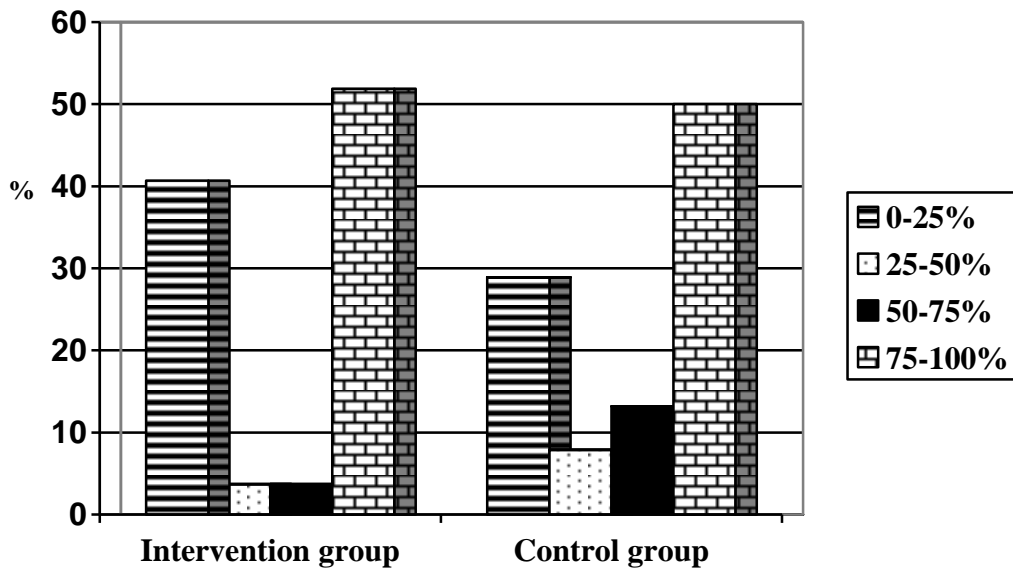
Figure 2.3. Percentage of cardiac rehabilitation sessions attended by study participants

	Intervention Group (n=31)		Control Group (n=41)		Total Sample (n=72)	
Characteristics	n	%	n	%	n	%
Age						
Young-old (50-64)	10	32.3	15	36.6	25	34.7
Middle-old (65-74)	9	29.0	18	43.9	27	37.5
Old-old (≥ 75)	12	38.7	8	19.5	20	27.8
Gender						
Male	24	77.4	28	68.3	52	72.2
Female	7	22.6	13	31.7	20	27.8
Race/Ethnicity						
African-American	5	16.1	3	7.3	8	11.1
White, non-Hispanic	26	83.9	38	92.7	64	88.9
Education level						
< high school	7	22.6	4	9.8	11	15.3
High school/ GED	15	48.4	24	58.5	39	54.2
> high school	9	29.0	13	31.7	22	30.5
Insurance status*						
Primary insurance	30	96.8	35	85.4	65	90.3
Self-pay	1	3.2	6	14.6	7	9.7
Secondary Insurance	15	48.4	19	46.3	34	47.2
Support person						
Yes	29	93.5	37	90.2	66	91.7
Employment status						
Employed	12	38.7	15	36.6	27	37.5
Unemployed	1	3.2	2	4.9	3	4.2
Retired	17	54.8	23	56.1	40	55.6
Disabled	1	3.3	1	2.4	2	2.7
CHD Event**						
AMI	12	38.7	15	37.5	27	38.0
Angioplasty	4	12.9	3	7.3	7	9.7
Stent	18	58.1	24	58.5	42	58.3
CABG surgery	7	22.6	16	39.0	23	31.9

Table 2.1. Demographic and clinical characteristics of participants at baseline

*Insurance status category is not mutually exclusive
** Acute CHD event category is not mutually exclusive

