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## Developing self-management education in coronary artery disease

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### Abstract

We describe a three-step approach to develop and evaluate a novel coronary artery disease (CAD) self-management educational workbook. First, we conducted interviews using grounded theory methods with a diverse CAD cohort (n=61) to identify needs and perceptions. Second, we developed the workbook, incorporating themes that emerged from the qualitative interviews. Finally, 225 people with CAD used the workbook in a longitudinal study and we evaluated their use of and experience with the workbook at 12 months. 12-month evaluation data revealed that the workbook: provided practical health information; enhanced behavior-specific self-efficacy; and reinforced that healthy behaviors decrease risk. Participants who read the workbook had greater within-patient increases in physical activity at 12-months compared with non-readers (p=0.093)

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and among Black/Hispanic participants, workbook readers' increases were significant (592 vs. -645,  $p=0.035$ ). A self-management educational workbook developed using qualitative methods can provide relevant, disease-specific health information for patients with CAD.

## Keywords

angioplasty; chronic disease; coronary artery disease; disease self-management; health behavior; patient education

## Introduction

Behavioral risk reduction in coronary artery disease (CAD) plays an important role in mediating health outcomes following coronary angioplasty.<sup>1</sup> However, many people with CAD lack critical knowledge about the role that behaviors (e.g., physical activity) can play in secondary prevention.<sup>2</sup> Further, people with CAD may underestimate the risk of disease progression if unhealthy lifestyle behaviors persist after sustaining an event such as coronary angioplasty.<sup>3-5</sup> For example, those with CAD who engage in physical activity can achieve significant and growing reductions in mortality and cardiovascular risk with maintenance of activity; a number of meta-analyses have established that people with CAD who participate in exercise-based cardiac rehabilitation have lower overall mortality (13%,<sup>6</sup> 20%<sup>7</sup> and 26–47%<sup>8,9,10</sup>) and decreased cardiac mortality (26%,<sup>6</sup> 26%<sup>7</sup> and 30%<sup>8,9,10</sup>) with program adherence at 12, 15 and 24 months, respectively. Despite these impressive reductions in outcomes, most people with CAD do not engage in sustained physical activity or other health behaviors consistently over time and rates of non-adherence are high.<sup>11,12</sup> According to data from NHANES (2009–2010), among those with cardiovascular disease (CVD), almost two-thirds engage in no physical activity.<sup>13</sup> Studies demonstrate that among people who have been hospitalized for CAD, physical activity levels increase initially following discharge and then begin to decline at about 2–4 months post-discharge.<sup>12,14</sup> Among people who participate in exercise-based cardiac rehabilitation programs, all age groups experience a downward trend in exercise over time and only 22% of people are adherent to guidelines after 12 months.<sup>11</sup> Therefore, new approaches are needed to both educate those with CAD and at risk for CAD about health behaviors, such as physical activity, as well as motivate sustained healthy behaviors over time.

Most people with CAD lack knowledge about the role that health behavior, such as physical activity, can play in decreasing risk of recurrent cardiac events.<sup>2,4</sup> Health education is a critical component of behavior change, but general health education alone has been shown to be inadequate to motivate physical activity in older adults.<sup>15</sup> Enhancing self-efficacy,<sup>16,17</sup> self-monitoring,<sup>16,18</sup> and goal-setting<sup>18,19</sup> are examples of proven approaches in the management of CAD risk factors and combinations of such approaches are recommended to promote behavior change.<sup>15,20,21</sup> Some of the strongest evidence in promoting health behavior supports the application of self-efficacy theory.<sup>22</sup>

Self-efficacy, a person's confidence to perform a specific behavior,<sup>23</sup> is a mediator of self-management activities and health outcomes and predicts both initiation and maintenance of health behaviors.<sup>24,25</sup> In women with CAD, self-efficacy has been shown to predict self-management behaviors including medication adherence, physical activity, stress management and diet.<sup>26</sup> Our overarching goal was to enhance CAD participants' behavioral self-efficacy, i.e., in this context, their confidence to engage in cardiovascular disease self-management strategies, such as increasing physical activity. We applied the following constructs from Social Cognitive Theory: 1) Self-efficacy enhancement; 2) Behavioral

