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# Learning a new way of living together: A qualitative study exploring the relationship changes and intervention needs of patients with cardiovascular disease and their partners

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## ABSTRACT

**Objectives:** Cardiovascular disease (CVD) not only affects the patient, but has implications for the partner. Emerging evidence suggests that supportive couple relationships enhance CVD outcomes and reduce patient and partner distress. To date, however, little has been done to address this potentially important component of care. This article examines the impact of CVD on the couple relationship and assesses the perceived needs and desired intervention components of patients with CVD and their partners.

**Design:** Qualitative study using directed and conventional content analysis.

**Setting:** Single-centre, tertiary cardiac care hospital that serves a population of 1.4 million in the Champlain region of Ontario, Canada.

**Participants:** Patients with CVD and their partners (N=32, 16 couples) participated in focus groups. Patients were mainly male (75%), white (87.5%), aged 63.4 years (range 31-81 years), with varied cardiac diagnoses (50% coronary artery disease; 18.75% valve disease; 18.75% heart failure; 12.5% arrhythmia).

**Results:** Five categories were generated from the data reflecting changes within the couple relationship as a result of CVD: 1) emotional and communication disconnection; 2) overprotection of the patient; 3) role changes; 4) adjustment to lifestyle changes; and, 5) positive relationship changes. Three categories were constructed regarding intervention needs and desired resources: 1) practical resources; 2) sharing with peers; and, 3) relationship enhancement.

**Conclusions:** Overall, the data suggest that there were profound changes in the couple relationship as a result of CVD, and that there is considerable need to better support the caregiving spouses and the couple as a unit. These results call for interventions designed to provide instrumental support, peer-sharing opportunities, and relationship quality enhancement to help couples cope with CVD. Future

studies should examine whether couples-based programming embedded into cardiac rehabilitation can be effective at improving relationship quality and reducing patient and partner stress in the aftermath of a cardiac event.

**Keywords:** cardiovascular disease, couples, relationship quality, intervention, cardiac rehabilitation

## ARTICLE SUMMARY

### Strengths and Limitations of this Study

- We assessed the need for couples-based interventions in cardiac rehabilitation from the perspective of patients with CVD and their partners
- We provide an in-depth description, from the couples' perspective, of specific relationship changes and intervention needs following a cardiac event or diagnosis
- This study is focused on patients and partners recruited from only one cardiac care hospital in Ontario, Canada
- The majority of couples consisted of male patients (75%) and female partners; all couples were heterosexual.

## INTRODUCTION

Cardiovascular disease (CVD) is a leading cause of mortality in most western nations. Multiple modifiable risk factors for CVD have been identified, including smoking, physical inactivity, hypertension, poor diet, metabolic syndrome, and stress. These factors are routinely targeted in primary and secondary prevention programs, which reduce morbidity and mortality, and improve mental health and quality of life outcomes among patients with CVD.[1] Interestingly, despite the well-established link between social relationships and the progression of CVD,[2,3] this component is rarely targeted in the prevention or management of CVD.[4]

Accumulating evidence indicates that positive social relationships are integral to health. To illustrate, a meta-analysis with over 300,000 participants revealed an increased survival rate of 50% for those in supportive relationships.[3] Socially isolated individuals or those in poor relationships, in contrast, experience increased morbidity and mortality. For example, a 29% increased risk of coronary artery disease was reported in a recent meta-analysis including over 35,000 participants.[2] Given the importance of intimate relationships for most adults, it is not surprising that partner support is the strongest determinant of wellbeing relative to other sources of support.[5] In fact, a recent systematic review revealed that simply being married is associated with fewer CVD risk factors and improved survival rates.[6] One cohort study with almost one million patients with acute coronary syndrome, for example, detected lower mortality rates for married (OR=0.86) and widowed patients (0.96), whereas single patients had increased rates (OR=1.07).[7]

Other evidence indicates, however, that the quality of the relationship, not just its presence, may dictate the impact on heart health. High-quality relationships are characterized by high relationship satisfaction, warmth, support, and closeness, while distressed relationships exhibit high levels of conflict, hostility, distance, and dissatisfaction.[8, 9] The presence of strong patient-partner relationships, high in relationship quality, has been associated with improved physical and mental health outcomes.

Marital discord, in contrast, has been related to elevated risk of CVD development and to the progression of established disease, even when other risk factors such as age, blood pressure, and BMI are controlled for in the analyses.[10-13] For example, one study found that the survival rates of patients who underwent coronary artery bypass surgery and reported satisfying relationships were 3 times higher than those in poor relationships.[14] Hypertension and increased heart rate is observed with marital conflict,[15, 16] whereas reductions in blood pressure are observed during supportive interactions.[17] Supportive spouses may also model heart-healthy behaviours such as consuming fruits and vegetables and engaging in physical exercise. Patients in well-adjusted relationships are more likely to adhere to medical prescriptions and to be more assiduous in their attendance at cardiac rehabilitation.[18, 19] There is evidence that high quality patient-partner relationships can also reduce caregiver burden, distress, and depressive symptoms.[20] Taken together, the evidence connecting poor patient-partner relationship quality to deleterious physical and mental health outcomes continues to mount, whereas high quality relationships appear to buffer the impact of CVD and to enhance physical and mental health.

Despite this evidence, few interventions for cardiac patients and their partner exist. To date, the focus, not surprisingly, has been on traditional CVD risk factors such as exercise, diet, and smoking behaviour. A systematic review of seven couples-based psychological interventions for patients with coronary artery disease reported modest improvements in patients' knowledge of disease and treatment, blood pressure, and quality of life with intervention participation, but no effect on morbidity or mortality.[4] Low quality methods were thought to explain the reduced efficacy. Methodological limitations of couples-based intervention include: outdated studies – many are over 20 years old and the medical care and related couple experience has changed substantially; interventions were not based in theory or were simply informational; small sample sizes; and data collection has been restricted to the patient and lacked measures of relationship quality.[4, 21-23] Further, to our knowledge, only one study in the CVD context has targeted the couple relationship as an intervention component to date.[24] Results of that study demonstrated improvements in exercise levels, but distressed couples did not maintain gains at intervention completion (18 weeks). A more targeted intervention aimed to improve relationship quality may be required to enhance couple-related, psychological, behavioural, and physical health outcomes.

In order to design more effective couples-based interventions, an in-depth understanding of the experience and needs of patients and partners in the context of CVD is required. Daltag and colleagues systematically reviewed qualitative and quantitative research investigating the impact of cardiac disease on the partner relationship.[25] Results indicated that the impact is extensive and distressing on multiple levels, including adjustment to illness and role changes, sexual concerns, and communication and overprotection. Unfortunately, the studies included in the review are now a decade old and, like the intervention research described above, they preclude a contemporary impression of the dyad's experience in the current medical environment. Since this review,[25] three additional studies were published.[26,27, 28] Findings highlighted difficulties living with the uncertainty of disease, feelings of worry and vigilance, and caregiver burden and support. Patients and partners also reported that caring involvement brought the couple closer together or, the opposite, a feeling a loss of the partner relationship and role changes. These studies, however, included select populations (i.e., patients with atrial fibrillation or heart failure) or spouses only. Further, only one [29] of the previously reviewed[25] or newer studies inquired about potential areas of support for the patient-partner dyad. With approximately 30% of couples with CVD reporting marital discord[30] and the potential physiological detriment on patients' cardiovascular health, more research on the experience and intervention needs of patients with CVD and their partners is required. This information may then be used to enhance intervention development and efficacy.

Employing a systematic framework, such as the ORBIT model for developing behavioural treatments for chronic diseases,[31] has been shown to produce stronger behavioural treatments and to avoid costly trials of those that have not been optimized. Phase I (design and define) aims to identify the essential features of a treatment. Qualitative research is often employed to engage the community of participants and reveal details of the clinical problem and potential treatment components. Practical aspects of the intervention are also investigated, including, for example, the preferred mode of delivery, setting, and frequency and duration of contact. With this information, an intervention that is acceptable to the target population and has promise for clinically significant benefit can be created. This phase is followed by preliminary testing such as proof of concept trials (Phase II) and, if positive results are detected, an RCT pilot study is then justified. Efficacy testing in the form of larger randomized controlled trials (Phase III) and effectiveness research (Phase IV) complete the process.

The present study describes Phase I for the development of a couples-based intervention for patients with CVD and their partners. The specific aims were: 1) to further understand the impact of CVD on the nature of the couple relationship and 2) to assess the intervention needs and desires of patients with CVD and their partners, including an exploration of their interest in a couples-based intervention in cardiac rehabilitation. The ultimate goal was to inform the development of relevant cardiac interventions that involve the couple as a unit.

## METHODS

### Design and setting

This study used an exploratory and qualitative design. The study was carried out at the University of Ottawa Heart Institute in Ottawa (UOHI), a quaternary care cardiac hospital that serves a population of 1.4 million in the Champlain region of Ontario, Canada.

## Participant recruitment

All participants were past or current participants of the UOHI cardiac rehabilitation program; no restrictions were placed on cardiac diagnosis. Patients were conveniently recruited from the cardiac rehabilitation classes as well as through signs posted at the UOHI. Participants were included if they had directly or indirectly (i.e., through a spouse) experienced a cardiovascular event, were in a couple relationship (married, common-law, or in a committed relationship for ≥ 2 years), were 18 years of age and older, and were able to speak English. There were no exclusion criteria for this study.