	Possible Range	Intervention Group (n = 31)		Control Group (n= 41)	
Measure		mean	SD	mean	SD
IPQ-R subscales					
Disease identity	(0-14)	3.8	2.26	4.1	2.67
Acute/Chronic timeline	(0-30)	18.7	5.13	20.1	3.99
Cyclical timeline	(0-20)	11.5	2.85	10.5	2.29
Personal control	(0-30)	23.2	3.54	23.9	2.28
Treatment control	(0-25)	19.6	2.01	19.2	2.05
Consequences	(0-30)	21.7	3.03	21.3	3.08
Illness coherence	(0-25)	16.3	4.52	17.4	3.91
Emotional representation	(0-30)	16.0	5.20	16.4	4.08
GDS total score	(0-15)	3.3	2.39	3.5	2.50
ISEL-SF total score	(0-16)	14.1	2.19	14.5	1.68
SF-36 v2 subscales					
Physical functioning	(0-30)	16.8	3.82	17.9	5.39
Role-physical	(0-20)	11.4	4.81	12.5	4.86
Bodily pain	(0-12)	7.8	2.67	7.8	2.72
General health	(0-25)	16.5	3.85	17.5	3.79
Vitality	(0-20)	11.3	3.17	11.5	3.66
Social functioning	(0-10)	7.5	2.33	7.6	2.60
Role-emotional	(0-15)	12.1	4.21	13.2	2.90
Mental health	(0-25)	20.5	3.83	19.4	4.05
Health transition*	(0-5)	**3.7**	**1.08**	**3.1**	**1.20**

Table 2.2. Baseline measures of illness representation, depression screening, social support, and quality of life between groups.

*BHT significantly different at baseline (t = -1.999, df = 70, p <.05).

IPQ-R subscales (possible range)	Baseline				1 Month				IPQ-R Change Scores			
	Intervention (n=31)		Control (n=41)		Intervention (n=26)		Control (n=34)		Intervention (n=26)		Control (n=34)	
	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD	mean	SD
Disease identity (0-14)	3.8	2.26	4.1	2.67	4.2	2.49	3.4	3.29	.27	3.29	-.26	3.60
Acute/Chronic timeline (0-30)	18.7	5.13	20.1	3.99	20.2	5.33	20.3	4.87	1.85	5.35	-.03	3.83
Cyclical timeline (0-20)	11.5	2.85	10.5	2.29	9.9	2.95	9.3	1.66	-1.54	3.35	-1.03	2.26
Personal control (0-30)	23.2	3.54	23.9	2.28	24.9	3.01	24.2	2.11	1.00	3.26	-.03	2.65
Treatment control (0-25)	19.6	2.01	19.2	2.05	20.2	2.32	19.0	2.07	.46	2.18	-.35	1.98
Consequences (0-30)	21.7	3.03	21.3	3.08	21.1	4.31	20.5	3.17	-.50	4.03	-.62	3.85
Illness coherence (0-25)	16.3	4.52	17.4	3.91	17.6	4.97	18.2	2.63	1.35	3.73	.26	3.12
Emotional representation (0-30)	16.0	5.20	16.4	4.08	15.3	5.00	15.1	3.62	-1.08	3.67	-1.21	3.61

Table 2.3. IPQ-R subscale mean scores by group at baseline and 1month with mean change scores for each subscale

Variables	Logistic Regression Coefficient	Wald Statistic	p	Exp(B)	95% Confidence Interval
Cyclical timeline change	.435	6.269	.012	1.545	1.099-2.172
Consequence change	-.320	7.031	.008	.726	.573-.920
Constant	1.869				

Table 2.4. Logistic Regression: Predicting cardiac rehabilitation utilization

Model Chi-Square = 14.961; df = 2; p = .001

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CHAPTER 3

STATEGIES TO IMPROVE OLDER ADULT PARTICIPATION IN RESEARCH

DURING HOSPITALIZATION

Introduction

Significant demographic changes in the United States (U.S.) are anticipated as the

number and proportion of older adults expands. Older adults will comprise

approximately 20% of the U.S. population by 2030 (Centers for Disease Control & The

Merck Company Foundation, 2007). The population of adults 75 years of age or older

will exceed those between 65 and 74 years of age by 2040. Increased life expectancy

will continue to influence rapid growth of the older adult population. Men and women

who reach 65 years of age can expect to live 17 and 20 years longer (National Center for

Health Statistics, 2006). Changing demographics and life expectancy will result in

increased chronic disease burdens among older adults.