Contracting; 3) Self-monitoring; 4) Outcome Expectations; and 5) Observational Learning/Modeling.<sup>23,27</sup>

In applying Social Cognitive Theory to ethnically diverse groups, Bandura asserts that the fundamental determinants of behavior operate similarly in all populations and that the theoretical approach can be adapted across demographic, racial and ethnic groups. Whether the society is primarily individualistic or communally-focused, a high perceived efficacy promotes both high effort and performance attainments.<sup>28,29</sup> In order to reach the increasingly diverse population in the United States, researchers and educators have recognized the need for and benefits of delivering care and health education that is tailored to address cultural attitudes and beliefs.<sup>30–33</sup> The current standard is to develop separate, disease-specific educational materials for different racial, ethnic or cultural groups; in one study the investigators created 12 versions of an educational guide.<sup>34</sup> We sought to create a self-management educational workbook that would be cross-cultural, that is, would be relevant and understood by our diverse population of people with CAD in New York City. Previously, cross-cultural and transcultural approaches have been applied to educating<sup>35</sup> and providing resources<sup>36</sup> to healthcare practitioners; this approach has not, to our knowledge, been universally applied in patient education.

This paper describes the process and methods used to create self-management education for people with CAD designed to address the needs of a racially/ ethnically diverse group, all of whom had recently undergone coronary angioplasty. Our approach involved three steps: 1) conducting qualitative interviews to identify needs and perceptions of disease in a cohort with CAD; 2) developing the self-management workbook employing Social Cognitive Theory and incorporating patient-generated themes that emerged from the qualitative interviews; and 3) implementing the workbook as a tool within a larger behavioral intervention study and evaluating patients' use and experience with the workbook at the end of 12 months.

## Qualitative Study

The goal of the qualitative study was to assess the needs, perceptions, knowledge, attitudes and beliefs of the population, and to gain a sense of our population's understanding of CAD self-management. The Institutional Review Board approved the study and all participants provided informed written consent. We interviewed 61 post-angioplasty patients 3 years after enrollment in a previous behavioral study. We used purposive sampling to make certain that half of our sample had been *successful* in behavior change in the previous study and that half had been *unsuccessful* in behavior change.<sup>4</sup> In this manner, we believed we would obtain a broad continuum of information about the barriers to and facilitators of behavior changes. In addition, we employed maximum variation sampling<sup>37</sup> to ensure oversampling of minority participants (33% Black, 33% Hispanic and 34% Caucasian) and women (48%) (Table 1). The methods and results of the qualitative study have been previously reported.<sup>4,30</sup>

The interview data generated four main themes (see Table 2).<sup>4</sup> In particular, theme 4 highlighted that knowledge deficits were common and that many people had misperceptions regarding the relationship between health behaviors and cardiovascular risk reduction. Participants undervalued health behaviors in secondary prevention, felt a lack of control over their health, and tended to minimize the seriousness of coronary angioplasty.

## Developing the Workbook

Our overarching goal was to enhance self-efficacy, and thus we developed a workbook that addressed the components of Social Cognitive Theory. Strategies to increase self-efficacy included incremental goal setting, behavioral contracting and self-monitoring.

### Behavioral Contracting

In addition to providing concrete strategies for increasing physical activity, we included a behavioral contract, whereby participants were encouraged to set their own reasonable goals for behavioral change.<sup>38</sup> The contract included four components: Do what? When? How often? How much?<sup>38</sup>

### Self-monitoring

We encouraged participants to keep track of their progress and provided space within the workbook to record their goals. We included a table for participants to track incremental progress, to facilitate regular review and adjustment of the behavioral goal.

### Outcome Expectations

In order to inform beliefs about the potential consequences resulting from particular health behaviors, we included educational information on topics such as: “*How can heart disease limit my activity?*” and “*What kinds of exercise should I be doing?*” We also described the potential health benefits of increasing physical activity.

### Observational Learning/ Modeling

We used vignettes and images to provide real life and relatable examples of participants who achieved successful behavior change and included strategies that participants in the qualitative study employed to overcome challenges to behavior change. Short, descriptive narrative vignettes are a valid means by which to convey medical information,<sup>39,40</sup> and may be particularly effective within the context of Social Cognitive Theory.

