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Challenges, Needs, and Experiences of Recently Hospitalized Cardiac Patients and Their Informal Caregivers

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Abstract

Background—Cardiovascular disease (CVD) is the leading cause of death in the United States. Unpaid family caregivers of patients who experienced a cardiac event may occupy a key position in disseminating continuous health messages to these patients, yet more information is needed to guide the development of educational and behavioral interventions targeting caregivers.

Objective—The purpose of this qualitative study was to assess the challenges, needs, and personal experiences of cardiac patients and their informal caregivers to explore the types of programs and services that would be most beneficial in promoting adherence to national CVD guidelines among cardiac patients and their caregivers.

Methods—Patients who had been admitted to the cardiovascular service line of a large urban academic medical center and their informal caregivers (N = 38, 63% women, 74% white) participated in semistructured interviews and focus groups. Participants were asked to speak about 4 major categories of their personal experiences: support, challenges, coping, and program delivery, to determine their needs, the kind of educational interventions that would be most helpful to them, and how they would prefer this information/education to be delivered.

Results—Both patients and caregivers ranked diet as the most pressing challenge (91% and 78%, respectively). The Internet, television, and social media were the preferred methods of delivery of such programs. Challenges most commonly cited by caregivers and patients included issues related to taking/administering prescribed medications and medication side effects, and mental stress. Caregivers expressed that not knowing what to expect after the patient's discharge from the hospital was a major stressor.

Conclusion—These findings may inform the development of educational interventions targeted to cardiac caregivers so that they may be more effective in assisting the patients in their care to adhere to national CVD prevention guidelines.

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Keywords

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Despite the decline in rates of death from cardiovascular disease (CVD) over the past 2 decades, it remains the number one killer of men and women in the United States.¹⁻³ Every day, 2300 Americans die of CVD, an average of 1 death every 38 seconds.¹ Eighty-one million Americans are living with CVD in the United States, nearly half of whom are 60 years or older.¹ The total direct and indirect yearly cost of CVD far exceeds that of the other leading causes of death at more than \$500 billion dollars per year compared with cancer at \$228 billion¹ and diabetes at \$174 billion.⁴

Many individuals with CVD need continual care and supervision, which is often provided by unpaid family members or friends.⁵⁻⁷ Such assistance ranges from personal hygiene, grooming, and feeding to grocery shopping, banking, and transportation to and from the physician's office. There are approximately 65 million unpaid family caregivers in the United States today,⁸ and it is estimated that the equivalent yearly cost of informal caregiving rendered in the United States is approximately \$257 billion.⁹ The overwhelming majority of research related to caregiving has explored the impact of providing informal care on the health of the caregiver himself/herself and has been conducted primarily in the context of cancer and mental health conditions, specifically dementia. Few studies have been conducted in the area of CVD, especially in the context of the relation between addressing caregiver needs and the potential for improving patient outcomes. Cardiac caregivers may represent a vast and untapped potential to improve quality CVD care and to reduce healthcare costs. It has been documented that informal cardiac caregivers are frequently involved in tasks that have the potential to improve CVD outcomes, such as medical follow-up, medication adherence, and nutrition.¹⁰ Little is known about the unique personal experiences of family caregivers of patients with CVD and the patients they care for; this information would be useful to identify priority areas for tailored interventions targeted to both patients and caregivers. Interventions that have been aimed to caregivers of patients with other chronic diseases cannot necessarily be applied to caregivers of CVD patients because of the differences in the nature and progression of the illnesses. As Given et al¹¹ affirm, family caregivers require specific knowledge bases and skill sets to administer disease-specific care. In addition, the most appropriate interventions need to correlate with the specific knowledge and skill requirements of those rendering care.