There is a critical need for research addressing disease prevention and chronic

disease management among older adults, a heterogeneous group with complex healthcare

needs. Approximately 80% of older adults have at least one chronic disease, 50% have at

least two, and 36% of adults 75 years of age or older have three or more chronic diseases

(Centers for Disease Control & The Merck Company Foundation, 2007; National Center

for Health Statistics, 2006). Chronic diseases can reduce health-related quality of life and create financial burden (Centers for Disease Control & The Merck Company Foundation, 2007). Unfortunately, older adults are frequently underrepresented in clinical trials (Bandyopadhyay, Bayer, & O'Mahony, 2001; Lee, Alexander, Hammill, Pasquali, & Peterson, 2001; Murthy, Krumholz, & Gross, 2004).

Identifying strategies to improve participation of older adults in research is a significant priority to determine evidence-based practices to decrease mortality and disability risks associated with chronic disease burdens. The primary aim of this paper is to report recruitment outcomes in a recent pilot study of an intervention to increase cardiac rehabilitation utilization among older adults (Keib and colleagues, 2007). Drawing from these findings, strategies to improve older adult participation in research during hospitalization are considered.

Methods

A two group randomized controlled trial was conducted to evaluate the effectiveness of a tailored intervention designed to increase cardiac rehabilitation utilization among older adults by optimizing illness representations of coronary heart disease (CHD) (Keib and colleagues, 2007). Participants were recruited from the heart hospital of an urban, academic, tertiary care medical center during hospitalization for an initial acute CHD event (acute myocardial infarction (AMI), angioplasty, stent, or coronary artery bypass graft surgery). Persons of both genders were recruited to the study if they were 65 years of age or older, able to speak English and provide written informed consent and willing to participate in a four month study follow-up. Interested

57

persons were excluded from participation if they were co-enrolled in another cardiac research study or had planned discharge to an extended care facility. A Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) score indicative of cognitive impairment (adjusted for the older adult's age and years of education, as suggested by Crum and others (1993)) was an exclusion criterion.

Inpatient cardiac rehabilitation clinicians identified potential participants during routine cardiac rehabilitation consults and introduced the study using an Institutional Review Board (IRB) approved recruitment script and flyer. When potential participants expressed interest in the study, the principal investigator received referral information. The principal investigator arranged initial recruitment meetings with potential participants. These meetings took place in private hospital rooms to avoid interruption of scheduled patient care priorities. Study criteria were reviewed and the MMSE was administered to interested patients. Following completion of eligibility screening, informed consent was obtained from study participants and baseline data collection was completed prior to hospital discharge.

Baseline data were collected using demographic (25 items) and self-report questionnaires (154 total items) exploring illness representations, depression, social support, and health-related quality of life. Older adults spent about an hour with the principal investigator during hospitalization (approximately 20 minutes for eligibility screening and informed consent, and approximately 45 minutes for baseline data collection). Participants were randomly assigned to the intervention or control group following baseline data collection. The intervention was delivered to intervention group

participants during a post-discharge telephone session in their home. Outcome

measurements (self-report questionnaires) were obtained from participants by mail at one

and four months post-discharge. To equalize attention between groups a standardized

retention letter was mailed to all study participants between the one and four month data

collection time points thanking them for their interest and willingness to participate. The

letter also reminded participants about the final data collection time point and the $20 gift

card incentive they would receive at study completion.