## Focus group interviews

Patients were invited to attend a 1.5 hour focus group with their partner. Focus groups were particularly suited for this study as it allowed for interactive and intensive discussions amongst both patients and partners. Furthermore, focus groups position participants as experts of their social worlds and can help to reduce unequal power relations amongst the researchers and participants that can manifest in individual interviews.[32] All focus groups took place at the UOHI and only included the participants and the interviewers. A semi-structured interview guide was used throughout the focus groups. Question development was guided by the clinical expertise of the investigators, analyses of transcripts of couple therapy sessions with heart patients, and previous research on couples and CVD.[33, 34, 25] Table 1 provides a sample list of questions that were asked in the focus group interviews. The interview guide was not piloted tested and there were no follow-up interviews. Four interviewers (3 women, 1 man) were involved throughout the study with two interviewers present at each focus group. All interviewers were licensed clinical psychologists with over 10 years experience working with couples and/or patients with cardiovascular disease. As participants were former or current patients of the UOHI, a clinician-patient relationship was established prior to the data collection period for some participants. All participants were aware that the aim of the research was to ascertain patients' and partners' perspectives of intervention approaches that would be relevant to their needs. Although the interviewers have experience providing individual and couples-based interventions, the purpose of the research was to learn whether this would be of interest to the participants and what intervention components might be included.

| **Table 1 Focus Group Sample Questions** |
|---|
| 1. Sometimes people say that heart disease brings them closer together. Other times they say that it just seems to create more problems and stresses on top of the ones they already have. How has your experience been? |
| 2. A lot of times patients and partners see heart disease differently. How similar or different would you say your perspectives on having heart disease are? |
| 4. What has been the most difficult part of having heart disease (or having a partner with heart disease)? |
| 5. How could the Heart Institute help you and your significant other cope better together? What have you found most helpful so far? |
| 6. Would you be interested in a couples-based intervention as part of cardiac rehabilitation? If so, what would it look like? |

## Data analysis

Audio recordings of the focus groups were transcribed verbatim and subjected to directed and conventional content analysis,[35] using a combination of deductive and inductive processes. Field notes were made during the focus group interviews but were not analyzed. The transcribed focus groups were not returned to patients for comment or correction. All coding of the transcripts was conducted using N-Vivo Software.[36] The focus group transcripts were subject to line-by-line coding and then similar codes were grouped into categories representing similar phenomena. General categories were defined by current research on patient-partner relationship quality, and newly emerging categories were added accordingly. Responses were coded by two independent researchers (MC & LM). Through discussing the categories with the first author (HT), the coders drew further analytic conclusions from the data; any discrepant items were discussed and resolved by consensus.

## ETHICS

As this study was a quality assurance and improvement project, the Ottawa Health Science Network Research Ethics Board exempted it from full review, but approved the publication of these data.

## PATIENT AND PUBLIC INVOLVEMENT

Although patients or the public were not directly involved in the development of the research, the authors devised the interview questions based on their clinical experience working with patients with CVD and their partners. Conducting these focus groups was the first step toward creating a couple-oriented intervention to ensure patient engagement from the outset. Further, the results from the study were incorporated into a "caregiver guide" that is provided to partners of patients at the UOHI upon patient discharge from the hospital. The guide was developed in close consultation with executive members of the Patient Alumni Association at the UOHI, a patient group that represents over 12,000 active members.

## RESULTS

The study included 16 cardiac patients and their partners (N=32). Patients were mainly older (M=64.4 years, range 31-81 years), White (87.5%), and well-educated (M=14.86 years). Twelve (75%) of the patients with CVD were male, 3 were female, and 1 couple both had a history of CVD. The cardiac diagnoses were varied: 50% had been diagnosed with coronary artery disease; 18.75% had valve disease; 18.75% had heart failure; and 12.5% had arrhythmia. All couples were heterosexual. One couple dropped out of the study (patient was too distressed to speak about her heart condition).

Three focus groups were conducted, each with a maximum of 6 couples. The following categories that were generated from the analysis describe the nature of changes to the relationship that resulted from CVD: 1) emotional and communication disconnection; 2) overprotection of the patient; 3) role changes; 4) adjustment to lifestyle changes; and, 5) positive relationship changes. Three categories emerged regarding the need for intervention and resources: 1) practical resources; 2) sharing with peers; and, 3) relationship enhancement. These categories describe the participants' perceptions of what is required to adequately support couples managing CVD.

**Table 2: Outcomes of Content Analysis**

| Category | Example Quote |
|---|---|
| **Changes to the Relationship** | |
| 1) Emotional and Communication Disconnection | *We have to slow down our conversations because we don't hear as fast as we used to, and I say something and he only listened to the first half and the second half is the most important. Then, he might get mad at me because I didn't do what he thought I said, I had said something else. We used to get along. Our daughter used to say that we do everything in short hand, and now we have to go back to long hand…I want to go back to what I had before.* |
| 2) Overprotection of the Patient | *I try to get independence…'I want to do this…' and she says 'well, you shouldn't do that' and I couldn't stay up at the cottage alone because it takes the paramedics too long, so I felt that my summer was a little hijacked. After the angioplasty, you tread on eggshells and that's the way it's gonna be now…I feel like a puppet on a string sometimes.* His spouse replied: *And, I feel like the ogre. I had to be the one who would say, 'you can't do that, or I can't let you do that.' I was some scared. It takes a long time getting over being scared to that degree.* |
| 3) Role Changes | *For me it's been a 6 month full-time job, and that's my problem…something I've struggled with is doctors and nurses and support people saying "take care of yourself…" that is the most difficult thing in the world because there is no time to take care of yourself because you are looking after yourself and somebody else and life goes on… And for me, I managed fine for 3 months and after 3 months I all of a sudden realized I wasn't even breathing, so how can you rebalance, so what happens is, I get short tempered, intense and stressed.* |
| 4) Adjustment to Lifestyle Changes | *One of the things that we enjoy a whole lot together is ballroom dancing, and we got up to a fairly reasonably advanced level and, then all of a sudden with this heart issue, I didn't have the energy to stay upright for very much time at all. I would sit in one of the chairs on the side and [partner] would find herself busy dancing with an instructor, so at least she isn't sitting on the side as well, but it's so frustrating to not be able to do the things you used to be able to do before.* |
| 5) Positive Relationship Changes | *What [the cardiac event] has done actually, it has brought us closer together. I feel our relationship is stronger. From a selfish point of view, I am the one being taken care of. I have a 24-hour nurse. I feel it would be completely different if that even hadn't happened, who knows, we might have gone in different directions…now we do stuff together all the time…we try to see the positive side of things* |
| **Intervention Needs and Resources** | |
| 1) Practical Resources | *I think some media to take home. Some pamphlets or DVDs or something. You could have like workshops for different things for couples.* |
| 2) Sharing with Peers | *It's been a roller coaster, up and down, we tried to pick up the good moments and continue doing the right things…but it's tough. I'd like to learn more about other people and experiences and be able to share.* |
| 3) Relationship Enhancement | *Sometimes people are secretive, and with [patient], he doesn't talk much. I've actually been to some of his rehab visits so that we have everything laid out and we are able to understand each other. I think communication is key to have people understand what's going on in your life, and sometimes you need that third party to get that communication going.* |

## Relationship Changes

### *Emotional and communication disconnection*

The most prominent category that arose in the focus-group discussions was a feeling of being disconnected both emotionally and in communication patterns. The presence of CVD created added stress to the relationship, causing the patient and or the partner to become more irritable, increasing their propensity for conflict. A common cause for conflict was a newfound disconnection in communication, typically manifested by withdrawal or being "shut down" emotionally. This often led to frustration, particularly among partners.

> *Spouse:* Totally frustrating, I'll say 'are you upset with me?' because I will talk or, or I will be talking about something and pouring my heart out, and he'll say 'did you see that truck over there?…' and I'll be like, he didn't even hear one word I said…it's kind of like he's in a bubble. So, sometimes I get very upset. I can get downright hostile about it, and sometimes I want to throw my hands up and say, that's it, I'm out of here. You need to be able to communicate, and meet each other where you are at, be honest about your relationship and be honest about how you feel, and if you are afraid, say something, not try to hide if from the other person.
>
> *Patient:* I've become much more sensitive, like in terms of things that normally wouldn't bother me start to bother me now. I'm much more emotional a lot faster, and I think he struggles with that. We were used to a certain set of signals and now he doesn't know if it is coming or going. Her spouse added: One minute she can be really nice, and the other real nasty.
>
> *Spouse:* Before, I found that if I would wake up in the middle of night with a problem he'd be right out of bed and be like 'let's go' and to this day if I have a problem he's raring to go and ready to help, but I find that there's not enough communication like how do you really feel inside, [to partner] I want to know what's going on inside of you.
>
> *Patient:* I don't remember much of the first part, so it's kinda crappy, you know, you are not a very nice person during that time…I know I was pretty cranky…We would fight a lot.
>
> *Spouse:* He could be irrational sometimes, and I feel like he is just going to pick on me…you always pick on the one who is closest to you…
>
> *Spouse:* You think you are coping…with a new way to cook or control portions and ensuring everyday physical activity, but then you forget to talk to each other.