It has been documented that caregivers whose psychological, emotional, and physical needs have not been met can adversely affect the patient's own state of physical and mental well-being in the recovery phase.¹²⁻¹⁴ Kettunen et al¹⁵ found that dysfunction in caregivers often stemmed from disease-related fears coupled with personal fears after a myocardial infarction in their spouses. Caregivers who are not acknowledged or affirmed may develop feelings of frustration and powerlessness,¹⁶ which can adversely affect the care they deliver to their recovering family member. However, a characteristic such as confidence in spouse caregivers has been predictive of better survival rates in the cardiac patient.¹⁶ Davies¹⁷ and Agren et al¹⁸ have stated that interventions designed to address the needs and/or perceptions of the cardiac caregiver and suitably provide educational and/or psychological support have the potential to enhance the care of the patient. Comprehensive, multifaceted interventions for caregivers may prove to be effective; however, most of the comprehensive caregiver interventions identified in the literature have been conducted in patients diagnosed with dementia.^{11,19,20}

The purpose of this qualitative study was to explore with cardiac patients and cardiac caregivers their greatest challenges, their most pressing needs in their respective roles, and their experiences as a cardiac patient and a caregiver, respectively. It was important to assess these issues to determine what types of programs and services might be needed to help both caregivers and patients in promoting adherence to CVD guidelines.

Methods

Design and Participants

This study consisted of in-depth, structured interviews and focus groups with cardiac patients (n = 20) and informal caregivers of patients with CVD (n = 18). The qualitative method of the study was selected to garner participants' perspectives in their own words to produce first-hand, descriptive data.²¹ Adult patients admitted to the cardiovascular service line at Columbia University Medical Center (CUMC)/New York-Presbyterian Hospital between November 2009 and September 2010 and/or their informal primary caregivers were included. Caregivers were defined as a family member, spouse, or friend who provided the primary assistance and care for a patient who had been hospitalized with CVD, without pay for service.

Hospital admission logs were reviewed to identify patients admitted to the CVD service line. Trained bilingual research staff approached patients and/or their primary informal caregivers (as identified by the patients) and offered an invitation to participate in either an individual interview or small focus group. Participants were excluded from the study if they were mentally incapacitated, spoke neither English nor Spanish, were younger than 18 years, or if they refused to participate in the study. Patients who had a primary diagnosis of stroke were also excluded. Interviews took place face-to-face in a private room on the cardiac floor of the hospital, at the patient's bedside, or over the telephone, depending on the participant's preference. Caregivers and patients were interviewed separately and not in the presence of the each other. Focus groups took place in a private CUMC/New York-Presbyterian Hospital conference room. All participants received and signed informed consent forms and the study was approved by the institutional review board of CUMC.

Data Collection

Demographic data were collected via standardized questionnaire. Interviews and focus groups were conducted by a trained research nurse and a trained health educator who received several sessions of instruction from a doctoral-level expert in qualitative research methodology. Participants were asked to speak about their personal experiences as a cardiac patient or a caregiver, any barriers to adhering to cardiac prevention guidelines (eg, diet, physical activity, weight management), and what types of programs/services might help facilitate adherence. Interview questions addressed the 4 primary domains of (1) support, (2) challenges, (3) coping, and (4) program delivery (this information would assist CUMC in formulating such programs for both patients and caregivers). Additional probing questions constructed with the assistance of a qualitative expert were used in each domain when necessary, to extract the maximum amount of related information. To ensure comfort in communicating sensitive information, caregivers were not interviewed in the presence of the patients in their care, and patients were not interviewed in the presence of their caregivers. Focus groups were conducted to validate the findings from the individual interviews and were conducted separately for patients and caregivers. The participants in the focus groups were different from the participants in the individual interviews. Two topics were recommended for focus group discussion by our qualitative expert; they were "challenges" and "coping." The total duration of the interviews and focus groups was approximately 60 minutes each.

In face-to-face interviews and in the focus groups, a second researcher recorded observations regarding the behaviors and demeanor of the participants as they were interviewed. Although all participants were fluent in English, 2 of the patients opted to be interviewed in Spanish by our bilingual research assistants. These digitally recorded transcripts were then sent to outside professional interpreters for translation and then returned to us for analysis. These transcripts were then analyzed in the same way that the other 36 were analyzed as described below in the data analysis section.