The principal investigator met with inpatient cardiac rehabilitation clinicians most

mornings to encourage consistent identification of potential participants and contacted

them by telephone or email in the afternoon to inquire about potential recruitment

referrals. Many adults age 65 years or older who were identified as potential participants

were ineligible because they were hospitalized for a repeat acute CHD event. The

combination of inclusion criteria (65 years of age or older and initial acute CHD event)

restricted recruitment more than anticipated. After 10 months of recruitment efforts and a

sample size of 41, the inclusion age was decreased to 50 years or older to address the

restrictive combination of inclusion criteria, as suggested by the inpatient cardiac

rehabilitation clinicians. The inclusion age modification increased referrals, and the

recruitment goal of 72 adults was achieved 5 months later. The criterion of an initial

acute CHD event was retained, due to the intervention design. The exclusion criterion of

planned discharge to an extended care facility also limited some older adult patients from

study participation. This criterion was also retained due to the timeframe of the post-

discharge intervention.

59

Results

Ninety-four older adults were referred and screened for study participation during a 15 month recruitment period and 88 older adults were determined to be eligible (See Table 3.1). A total of 72 older adults (82% of those eligible) were enrolled into the study. An average of 4.8 older adults was recruited each month. Sixty-five percent of the sample was 65 years of age or older and almost 75% was male. The most commonly experienced initial acute CHD event was stent placement.

Twenty-two of the 94 older adults who were referred for eligibility screening were not enrolled into the study. Of these, six older adults were determined to be ineligible for participation and sixteen older adults who were eligible declined to participate in the study (See Table 3.1). The majority of those who declined participation were between 65 and 74 years of age. Females were slightly more likely to be non-participants than males. Stent placement was the most common initial acute CHD event experienced by those who decided not to enroll in the study. The most common reasons for non-participation were a lack of interest in completing study paperwork during hospitalization at baseline and not feeling well (See Table 3.2).

Discussion

Improving the participation of older adults in research studies is an important step towards establishing evidence-based practices to reduce the burden of chronic disease among older adults. Older adults were recruited during hospitalization into our recent pilot study of an intervention to increase cardiac rehabilitation utilization after an acute CHD event. Our recruitment efforts over 15 months resulted in an 82% enrollment rate.

60

The involvement of cardiac rehabilitation clinicians in the recruitment process was important for our positive recruitment outcome. Recruitment meetings were planned with consideration of patient care priorities. Restrictive inclusion criteria on age were modified during the study through an IRB amendment to improve referral rates of potential participants for eligibility screening. These and other strategies (See Table 3.3) contributed to the successful recruitment of older adults during hospitalization in this pilot study.

Early in the research planning process we involved key hospital administrators and cardiac rehabilitation clinicians to build rapport and gain cooperation for obtaining access to older adult CHD patients as recommended by Berkman and colleagues experience conducting research on hospitalized older adults and Witham and McMurdo's review on how to get older people included in clinical studies (Berkman, Leipzig, Greenberg, & Inouye, 2001; Witham & McMurdo, 2007). Through a collaborative effort between the investigators and cardiac rehabilitation clinicians, recruitment strategies were tailored to the older adult population of interest (CHD patients) and the circumstance of hospitalization (Witham & McMurdo, 2007) . Recruitment procedures were established with cardiac rehabilitation clinician input for identifying, accessing and collecting information about older CHD patients who appeared to meet eligibility criteria, as suggested from Chouliara and colleagues' experience with challenges in conducting research with hospitalized older people (Chouliara, Kearney, Worth, & Stott, 2004). Inpatient cardiac rehabilitation clinicians approached potential older adult participants during routine cardiac rehabilitation consults and provided information in this study.

Previous research has found that older adults are willing to participate in cardiac clinical trials (Peterson, Lytle, Biswas, & Coombs, 2004; Sen Biswas, Newby, Bastian, Peterson, & Sugarman, 2007) but they are unlikely to purposefully inquire about research participation (Townsley et al., 2006). Because many older adults want to participate in research but may not actively request study information, recruitment procedures should be designed so potential older adult participants are approached with study related information.