### Content Validity

First, to establish the domains that would be represented in the workbook, a cardiac nurse specialist, a behavioral scientist and a physician, each experts in their field and co-investigators on the study, reviewed the proposed workbook content and then met to reach consensus and establish content validity. The panel of experts decided to include the domains of physical activity, diet, stress reduction, smoking cessation, medication adherence, and doctor-patient communication, employing Social Cognitive Theory to enhance self-efficacy.<sup>27</sup> Second, we incorporated education on topics specific to the areas of knowledge deficit identified in the qualitative interview phase. Third, we incorporated the qualitative themes. Based on the analysis of participants’ comments regarding their beliefs and perceptions about heart disease, as well as the barriers and facilitators to behavior change, we determined that what participants wanted most was a practical guide to disease self-management that was both culturally and personally relevant. The interview data also revealed that participants lacked information that would not only help them to better understand their heart disease and its consequences, but also provide them with practical advice on how they could manage their disease following angioplasty. We next used these data to design a self-management educational workbook that would satisfy these requirements. We addressed these goals with the content and teaching methods described in Table 3. Finally, the panel of experts met to review the self-management workbook content and reached consensus.

## Workbook format

The workbook, *Living with Heart Disease: Taking Control after Angioplasty*© is a 29-page, colorfully illustrated spiral-bound booklet containing seven chapters.

## Implementing and Evaluating the Cross-Cultural Workbook

We distributed the workbook to a second post-coronary angioplasty cohort, all enrolled as participants in a behavioral randomized controlled trial (RCT) designed to motivate increased physical activity over 12 months (2004–2008).<sup>14,30</sup> The Institutional Review Board approved the study and all participants provided informed written consent. We enrolled participants immediately following coronary angioplasty and followed them for one year. Participants in both the control group and intervention group received a copy of the workbook. We contacted participants by telephone at bimonthly intervals and instructed them to read a specific chapter of the self-management workbook.

To evaluate the workbook, we focused on physical activity to assess health behavior change, given the high potential for reductions in cardiac morbidity and mortality that are associated with increases in physical activity.<sup>6–10</sup> Using the Paffenbarger Physical Activity and Exercise Index,<sup>41</sup> we measured physical activity levels, in kilocalories (kcal) per week, bi-monthly from baseline to 12-months. The Paffenbarger, one of the most frequently used self-report measures of physical activity,<sup>42–45</sup> has demonstrated validity and reliability.<sup>46</sup> The Paffenbarger has a one month test-retest reliability of  $r=0.72$ <sup>47</sup> and a moderately strong correlation with activity diaries ( $r=0.62$ – $0.65$ ).<sup>48</sup> We also assessed participants' self-efficacy for their physical activity goal (0–10) at each bi-monthly follow-up. The entire team, which included clinical epidemiologists, behavioral scientists, psychologists, and qualitative experts, met to develop with the qualitative evaluation questions, and performed item generation for the open-ended questions. At 12 months we evaluated participant's use and experience with the workbook using 2 items (e.g., *Was the workbook helpful?* “yes, a lot helpful”; “yes, somewhat helpful”; “yes, a little helpful”; “no, it was not helpful”; or “did not read”; and *If yes, in what way was it most helpful?*). We used student's t-tests and the Fisher Exact test to compare within-patient change from baseline to 12 months. We used grounded theory methods, as described above, to analyze all qualitative data.

## Evaluation Results

225 post-coronary angioplasty patients who used the workbook over 12 months in the RCT provided valid feedback during the evaluation. The average age was  $63 \pm 11$ ; 81% were non-Hispanic Caucasian, 12% Hispanic and 10% Black. The cohort was 29% female, 7% had not completed high school (Table 1). 89% of participants reported that they had read the workbook.

**Qualitative**—Participants reported that the workbook: 1) provided practical health information ( $n=75$ ) (e.g., “It explained... what I had to do to prevent this from happening again”); 2) enhanced their confidence ( $n=34$ ) (e.g., “Helped me to practice the things I wanted to do”); 3) reinforced the concept that health behaviors decrease risk ( $n=7$ ) (e.g., “It's a reminder of vulnerability and that you can do something about it”); and 4) provided stories about people like them who face similar challenges ( $n=2$ ) (e.g., “Knowing other people have the same problems”) (Table 4).

