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Marcie M. Tempel
Illinois Wesleyan University

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Living With Unstable Coronary Artery Disease

Marcie M. Tempel
and
Kathryn A. Scherck

Illinois Wesleyan University
Bloomington, Illinois

Abstract

Coronary artery disease (CAD) remains a leading cause of mortality and morbidity in the United States. CAD can be a long term, recurrent health problem placing a heavy burden on the afflicted individual. Although the mean age of individuals experiencing their first clinical symptoms of CAD is usually reported to be in the fifth or sixth decade of life, individuals may also experience symptoms of disease at an earlier age when actively engaged in career, family, and vigorous leisure activities. There is a sparsity of experiential information and nurses need to be sensitive to the psychosocial impact of this experience on daily living. This study proposes to examine the lived experience of one middle-aged man with unstable CAD using qualitative research methods.

Living With Unstable Coronary Artery Disease

Background

Coronary artery disease (CAD) remains a leading cause of mortality and morbidity in the United States (U.S. Department of Health and Human Services, 1995). According to 1990 statistics, approximately 6.2 million Americans have significant heart disease (National Heart, Lung and Blood Institute, 1990). Although the incidence of CAD increases with age, 45% of all heart attacks occur in individuals under the age of 65 (American Heart Association, 1992). Individuals may also experience this disease while in their forties when they are actively engaged in career, raising a family, and enjoying vigorous leisure activities.

It is generally acknowledged that any illness imposes hardships on the individual. The outcome of the illness is often unknown and the individual experiences anxiety regarding disability, physical suffering and perhaps even death (Orem, 1991). The emotional burden of CAD has been reported by experts to be especially high (Alspach, 1990). Mullen (1978) notes that this illness is unlike other chronic diseases that usually have a slow and insidious onset. The onset of CAD tends to thrust the individual into self-conscious consideration of what has previously been taken for granted.

Despite the substantial volume of research addressing the psychosocial aspects of CAD, relatively little has been documented about individual adjustment to living with this disease. Johnson & Morse (1990), in reviewing the accumulated literature, report that studies have tended to focus on aspects of rehabilitation, anxiety, denial, depression, and return to work. A number of studies describe coping methods used by cardiovascular clients (Cronin, 1990; Dracup, 1982; Ell & Haywood, 1985; Lowery, 1991; Malan, 1992; Miller, Garrett, McMahon, Johnson & Wikoff, 1985; Venderber, Shively, & Fitzsimmons, 1990; Wiklund, Sanne, Vedin, & Wilhelmson, 1985) but there is a void in the literature with regard to the actual experience of living with the disease on a day-to-day basis.

Significance

An in depth examination of two years in the life of one man living with this disease documenting the facts, events, concerns and emotions in temporal sequence may lead to an increased sensitivity in nurses delivering care to patients with CAD. As nurses gain more understanding of the patient's perspective, they might incorporate into their care such practices as preparing patients for setbacks and managing disappointment, as well as strategies for coping with uncertainty and fear.

Purpose

The purpose of this study was to describe the experience of living with CAD from the perspective of one middle-aged man. Examination of significant events, thoughts, concerns, and emotions of a two-year period were used to document the experience and characterize living with this chronic illness.

Method

The case study method as described by Lincoln and Guba (1985) and Mariano (1993) was the research method chosen for this study. This qualitative methodological approach focuses attention on a person in a particular situation, explores a present-oriented event, and is intensive in its examination of the phenomenon. The single-case design was selected as a "revelatory case" as described by Yin (1989); the principle researcher was a member of the informant's immediate family and privy to information not previously described in the clinical literature.

The informant was a 48-year-old husband, father, and airport maintenance mechanic living in rural Central Illinois, who experienced the onset of CAD in late fall of 1993. The period of inquiry included the initial experiences dating from November 30, 1993 through November 30, 1995. At the time of the appearance of symptoms which led to hospitalization, the informant was leading a very active life at work and with his family.

Verbal consent to participate was obtained as well as a release to identify the subject of the case study by name (see Appendix A). As details of this participant's situation were well known in the various communities where both the informant and principle investigator live and work, anonymity was not considered possible. Furthermore, this individual expressed a strong desire to be identified as the subject of the case study in his effort to share his acquired knowledge with others. Human subject's review to conduct the study was sought through the appropriate institutional body.

Data were collected from multiple sources and included audiorecorded open-ended interviews, telephone interviews, observational notes, personal diaries and medical records. An interview guide (see Appendix B) directed the initial interview. Care was taken to preserve the audit trail to enhance confirmability of the case (Lincoln & Guba, 1985). Subsequent interviews (see Appendix C) clarified and further explored the information provided in the initial interview, and a narrative of events was reconstructed from diaries and medical records. As data collection proceeded, the informant was also asked to graph his experiences on a time line identifying significant events and their emotional impact as a means of clarifying his verbal descriptions (see Figure 1).

Data analysis was guided by inductive procedures recommended for this type of case study by Yin (1989), Miles and Huberman (1994), Riessman (1993), and Lincoln and Guba (1985). These included: (a) reflective examination of content to uncover overall meaning; (b) line by line examination of transcripts, interview notes, diaries, and records to identify units of information; (c) labelling or naming units; (d) sorting, clustering, and categorizing units of information; and (e) examination of resulting categories for emerging content and themes. Documentation of process and procedure was maintained to support dependability. Data analysis proceeded concurrent with data collection. Procedures to assure credibility included clarification and confirmation from the informant of emerging content and themes.