Qualitative Data Analysis

The data derived from this qualitative study were analyzed by conventional content analysis; this method was selected because it is appropriate when there is limited research in a particular topic area.²² Interviews and focus groups were transcribed verbatim. Categories or themes were established based on the available caregiver literature, and using the conceptual framework based on the literature, the data/responses were organized into themes. Under the category of “support,” subcategories were generated to include physical/practical/logistical support and emotional support/social support. The category of “challenges” was divided into subcategories including communication with health professionals, physical challenges, and adherence challenges. The “coping” category was divided into the subcategories of psychosocial, physical activity, and self-determination, and the category of “program delivery” was subdivided into the subcategories of education topics and methods of delivery. Subcategories were further divided as needed to fully capture the essence of participants’ expression. All themes or categories were coded and a codebook was created, which served as a guide for analysis of the transcript data. The first author read and coded the transcripts using this codebook until saturation of themes was reached. Similarly, the second and third researchers identified categories/themes independently and coded them until saturation was reached. If the second and third researchers found themes that were different from those of the first, the matter was discussed until reconciliation was achieved.

Establishing Trustworthiness

Several measures were taken to ensure the integrity and rigor of this qualitative research study, using the criteria established by Lincoln and Guba²³ to ascertain the trustworthiness of qualitative research, including credibility, dependability, confirmability and transferability.²⁴ Method triangulation was used through interviews, focus groups, as well as field notes that described the demeanor, body language, and behaviors of the participants during the interviews. Ongoing member checking²⁴ was used in which information received from participants was restated to confirm understanding; the use of probing questions further ensured clarity of the thoughts expressed by the participants. Audio taping and the use of verbatim transcripts to derive common themes gave precision to the voices of the participants, and descriptive data were collected in their undiluted form (digitally audio-taped interviews). Finally, interrater reliability was achieved by having 3 different investigators analyze the transcripts using a codebook developed for that purpose.

Results

The characteristics of the participants are presented in Table 1. Nine caregivers and 9 patients participated in focus groups; 9 caregivers and 11 patients participated in individual interviews. Eighty-seven percent of the participants in this study were married, and 71% of the participants were spouse-partner dyads. Most patients interviewed were men, and most of the caregivers were their female spouses. Three-quarters of participants were white, 47% were between the ages of 60 and 69 years, and more than half were college educated.

Overall responses related to caregiver and patient needs are presented in Table 2. In the “support” category, the patients’ greatest need for support was for assistance with the cardiac diet. Caregivers expressed that the diet was the area that demanded the most attention in supporting the patient. The greatest challenge for patients was their restricted activity/movement, whereas the greatest challenge for the caregiver was providing the right diet for the patient within CVD guidelines. In the “coping” category, patients voiced that family, friends, and colleagues helped them to cope best, whereas caregivers reported that they too were most able to cope because of the support they received from family, friends, and colleagues. The answers to the question about the type of programs they would need and how they wanted them delivered were the same. Both patients and caregivers requested education about diet delivered via Internet/television (TV)/social media.

Other major issues that presented a challenge for both patient and caregiver were those related to the procurement and administration of cardiac medications and dealing with the mental stress associated with being a cardiac caregiver or cardiac patient.

Support

Many of the caregivers in this study reported providing several different types of support for the patient, including physical, practical, and logistical support such as scheduling physician appointments; transportation to the physician’s office; grocery shopping; and picking up, tracking, and administering medications. The caregiver, who was typically the female spouse, often carried out household responsibilities such as laundry, cooking, and cleaning in addition to assisting the patient with other activities of daily living, such as physically helping the patient to move from place to place. For patients who had cardiac surgery, the spouse/caregiver expressed having to learn how to keep the wound clean and change bandages at home after discharge from the hospital. Caregivers also reported needing to recognize the signs of infection and/or the signs of a cardiac event and relaying this information to the physician.

In the words of one female caregiver:

I pretty much do everything for him. I give him his medications, take him to doctor’s appointments, I drive him everywhere. I pick up his medicines at the pharmacy. Not once has he ever had to make a trip to the pharmacy to get his medications. I do that for him. I cook his food; he can’t have salt so I cook without salt.

Among spouse-caregivers, many expressed that the support given was an expected function of the marriage partnership.

Patients reported similar tasks when asked to describe the support they received from their caregivers. One male patient who was hospitalized with congestive heart failure shared a description of his wife’s caregiving activities and the gratitude he felt for her assistance:

She helps me most importantly with my medications. And before she goes to work, she makes sure I have all my meals ready and when she comes home she will sit down and talk to me and if it’s a good day we go around the block and come back home. Ever since I have been sick she would care for me...she gives me all the support she has. She encourages me. Every time I have to go to the doctor she makes sure she goes with me.