**Quantitative**—We evaluated physical activity over 12 months by assessing within-patient changes in kcal/week expenditure (12-months – baseline). Those who read the workbook reported greater within-patient increases in kcal/week at 12 months, as compared with those who did not read the workbook (Figure 2), although this difference was not statistically

significant at 12-months ( $p=0.093$ ). However, Black and Hispanic participants who read the workbook reported significantly greater within-patient increases in kcal/week at 12 months compared with Black and Hispanic participants who did not read the workbook ( $592$  vs.  $-645$  kcal/week,  $p=0.035$ ). For those who read the workbook, mean self-efficacy over 12 months was  $8.5 \pm 1.6$  vs.  $8.9 \pm 1.4$  among those who did not read the workbook ( $p=0.06$ ). When we examined within-patient change in self-efficacy from baseline to 12 months, there were no differences between the two groups ( $p=0.68$ ).

## Discussion

Patient education enables people with chronic disease to better self-manage their disease.<sup>49</sup> Off-the-shelf, generic health education may not meet the educational needs of specific groups. We have described a reproducible three-step approach to the design and evaluation of self-management educational material that can be employed to develop new materials for other chronic disease groups. We employed qualitative methods to develop materials to address the learning needs of several racial and ethnic groups with a shared chronic disease, thus offering a new and cost-effective approach to providing culturally relevant, disease-specific education. Other studies have used qualitative approaches, including focus groups, to develop educational materials;<sup>40,50–52</sup> however, to our knowledge, the use of a multiple-step, formative approach to develop disease-specific health behavior education materials has not been previously described.

Participants who reported reading the workbook had greater mean increases in physical activity and were able to maintain and gradually increase activity throughout the 12-month study period; participants who did not read the workbook had much less improvement in physical activity, and in fact, decreased kcal expenditure over time (Figure 2). Not surprisingly, those who did not read the workbook had slightly higher mean self-efficacy over 12 months (although not significantly higher than workbook readers); higher self-efficacy may be one reason why these participants chose not to read the workbook.

A major strength of our approach to developing patient self-management is the use of participatory strategies. According to Kreuter, such participatory strategies enhance the perceived relevance of health issues for a cultural group by drawing on the experience of group members.<sup>53</sup> The use of patient vignettes is an effective method to convey health information in a way that is easily understood and retained.<sup>40</sup> Another strength of our approach is the incorporation of Social Cognitive Theory. Finally, the development of one workbook for a multi-racial/ethnic audience, as opposed to the development of separate workbooks for each racial and ethnic group, offers a more efficient approach. This is an important advantage when resources are limited.

Our study had the following limitations. First, the qualitative information we gathered may not be generalizable beyond New York City. Second, we sampled only Black, Hispanic and Caucasian participants who were English speaking; other groups may not find this workbook as relevant. Third, our evaluation cohort was not as diverse as our qualitative cohort, and we were not powered to evaluate differences between ethnic/ racial groups in the evaluation cohort. Fourth, in the evaluation phase, physical activity data were provided via self-report. Fifth, patient education materials should be developed for the populations and disease group for whom they are intended.

## Conclusion

Patients with coronary disease often perceive that they do not have adequate information from their health care provider about etiology, prognosis and ongoing challenges of living



with their disease, including symptom management.<sup>54</sup> Patient education materials should provide both basic information about the clinical aspects of a particular disease and practical advice on how to achieve and maintain important behavioral changes. Moreover, educational materials should be adapted to the population in which they will be used. This can be accomplished through the development and pilot-testing of self-management materials that are grounded in user needs and perceptions.