Results

Two Years of Living with Unstable CAD

Significant events and occurrences in the two-year period between November 30, 1993 and November 30, 1995 are identified in Figure 1. These events and occurrences depict the roller coaster ride analogy that Mr. Tempel uses to describe his experiences. When he was asked to produce a visual representation of this ride, he drew the accompanying figure which has been modified only by transcription, rather than being hand written. The following narrative describes his experience day by day over a two-year period.

A Fearful Beginning

On November 30, 1993, Christopher Tempel was admitted to the hospital emergency room (ER) with shortness of breath and crushing chest pain radiating to his left arm and lasting for three to four minutes. He rated the pain as a 6 on a scale of 1 to 10, stating it felt "Like an elephant sitting on my chest." He was scared to death, as was his family; until this time no one had any idea that he had CAD. Mr. Tempel was placed on a nitroglycerine (NTG) drip to control his pain. A cardiac catheterization performed on December 1 revealed 90 % occlusion of his three main coronary arteries.

December 1993 - Overwhelming Revelations

After that first cardiac catheterization revealed his disease, Mr. Tempel consulted with his "new" cardiologist who recommended he undergo a second cardiac catheterization for a percutaneous transluminal coronary angioplasty (PTCA) to relieve the occlusions in his coronary vessels. The PTCA was successful at opening these vessels, but there was concern that the circumflex artery might close off by morning. Although he had not anticipated again being in the intensive care unit (ICU), Mr. Tempel was monitored there overnight. He was prescribed a "basket-full of pills" (see Appendix D), was taught about CAD, was instructed to stop smoking immediately, begin a regular exercise program and eliminate fat and cholesterol from his diet. He returned home on December 7 after eight days in the hospital and returned to work on December 8. Following this hospitalization he had only one episode of a "tight feeling" in his chest and once felt "hard pain in the right top part of his heart," but both incidents subsided without intervention. On December 17 he wore a Holter monitor for 24 hours; no electrical problems were detected so Mr. Tempel spent the afternoon painting. At this point he had accepted his "basket full of pills" as a remedy for his disease and expected life to return to normal.

January 1994 - The Roller Coaster Ride Begins

After a "happy" holiday season at home with his family, Mr. Tempel entered the hospital for the second time on January 13 with chest pain. He underwent his third catheterization and second PTCA which were determined successful. He returned home from the hospital on January 16, rested three days and returned to work on January 20.

February 1994 - Relatively Pain Free

Mr. Tempel met with a dietician on February 2 to discuss his new eating habits and agreed to limit cholesterol and fat in his diet. He was relatively free of chest pain and notes in his diary that he could even work overtime until February 28. He then started having chest pain at work and needed both rest and NTG to relieve it four of five days that week. But even this pain did not keep him from working as hard as usual.

March 1994 - Recurrence

March 14 brought a tightness in his chest; "flutters" sent him to the hospital ER the afternoon of March 15. He was admitted to ICU on March 16 for aggressive treatment of his pain with a NTG drip. He underwent his fourth cardiac catheterization and discovered that two of the blockages had recurred. He started a new medication, Nitrobid and continued to conform to dietary restrictions. On March 18 he returned home after "passing" a treadmill stress test. The next day his chest felt tight all day; he took two NTG to control the pain he experienced while digging at church. He experienced "flutters" during church on March 20. The following morning he called his cardiologist who advised him to increase the Nitrobid. He went to work but suffered fair to moderate chest pain all day, taking NTG in the evening. Again, he experienced chest pain and shortness of breath intermittently the following day at work. He was "stubborn" and "did not take NTG." Wednesday the pain continued, requiring two NTG for increasing chest pain. He called the doctor again and was instructed to report to the hospital the next morning for a fifth cardiac catheterization and third PTCA. The PTCA was successful and he was discharged two days later.

April 1994 - Could the Pain Be Something Else?

His physicians were increasingly frustrated with the inability to control Mr. Tempel's chest pain. They began to look for other causes although Mr Tempel was convinced that his pain was coming from his heart. He had chest pain or pressure almost daily and NTG was needed to relieve his pain at least twelve times the first week of April. On April 1 he underwent an esophageal endoscopy; results were negative. On April 5 he had tightness and "butterflies" in his chest while at work and reported quickly to the hospital where his pain was relieved by NTG and morphine drips. April 7 his chest pain returned, leading to his sixth cardiac catheterization. Again, doctors held him in the ICU. This time for close observation until he could be transported by ambulance to another hospital where he could undergo a rotoblator procedure on April 12. He was informed the procedure was successful and returned home with high hopes for resuming a "normal" life. However, he had chest pain that required use of NTG the entire following week. He rested at home until April 21 when he finally returned to work. April 26 he visited a gastroenterologist and was started on a new "stomach" pill. He saw his cardiologist on April 28 and reported he had taken NTG three days that week while working; his diary indicated this occurred once while mowing with a push lawn mower.