### *Overprotection of the patient*

As partners attempted to deal with the fear of potentially losing their loved one and an associated desire to keep them healthy enough to prevent another cardiac event, they became quite protective, often overprotective. Despite good intentions, the overprotected patients tended to withdraw from their partners, which exacerbated the partner's fear. As such, overprotection was frequently another cause of conflict for the couples.

> *Patient*: Even now, she said 'I'm not going to let you do anything.' Even in the truck she would stand on the ramp and say no….it is really a lot of reminding me what I can and can't do.
>
> *Spouse*: From the spouse point of view, we haven't lived in your position so we don't know, but we are there to help you, and sometimes it looks bad, or we're nagging, it's just we want what is best for you.
>
> *Patient*: Sometimes it's nice to have an alarm [spouse] in your ear saying 'you shouldn't do that,' and you say thank you for the alarm, but in my mind this is the biggest emotional toll that there is.
>
> *Spouse*: Sometimes I feel like I've been a bad mom, holding the reins back and not letting him have [unhealthy food].
>
> *Spouse*: She likes to dive in, and she gets so far into it she doesn't realize how far she's gotten in. I try to yell warning signs, but try to get her to listen…she's too headstrong, she'll do whatever she wants to do and it makes it difficult to warn her and it causes problems [between us] because of it.

### *Role changes and related stress*

The onset of CVD led to changes in the roles each member assumed within the relationship on a day-to-day basis. One aspect of this was an increased caregiver burden, where the increased responsibility of caring for the patient became a "full-time job" for the partners. Many partners felt the need to take on more responsibilities to help their partner in light of their cardiac condition. As a result, there was also an apparent increase in stress and compassion fatigue among some of the partners.

> *Spouse:* Our children live [elsewhere], so it is basically just us, and when it comes down to it, it's basically just me…I continue to get stronger, but it has been heavy going, very stressful and very

> anxiety-making, and borderline situational depression or something like that, really just a different me inside, and it's coming back, but it's a piece of work.
>
> *Spouse*: I'm the one who maintains the menu, and the food buying and I feel very responsible about that…we've maintained a healthy diet, and that's good for both of us. I don't resent that, but I feel very responsible.
>
> *Spouse*: As the spouse, you spend 80-90% of the driving and then sitting through [appointments]…there is no time for me to get to a gym and do exercise, but I sit through cardio rehab and watch, which really bothers me.
>
> *Spouse*: He couldn't drive, and once again, that's adding extra burden on me.

In contrast, patients with a cardiac condition tended to perceive a loss of their previous roles. Male patients especially felt that they were judged by those around them for not being able fulfill expected masculine social roles. One patient said that he felt 'worthless' and 'unimportant' as a result of not being able to 'perform' as a man. Patients expressed guilt for being an added burden to their partner and for having a decreased ability to support them.

> *Patient:* There is definitely guilt involved. You put this on the other person. It's my heart problem, but now it's her problem…so, guilt is a big thing and you can hear the other person say 'It's ok, and its good and I love you and I support you,' but it's still guilt.
>
> *Patient:* I think people look at me, or look at you and think yeah sure your fine, but internally we don't feel fine... Like, they think you're being lazy, or they think you're being depressed, but it's sometimes it's not that it's a choice.
>
> *Patient:* I don't think it's only the role of the man, you're expected to be working together…we went to Costco after the surgery and I couldn't move my arms, and you know, I was there with arms crossed, which is the most comfortable position, and my mother and wife were putting stuff on the cart and the cashier got so upset, and got up and went there and helped them and gave me the look.
>
> *Patient:* I think it's a newfound or rekindled dependency on him that I'm not sure he is accustomed to or that he's aware of how dependant I've become on him, so that is a new sensation as well.

### *Adjusting to lifestyle changes*

It was apparent that the patient-partner relationship was impacted by the many lifestyle changes that were required following the onset of CVD. Many of the couples found that they needed to get accustomed to a ‘new normal,’ a loss of previous activity and the presence of new restrictions to various aspects of their lives. Some of these included the restrictions on strenuous physical activity, management of various doctor’s appointments and medications, and adopting new diets:

> *Spouse:* I cook and buy the groceries, so suddenly, I was very aware of fish twice a week and chicken, and once in a while I’m very aware of something red, but it is rare, and just being careful all the time.
>
> *Spouse:* I got home with all these bottles of medications and I had some idea about what some of them were for, but the others…it’s very important to learn…we were on a colour and number basis and I did this every day. It was overwhelming.
>
> *Spouse:* Many of our little habits that we do together, well, we can’t do the same thing anymore… everything has to slow down and much more directed, and we have to check with the other person much more than we ever did before… And it takes time, what I want is what I had before but I can’t have that so now I have to get something different.
>
> *Patient:* I am struggling with taking pills everyday, that’s not what I do. And, I know it sounds silly, but it difficult for me to know and admit that I have a problem, and that this is what I have to look forward to. Really, I’m very fortunate, but I’m struggling with some of that…the medication forces limitations on us, it’s about the way we feel, and without it, what would our quality of life be, but it does change who we are and what we can do.

It was also apparent that partners and other members of the patients’ support network made similar changes in lifestyle because of the cardiac event. In particular, some couples lamented that they were not able to pursue personal or vocational activities they used to enjoy or joint activities that they did together:

> *Spouse*: We were very active people, sports wise, and…culturally being members of the [arts venue], so with the bypass surgery we are not able to do all the activities that we had before. So our life has changed significantly.
>
> *Patient*: People come up to you and say, ‘oh, you look really good,’ but yeah, you look good physically, but mentally you are still a jumble of all kinds of stuff. And, you are thinking between you and your partner, she should have a normal life, but now I’ve created an obstacle for her to carry on. And, when I go to work, I get tired and I sit down and everyone else is working and now you feel that you are not yourself anymore because you would be helping them before and now you’re not because you are physically exhausted.

*Positive changes within the relationship*

In contrast, some couples expressed that the event brought them closer together and had made their relationship even stronger, despite the changes that occurred in their lives as a result of the CVD. By working through the challenges of adjusting to their illness, they found new ways of showing affection and care for one another. Example statements include the following:

> *Spouse*: The [cardiac event] made us realize, even though we don't admit it to each other, how much we really do need each other. And it goes both ways.
>
> *Patient*: Whatever you've had, that's an incident that opens the door that the relationship all of sudden has new facets, there are new things you find out about each other, strengths that you never realized about each other. You find out things that you probably wouldn't have told each other about your past. I think the incident is unique and it's a tool that can be used to strengthen a weak relationship or to reinforce one that is already fairly strong.
>
> *Patient*: I've told her, I wouldn't know what to do without her.
>
> *Spouse*: It's made us both realize how precious we are to each other.

## Perceived Needs and Desired Interventions

Throughout the discussions, couples highlighted multiple needs and areas of potential intervention. Three themes emerged including: 1) practical resources and information; 2) the opportunity to share with peers; and, 3) help with relationship enhancement. Further, all couples reported an interest in couples-based interventions. One participant noted that, after dealing with three other major medical conditions, this was the first time anyone had asked about the needs of the patient *and* the partner. Patients and partners specifically requested that partners be involved in the care; one spouse pleaded "include us in that training" when speaking about teachings for lifestyle and medication management. One patient felt that it was "unfair" that spouses were not offered the program he was in, especially because he had a positive experience "connecting with the people in the rehab program."

### *Practical information and resources*

Participants requested practical information to help them cope with CVD management such as workshops on stress management, medication management, healthy eating, and generally what to expect when discharged from hospital. A recurrent theme was the importance of having information given to patients and partners about support they could be receiving. Spouses spoke about the need to repeat this information as they tended to be "numb" after first learning of the cardiac event. Participants noted the need for intervention at various times, including while in hospital, at the time of hospital discharge, and in the months post-discharge.

> *Spouse*: First, there is the shock, oh, it was a heart attack, and then in the hospital there is so much information, but I didn't get a lot of it because there is only so much I could take in my brain, because I had all this other stuff like 'what…it really was?'
>
> *Patient*: We need information sessions and information on the [hospital] website.
>
> *Spouse*: Something I've struggled with is doctors and nurses and support people saying, 'take care of yourself'…but nobody says, 'this is a helpful way to take care of yourself…if you could do a, b, c…' for example, techniques for stress. A group to help learn new ways of doing something, even how to help yourself as your spouse recovers.

### *Opportunity for sharing with peers*

The second area for intervention suggested by participants was the opportunity to meet and share experiences with other patients and partners. Many participants expressed the desire to have support groups where they can meet other couples who are coping with heart disease. This sharing was viewed as part of the healing process that could assist in normalizing feelings, as well as provide an opportunity to learn from others' experiences and successes.

> *Patient*: I think a support group would be good…sometimes you hear others and it kind of sparks something in you, you have a common ground you can talk about. I went to a support group after I left here to meet with people who had similar difficulties and I found that very helpful to meet with people who were having the same issues. Even a doctor who had never experienced it would probably not have the same input as patient to patient, because you really don't understand how a person feels until you've been there.