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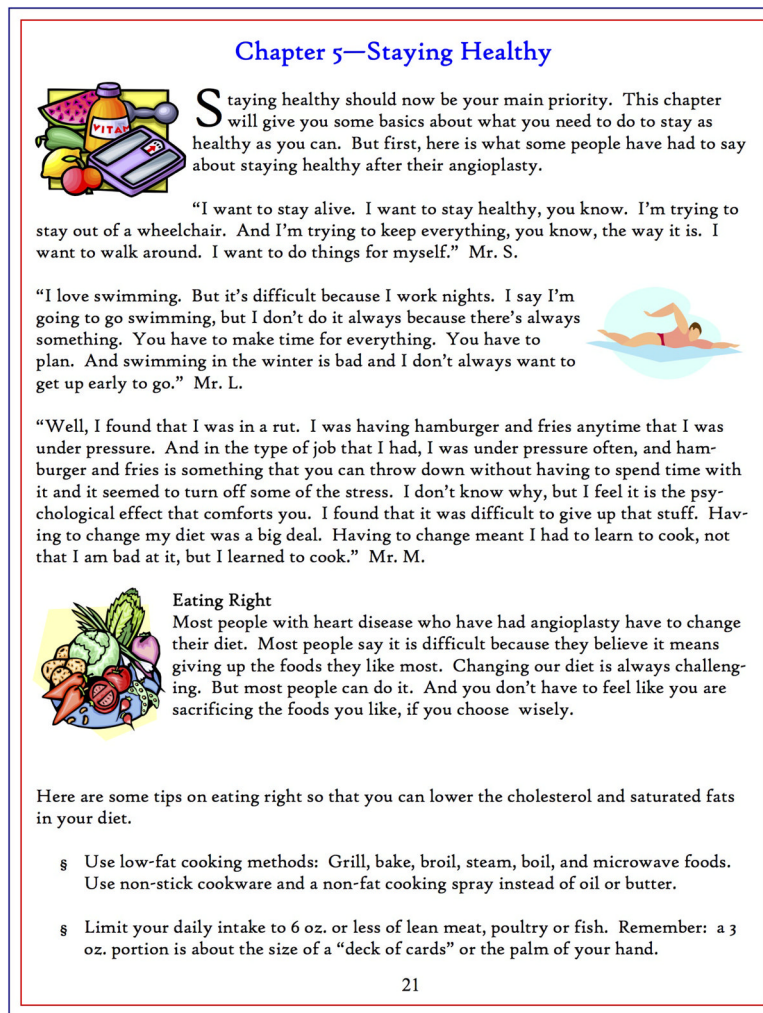
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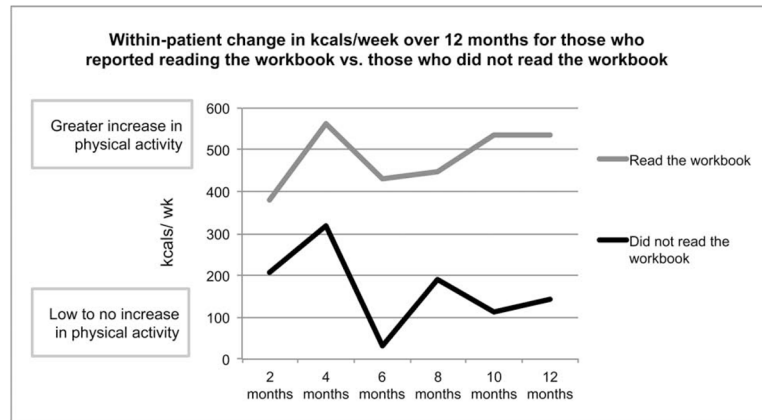


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**Figure 1.**  
Page (21) from Chapter 5—Staying Healthy—illustrating the use of narrative vignettes.  
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**Figure 2.** Within-patient change in physical activity in kilocalories per week for those who reported reading the workbook (n=200) vs. those who did not read the workbook (n=25).

**Table 1**

Demographic and clinical characteristics for the qualitative and evaluation cohorts used in development of the self-management workbook.