May 1994 - The Seemingly Endless Search Continues

Mr. Tempel had a few good days with no chest pain. Doctors continued to look for a non-cardiac reason for recurring pain and ordered an esophageal motility test on May 5; Mr. Tempel annotated his diary with "gross, gag, choke, sore throat." He had three NTG for chest pain at work on May 11 and three more before he went to the hospital. He was admitted overnight for a sonogram and radioactive dye test of the gallbladder followed by a dobutamine stress test. All test were negative and he returned to work on May 13. He had a few good days during mid-May and even walked and jogged a total of a mile with no chest pain on May 22. However, chest pain sent him back to the hospital on May 25 and he underwent his seventh cardiac catheterization and fourth PTCA on the left anterior descending artery (LAD) on May 26; he was starting to pay attention to vessel anatomy and this terminology was taking on meaning. He underwent his eighth cardiac catheterization on May 27 after having extreme pain despite intervention with pain medication. No ECG changes were noted so he was discharged on May 28 and returned to work on May 31 feeling sore inside "but getting better." He celebrated six months without smoking on May 30. It was at this time that Mr.

Tempel began to object to going to the hospital as he felt it was not worth the expense when there was not much that could be done.

June 1994 - Daily Pain and More Tests

June of 1994 brought two more hospitalizations to control pain with a NTG drip. He experienced chest pain that required NTG for relief 10 of 12 days in the first two weeks of June. On June 15 the pain became more severe and after working all day Mr. Tempel was admitted to the hospital. He underwent magnetic resonance imaging (MRI) on June 16 and his ninth cardiac catheterization on June 17, which showed no significant changes in the occlusion of the vessels so he was discharged on the following day. On June 26 he returned to the hospital for relief of his chest pain. After "passing" another dobutamine stress test on June 27, he returned home and was back to work.

July 1994 - More Pain and Still Searching

On July 18 Mr. Tempel was sent to a pain center for evaluation. There he underwent steroid injection therapy in his back. The pain was not relieved and he returned to the hospital on July 29 for his tenth cardiac catheterization. Again there were no significant changes in vessel occlusion. He returned home on July 31 feeling very frustrated and wondering how long he would be able to control his disease without hospitalization.

August 1994 - One Month Without Hospitalization - New Hope

Mr. Tempel's hopes soared again as he made it through the entire month of August without being hospitalized. He had some pain at times, but it was not severe and could be controlled with rest and NTG. He had another appointment at the pain center on August 3. Again, the steroid injection in his back seemed to have no effect on the chest pain.

September 1994 - Crashing to the Bottom - A Heart Attack and Emergency Cardiac Surgery

Hopes that he was finally back in control were crushed when he returned to the hospital on September 1 with chest pain. He was released the following day after a negative stress test and additional adjustment in his medications. He had chest pain intermittently throughout the following week and returned to the hospital September 11 for the longest stay of his CAD experience. On September 12, he underwent his 11th cardiac catheterization, which revealed 90% occlusion of the LAD. He had his 12th cardiac catheterization with laser ablation on September 13. This procedure was complicated by a tear of the inner wall of the vessel requiring placement of an intracoronary stent to insure patency. Still hospitalized, Mr. Tempel experienced the recurrence of chest pain on September 18 and returned to ICU. September 20 was the date of another dobutamine stress-test.

On the morning of September 22 he was scheduled for discharge when he experienced the most severe chest pain of his life. This time there were electrocardiographic (ECG) changes and an acute myocardial infarction was diagnosed. He was rushed to the catheterization lab for his 13th cardiac catheterization. The physician reported he was unable to "get through the clot" and Mr. Tempel underwent emergency two-vessel coronary artery bypass surgery (CABG) using a mammary artery and a saphenous vein graft. The saphenous graft was suspected of closing within the first few days post-operatively. Mr. Tempel spent four days in ICU on intra-aortic balloon pumping. On September 25 the pump was removed and he got up for the first time since surgery.

On September 27 he had a spell of dizziness with blurred vision and ringing ears. Doctors suspected a clot and ordered a carotid artery check and computerized scan, but symptoms subsided without intervention. He had a 26 minute shower, the first in many days on September 27 before returning home to begin outpatient cardiac rehabilitation and to be cared for by his family. At this time he was also advised to become a vegetarian.

October 1994 - Steady Uphill Climb

He was sure that after having made it through this intense crisis and the excruciating pain of the heart attack and surgery, that he would finally begin his journey back to a healthy, hospital-free lifestyle. During his time at home he experienced a great deal of depression and felt "worthless"; he was too weak. His 77-year-old mother-in-law stayed with him during the day. He did light housework, his cardiac rehabilitation workouts, and was even able to tolerate sneezing! Since surgery sneezing had been extremely painful; "it jarred your whole framework." This was a milestone, "a healing point I knew I would reach, but I didn't know how long it was going to take." On October 31 he "didn't feel good all day" and took NTG in the evening to relieve his chest pain.