> *Spouse*: We have really sick spouses at some point who are very critical, and we get a lot of information about them, but it seems to me that the spouse themselves is also critical in this area..it would be wonderful to actually have some support groups for us because most often we don't know anybody else in the same critical situation and we flounder.
>
> *Patient*: A lot of problems were solved in the locker room, you know, and knowing that someone else is going for it, and 'did you have your appointment yet?' and they understand how important that is.
>
> *Spouse*: This kind of thing [group discussion] would have been really helpful in the beginning, to see what we are going through is normal and other people are to and it is normal.

*Relationship enhancement*

Lastly, participants spoke about a desire for assistance to enhance their relationship. As noted above, they were keenly aware of the changes in their relationship in light of the new stressor and wished to rebuild connections. They reported an interest in learning ways to communicate, reassure, and help each other, in order to strengthen the relationship. In fact, one spouse recommended offering a phone line for couples to obtain counseling, noting that what they are dealing with is 'not just a health thing.'

> *Spouse*: I think it would have helped to know what I could do more to help, instead of fighting back or pushing him away.
>
> *Patient*: I think the incident [cardiac event] is unique and it's a tool that can be used to strengthen a weak relationship, or reinforce one that is already fairly strong. If you were going to use a group, you might want to concentrate on that aspect rather than just the incident, we've all been through the painful part. More on how to rebuild and keep building or strengthen what you have. His spouse added: And, how to cope with the sensitivity of the other, and that he is not the same human being any more. The challenge is to stay close to this person that is so special to you as they change, and of course, as they change, so do you. His life has changed, but mine too.
>
> *Spouse*: We have this long relationship together. He contributes to my stuff and I contribute to his stuff…Finding out what is not so good is important as well as what's good so that we can capitalize on the good and try as much as possible to eliminate things that are not very good…so that is what we need to work on.

## DISCUSSION

Utilizing focus groups, this study explored relationship changes among patients with CVD and their partners. The data demonstrated that both patients and partners grappled with many adjustments to their relationship after the cardiac event, and were challenged to adapt to a 'new normal.' Similar to previous studies [25, 33] our findings call attention to the emotional and communication disconnection between partners, and distress related to role changes, lifestyle adjustments and overprotective behaviours. Like other studies,[25, 33] we also observed a silver lining to the CVD cloud - the strengthening of the couple bond. Possibly the most novel aspect of our study, however, was the exploration of needs and desired areas of intervention proposed by participants. To our knowledge, only one other study engaged patients with CVD (i.e., heart failure) and their partners on this topic, particularly regarding information and education support.[28] While our participants noted value in instrumental support and practical resources, they clearly communicated the importance of assistance in building connections with their peers and partners to help them cope. Our results underscore the need for interventions that target both members of the dyad, instead of the current status quo which, for the most part, includes only the patient in care.

More specifically, a systematic review by Dalteg and colleagues found that the themes of overprotection, communication deficiency, sexual concerns, changes in domestic roles, and adjustment to illness were the most common themes across 20 different studies. [25] These themes, except sexual concerns, were major topics that arose in the group interviews conducted in this study. Similar to findings from a study of couples managing atrial fibrillation,[27] we observed that some couples would collaborate and agree upon adjustments in lifestyle as a way to cope with uncertainty. In contrast, our patient population also described distancing themselves from their partners in an attempt to protect their partner from distress or worry. Further, our findings indicated that a cardiac event changed the communication and emotional aspects within the relationship as well as the logistical aspects of everyday habits, activities, and roles. Any change in circumstance in any of these aspects for one partner would inevitably affect similar aspects of the other partner, as well as the identity of the couple. Each member of the couple needed to relearn aspects of each other in order to reduce conflict and sustain the relationship.

Evidence continues to link poor spousal relationships to worsened cardiovascular health and negative behaviours affecting CVD outcomes;[37] as such, screening and monitoring changes in patient-partner relationship quality may be an important task for clinicians. Table 3 provides some suggested questions that clinicians and other healthcare professionals may use to inquire about changes to the patient-partner relationship. Further, when couples spoke about what they would find useful in a couples-based intervention, several individuals mentioned the benefit of meeting other couples with similar experiences and learning strategies to improve their relationship in order to help the other person cope with CVD management.

**Table 3: Potential questions for clinicians & healthcare professionals to ask patients and partners**

1. It is common for your relationship to change after experiencing a heart event. Have you noticed any changes to your relationship with your spouse?
2. Have changes to your relationship with your spouse made it more difficult for you to cope with the challenges of heart disease?
3. What do you and your partner do to help promote a positive relationship with each other?
4. What would you and your partner require to help you cope better together?

Attachment theory provides a strong model for the behaviors observed within the couple dyad and provides a possible explanation for why couples experience CVD differently. It is likely that the overprotection by some partners reflects high attachment anxiety, which is known to occur in the face of threats to the integrity of the attachment relationship, such as chronic disease.[38] Similarly, some of the patients might have been high in attachment avoidance, which involves a level of self-reliance that might lead patients to withdraw emotionally from their partners, leading both members of the couple to perceive their relationship more negatively. In contrast, those who have a secure attachment bond in their relationship may have been more comfortable asking for reassurance and specifying the level of support they needed, allowing for a reduction in distress levels intra- and interpersonally. An assessment of the quality of the attachment bond in the relationship and interventions that appropriately targeting the couples' practical and attachment needs may improve the relationship quality and the dyad's combined ability to manage CVD.

Some patients seemed to have an ambivalent attitude toward their partners who have taken more of a policing and caregiver role. It was clear that although they appreciated the support they received, it was a cause of stress and guilt for patients as well. Uchino, Smith, and Berg[39] found that members of couples who felt ambivalently towards their spouse were less likely to seek support from them and were less likely to benefit from the support of that relationship. Using predicted coronary-artery calcification (CAC) scores as a measure, the authors further demonstrated that prolonged ambivalence was tied to increased risk of CVD. Clinically, this indicates that the presence of discord in the relationships of cardiac patients, as was found in the present study, may increase their risk of recurrent disease and result in poorer quality of life for this population.

It is apparent that partners have been neglected and deprived of care to date, despite their clear contribution to our health care system. This fact is disturbing considering the mounting evidence to suggest that partners of patients with CVD are also vulnerable to developing poorer health outcomes, such as increased distress and depressive symptoms, higher blood pressure, weight gain, and disordered sleep.[40,41] In our focus groups, it was evident that many of the partners provided care without the adequate resources to do so and were more isolated than the patient in facing the uncertainty of the CVD they were helping to manage. Despite the psychological benefits of cardiac rehabilitation,[1] partners of patients with CVD are often excluded from this important intervention. The present study shows the vital role of partners in the care of cardiac patients; thus, it is important to recognize that providing support to partners is critical for both partners' psychosocial and medical health outcomes.[26]

## LIMITATIONS

This study is not without limitations. First, although the sex distribution is similar to that of the cardiac rehabilitation population, the majority of the patient participants were heterosexual males, potentially biasing the data by sex and preventing meaningful analyses between the sexes. Second, the data were collected from one cardiac centre in Canada; an exploration of needs and desires of this population in other centres would strengthen our findings. It is important to note, however, that the systematic review of 20 studies from various countries identified similar categories.[25] Despite these limitations, this is the first study that explored, in-depth, the desired intervention components of patients and their partners to help them better manage CVD. Findings allowed for the elucidation of strengths and weaknesses in cardiac rehabilitation programming and better determine the needs of this patient population and their partners.

## CONCLUSION

In summary, the present study demonstrated that the acute onset and chronic effects of CVD cause both positive and negative changes to the couples' relationship. The results highlight the need for more specialized couples-based interventions that aid both patients and their partners through the new reality of living with CVD. Changes within the relationship are inevitable after a cardiovascular event; therefore, it is essential to support couples cope with these changes in ways that strengthen their connections to peers and each other and improve their health.

## IMPLEMENTATIONS FOR PRACTICE

- Partners should be actively included in interventions aimed at improving recovery of patients with CVD. Practical resources, opportunities to share with peers, and couples-based interventions are required.

- Changes to patients' and partners' relationship quality should be assessed within cardiac rehabilitation programming and action taken to support patients and partners in strengthening their relationship.
- Future research should investigate whether couples-based programming is effective in reducing both partners' stress brought on by CVD and whether meaningful changes to relationship quality and clinical outcomes are observed as a result of participating in such couples-based programming.

**Contributors:** HT, PG designed the study. HT, PG, SJ, & ND collected the focus group data and HT, LM & MC conducted the analysis. HT, KB & LM wrote the manuscript with contributions from all authors.

**Competing interests:** None declared.

**Ethics approval:** The Ottawa Health Science Network Research Ethics Board (OHSN-REB) deemed this study as a quality assurance/improvement project; therefore, full ethics review was not required, but approval was granted to publish these data.