The timing of the recruitment approach for eligibility screening has great significance for hospitalized older adults. From their data based findings, Berkman and colleagues (2001) have recommended that the recruitment approach should be appropriately delayed when potential competing circumstances are identified: scheduled patient care activities (i.e. assessments or clinical procedures); actual or anticipated competing patient priorities (i.e. mealtime or visitors); and difficult patient health-related circumstances (i.e. symptomatic distress, agitation, or fatigue) (Berkman et al., 2001). Jairath and colleagues (2005) found that hospitalized cardiovascular patients were more receptive to their recruitment approaches during less active weekend or afternoon hours (Jairath, Ulrich, & Ley, 2005).

In this study, the combination of inclusion criteria (65 years of age or older and initial acute CHD event) was more restrictive for recruitment efforts than expected. While upper age limits and co-morbid disease state exclusions were minimized to avoid unnecessary restriction (as noted in two reviews addressing barriers to the participation of older adults in clinical studies) (Townsley, Selby, & Siu, 2005; Witham & McMurdo,

2007), we found that many potential participants who were 65 years of age or older were admitted for a repeat CHD event. This was surprising as the mean age for an initial AMI is 65.8 years for men and 70.4 years for women (American Heart Association, 2007). The heterogeneity inherent within older adult cohorts and the need for flexibility in the design of research protocols to promote older adult participation was illustrated in this finding.

Our research protocol could have been designed with more flexibility to encourage enrollment during hospitalization. We designed a single recruitment interview to include eligibility screening, the informed consent process, and baseline data collection. Older adults were asked to complete 179 questionnaire items for demographic and baseline data collection. The questionnaires were pre-tested for a time estimate but not with the full age range within the sample. This resulted in an inaccurate time estimate of 35 minutes for completion. The recruitment interview often lasted more than one hour. Thirty to 45 minutes have been recommended as the maximum hospital recruitment interview length for older adult tolerability (Berkman et al., 2001). Enrollment during hospitalization may have been encouraged through decreased participant burden with flexible research protocol options for shorter, separate recruitment interview sessions and post-discharge baseline data collection for more critically ill older adults (Berkman et al., 2001).

Aging changes and sensory impairment were considered within the design of our research protocol, based upon the recommendations of McNeely and Clements' review on challenges in the recruitment of older adult participants. (McNeely & Clements,

1994). Large, black, plain font types were used on matte paper for all study related

documents to optimize contrast for those with vision impairments (Berkman et al., 2001;

Witham & McMurdo, 2007). Potential participants were encouraged to use glasses,

hearing aids, and adequate lighting as appropriate during the recruitment interview. The

principal investigator sat face to face with older adults during the interview process and

spoke clearly and slowly (Berkman et al., 2001). Adequate time for comprehension and

questioning was provided for the older adults during the interview (Witham & McMurdo,

2007).

   Research conducted with older adult cohorts has the potential for selection bias

and low participation rates (Chouliara et al., 2004). Potential strategies to limit selection

bias and improve older adult participation in research have been suggested. Chouliara

and colleagues recommend negotiation with key hospital administrators and clinicians to

determine procedures for recruitment and research implementation that are not

methodologically and/or ethically cumbersome for older adult patients or the usual care

process (Chouliara et al., 2004). The importance of the research question to the older

adult patient population of interest and clinical practice to limit selection bias and

improve participation rates has been noted by Ross and colleagues in their systematic

review on barriers to participation in randomized controlled trials (Ross et al., 1999).

Selection bias and low participation rates were not problematic in this pilot study. The

recruitment process for this pilot study, while longer than anticipated, was found to be

effective in encouraging older adult participation in research during hospitalization.

Summary

The older adult population is expected to grow at a faster rate than the total U.S. population from now until 2050 (National Center for Health Statistics, 2006). The chronic disease burden among older adults will contribute to rising health care costs, and increased pain and disability in this population (Centers for Disease Control & The Merck Company Foundation, 2007). Therefore, representation of older adults in research studies is essential to identify evidence-based strategies to prevent disease and effectively manage chronic diseases in this increasing population. Strategies to enhance participation of older adults need to be considered early in the design and implementation of research studies investigating older adult population issues.