November 1994 -"I Know Chest Pain!" - New Diagnosis

On November 4 Mr. Tempel was once again rushed to the ER with severe chest pain. He was told by his cardiologist it was only chest wall pain, but Mr Tempel was sure it was his heart again. "I know better! WAS NOT," he wrote in his diary. He returned home that afternoon with a slight adjustment in medication. On November 5 he took seven NTG and an Ativan which did not relieve the pain that radiated to his arms and caused numbness and tingling. On November 6, while walking on the treadmill at home, his chest pain required three NTG for relief. He finally gave in and went to the hospital at 10:30 that night. He underwent his fourteenth cardiac catheterization on November 9 which revealed one graft patent; the second graft was nonfunctional. At this time his cardiologist diagnosed small vessel disease. This meant that the pain would have to be controlled with medications and that PTCA and surgery would not be of further help in treating the disease. He began to realize this disease was not going to disappear and would need to be managed with medications, diet, and a limit to his activities.

He continued to have chest pain and treated it with NTG. On Sunday, November 10, he experienced a stabbing pain in his neck and shoulder during church which almost caused him to pass out. The pain persisted on Monday and he resumed taking Mevacor. That week he needed NTG only once when he took his medication late. He underwent a stress test on November 11 and "passed", but had chest pain and took NTG four times that evening. November 12 was another day of pain and NTG and on the 13th his doctor changed his medications again, taking him off Nitrobid and adding Imdur. He returned home and to his normal activities on November 14; he washed his truck, walked outside, and shoveled trash without pain later that week. On November 26 he experienced a pain as a 7-8 on the now familiar 1 to 10 scale. The pain went "clear through" and caused numbing in both arms; it was relieved by NTG. On Monday November 28, Mr Tempel worked very hard in his garage, bringing in firewood and sweeping, and experienced light chest pain only three times which went away without NTG. Mr. Tempel noted in his diary, "Bad temper at times!", which he later explained to mean that when he got mad at his heart disease he pushed himself physically. On November 30, one year since his first pain and his last cigarette, he cut and burned three trees. This required three NTG and yet another while applying a license plate sticker to a car.

December 1994 - Normal Life

On December 1 he reported to the Heart Center for supervised cardiac rehabilitation. Later he tried walking on the treadmill at home and had chest pain; he stopped and took NTG. That week he continued light weight workouts and walked on the treadmill with only light chest pain that subsided with rest. He had light chest pain on the 10th when he forgot to wear his NTG patch. The following week he reported only light chest pain after moving a ladder to put up Christmas lights. He reported no chest pain while scrubbing the kitchen floor or doing his cardiac workout.

He saw his doctor on December 16 and was released to return to work on December 19. He did so in high spirits and took it easy doing light work with no problems. That week he experienced "muscle pain", but said the chest pain was very light after working out. He washed two cars on December 24 and experienced pain he rated as a 2. He reasoned it occurred because he did not wear his NTG patch. He took one NTG on Christmas day. On December 26 he had four episodes of light chest pain, but discovered that breathing slowly for one to two minutes "fixed" the pain. The 29th he took one NTG when the pain was a 4 and was "stabbing" him in the chest.

January 1995 - Beginning A Better Year

January 3, Mr. Tempel discovered that cold air is a "definite no-no." He learned to wear a face mask when out in the cold to prevent chest pain while working outdoors. He was up to four pound weights for his workout by January 4 and walking 24 minutes on the treadmill. He was controlling chest pain at work by stopping his activity and taking deep breaths, without needing NTG. He worked overtime several times, plowing snow without chest pain. January 10 he had light chest pain walking out to get the mail. January 16 his doctor took him off Zantac, reduced the Vasotec to one per day, and scheduled the next appointment in one month. The doctor was reducing medications and decreasing the frequency of appointments, a sign of improvement. However, Mr. Tempel experienced chestpain while carrying in groceries on January 21 and chest pain of 4-5 on January 30, noting in his diary, "working too much?". January 31 he felt light chest pain while digging with a shovel.

February 1995 - Progress, A Smoother Ride

During February Mr. Tempel was able to work with little or no chest pain, although he would occasionally experience pain while at rest. Mr. Tempel noted in his diary that "most chest pain is caused by being at rest and then working outside in the cold", an example of learning to live with his disease through knowing his limitations. February 14 marked 90 days out of the hospital. At his doctors appointment on the 20th, he was taken off potassium supplement and Lasix, another sign of improvement. Despite this progress, he had chest pain walking uphill in the cold that required NTG on February 25.

March 1995 - Gradually Resuming the Old Pace

March brought several days with no chest pain at all, even while digging and doing hard work. However, NTG was needed to relieve pain after pushing a wheelbarrow in the cold air. When he visited his cardiologist on March 28 his Norvasc was reduced to one-half per day and his next appointment was set for May 19, six weeks away. This was another sign of progress.

April 1995 - Continuing "Normal" Life

Chest pain on April 10 required NTG at three in the afternoon, after which the doctor doubled the Mevacor. April 14, he celebrated 120 days since his last hospitalization. He had been feeling very "achy" all over and his muscles hurt a great deal, a common side effect of Mevacor. His doctor reduced the dose. Mr. Tempel was feeling less achy by the 21st, but by the following week was feeling "poorly" again and experiencing increased chest pain. He called the doctor after experiencing light chest pain all day, but the doctor could not see him until late the following week.