Most of the patients expressed that their family caregivers were devoted, vowing to do whatever they could to help their loved one recover and maintain health.

Challenges

The caregiving experience was not without its challenges. One spouse reported increased physical and mental stress and that she needed a reprieve, as well as increased social support.

I need to be near home; I can't leave him alone for a few hours to take my daughter to the beach. I am dealing with his depression, I am dealing with his grumpiness; he is very impatient. I am stressed out in my own way, I am eating ice cream at night, which I never did before, and I keep a lot of my worries to myself.

One caregiver expressed her frustration with a lack of acknowledgment from the patient's healthcare providers this way:

What bothers me is that doctors that I meet here, they ignore the caretakers. Like you can go to the office and the doctor just solely concentrates on the patients, that's wonderful...and we sit in a little corner and we are not allowed to say anything...if I said something they will just say, "He is the patient; let him say it to me."

Caregivers acknowledged that they felt fulfilled by their functions in the caregiver role yet often experienced a great deal of mental stress, such as expressed by the daughter of a patient who had been sick with multiple heart issues for 3 years:

It makes me feel like I've accomplished something; it makes me feel like I have given back to her what she has given to me my entire life...it makes me feel stressed, extra stress because I work and am fitting 2 full-time jobs in. Obviously, before my mother was sick, it was less stressful than what it is now.

The frustrations with grocery shopping for food for her husband, the cardiac patient, were expressed by another caregiver:

So before it would take me 20 minutes to go to the supermarket and now it takes me an hour and a half reading every single carton and low-sodium, low-carb, low this, low that...and ah...so it's been a challenge. I cook every meal now.

Constantly not knowing what to expect and fear of the unknown were other frequently voiced concerns among caregivers of cardiac patients. One caregiver stated that her family member fainted in the street and that she did not know what to do.

Patients reported experiencing a separate set of challenges from those experienced by the caregivers in the recovery process after a cardiac event. Patients who had had a surgical procedure expressed challenges with pain and discomfort that drastically curtailed their physical activities. One patient stated:

Well, it's painful. The worst part of the pain is when I have to cough. And just that process of coughing is actually very painful...makes me feel kind of helpless in a way...I can't drive, I can't do any of the chores around the house that I normally do. It has tremendously limited my life.

Another patient stated:

Yes, it has affected my sexual activity, yes, yes, if I don't function.... I am in treatment too, because of the many operations. I don't know what has happened—they failed in something—the urologist is working to see what they can do.

A patient who was admitted to the hospital for heart failure exacerbation shared his regrets of not being able to do the activities he had become accustomed to:

I gave up everything I used to do...I used to help her [his wife] when she came home, and before she came home, I would have dinner ready for both of us. The doctor doesn't want me to go behind that stove anymore...anytime she is off for a long weekend, we'd go some place and that has changed because I can't go anyplace anymore...she used to say, "can you go and pick this up for me?" and now I can't do that. It makes me feel so little.

One 81-year-old male patient expressed his challenges with diet adherence in this way:

You really understand that you should eat more vegetables, salads, greens, and less fatty foods—it is not that most people in today's environment don't understand that. How do you convince yourself to follow that, especially when you have children and you are aging? It is difficult!

One male patient who was awaiting cardiac surgery verbalized his challenge with medications like this:

She [referring to his wife] would take care of my medicines, she's the one who gives me the medicines because I don't even know all of them, but she has an idea of these things because she works in a hospital.

Many patients expressed to the researchers how mentally stressed and frustrated they were by having CVD and/or having had a recent cardiac event or surgery; mental stress was among the highest ranking challenges for patients:

Every minute it seems I'm in the hospital. I can't stay out of the hospital ...I feel real bad to know that I'm in this position, it worries me.

The issues of financial challenges surfaced in the words of one female patient:

Then also it's another co-pay...I am still paying off my hospital bills from my knee surgery, and now I'm going to get hit with bills for the ambulance transfer, which I think is absurd! I pay extra for [insurance], for the top one, and even that doesn't cover fully everything.