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## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No. Item | Guide questions/descriptions | Reported on Page # |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| **1. Interviewer/facilitator:** | Which author/s conducted the interview or focus group? | Page 24 |
| **2. Credentials:** | What were the researcher's credentials? E.g. PhD, MD | Page 8 |
| **3. Occupation:** | What was their occupation at the time of the study? | Page 8 |
| **4. Gender:** | Was the researcher male or female? | Page 8 |
| **5. Experience and training:** | What experience or training did the researcher have? | Page 8 |
| *Relationship with participants* | | |
| **6. Relationship established:** | Was a relationship established prior to study commencement? | Page 8 |
| **7. Participant knowledge of the interviewer:** | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | Page 8 |
| **8. Interviewer characteristics:** | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Page 8-9 |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| **9. Methodological orientation and Theory:** | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Page 9 |
| *Participant selection* | | |
| **10. Sampling:** | How were participants selected? e.g. purposive, convenience, consecutive, snowball | Page 8 |
| **11. Method of approach:** | How were participants approached? e.g. face-to-face, telephone, mail, email | Page 8 |
| **12. Sample size:** | How many participants were in the study? | Page 10 |
| **13. Non-participation:** | How many people refused to participate or dropped out? Reasons? | Page 10 |

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| | | |
|---|---|---|
| *Setting* | | |
| **14. Setting of data collection:** | Where was the data collected? e.g. home, clinic, workplace | Page 8 |
| **15. Presence of non-participants:** | Was anyone else present besides the participants and researchers? | Page 8 |
| **16. Description of sample:** | What are the important characteristics of the sample? e.g. demographic data, date | Page 10 |
| *Data collection* | | |
| **17. Interview guide:** | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Page 9 |
| **18. Repeat interviews:** | Were repeat interviews carried out? If yes, how many? | Page 8 |
| **19. Audio/visual recording:** | Did the research use audio or visual recording to collect the data? | Page 9 |
| **20. Field notes:** | Were field notes made during and/or after the interview or focus group? | Page 10 |
| **21. Duration:** | What was the duration of the interviews or focus group? | Page 8 |
| **22. Data saturation:** | Was data saturation discussed? | Page 9 |
| **23. Transcripts returned:** | Were transcripts returned to participants for comment and/or correction? | Page 9 |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| **24. Number of data coders:** | How many data coders coded the data? | Page 9 |
| **25. Description of the coding tree:** | Did authors provide a description of the coding tree? | Page 11 |
| **26. Derivation of themes:** | Were themes identified in advance or derived from the data? | Page 9 |
| **28. Participant checking:** | Did participants provide feedback on the findings? | Page 9 |
| **27. Software** | What software, if applicable, was used to manage the data? | Page 9 |
| **29. Quotations presented:** | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number | Page 11-18 |

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| | | |
|---|---|---|
| **30. Data and findings consistent:** | Was there consistency between the data presented and the findings? | Page 11-18 |
| **31. Clarity of major themes:** | Were major themes clearly presented in the findings? | Page 10-11 |
| **32. Clarity of minor themes:** | Is there a description of diverse cases or discussion of minor themes? | Page 10-11 |

BMJ Open

# Learning a new way of living together: A qualitative study exploring the relationship changes and intervention needs of patients with cardiovascular disease and their partners

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For peer review only

# Learning a new way of living together: A qualitative study exploring the relationship changes and intervention needs of patients with cardiovascular disease and their partners

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## ABSTRACT

**Objectives:** Cardiovascular disease (CVD) not only affects the patient, but has implications for the partner. Emerging evidence suggests that supportive couple relationships enhance CVD outcomes and reduce patient and partner distress. To date, however, little research has been done to address the couple relationship as a potentially important component of cardiac care. This article examines the impact of CVD on the couple relationship and assesses the perceived needs and desired intervention components of patients with CVD and their partners.

**Design:** Qualitative study using directed and conventional content analysis.

**Setting:** Single-centre, tertiary cardiac care hospital that serves a population of 1.4 million in the Champlain region of Ontario, Canada.

**Participants:** Patients with CVD and their partners (N=32, 16 couples) participated in focus groups. Patients were mainly male (75%), white (87.5%), aged 63.4 years (range 31-81 years), with varied cardiac diagnoses (50% coronary artery disease; 18.75% valve disease; 18.75% heart failure; 12.5% arrhythmia).

**Results:** Five categories were generated from the data reflecting changes within the couple relationship as a result of CVD: 1) emotional and communication disconnection; 2) overprotection of the patient; 3) role changes; 4) adjustment to lifestyle changes; and, 5) positive relationship changes. Three categories were constructed regarding intervention needs and desired resources: 1) practical resources; 2) sharing with peers; and, 3) relationship enhancement.

**Conclusions:** Overall, the data suggest that there were profound changes in the couple relationship as a result of CVD, and that there is considerable need to better support the caregiving spouses and the couple as a unit. These results call for interventions designed to provide instrumental support, peer-sharing opportunities, and relationship quality enhancement to help couples cope with CVD. Future

studies should examine whether couples-based programming embedded into cardiac rehabilitation can be effective at improving relationship quality and reducing patient and partner stress in the aftermath of a cardiac event.

**Keywords:** cardiovascular disease, couples, relationship quality, intervention, cardiac rehabilitation

## ARTICLE SUMMARY

### Strengths and Limitations of this Study

- This study is the second, to our knowledge, to explore potential areas of intervention for couples in which one partner has cardiovascular disease.
- The ORBIT model for developing behavioural treatments for chronic diseases was employed.
- Generalizability is limited by recruitment at one site, mainly male patients, and heterosexual couples.
- The findings cannot reveal how couples' needs may change over time as the focus groups were conducted at one time point.
- The unique needs of specific CVD diagnostic groups was not analyzed due to limited sample size.

## INTRODUCTION

Cardiovascular disease (CVD) is a leading cause of mortality in most western nations. Multiple modifiable risk factors for CVD have been identified, including smoking, physical inactivity, hypertension, poor diet, metabolic syndrome, and stress. These factors are routinely targeted in primary and secondary prevention programs, which reduce morbidity and mortality, and improve mental health and quality of life outcomes among patients with CVD.[1] Interestingly, despite the well-established link between social relationships and the progression of CVD,[2,3] this component is rarely targeted in the prevention or management of CVD.[4]

Accumulating evidence indicates that positive social relationships are integral to health. To illustrate, a meta-analysis with over 300,000 participants revealed an increased survival rate of 50% for those in supportive relationships.[3] Socially isolated individuals or those in poor relationships, in contrast, experience increased morbidity and mortality. For example, a 29% increased risk of coronary artery disease was reported in a recent meta-analysis including over 35,000 participants.[2] Given the importance of intimate relationships for most adults, it is not surprising that partner support is the strongest determinant of wellbeing relative to other sources of support.[5] In fact, a recent systematic review revealed that simply being married is associated with fewer CVD risk factors and improved survival rates.[6] One cohort study with almost one million patients with acute coronary syndrome, for example, detected lower mortality rates for married (OR=0.86) and widowed patients (OR=0.96), whereas single patients had increased rates (OR=1.07).[7]

Other evidence indicates, however, that the quality of the relationship, not just its presence, may dictate the impact on heart health. High-quality relationships are characterized by high relationship satisfaction, warmth, support, and closeness, while distressed relationships exhibit high levels of conflict, hostility, distance, and dissatisfaction.[8, 9] The presence of strong patient-partner relationships, high in relationship quality, has been associated with improved physical and mental health outcomes. Marital discord, in contrast, has been related to elevated risk of CVD development and to the progression of established disease, even when other risk factors such as age, blood pressure, and BMI are controlled for in the analyses.[10-13] For example, one study found that the survival rates of patients who underwent coronary artery bypass surgery and reported satisfying relationships were 3 times higher than those in poor relationships.[14] Hypertension and increased heart rate is observed with marital conflict,[15, 16] whereas reductions in blood pressure are observed during supportive interactions.[17] Patients in well-adjusted relationships are more likely to adhere to medical prescriptions and to be more assiduous in their attendance at cardiac rehabilitation.[18, 19] There is evidence that high quality patient-partner relationships can also reduce caregiver burden, distress, and depressive symptoms.[20] Taken together, the evidence connecting poor patient-partner relationship quality to deleterious physical and mental health outcomes continues to mount, whereas high quality relationships appear to buffer the impact of CVD and to enhance physical and mental health.

Despite this evidence, few interventions for cardiac patients and their partner exist. To date, the focus, not surprisingly, has been on traditional CVD risk factors such as exercise, diet, and smoking behaviour. A systematic review of seven couples-based psychological interventions for patients with coronary artery disease reported modest improvements in patients' knowledge of disease and treatment, blood pressure, and quality of life with intervention participation, but no effect on morbidity or mortality.[4] Low quality methods were thought to explain the reduced efficacy. Methodological limitations of couples-based interventions include: outdated studies – many are over 20 years old and the medical care and related couple experience has changed substantially; interventions were not based in theory or were simply informational; small sample sizes; and data collection has been restricted to the patient and lacked measures of relationship quality.[4, 21-23] Further, to our knowledge, only one study in the CVD context has targeted the couple relationship as an intervention component to date.[24] Results of that study demonstrated improvements in exercise levels, but distressed couples did not maintain gains at intervention completion (18 weeks). A more targeted intervention aimed to improve relationship quality may be required to enhance couple-related, psychological, behavioural, and physical health outcomes.