May 1995 - Back to the Hospital, Scared and Depressed

The first week of May he was having chest pain, shortness of breath, and taking NTG almost every day. On May 12 he went in to have an ECG which showed no changes. He continued to have chest pain over the weekend and was admitted to the hospital on May 17 for his fifteenth catheterization. This showed no changes in his main vessels. He returned home on the 18th with another adjustment to his medications; they were adjusted again on May 30.

June/July 1995 - A Great Summer

Mr. Tempel was back to vigorous work with no or very light chest pain. He had a wonderful summer and was able to return to a level of activity that enabled him to do, almost, whatever he chose to do, "As long as I behave", he noted in his diary. He made it through the very hot weather with relatively few problems. To Mr. Tempel, this meant he controlled his symptoms with rest and sublingual NTG.

August 1995 - From a Great Summer to the Unexpected Recurrence

August 3 Mr. Tempel experienced chest pain while polishing his boots. Six days later he experienced chest pain of 5-6 that "put me on the floor...after walking, not running, out to feed the dog". He took NTG to relieve the pain and felt "very tired". August 10-12 he felt very "achy" every day, August 13 he experienced chest pain "off and on all day". He took two NTG at rest on August 15 and again on the 20th after climbing stairs while carrying a heavy load of books. He had light chest pain five to six times during the day on the 21st, on the 22nd he experienced chest pain off and on all day. On the 23rd he had four different episodes of chest pain requiring four NTG with each occurrence to relieve his pain. He visited the doctor that day who increased his Imdur. By the 24th his "energy level was up", although he took two NTG on the 29th and experienced light chest pain all day on the 30th.

September 1995 - Back to the Hospital - Yet Another Cardiac Catheterization

He started September feeling chest discomfort almost continuously. His doctor scheduled him for his sixteenth catheterization on September 6 which revealed, once again, no changes. At this time the doctor said that he would call CAD stable at this time and other cardiologists agreed when they met to discuss this case on September 7. On September 8 Mr. Tempel returned home after being taken off his Coumadin and adding two aspirin per day to his list of medications. He underwent a dobutamine stress test on September 11 and had a positron emmission tomography (PET) scan done on September 21. He had some chest pain and called the doctor on the 25th to have the Lopressor decreased.

October/November 1995 - Stable Again?

During October and November Mr. Tempel controlled his chest pain with rest and by "shifting down a gear" and functioning at a "slower pace." With only a few exceptions he did this without NTG. He has learned to live with this disease, despite the frustrations it has brought to his everyday living.

Summary

In the two year period, November 30, 1993 to November 30, 1995, Mr. Tempel underwent sixteen diagnostic catheterizations, five PTCAs, double bypass surgery, and numerous stress tests. He spent 82 days in the hospital and lost more than 100 days of work (see Appendix E). He has spent numerous hours at doctors appointments, laboratory blood testing, and cardiac rehabilitation. He underwent many medication changes, quit smoking, began a regular exercise program, and maintained a low sodium, low fat, cholesterol-free diet. The total financial burden exceeded $288,000; the average cost for a simple cardiac catheterization was $3,700.

The chronology of events uncovers a part of the experience of living with unstable CAD. Mr. Tempel's narrative revealed facts and events of particular significance. For example, even small things became important, a shower, the ability to sneeze, days without chest pain, working, a suggestion that pushing limits may be a part of this lived experience. Each return to the hospital was associated with deviation from normal life into fear and depression that was often a brief episode, but at times became more sustained as indicated on Mr. Tempel's graph (Figure 1). Daily chest pain had become a part of "normal" living.

The Themes of Living with Unstable CAD

Living with unstable CAD was an ongoing process, as Mr. Tempel continued to incorporate changes into his daily living, learning to take personal control of this disease. "It's a new living, learning experience, everyday." Analysis of narratives revealed several major themes which characterize living with unstable CAD.

Living the Roller Coaster of Unstable CAD

As already reported, Mr. Tempel has related his experience of living with unstable CAD to riding a roller-coaster. "The roller coaster itself would have to be my heart because that's what is going up and down and causing the problems." The discovery of his symptoms marked the beginning of a treacherous ride that continues even today. As he describes the roller-coaster of living with CAD he speaks of "good days and bad days." "You know, you have your ups and downs, of course everybody has those, but with heart disease you have more." He speaks of "shifting down a gear" as he is forced by crushing chest pain to rest and not work at his accustomed pace. Just as a roller-coaster changes speed along its course, so has Mr. Tempel had to change the pace of his life. Each complication has forced a change along the track of his roller coaster ride. A long hospitalization might mean an emotional as well as a physical dip in the roller-coaster track, with discharge and feeling well resulting in a return to "normal life". Physical difficulties or successes and their accompanied "ups and downs" relate to emotional responses in the same direction. He diagramed his heart attack as the lowest point on the track as his health and hopes crashed to the "bottom of the barrel" and were slow in returning to a functional level. However, Mr. Tempel stated, "I'm living and enjoying it!"

Learning to Live With It. There are many components to this theme of learning to live with unstable CAD. Mr. Tempel has stated on several occasions, "so, I learn to live with it", or "that's a part of it", as he has gained insight over time through his many experiences. He has regained a sense of personal control through conscious decisions to adapt to changed physical abilities and radical lifestyle changes; "so there's a lot of adjusting and doing things differently." These adjustments are all a part of keeping his emotions positive and successfully regaining a sense of personal control. He has learned to refocus attention on other aspects of life so that heart disease or the heart attack is no longer the primary concern. "I think about it every day, I don't worry about it every day." Mr. Tempel has learned that he can no longer tolerate paint fumes or cold air, and must wear a dust mask to prevent chest pain when he encounters these situations.