Characteristics, n (%)	Qualitative Cohort (n=61)	Evaluation Cohort (n=225)	p-value
Age (mean $y \pm SD$ )	63.8 $\pm$ 9.1	63.0 $\pm$ 11.0	0.60
Female	29 (48.0)	66 (29.3)	0.0074
Caucasian	21 (34.4)	183 (81.3)	<0.0002
African-American	20 (32.8)	23 (10.2)	<0.0002
Other race (Mixed or Asian)	0 (0.0)	19 (8.4)	0.019
Hispanic Ethnicity	20 (32.8)	26 (11.6)	<0.0002
Completed high school or greater	44 (72.0)	209 (92.9)	<0.0002
Working full or part time	23 (37.7)	129 (57.3)	0.0064
Married	30 (49.2)	159 (70.7)	0.0017
Body mass index (mean $kg/m^2 \pm SD$ )	29.3 $\pm$ 5.7	29.0 $\pm$ 5.8	0.72
Overweight (25.0 – 29.9)	28 (45.9)	90 (40)	0.41
Obese (>30.0)	21 (34.4)	82 (36.4)	0.77
Previous PCTA	24 (39.0)	82 (36.4)	0.68
Previous CABG	11 (18.0)	31 (13.8)	0.40
MI	22 (36.0)	65 (28.9)	0.28
Stroke	5 (8.2)	12 (5.3)	0.40
Diabetes mellitus	21 (34.4)	58 (25.8)	0.18
Former smoker	31 (50.8)	152 (67.6)	0.016
Current smoker	10 (16.4)	20 (8.9)	0.090

Adapted from <sup>4,23</sup>

**Table 2**

The qualitative themes from the semi-structured interviews in the Qualitative Study (n=61).

Qualitative Themes	Sample Quotes
1) Feelings of vulnerability and fear of uncertainty and death	"It's scary to know if [the angioplasty] is going to work or not"
2) Experiencing a "turning point" in life that helped some people to change health behaviors	"You have to rethink how you are going to run the rest of your life"
3) The need for social support from family, friends and other CAD patients that helped them cope	"I found out more from the other patients sitting in the cardiologist [waiting room] than I did from the doctors. Somebody said 'Don't be surprised if this happens...and this happens'"
4) Beliefs that "nothing helps" CAD or beliefs that CAD has been "cured" by coronary angioplasty – both of which were associated with unsuccessful behavioral change	"Angioplasty, I don't think it was a dangerous thing. I mean, this is half an hour to an hour job...if I had to go again, I would go with no problem"



**Table 3****Workbook Content**

<b>Goals</b>	<b>Content</b>	<b>Teaching Methods</b>
Increase knowledge on cardiovascular disease	<ul style="list-style-type: none"> <li>The basics of cardiovascular disease, symptoms and treatment</li> <li>Modifiable and non-modifiable risk factors</li> <li>Being responsible for one's disease</li> <li>Medications and risk factor management</li> </ul>	<ul style="list-style-type: none"> <li>Information drawn from established sources, including the American Heart Association and the National Heart, Lung and Blood Institute</li> <li>Anatomical graphics</li> <li>Action-oriented graphics</li> </ul>
Provide information that is relevant to a diverse patient population	<ul style="list-style-type: none"> <li>Brief narrative vignettes<sup>40</sup> and quotations derived from participants in the qualitative interview</li> <li>Examples of successful behavior change and its consequences (Figure 1)</li> <li>Tips for making successful behavior changes provided by other patients</li> </ul>	<ul style="list-style-type: none"> <li>Vignettes – storytelling of real life situations by relatable characters who are similar to the audience<sup>40,53</sup></li> <li>Establish “credibility” with the audience<sup>53</sup></li> <li>Illustrations depicting racial/ethnic diversity</li> </ul>
Address barriers to and facilitators of behavior change	<ul style="list-style-type: none"> <li>Tips for engaging in behavior change and incorporating health behaviors into daily routines</li> <li>Information about how to safely resume activities after coronary angioplasty</li> </ul>	<ul style="list-style-type: none"> <li>Utilized the actual words of participants from the qualitative interviews to convey culturally relevant, pragmatic health information.</li> </ul>
Encourage and facilitate self-management activities	<ul style="list-style-type: none"> <li>Space for participants to document questions for healthcare providers</li> <li>Blank medication list, including the purpose of the medicine and their feelings about taking the medicine</li> <li>Record a comprehensive medical history, including previous medical problems, surgeries and allergies</li> <li>Behavioral goal progress tracking table</li> </ul>	<ul style="list-style-type: none"> <li>Interactive format</li> <li>Self-monitoring</li> <li>Encourage participants to be an active participant in their health care</li> <li>Behavioral contracting</li> </ul>
Communicate information such that it can be readily understood <sup>55–60</sup>	<ul style="list-style-type: none"> <li>Non-technical, non-medical language</li> <li>Included definitions of medical terms (e.g. angina) prior to discussing them</li> </ul>	<ul style="list-style-type: none"> <li>Organization and format to facilitate ease of reading (e.g. font &amp; typeface)</li> <li>Sequence information logically</li> <li>“Chunking” to facilitate mastery of small groups of information</li> <li>Active voice with short, easy to read sentences</li> <li>Writing at an 8<sup>th</sup>-grade literacy level that was appropriate for all education levels within our qualitative sample.<sup>a</sup></li> </ul>