In order to design more effective couples-based interventions, an in-depth understanding of the experience and needs of patients and partners in the context of CVD is required. Daltag and colleagues systematically reviewed qualitative and quantitative research investigating the impact of cardiac disease on the partner relationship.[25] Results indicated that the impact is extensive and distressing on multiple levels, including adjustment to illness and role changes, sexual concerns, and communication and overprotection. Unfortunately, the studies included in the review are now a decade old and, like the intervention research described above, they preclude a contemporary impression of the dyad's experience in the current medical environment. Since this review,[25] to our knowledge, three additional studies in the cardiac context were published.[26,27, 28] Findings highlighted difficulties living with the uncertainty of the disease, feelings of worry and vigilance, and caregiver burden and support. Patients and partners also reported that caring involvement brought the couple closer together or, the opposite, a feeling of loss of the partner relationship and role changes. These studies, however, included select cardiac populations (i.e., patients with atrial fibrillation or heart failure) or spouses only. Further, only one [29] of the previously reviewed[25] or newer studies inquired about potential areas of support for the patient-partner dyad. With approximately 30% of couples with CVD reporting marital discord[30] and the potential physiological detriment on patients' cardiovascular health, more research on the experience and intervention needs of patients with CVD and their partners is required. This information may then be used to enhance intervention development and efficacy.

Employing a systematic framework, such as the ORBIT model for developing behavioural treatments for chronic diseases,[31] has been shown to produce stronger behavioural treatments and to avoid costly trials of those that have not been optimized. Phase I (design and define) aims to identify the essential features of a treatment. Qualitative research is often employed to engage the community of participants and reveal details of the clinical problem and potential treatment components. Practical aspects of the intervention are also investigated, including, for example, the preferred mode of delivery, setting, and frequency and duration of contact. With this information, an intervention that is acceptable to the target population and has promise for clinically significant benefit can be created. This phase is followed by preliminary testing such as proof of concept trials (Phase II) and, if positive results are detected, an RCT pilot study is then justified. Efficacy testing in the form of larger randomized controlled trials (Phase III) and effectiveness research (Phase IV) complete the process.

The present study describes Phase I for the development of a couples-based intervention for patients with CVD and their partners. The specific aims were: 1) to further understand the impact of CVD on the nature of the couple relationship and 2) to assess the intervention needs and desires of patients with CVD and their partners, including an exploration of their interest in a couples-based intervention in cardiac rehabilitation. The ultimate goal was to inform the development of relevant cardiac interventions that involve the couple as a unit.

## METHODS

### Design and setting

This study used an exploratory and qualitative design. The study was carried out at the University of Ottawa Heart Institute in Ottawa (UOHI), a quaternary care cardiac hospital that serves a population of 1.4 million in the Champlain region of Ontario, Canada.

### Participant recruitment

All participants were past or current participants of the UOHI cardiac rehabilitation program; no restrictions were placed on cardiac diagnosis. Patients were recruited using purposive sampling from UOHI cardiac rehabilitation classes by one of the researchers (HT). Announcements were made stating, “we recognize that dealing with a heart condition can be difficult for patients and their significant others. We are recruiting patients and their partners to participate in a focus group meeting so that we might better understand your experiences, concerns, and needs with heart disease. Our goal is to improve the services we offer to the patients and their spouses.” Interested patients approached the researcher who then screened them for eligibility and, if eligible, scheduled them for a focus group session. Participants were included if they had directly or indirectly (i.e., through a spouse) experienced a cardiovascular event, were in a couple relationship (married, common-law, or in a committed relationship for ≥ 2 years), were 18 years of age and older, and were able to speak English. There were no exclusion criteria for this study.

**Focus group interviews**

Patients were invited to attend a 1.5 hour focus group with their partner. Focus groups were particularly suited for this study as it allowed for interactive and intensive discussions amongst both patients and partners. Furthermore, focus groups position participants as experts of their social worlds and can help to reduce unequal power relations amongst the researchers and participants that can manifest in individual interviews.[32] All focus groups took place in meeting rooms at the UOHI; only the participants and the interviewers were present. A semi-structured interview guide was used throughout the focus groups. Question development was guided by the clinical expertise of the investigators, analyses of transcripts of couple therapy sessions with heart patients, and previous research on couples and CVD.[33, 34, 25] Table 1 provides a sample list of questions that were asked in the focus group interviews. The interview guide was not piloted tested and there were no follow-up interviews. Four interviewers (3 women, 1 man; authors HT, SJ, ND, PG) were involved throughout the study with two interviewers present at each focus group. All interviewers were licensed clinical psychologists with over 10 years experience working with couples and/or patients with cardiovascular disease. As the patient participants were former or current patients of the UOHI, a clinician-patient relationship was established prior to the data collection period for some participants (n=4; none of the partners were known). The focus of these relationships was individual care as part of cardiac rehabilitation. All participants were aware that the aim of the research was to ascertain patients' and partners' perspectives of intervention approaches that would be relevant to their needs. Although the interviewers have experience providing individual and couples-based interventions, the purpose of the research was to learn whether this would be of interest to the participants and what intervention components might be included.

| **Table 1 Focus Group Sample Questions** |
|---|
| 1. Sometimes people say that heart disease brings them closer together. Other times they say that it just seems to create more problems and stresses on top of the ones they already have. How has your experience been?<br>2. A lot of times patients and partners see heart disease differently. How similar or different would you say your perspectives on having heart disease are?<br>4. What has been the most difficult part of having heart disease (or having a partner with heart disease)?<br>5. How could the Heart Institute help you and your significant other cope better together? What have you found most helpful so far?<br>6. Would you be interested in a couples-based intervention as part of cardiac rehabilitation? If so, what would it look like? |

## Data analysis

Audio recordings of the focus groups were transcribed verbatim and subjected to directed and conventional content analysis,[35] using a combination of deductive and inductive processes. Field notes were note taken. The transcribed focus groups were not returned to patients for comment or correction due to concerns regarding the sensitivity of the data (e.g., medical history, relationship concerns) and previous research indicating that their corrections result in minimally higher data quality.[36] All coding of the transcripts was conducted using N-Vivo Software.[37] The focus group transcripts were subject to line-by-line coding and then similar codes were grouped into categories representing similar phenomena. General categories were defined by current research on patient-partner relationship quality, and newly emerging categories were added accordingly. Responses were coded by two independent researchers (MC & LM). Through discussing the categories with the first author (HT), the coders drew further analytic conclusions from the data; any discrepant items were discussed and resolved by consensus.

## ETHICS

As this study was a quality assurance and improvement project, the Ottawa Health Science Network Research Ethics Board exempted it from full review, but approved the publication of these data.

## PATIENT AND PUBLIC INVOLVEMENT

Although patients or the public were not directly involved in the development of the research, the authors devised the interview questions based on their clinical experience working with patients with CVD and their partners. Conducting these focus groups was the first step toward creating a couple-oriented intervention to ensure patient engagement from the outset. Further, the results from the study were incorporated into a “caregiver guide” that is provided to partners of patients at the UOHI upon patient discharge from the hospital. The guide was developed in close consultation with executive members of the Patient Alumni Association at the UOHI, a patient group that represents over 12,000 active members.

## RESULTS

All patients that approached the researcher regarding participation met the eligibility criteria. The study included 16 cardiac patients and their partners (N=32). Data saturation was reached with this sample size.[38, 39] Patients were mainly older (M=64.4 years, range 31-81 years), White (87.5%), and well-educated (M=14.86 years). Twelve (75%) of the patients with CVD were male, 3 were female, and 1 couple both had a history of CVD. The cardiac diagnoses were varied: 50% had been diagnosed with coronary artery disease; 18.75% had valve disease; 18.75% had heart failure; and 12.5% had arrhythmia. All couples were heterosexual. One couple dropped out of the study (patient was too distressed to speak about her heart condition).

Three focus groups were conducted, each with a maximum of 6 couples. The following categories that were generated from the analysis describe the nature of changes to the relationship that resulted from CVD: 1) emotional and communication disconnection; 2) overprotection of the patient; 3) role changes; 4) adjustment to lifestyle changes; and, 5) positive relationship changes. Three categories emerged regarding the need for intervention and resources: 1) practical resources; 2) sharing with peers; and, 3) relationship enhancement. These categories describe the participants' perceptions of what is required to adequately support couples managing CVD. Please see Table 2 for the outcome categories and example quotes.