Recognizing the Need to Change. Mr. Tempel realized from the discovery of his disease that his lifestyle was in need of change. Beginning with his first hospitalization he quit smoking, changed his diet to low-fat, cholesterol-free, and always complied with his medication regimen. "You take medications in good faith, hoping they will do what they are supposed to do." After his heart attack and learning about the heart as a muscle, he realized the importance of regular exercise and stated, "If you don't race your heart everyday, in some way, shape, or form, you've wasted the day as far as your body goes." As Mr. Tempel has identified, you have to learn to do things differently, "...and, if you don't change, you're either going to die or you're going to be in a state where you can't do anything."

Changing the Pace of Living. When asked to describe the most significant effect of having unstable CAD, Mr. Tempel comments, "it slows me down. I have to watch what I'm doing every day so I don't cause myself to have chest pain." In learning to live with his disease Mr. Tempel has realized that he cannot continue the constant fast pace at which he functioned before the disease was discovered. At times, when his disease is stable he can do nearly anything he wants, but during the times he is encountering problems he does not have sufficient energy to do everything he would like to do. Pacing is a learned process of adjustment that Mr. Tempel does not view negatively but accepts as part of his life. Just as a roller coaster slows at points along its path, so has Mr. Tempel had to slow his course through life.

Slowing down means some loss of freedom, related to a loss of energy. "If I start having tightness in my chest, or something, I just slow down." "Your ability or energy level is lower." "It's like you're driving a truck and you're going along and everything is just fine. And then you have to shift down a gear, and you can't go as fast through life, or into life as you would like. And you can't put forth as much effort or energy into doing just about anything. So you have to shift down, to adjust, to slow down. And it's not that life's quality is less, it's just you have to take life at a slower pace." "I'd say it's readjusting goals and gradually deciding to be happy with new ones."

Testing Limits. "Then, after the heart attack there are limits; you can only go so far in a day or you get really tired and sore, or something bothers you. And you want to be the way you were before the heart attack because that is the way you felt better and you enjoyed life more then." The loss of freedom associated with changing the pace of living means that Mr. Tempel has to calculate his limitations. This includes a process of testing his parameters. He explained, "Well, sometimes I push myself to the point where I just have to sit down. I do it deliberately; and I call myself names, like 'stupid' you know chest pain is coming if you keep going. But I do it anyway."

"When you know, actually know what your limitations are, it just makes you think about it that much more," Mr. Tempel explained with a story. He was going for his daily walk and was a half-mile from home when he started having chest pain. He asked himself, "do I turn around and go back home where I feel safe and I can sit down, or do I say, 'well let's push it a little bit and see how this is going to be?' You have to set new goals and know for sure that you can attain them without causing yourself a lot of pain, unbearable pain." When asked why he pushes himself, Mr. Tempel responded, "Because I feel that I can. Whereas, if I have another heart attack, that is going to disable me, to where I'm just in pain or gasping for air every time I exert myself. I'm not looking forward to that and I do fear that. But it never happens; there's always that possibility there. So I push myself when I know I can and get away with it, just to show myself that I'm still capable of working up to almost 100% of my potential." He further explains, "I'd say it's more of a test. I don't want to be stressing my heart to the point where it is crying out in pain, but yet, it is a muscle, it needs to be exercised."

Mr. Tempel, in exploring his limitations, seems to be testing himself against his stamina to determine his threshold. He tells a story of a day the temperature was dropping quickly. He decided to go outside without his mask and see what would happen. Consequently, he had chest pain, stopped, put the dust mask on, and breathed slowly until the pain went away. He was trying to determine exactly what temperature would require he wore the dust mask. As Mr. Tempel has tested the limits that his disease has imposed upon his pace of living, he has, to an extent, learned to control his chest pain. He further explains this behavior, "if I don't push myself every once in a while and do more than I am supposed to do, how will I ever know if I start to get better; I don't want to continue to limit my activity just because I **think** I can't do more. I want to prove to myself [and others] what I am capable of."

Being Strong. "Being strong means being able to control the situation." Mr. Tempel has complied with his medical regimen to elicit personal control over the disease. This attitude or ability is what he speaks of when he states, "then you can't help but succeed if you put forth the effort that's required." He related a story of being strong as he was able to control his fear immediately after surgery by relaxing and concentrating on breathing with the endotracheal tube. He has also demonstrated that being strong may involve consciously turning over control, trusting the professionals. When referring to his cardiologist, Mr. Tempel states, "He's been around heart patients longer than I have. This disease is new to me, so I just do what I'm told."

Where does this strength come from? The caring of others gives strength; "I figure if these people care enough about me to be there and worry about me, then I have to find the inner-strength in myself to put forth the effort to keep going." He finds strength in those around him and how they react to him; there is an element of family involvement in finding strength.

Another contributor to being strong is knowing what to expect. "I realize it's not going to be great, but its liveable." This may be the essence of being strong, finding reason enough to live even though it is now very different than before illness and may involve deciding to be happy or satisfied with less.