<sup>a</sup>We evaluated the reading level of the workbook using the Flesch-Kincaid Grade Level.

**Table 4**

The qualitative themes, categories and in-vivo patient quotes from the workbook evaluation (Step III) (N=172). The following themes were generated from participant responses to the open-ended question, “In what ways was the workbook helpful?”

Qualitative Themes	n
<b>1) Provided practical health information</b>	<b>75</b>
Specific instructions about how to modify diet and exercise	34
<ul style="list-style-type: none"> <li>“Eat more human proportions and eat in moderation”</li> <li>“It provided good guidelines to focus on in the chapters”</li> <li>“It explained... what I had to do to prevent this from happening again”</li> </ul>	
Understanding what heart disease is	16
<ul style="list-style-type: none"> <li>“It explained exactly what happened to me”</li> <li>“It made me more knowledgeable about modern cardiac therapy”</li> </ul>	
Imparted new information	11
<ul style="list-style-type: none"> <li>“It gave me knowledge I didn’t have prior”</li> <li>“Informative – it has things you don’t read in other places”</li> </ul>	
Clear and straightforward content	8
<ul style="list-style-type: none"> <li>“Breaks it down for ordinary people”</li> <li>“It was written in a clear and expressive way”</li> </ul>	
Gave approaches how to make behavior changes	6
<ul style="list-style-type: none"> <li>“The aspect about making things habit-forming was helpful”</li> <li>“How to approach doing [the goal]”</li> </ul>	
<b>2) Enhanced confidence to engage in behavior change</b>	<b>34</b>
Reinforcement/ Keeping track	11
<ul style="list-style-type: none"> <li>“Helped me to practice the things I wanted to do”</li> <li>“Reinforced a lot of the other information I received along the way”</li> </ul>	
Motivation/ Incentive	10
<ul style="list-style-type: none"> <li>“Inspired me to grow stronger”</li> <li>“I read about how important [exercise] is and it encourages me to do it”</li> </ul>	
Empowerment	6
<ul style="list-style-type: none"> <li>“Made me determined to do more distance”</li> <li>“It made me feel more confident”</li> </ul>	
Helped to get started making behavioral changes	4
<ul style="list-style-type: none"> <li>“It helped in the beginning to get started”</li> <li>“Helped to refocus”</li> </ul>	
Helped to be prepared	3

Qualitative Themes	n
<ul style="list-style-type: none"> <li>• “It helped me to understand my situation and be prepared for things”</li> <li>• “A blueprint of... what to expect”</li> </ul>	
Helped to read others’ stories	2
<ul style="list-style-type: none"> <li>• “Knowing other people have the same problems”</li> <li>• “Hearing about other people’s stories and accomplishments”</li> </ul>	
<b>3) Reminder of vulnerability</b>	<b>7</b>
Eye-opening – “this is your reality”	4
<ul style="list-style-type: none"> <li>• “It forced me to realize what heart disease was”</li> <li>• “The book alerted me that I had a problem”</li> </ul>	
Reminder of vulnerability	3
<ul style="list-style-type: none"> <li>• “It’s a reminder of vulnerability and that you can do something about it”</li> <li>• “Knowing that it can happen to younger people”</li> </ul>	
<b>4) Provided stories that were relatable</b>	<b>2</b>
People like them who face similar challenges	
<ul style="list-style-type: none"> <li>• “Knowing other people have the same problems”</li> </ul>	