Characteristics	Eligible** (n=88)		Refused (n=16)		Enrolled (n=72)	
	n	%	n	%	n	%
Age						
Young-old (50-64)	27	30.7	2	13.3	25	34.7
Middle-old	35	39.8	8	53.3	27	37.5
(65-74)	25	28.4	5	33.4	20	27.8
Old-old (≥ 75)						
Gender						
Male	59	67.0	7	43.8	52	72.2
Female	29	33.0	9	56.2	20	27.8
Race/Ethnicity						
African-American	10	11.4	2	66.7	8	11.1
White (non-	65	73.9	1	33.3	64	88.9
Hispanic)						
Acute CHD						
Event*	31	35.2	4	25.0	27	38.0
AMI	9	10.2	2	12.5	7	9.7
Angioplasty	50	56.8	8	50.0	42	58.3
Stent	29	33.0	6	37.5	23	31.9
CABG surgery						

Table 3.1. Demographic and clinical characteristics of older adults eligible and enrolled

* Acute CHD event categories are not mutually exclusive

** Six screened and were ineligible

Circumstances of non-participation by 16 respondents		n
Patient reasons		
Not interested in paperwork	Patients did not wish to answer questionnaires for baseline data collection during hospitalization	9
Not feeling well	Patients were not feeling well when approached by the principal investigator (e.g. "head feels fuzzy", nauseated, and tired)	5
Not interested	No other information provided	3
Feeling overwhelmed	Patient was overwhelmed since finding out about heart disease and did not wish to participate	2
Personal health information use	Patient expressed concern about use of personal health information in research	1
Would need help from someone	Patient would need help from someone to complete follow-up questionnaires at home and did not want to depend on someone in order to participate	1
Caregiver responsibilities	Patient was focused on getting home quickly to help a significant other with cancer treatments and did not want to add any new responsibility	1

Table 3.2. Patient reasons given for non-participation*

* Categories are not mutually exclusive

Strategies to improve older adult participation in research during hospitalization

- Involve key hospital administrators and clinicians early in the research process
- Tailor recruitment strategies to the older adult population of interest and circumstance of hospitalization
- Negotiate to establish procedures for identifying, accessing, and collecting information about eligible patients
- Approach potential participants with study related information
- Delay the recruitment approach when competing circumstances are identified
- Plan recruitment approach during less active hours
- Select inclusion and exclusion criteria carefully
- Embrace heterogeneity inherent within an older adult sample
- Limit the recruitment interview to 30-45 minutes for tolerability
- Provide options for separate, shorter recruitment interview sessions and post-discharge baseline data collection
- Decrease participant burden to the extent possible
- Consider the impact of sensory impairment on recruitment efforts
- Research implementation should not be methodologically or ethically cumbersome for patients or interfere with their care
- Ask an important research question for the population and clinical practice

Table 3.3. Strategies to improve recruitment of older adults in research studies

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APPENDIX A

REVISED ILLNESS PERCEPTION QUESTIONNAIRE

Illness Perception Questionnaire (IPQ-R)

YOUR VIEWS ABOUT YOUR HEART DISEASE

Listed below are a number of symptoms that you may or may not have experienced since your heart disease. Please indicate by *circling Yes or No,* whether you have experienced any of these symptoms since your heart disease.

I have experienced this symptom since my heart disease . . .

Pain	YES	NO
Sore Throat	YES	NO
Nausea	YES	NO
Breathlessness	YES	NO
Weight Loss	YES	NO
Fatigue	YES	NO
Stiff Joints	YES	NO
Sore Eyes	YES	NO
Wheeziness	YES	NO
Headaches	YES	NO
Upset Stomach	YES	NO
Sleep difficulties	YES	NO
Dizziness	YES	NO
Loss of Strength	YES	NO

Listed below are a number of symptoms that you may or may not have experienced since your heart disease. Please indicate by *circling Yes or No*, whether you believe that these symptoms are related to your heart disease.

This symptom is related to my heart disease . . .