Expected vs. Unexpected. As Mr. Tempel states, "I know more and more what to expect all the time." "When I first started having chest pain it scared me, you know real bad, because you don't know how intense the pain was going to get, and you really didn't have any control over it. You couldn't make sure it was going to be gone in just a little bit." And now, "I know what to expect more, and I am less fearful." He has learned to distinguish the activities or conditions that elicit chest pain and defines these parameters as what is expected. Just as he has grown accustomed to the hospital routines, he knows what to expect with each admission. Therefore, when the unexpected occurs he becomes fearful; "that's another part of fear," when the unexpected happens. "But every time you get a big pain, I mean one that you're not expecting, you get worried, or I do."

After open heart surgery, "I was told by a nurse to expect ups and downs, and feeling tired and achy, lacking the will to live, and I had those days. But I think everybody should be warned before they have an open-heart, or serious operation, that you're gonna feel that way."

Discussion

Mr. Tempel's narrative demonstrates an ongoing lived experience that involves change and learning on a daily basis as he adapts to a chronic, episodic disease. Mullen (1978) explains that CAD is "quite unlike other chronic illnesses with insidious beginnings and longer periods of realization"; this disease forces one to take into consideration those aspects of life which are commonly taken for granted. Mr. Tempel was forced to examine his life-style and immediately recognized the need to change.

Mr. Tempel describes his experience of learning to live with unstable CAD as a roller coaster and a continuous challenge to regain control of his life through several means. Personal sense of control has been associated with cardiac recovery (Ell & Haywood, 1985; Johnson & Morse, 1990). As described in the study by Johnson and Morse (1990), patients seemed to seek a life-style that they could tolerate and maintain as they learned to trust their own abilities. Through changing the pace of living and establishing parameters for himself, Mr. Tempel has found a life-style he can enjoy.

Mr. Tempel has sought to learn what he can about his disease and to commit himself to his medical regimen. He now knows what to expect in certain situations and even distinguishes episodes of pain as expected or unexpected. This is similar to Johnson and Morse's (1990) study that described how patients seek to minimize uncertainty through learning about their disease, testing their limits, practicing cautiousness, and following prescribed treatment plans. Mr. Tempel demonstrates limit testing as a means of defining the parameters of his limitations and maintaining control over his life. "A heart patient's ability to overdo puts him in jeopardy, so that the challenge becomes reaching one's limit minus one" (Mullen, 1978, p. 298).

Yet another means of regaining control was to establish parameters for living. Johnson and Morse (1990) reported that establishing guidelines for living included: testing their limitations, learning to read their bodies, and modifying their life-styles. The person must face the task of accepting limitations that they are unable to change by decreasing or altering their expectations. Mr. Tempel describes this process as changing his pace of living. He has readjusted his goals to be happy with this slower pace of living, stating that, "the quality of life is not less."

Although researchers have reported a frequent use of denial by CAD patients (Froese, Vasquez, Cassem, & Hackett, 1974; Gentry, Foster, & Haney, 1972; Croog, Shapiro & Levine, 1971; Bigos, 1981; Cassem & Hackett, 1971), Mr. Tempel's reports suggest that this behavior could be viewed as "limit-testing" as a means to regain control. This patient knows he has a serious, potentially life-threatening disease, yet he still behaves in ways that test his heart in an attempt to discover his physiologic limits.

This study is limited by a focus on the experiences of one individual living with severe CAD and the experiences of others may be very different. However, it may be the extreme nature of his experience and intense focus that might assist health care professionals to grasp a sense of living with CAD on a daily basis. Mr. Tempel's experiences would indicate that nurses should prepare patients for the emotional demands of setbacks by telling them about the "ups and downs". Nurses might further assist in managing disappointment, and coping with uncertainty and fear, in turn, preparing patients to expect some distressing emotions and conveying empathy by legitimizing the discussion of emotional demands. Nurses might coach patients to recognize that "normal life" may now be different. These nurses may then plan appropriate rehabilitative programs and assist in the formulation of realistic expectations and goals (Johnson & Morse, 1990).

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Appendix A

Informed Consent Form

Project Title: Living With Coronary Artery Disease

Investigators: Marcie Tempel, WSN
Senior Student, Nursing
Illinois Wesleyan University
Campus: (309)556-3213

Kathryn Ambur Scherck, DNSc, RN
Assistant Professor
Illinois Wesleyan University
Office: (309)556-3271 / Home: (309)662-6576

The purpose of this study is to describe the experience of living with coronary artery disease (CAD). I plan to use diaries, hospital and other medical records, notes, audiorecorded interviews and phone interviews to describe this experience. Information appearing in the final report will be approved by you. You will be identified by name in the study.

There may or may not be direct benefit to you from participating in this study, but the results may lead to future improvements in hospital care.

THIS IS TO CERTIFY THAT I, ______________________________
HEREBY agree to participate as a volunteer in the above named project.

I understand that there will be no health risks to me resulting from my participation in the research. I hereby give my permission to be interviewed, respond to questions, provide diaries, medical records and personal notes. The methods have been explained to me thoroughly. I understand that audiotapes will be secured and I will have the opportunity to approve the personal information included in the final report which may be published in various forms.