Coping

Caregivers credited family, friends, and colleagues with helping them to cope with their stress during their times of need. Other coping mechanisms included having the determination that they were going to maintain a positive attitude and do what was required to help their loved ones through the crisis. Attempting to adhere to national CVD prevention guidelines (eg, eating a healthy diet and staying physically active) and taking time for hobbies were other means of coping used by caregivers. Some caregivers sought help from mental health professionals to assist them in coping with their new challenges:

I can unload on his sister about how I really feel and I can unload on you [referring to the researcher] on how I really feel...actually I'm going to therapy once a week.

Another caregiver, when asked how she coped, stated:

I pray constantly. Any problems I have in my life, I pray about it. That's what keeps me strong. My cousin is a priest and I sometimes talk to him about things that weigh me down. My children help me too...all the children are supportive during this time.

Some of the caregiver/patient spouses reported becoming closer as a result of the onset or exacerbation of cardiac illness. One spouse, when asked how he coped with the changes after his wife experienced a cardiac event, stated:

Actually, we have a great relationship and I would do absolutely anything for her, and if anything, it made us closer and happier and I was glad to help out. Again, it hasn't been a long-term thing or a burden at all.

The positive attitude in caregivers was typified by the following comment:

I don't really consider them challenges. I just do it. I want to make sure I take the best care of him and I just do whatever needs to be done and don't think about it.

Of practicing hobbies, one caregiver stated:

It's more of just spending 20 minutes with yourself and just trying to read, maybe read during the day or just trying to take your mind off of things.

Among the cardiac patients in the study, support from family, friends, and colleagues; having confidence in healthcare professionals; and attempting to adhere to diet and physical activity guidelines were the primary means of coping with their illness. In the words of one patient, when asked how he coped:

I have friends...I have people in Florida, my son is in Hawaii, friends locally, they call and check on me see how I'm doing. We go out for lunch or dinner...I am very lucky to be surrounded by good friends...I am surrounded by my wife and family and my children and grandchildren, and I don't have any problems coping with the situation.

Other patients verbalized:

Well, I have my husband, you know, and my sister, they are there if I need any help and I also have them to lean on if I need it. I have my family group for support. I just keep an open mind and you know, I don't let anyone get me down, you know, because the more you sit and worry....try not to worry too much, although you know you will.

I've certainly cut back on eating red meat and things like that, I'm trying to eat a little healthier, more fruits and vegetables and things like that. I'm trying to stay a little healthier and take care of things. I need to get on the treadmill or the elliptical anywhere from 3 to 5 days per week. I'm still doing that, which I had to stop for 2 weeks, but I'm back to that again...try to take care of yourself a little better, you know.

Program Delivery

Caregivers shared a variety of thoughts with the researchers when asked what kind of educational programs and services they would like to see provided by the hospital for them as caregivers of cardiac patients. Top priority areas were education about diet and physical activity, which they wanted to be delivered to them via Internet, TV/video, or social media. Alternatively, they would prefer the educational materials to be prepared in printed form and mailed to them.

Caregivers' responses to how they would like educational programs delivered included the following:

The television programs are very useful and we watch those...my husband spends a lot of time on the Internet...telephone is not real great for us to be contacted and I don't hear too well.

I believe that you should be given a whole packet of information, with sections that talk about: okay this is diet that you should be aware of, okay this is medications they may or may not be on, these are the side effects, these are what you have to

watch out for. I think there should be a section that says ok, you are going to be under some stress. If you need to meditate, if you need to do yoga, these are the places that you may be able to go. There should be a whole packet of suggestions.

You could provide nutrition classes or information about the illness or even make some phone calls to people and share information with them that way...you could mail something, a brochure or booklet or some other kind of printed material to homes.

Two caregivers expressed that knowing more about practical skills for taking care of the patients after hospital discharge would be helpful:

Maybe we should be encouraged as caretakers to learn how to take blood pressure, you know, do that for ourselves so that we would know what's going on.

However, another caregiver recommended a hotline for caregivers to call if they needed help and support:

I suggest a hotline. Different people may answer and call you back and when they do, they'll listen to whatever your issue is and refer you sometimes.