**Table 2: Outcomes of Content Analysis**

| Category | Example Quote |
|---|---|
| **Changes to the Relationship** | |
| 1) Emotional and Communication Disconnection | *Partner 04:We have to slow down our conversations because we don't hear as fast as we used to, and I say something and he only listened to the first half and the second half is the most important. Then, he might get mad at me because I didn't do what he thought I said, I had said something else. We used to get along. Our daughter used to say that we do everything in short hand, and now we have to go back to long hand…I want to go back to what I had before.* |
| 2) Overprotection of the Patient | *Patient 10: I try to get independence…'I want to do this…' and she says 'well, you shouldn't do that' and I couldn't stay up at the cottage alone because it takes the paramedics too long, so I felt that my summer was a little hijacked. After the angioplasty, you tread on eggshells and that's the way it's gonna be now…I feel like a puppet on a string sometimes.* His spouse replied: *And, I feel like the ogre. I had to be the one who would say, 'you can't do that, or I can't let you do that.' I was some scared. It takes a long time getting over being scared to that degree.* |
| 3) Role Changes | *Partner 02:For me it's been a 6 month full-time job, and that's my problem…something I've struggled with is doctors and nurses and support people saying "take care of yourself…" that is the most difficult thing in the world because there is no time to take care of yourself because you are looking after yourself and somebody else and life goes on… And for me, I managed fine for 3 months and after 3 months I all of a sudden realized I wasn't even breathing, so how can you rebalance, so what happens is, I get short tempered, intense and stressed.* |
| 4) Adjustment to Lifestyle Changes | *Patient 04: One of the things that we enjoy a whole lot together is ballroom dancing, and we got up to a fairly reasonably advanced level and, then all of a sudden with this heart issue, I didn't have the energy to stay upright for very much time at all. I would sit in one of the chairs on the side and [partner] would find herself busy dancing with an instructor, so at least she isn't sitting on the side as well, but it's so frustrating to not be able to do the things you used to be able to do before.* |
| 5) Positive Relationship Changes | *Patient 09: What [the cardiac event] has done actually, it has brought us closer together. I feel our relationship is stronger. From a selfish point of view, I am the one being taken care of. I have a 24-hour nurse. I feel it would be completely different if that even hadn't happened, who knows, we might have gone in different directions…now we do stuff together all the time…we try to see the positive side of things* |
| **Intervention Needs and Resources** | |
| 1) Practical Resources | *Patient 12: I think some media to take home. Some pamphlets or DVDs or something. You could have like workshops for different things for couples.* |
| 2) Sharing with Peers | *Partner 06: It's been a roller coaster, up and down, we tried to pick up the good moments and continue doing the right things…but it's tough. I'd like to learn more about other people and experiences and be able to share.* |
| 3) Relationship Enhancement | *Partner 13: Sometimes people are secretive, and with [patient], he doesn't talk much. I've actually been to some of his rehab visits so that we have everything laid out and we are able to understand each other. I think communication is key* |

*to have people understand what's going on in your life, and sometimes you need that third party to get that communication going.*

## Relationship Changes

### *Emotional and communication disconnection*

The most prominent category that arose in the focus-group discussions was a feeling of being disconnected emotionally and in communication patterns. The presence of CVD created added stress to the relationship, causing the patient and or the partner to become more irritable, increasing their propensity for conflict. A common cause for conflict was a newfound disconnection in communication, typically manifested by withdrawal or being "shut down" emotionally. This often led to frustration, particularly among partners.

> *Partner 13:* Totally frustrating, I'll say 'are you upset with me?' because I will talk or, or I will be talking about something and pouring my heart out, and he'll say 'did you see that truck over there?…' and I'll be like, he didn't even hear one word I said…it's kind of like he's in a bubble. So, sometimes I get very upset. I can get downright hostile about it, and sometimes I want to throw my hands up and say, that's it, I'm out of here. You need to be able to communicate, and meet each other where you are at, be honest about your relationship and be honest about how you feel, and if you are afraid, say something, not try to hide if from the other person.
>
> *Patient 07:* I've become much more sensitive, like in terms of things that normally wouldn't bother me start to bother me now. I'm much more emotional a lot faster, and I think he struggles with that. We were used to a certain set of signals and now he doesn't know if it is coming or going. Her spouse added: One minute she can be really nice, and the other real nasty.
>
> *Partner01:* You think you are coping…with a new way to cook or control portions and ensuring everyday physical activity, but then you forget to talk to each other.

### *Overprotection of the patient*

As partners attempted to deal with the fear of potentially losing their loved one and an associated desire to keep them healthy to prevent another cardiac event, they became protective, often overprotective, leading to relationship conflict.

> *Patient 13*: Even now, she said 'I'm not going to let you do anything.' Even in the truck she would stand on the ramp and say no….it is really a lot of reminding me what I can and can't do.
>
> *Partner 01*: From the spouse point of view, we haven't lived in your position so we don't know, but we are there to help you, and sometimes it looks bad, or we're nagging, it's just we want what is best for you.
>
> *Patient 15*: Sometimes it's nice to have an alarm [spouse] in your ear saying 'you shouldn't do that,' and you say thank you for the alarm, but in my mind this is the biggest emotional toll that there is.
>
> *Partner 07*: She likes to dive in, and she gets so far into it she doesn't realize how far she's gotten in. I try to yell warning signs, but try to get her to listen…she's too headstrong, she'll do whatever she wants to do and it makes it difficult to warn her and it causes problems [between us] because of it.

### *Role changes and related stress*

The onset of CVD led to changes in the roles each member assumed within the relationship on a day-to-day basis. One aspect of this was an increased caregiver burden and stress, where the increased responsibility of caring for the patient became a "full-time job" for the partners.

> *Partner 10:* Our children live [elsewhere], so it is basically just us, and when it comes down to it, it's basically just me…I continue to get stronger, but it has been heavy going, very stressful and very anxiety-making, and borderline situational depression or something like that, really just a different me inside, and it's coming back, but it's a piece of work.
>
> *Partner 16*: I'm the one who maintains the menu, and the food buying and I feel very responsible about that…we've maintained a healthy diet, and that's good for both of us. I don't resent that, but I feel very responsible.

In contrast, patients with a cardiac condition tended to perceive a loss of their previous roles. Male patients especially felt that they were judged by those around them for not being able fulfill expected masculine social roles. One patient said that he felt 'worthless' and 'unimportant' as a result of not being able to 'perform' as a man. Patients expressed guilt for being an added burden to their partner and for having a decreased ability to support them.

> *Patient 05:* There is definitely guilt involved. You put this on the other person. It's my heart problem, but now it's her problem…so, guilt is a big thing and you can hear the other person say 'It's ok, and its good and I love you and I support you,' but it's still guilt.

> *Patient 06:* I don't think it's only the role of the man, you're expected to be working together…we went to Costco after the surgery and I couldn't move my arms, and you know, I was there with arms crossed, which is the most comfortable position, and my mother and wife were putting stuff on the cart and the cashier got so upset, and got up and went there and helped them and gave me the look.

### *Adjusting to lifestyle changes*

It was apparent that the patient-partner relationship was impacted by the many lifestyle changes that were required following the onset of CVD. Many of the couples found that they needed to become accustomed to a 'new normal,' a loss of previous activity, and the presence of new restrictions to various aspects of their lives. Some couples lamented that they were not able to pursue personal or vocational activities they used to enjoy or joint activities that they did together:

> *Partner 04:* Many of our little habits that we do together, well, we can't do the same thing anymore… everything has to slow down and be much more directed, and we have to check with the other person much more than we ever did before… And it takes time, what I want is what I had before but I can't have that so now I have to get something different.

> *Patient 07:* I am struggling with taking pills everyday, that's not what I do. And, I know it sounds silly, but it difficult for me to know and admit that I have a problem, and that this is what I have to look forward to. Really, I'm very fortunate, but I'm struggling with some of that…the medication forces limitations on us, it's about the way we feel, and without it, what would our quality of life be, but it does change who we are and what we can do.

> *Partner 09*: We were very active people, sports wise, and…culturally being members of the [arts venue], so with the bypass surgery we are not able to do all the activities that we had before. So our life has changed significantly.

> *Patient 01*: People come up to you and say, 'oh, you look really good,' but yeah, you look good physically, but mentally you are still a jumble of all kinds of stuff. And, you are thinking between you and your partner, she should have a normal life, but now I've created an obstacle for her to carry on. And, when I go to work, I get tired and I sit down and everyone else is working and now you feel that you are not yourself anymore because you would be helping them before and now you're not because you are physically exhausted.

*Positive changes within the relationship*

In contrast, some couples expressed that the event brought them closer together and made their relationship even stronger, despite the changes that occurred in their lives as a result of the CVD. By working through the challenges of adjusting to their illness, they found new ways of showing affection and care for one another. Example statements include the following:

> *Partner 11*: The [cardiac event] made us realize, even though we don't admit it to each other, how much we really do need each other. And it goes both ways.
>
> *Patient 09*: Whatever you've had, that's an incident that opens the door that the relationship all of sudden has new facets, there are new things you find out about each other, strengths that you never realized about each other. You find out things that you probably wouldn't have told each other about your past. I think the incident is unique and it's a tool that can be used to strengthen a weak relationship or to reinforce one that is already fairly strong.

**Perceived Needs and Desired Interventions**

Throughout the discussions, couples highlighted multiple needs and areas of potential intervention. Three themes emerged including: 1) practical resources and information; 2) the opportunity to share with peers; and, 3) help with relationship enhancement. Further, all couples reported an interest in couples-based interventions. One participant noted that, after dealing with three other major medical conditions, this was the first time anyone had asked about the needs of the patient *and* the partner. Patients and partners specifically requested that partners be involved in the care; one spouse pleaded "include us in that training" when speaking about teachings for lifestyle and medication management. One patient felt that it was "unfair" that spouses were not offered the program he was in, especially because he had a positive experience "connecting with the people in the rehab program."

*Practical information and resources*

Participants requested practical information to help them cope with CVD management such as workshops on stress management, medication management, healthy eating, and generally what to expect when discharged from hospital. A recurrent theme was the importance of having information given to patients and partners about support they could be receiving. Spouses spoke about the need to repeat this information as they tended to be “numb” after first learning of the cardiac event. Participants noted the need for intervention at various times, including while in hospital, at the time of hospital discharge, and in the months post-discharge.