I understand that I may refuse to answer any questions or withdraw my consent and terminate my participation at any time.

I have had the opportunity to ask questions concerning this study and they have been answered to my satisfaction.

____
(participant's signature and date)

____
(witness's signature and date)

Appendix B

Interview Guide #1

1) Learning to live with CAD -- Surviving vs. Living

-How do you feel about having coronary artery disease?

-How do you feel physically? Emotionally?

-Describe a typical "good" day.

-Describe a memorable "bad" day.

-Do you feel that having this disease makes you different?

-Describe what it means to you to be "different".

-Describe your functional level.

-Describe your optional functional level.

-How are you coping with your disease?

-Describe ways you are learning to live with this disease?

-How do you feel about making changes?

-Do you feel that you are surviving or really living?

-Describe what surviving means to you.

-To what degree do you feel you are surviving? Living?

2) Being Strong -- Finding Strength

-Tell me a story, a time you'll never forget, about being strong.

-How do you define strength?

-Where do you find your strength? God? Self? Other person?

-Do you feel a sense of inner strength?

-If yes, can you describe what it is? What is feels like?

-How do you feel your family has been involved in finding strength?

-What inspires hope?

-What is hoped for?

-Do you have a role model? Describe this person/thing? Why?

-What significant effects does this person/thing have on your behavior/outlook?

3) Effects on Life

-What effects have this disease had on your life? Physical? Psychological?

-What lifestyle changes have you made?

-Have your family relationships changed? If so, how?

-Describe any changes in spirituality.

-Describe your level of self-esteem/self-worth. Has it changed?

-Have your values or priorities changed? How?

-What is your outlook on life?

-Do you feel you have adequate resources to live with CAD? Psychological? Spiritual? Financial?

-Do you feel you have lost a way of being?

-Do you feel a sense of loss? If so, what kind?

-Have you experienced any loss of independence?

-Do you feel any anger? Toward who/whom?

Appendix C

Interview Guide #2

In our first interview you gave me a lot of information and many examples of what it is like to live with coronary artery disease. The purpose of this second interview for you to clarify that I have understood you correctly and for you to elaborate on several points.

In our first interview you told me about the ups and downs of having coronary artery disease, and likened this to being on a roller coaster. Do you think this is a correct understanding?

How would you say the down times are related to the roller coaster? Emotionally wise?

As we reviewed your history of hospital admissions, test and procedures you have undergone, you told me that the narrative is accurate. You said yourself that it's pretty amazing to sit and look at all you have been through. Can you reflect back on how you felt after some of those experiences? I know in the history I wrote how sometimes after big procedures, you'd think well maybe this is it, this will fix it. Can you describe that feeling of hope, and then how you felt later when something went wrong?

How did you feel when you'd come home, when they did all these extra tests on you and all along you knew it was your heart? Did you get frustrated or angry? Did your trust toward your doctor remain the same?

Why do follow your physicians orders without question? Is this a part of taking control of your disease?

Do you think that making these kind of adjustments and taking medications and is all a part of learning to live with unstable CAD? How did you feel about learning about all these medications?

What have you learned about exercise as it relates to your coronary artery disease? What about aerobic work out now?

What about your eating habits, I know they advised you to become a vegetarian and cut out all of the fat and cholesterol and sodium; which of these parts do you follow, and which do you disregard? Do you like your diet now more than you did when you first started?

Now you talked about when you go into the hospital you, you don't worry anymore, you just let them care for you and you know what to expect. Why do you feel that you can trust health care providers so much? I mean, in a sense you're giving up control of your own care and you're letting them do all the care for you. How did you come to allow that to happen? Has it always been that way? Or is it a matter of becoming an experienced patient and building trust with those particular people? Or is it that part of living with the disease is knowing what pain to expect and knowing what relieves it?

What about general knowledge about your heart? We were talking just earlier about how you seem to be living well with your disease but you've really taken an initiative to learn about your disease whereas other people don't necessarily do that. They don't care, they don't follow their regimen. What within yourself makes you want to know these things and want to follow these instructions?

Will you continue to make the adjustments that you need to make as you continue living with this disease?

Appendix D

Summary of medications prescribed over two year period.

Advil

Aspirin

Ativan

Baby Aspirin

Clindex

Colace

Coumadin

Darvocet N

Dypridamole

Elavil

Imdur

Isordil

Lasix (Furosemide)

Librax

Lopressor (metoprolol)

Mevacor

Naprosyn

Nitrobid

Nitrostat-25 SLT

Norvasc

Phyzyme

Potassium

Procardia XL

Transderm NTG patch

Tylenol with Codeine #3

Vasotec

Vitamin E

Zantac

Appendix E

	November 1993 - December 31,1994	1995
Hospital Days	77	5
Days off work related to CAD	103.5	6
	35.5 before heart attack	
	68 from 9-11-94 to 12-19-94	
	60 days without pay	
Catheterizations	14	2
PTCA	5	0
Stress tests	7	2
Endoscopy	1	
Esophageal motility	1	
Sonogram	1	
MRI	1	
Rotoblator	1	
Stent	1	
CABG	1	
PET scan	1	

Figure 1. Graph of life with unstable coronary artery disease.

Christopher F. Tempel = My Heart ♥ History