Patients had similar ideas for educational programs or services, with the addition of wanting to receive more information directly from their healthcare providers. Concerns about diet ranked the highest on the patients' list of educational needs, followed by information about physical activity. Very few patients expressed interest in reading printed material. Patients stated:

What most people need is just teaching as far as nutrition goes and exercise, and just somebody to help them get to do those things you know or to teach them how to do those things.

To me, the things that are important to somebody like myself who's had this for several years—diet is number one, exercise is number two, and good healthcare is number three...the Internet is a great way to do things.

Physicians don't see people until after they've had the problems coming in, you know? Everybody goes for check-ups at primary care, maybe they could give people a little incentive about exercise and diet and things like that, or suggest a nutritionist.

Discussion

This study provides important insight into the experiences of cardiac patients and their informal caregivers and adds to the small body of existing literature that addresses the needs of this population. In examining the 4 areas of support, challenges, coping, and program delivery, the goal was to identify firsthand what the most pressing issues were, to inform the types of programs and services that would best meet the needs of cardiac caregivers and, ultimately, the patients. The primary findings were that patients and caregivers alike needed guidance regarding the patients' specific dietary requirements, instructions about physical activity after a cardiac event, and education regarding medication administration, including their adverse effects. Both groups reported family, friends, and colleagues as their main sources of support and expressed the need for more involvement of their healthcare providers in their recovery process. This was important particularly to caregivers, 56% of whom did not know what to expect when they returned home with a newly discharged cardiac patient, underscoring the need for adequate follow-up after discharge. Financial issues were also a concern reported by caregivers, especially in cases in which medical insurance did not cover such services as an ambulance ride to the hospital, and the lack of

income given that one partner may not be able to work any longer. This is a challenge expressed by both caregivers and patients.

The overwhelming majority (89%) of caregivers cited mental stress as one of their greatest challenges, and many requested some type of psychosocial intervention to assist them through the caregiving process, such as group therapy or yoga classes. This finding is consistent with research showing that cardiac caregivers often experience higher levels of strain and depression and lower social support than noncaregivers do.⁵ Mental stress was slightly less prevalent among the patient group in this study, but many expressed the strong desire to communicate with other patients like themselves who had experienced a cardiac event.

Issues surrounding follow-up care and the need to learn more about symptoms of particular cardiac events such as a myocardial infarction or a stroke were also a major concern among cardiac caregivers. Concordant with our results, Kettunen et al¹⁵ found that the spouses of cardiac patients who have had a myocardial infarction suffered psychologically by feeling stressed about the occurrence of another myocardial infarction, financial issues, the recovery process, and the possibility of losing their spouse to heart disease. They also found that spouses felt vulnerable and unsupported in the caregiving experience, experiencing fatigue, sleep disturbances, anxiety, and tension,¹⁵ all of which were clearly voiced by the participants in our study.

The cardiac patients in our study reported physical issues of fatigue, pain, lack of sleep, and psychosocial factors such as depression as major challenges after discharge, potentially affecting their long-term recovery. Schulz et al²⁵ found that symptoms of depression, anxiety, and fatigue experienced by cardiac patients, often lasting as long as several months after their surgery, grossly affected patients' adherence to their prescribed medications.

Davies¹⁷ documented that caregivers of patients who had cardiac surgery expressed fear about the first few days home after the patients' hospitalization when they did not quite know what to expect, consistent with our findings in this qualitative study. Caregivers expressed concerns about not knowing what to do in an emergency, a lack of knowledge regarding wound care, and the desire to have more accessibility and communication with their loved ones' healthcare providers about the disease and recovery processes. They also reported a lack of respect and acknowledgement from healthcare providers and a desire to be recognized for the integral part they play in the patients' recovery and rehabilitation. Similar to our results, Knoll and Johnson,⁶ in a study of 8 caregivers of postsurgical patients, found that caregivers emphasized the importance of follow-up care from nurses and other healthcare providers in the postdischarge period. Given et al¹¹ also state that caregivers need to have appropriate access to a patient's healthcare providers to fully participate in the care of the patient.