Pain	YES	NO
Sore Throat	YES	NO
Nausea	YES	NO
Breathlessness	YES	NO
Weight Loss	YES	NO
Fatigue	YES	NO
Stiff Joints	YES	NO
Sore Eyes	YES	NO
Wheeziness	YES	NO
Headaches	YES	NO
Upset Stomach	YES	NO
Sleep difficulties	YES	NO
Dizziness	YES	NO
Loss of Strength	YES	NO

We are interested **in your own personal view of how you now see your heart disease.** Please indicate how much you agree or disagree with the following statements about your heart disease by **marking (X) the appropriate box.**

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
IP1	**My heart disease will last a short time.**					
IP2	**My heart disease is likely to be permanent rather than temporary.**					
IP3	**My heart disease will last for a long time.**					
IP4	**This heart disease will pass quickly.**					
IP5	**I expect to have heart disease for the rest of my life.**					
IP6	**My heart disease is a serious condition.**					
IP7	**My heart disease has major consequences on my life.**					
IP8	**My heart disease does not have much effect on my life.**					
IP9	**My heart disease strongly affects the way others see me.**					
IP10	**My heart disease has serious financial consequences.**					

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
IP11	**My heart disease causes difficulties for those close to me.**					
IP12	**There is a lot which I can do to control my symptoms.**					
IP13	**What I do can determine whether my heart disease gets better or worse.**					
IP14	**The course of my heart disease depends on me.**					
IP15	**Nothing I do will affect my heart disease.**					
IP16	**I have the power to influence my heart disease.**					
IP17	**My actions will have no affect on the outcome of my heart disease.**					
IP18	**My heart disease will improve in time.**					
IP19	**There is very little that can be done to improve my heart disease.**					
IP20	**My treatment will be effective in curing my heart disease.**					

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
IP21	**The negative effects of my heart disease can be prevented (avoided) by my treatment.**					
IP22	**My treatment can control my heart disease.**					
IP23	**There is nothing which can help my heart disease.**					
IP24	**The symptoms of my heart disease are puzzling to me.**					
IP25	**My heart disease is a mystery to me.**					
IP26	**I don't understand my heart disease.**					
IP27	**My heart disease doesn't make any sense to me.**					
IP28	**I have a clear picture or understanding of my heart disease.**					
IP29	**The symptoms of my heart disease change a great deal from day to day.**					
IP30	**My symptoms come and go in cycles.**					

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
IP31	**My heart disease is very unpredictable.**					
IP32	**I go through cycles in which my heart disease gets better and worse.**					
IP33	**I get depressed when I think about my heart disease.**					
IP34	**When I think about my heart disease I get upset.**					
IP35	**My heart disease makes me feel angry.**					
IP36	**My heart disease does not worry me.**					
IP37	**Having heart disease makes me feel anxious.**					
IP38	**My heart disease makes me feel afraid.**					

CAUSES OF MY ILLNESS

We are interested in **what YOU consider may have been the cause(s) of your heart disease**. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your heart disease rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your heart disease. Please indicate how much you agree or disagree that they were causes for you by **marking (X) the appropriate box.**

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
C1	**Stress or worry.**					
C2	**Hereditary- it runs in my family.**					
C3	**A germ or virus.**					
C4	**Diet or eating habits.**					
C5	**Chance or bad luck.**					
C6	**Poor medical care in my past.**					
C7	**Pollution in the environment.**					
C8	**My own behavior.**					
C9	**My mental attitude- thinking about life negatively.**					
C10	**Family problems or worries.**					

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
C11	**Overwork.**					
C12	**My emotional state- feeling down, lonely, anxious, empty.**					
C13	**Ageing.**					
C14	**Alcohol.**					
C15	**Smoking.**					
C16	**Accident or injury.**					
C17	**My personality.**					
C18	**Altered immunity.**					

In the table below, please list in rank-order the 3 most important factors that you now believe caused **YOUR** heart disease. You may use any of the items from the boxes above, or you may have additional ideas of your own.

The most important causes for me:

1. _____

2. _____

3. _____