Limitations of the study include that the focus group topics recommended for discussion addressed only "challenges" and "coping." In addition, this study was conducted in a large, urban academic medical center in New York City, among participants who were primarily white and college educated. Therefore, the findings may not be transferable across all communities. Future research may consider replicating our results in a larger, more heterogeneous sample in terms of race and socioeconomic status. An additional limitation of the study would include the self-selection of the participants in the study.

In conclusion, this study has served to shed light on the human challenges, needs, and experiences of cardiac patients and their caregivers; these findings may help to inform preventive interventions designed to help improve quality of life in both caregivers and patients, and help caregivers improve CVD outcomes. These findings may also help

healthcare providers to identify and empower cardiac caregivers such that they may render the best care possible to the patients in their care and foster positive patient health outcomes.

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What's New and Important

- Qualitative data from individual interviews and focus groups conducted among cardiac patients and their informal caregivers documented that both patients and caregivers cited dietary issues and medications as 2 major issues requiring the greatest educational need. Preferred modes of delivery for educational materials addressing these needs were computer/technology based (the Internet, television, and social media).
- Challenges most commonly cited by caregivers and patients included issues related to medications and adverse effects and mental stress. Caregivers expressed that not knowing what to expect after the patient's discharge from the hospital was a major stressor.
- This information could potentially be used to help guide the development of educational/behavioral interventions targeting cardiac patient-caregiver dyads.

TABLE 1

Characteristics of the Participants (N = 38)

Characteristic	Caregivers (n = 18), n (%)	Patients (n = 20), n (%)
Age (≥ 60 vs <60 y)	11 (61)	15 (75)
Female	17 (94)	7 (35)
Male	1 (6)	13 (65)
White vs black/Hispanic/Asian	15 (83)	13 (65)
Married vs single/divorced/separated	16 (89)	17 (85)
Education (≥ college vs <college)	15 (83)	13 (65)
Self-reported knowledge about CVD and/or CVD risk factors (very knowledgeable vs somewhat knowledgeable/not at all/unsure)	7 (39)	5 (25)
History of initial diagnosis of CVD (≥ 2 vs <2 y)	—	14 (70)
Length of time in caregiver role (≥ 2 vs <2 y)	13 (72)	—
Insurance type ^a		
Medicaid	1 (5.6)	1 (5)
Medicare	4 (22.2)	10 (50)
Private	16 (89)	16 (80)
Other	0 (0)	2 (10)
Relationship to the patient/caregiver	Overall (n = 38), n (%)	
Spouse/partner	27 (71)	
Son/daughter	7 (18)	
Parent	2 (5)	
Other	2 (5)	

Abbreviation: CVD, cardiovascular disease.

^aCan have more than 1 plan type.

TABLE 2

Frequently Cited Themes by Caregivers and Patients

Themes	Caregiver Responses	Themes	Patient Responses
Areas of support provided		Areas of support received	
Dietary/grocery shopping	100%	Dietary/grocery shopping	82%
Picking up/tracking/administering medications	100%	Physical activity and mobility	73%
Physical activity and mobility	89%	Transportation to physician visits/hospital	73%
Moral support	67%	Picking up/tracking/administering medications	82%
Challenges faced			
Patient activity restriction/moving patient	100%	Dietary: Knowing the cardiac diet, reading food labels, etc.	100%
Knowledge of cardiac diet/enforcing adherence/meal preparation	89%	Mental stress	91%
Procuring, tracking, administering medications	56%	Picking up/tracking/administering medications	73%
Mental stress	56%	Not knowing what to expect	73%
Coping mechanisms			
Support from family, friends, colleagues	100%	Family, friends, colleagues	100%
Support from healthcare professionals	78%	Self-determination to deal with problems despite odds	100%
Following CVD prevention lifestyle guidelines	78%	Following CVD prevention lifestyle guidelines	91%
Exercise	67%	Hobbies	64%
Suggested educational program topics			
Diet	78%	Diet	91%
Physical activity	67%	Physical activity	82%
Method of delivery			
Internet/TV/video/social media	56%	Printed/mailed materials	82%
Healthcare provider	44%	Internet/TV/video/social media	82%

Abbreviations: CVD, cardiovascular disease; TV, television.