> *Partner 04*: First, there is the shock, oh, it was a heart attack, and then in the hospital there is so much information, but I didn’t get a lot of it because there is only so much I could take in my brain, because I had all this other stuff like ‘what…it really was?’
>
> *Patient 02*: We need information sessions and information on the [hospital] website.
>
> *Partner 02*: Something I’ve struggled with is doctors and nurses and support people saying, ‘take care of yourself’…but nobody says, ‘this is a helpful way to take care of yourself…if you could do a, b, c…’ for example, techniques for stress. A group to help learn new ways of doing something, even how to help yourself as your spouse recovers.

*Opportunity for sharing with peers*

The second area for intervention suggested by participants was the opportunity to meet and share experiences with other patients and partners coping with heart disease. This sharing was viewed as part of the healing process that could assist in normalizing feelings, as well as provide an opportunity to learn from others’ experiences and successes.

> *Patient 13*: I think a support group would be good…sometimes you hear others and it kind of sparks something in you, you have a common ground you can talk about. I went to a support group after I left here to meet with people who had similar difficulties and I found that very helpful to meet with people who were having the same issues. Even a doctor who had never experienced it would probably not have the same input as patient to patient, because you really don’t understand how a person feels until you’ve been there.
>
> *Partner 02*: We have really sick spouses at some point who are very critical, and we get a lot of information about them, but it seems to me that the spouses themselves are also critical in this area..it would be wonderful to actually have some support groups for us because most often we don’t know anybody else in the same critical situation and we flounder.
>
> *Partner 15*: This kind of thing [group discussion] would have been really helpful in the beginning, to see what we are going through is normal and other people are too and it is normal.

### *Relationship enhancement*

Lastly, participants spoke about a desire for assistance to enhance their relationship. As noted above, they were keenly aware of the changes in their relationship in light of the new stressor and wished to rebuild connections. They reported an interest in learning ways to communicate, reassure, and help each other, in order to strengthen the relationship. In fact, one spouse recommended offering a phone line for couples to obtain counseling, noting that what they are dealing with is 'not just a health thing.'

> *Partner 12*: I think it would have helped to know what I could do more to help, instead of fighting back or pushing him away.
>
> *Patient 09*: I think the incident [cardiac event] is unique and it's a tool that can be used to strengthen a weak relationship, or reinforce one that is already fairly strong. If you were going to use a group, you might want to concentrate on that aspect rather than just the incident, we've all been through the painful part. More on how to rebuild and keep building or strengthen what you have. His spouse added: And, how to cope with the sensitivity of the other, and that he is not the same human being any more. The challenge is to stay close to this person that is so special to you as they change, and of course, as they change, so do you. His life has changed, but mine too.
>
> *Partner 04*: We have this long relationship together. He contributes to my stuff and I contribute to his stuff…Finding out what is not so good is important as well as what's good so that we can capitalize on the good and try as much as possible to eliminate things that are not very good…so that is what we need to work on.

## DISCUSSION

Utilizing focus groups, this study explored relationship changes among patients with CVD and their partners. The data demonstrated that both patients and partners grappled with many adjustments to their relationship after the cardiac event, and were challenged to adapt to a 'new normal.' Similar to previous studies [25, 33] our findings call attention to the emotional and communication disconnection between partners, and distress related to role changes, lifestyle adjustments and overprotective behaviours. Like other studies,[25, 33] we also observed a silver lining to the CVD cloud - the strengthening of the couple bond. Possibly the most novel aspect of our study, however, was the exploration of needs and desired areas of intervention proposed by participants. To our knowledge, only one other study engaged patients with CVD (i.e., heart failure) and their partners on this topic, particularly regarding information and education support.[28] While our participants noted value in instrumental support and practical resources, they clearly communicated the importance of assistance in building connections with their peers and partners to help them cope. Our results underscore the need for interventions that target both members of the dyad, instead of the current status quo which, for the most part, includes only the patient in care.

A systematic review by Dalteg and colleagues found that the themes of overprotection, communication deficiency, sexual concerns, changes in domestic roles, and adjustment to illness were the most common themes across 20 different studies. [25] These themes, except sexual concerns, were major topics that arose in the focus groups conducted in this study. Similar to findings from a study of couples managing atrial fibrillation,[27] we also observed that some couples would collaborate and agree upon adjustments in lifestyle as a way to cope with uncertainty. Developing shared appraisals of a stressor and (i.e., viewing a problem as “ours” versus “yours”) and then engaging in collaborative problem solving has been described as a process of communal coping.[40] Burgeoning evidence indicates that these shared appraisals may facilitate better adjustment to chronic illness and improve health behaviours.[41]

In contrast, many of the patient participants described distancing themselves from their partners in an attempt to protect their partner from distress or worry. Further, our findings indicated that a cardiac event changed the communication and emotional aspects within the relationship as well as the logistical aspects of everyday habits, activities, and roles. Any change in circumstance in any of these aspects for one partner would inevitably affect similar aspects of the other partner, as well as the identity of the couple. Each member of the couple needed to relearn aspects of each other in order to reduce conflict and sustain the relationship.

Evidence continues to link poor spousal relationships to worsened cardiovascular health and negative behaviours affecting CVD outcomes;[42] as such, screening and monitoring changes in patient-partner relationship quality may be an important task for clinicians. Table 3 provides some suggested questions that clinicians and other healthcare professionals may use to inquire about changes to the patient-partner relationship. Further, when couples spoke about what they would find useful in a couples-based intervention, several individuals mentioned the benefit of meeting other couples with similar experiences and learning strategies to improve their relationship in order to help the other person cope with CVD management.

| Table 3: Potential questions for clinicians & healthcare professionals to ask patients and partners |
|---|
| 1. It is common for your relationship to change after experiencing a heart event. Have you noticed any changes to your relationship with your spouse? |
| 2. Have changes to your relationship with your spouse made it more difficult for you to cope with the challenges of heart disease? |
| 3. What do you and your partner do to help promote a positive relationship with each other? |
| 4. What would you and your partner require to help you cope better together? |

Some patients seemed to have an ambivalent attitude toward their partners who have taken more of a policing and caregiver role. It was clear that, although they appreciated the support they received, it was a cause of stress and guilt for patients as well. Uchino, Smith, and Berg[43] found that members of couples who felt ambivalently towards their spouse were less likely to seek or benefit from the support of their relationship; this ambivalence was related to increased CVD risk-factors. Clinically, this suggests that the presence of discord in the relationships of cardiac patients, as was found in the present study, may increase their risk of recurrent disease and result in poorer quality of life for this population.

It is apparent that partners have been neglected and deprived of care to date, despite their clear contribution to our health care system.[44, 45] This fact is disturbing considering the mounting evidence to suggest that partners of patients with CVD are also vulnerable to developing poorer health outcomes, such as increased distress and depressive symptoms, higher blood pressure, weight gain, and disordered sleep.[46,47] In fact, research shows up to 25% of partners of CVD patients experience symptoms of post-traumatic stress.[48] In our focus groups, it was evident that many of the partners provided care without the adequate resources to do so and were more isolated than the patient in facing the uncertainty of the CVD they were helping to manage. Despite the psychological benefits of cardiac rehabilitation,[1] partners of patients with CVD are often excluded from this important intervention. The present study shows the vital role of partners in the care of cardiac patients; thus, it is important to recognize that providing support to partners is critical for both partners' psychosocial and medical health outcomes.[26]

## LIMITATIONS

This study is not without limitations. First, although the sex distribution is similar to that of the cardiac rehabilitation population, the majority of the patient participants were heterosexual males, potentially biasing the data by sex and preventing meaningful analyses between the sexes. Second, the data were collected from one cardiac centre in Canada; an exploration of needs and desires of this population in other centres would strengthen our findings. It is important to note, however, that the systematic review of 20 studies from various countries identified similar categories.[25] Third, a clinician-patient relationship existed with four of the patient participants, but not their partners. Although conventional content analysis assumes that there are multiple perspectives of the data and that the researchers' positionality (i.e., their thoughts and feelings towards the data, subject matter, and participants) necessarily influences the data analysis,[35] one must be mindful of how their relationship to the participant the topic may ultimately shape their interpretation of the data. Fourth, we did not record the range of years that participants were in their couple relationship. Future research would do well to collect this information and investigate whether this variable influences the themes reported. Fifth, since the interviews were conducted at one time point only, the findings cannot reveal how intimate relationships and participants' needs may change over time. As the effects on martial satisfaction may be different depending on the cardiac illness timeline,[49] future studies employing a longitudinal design may be beneficial. Sixth, although our inclusion of CVD patients of any diagnostic group builds on previous research with select CVD populations and provides a starting point for the general understanding of couples' needs, it precludes an evaluation of the unique needs specific to one diagnostic group. Future research with a larger number of dyads from many diagnostic groups may uncover different needs highlighted by each group. Lastly, focus groups were used to facilitate interaction and discussion among participants, however, this format may inhibit sharing of some intimate information. As such, we recommend that focus groups be augmented with individual interviews in future studies. Despite these limitations, this is the first study that explored, in-depth, the desired intervention components of patients and their partners to help them better manage CVD. Findings allowed for the elucidation of strengths and weaknesses in cardiac rehabilitation programming and better determine the needs of this patient population and their partners.

## CONCLUSION

In summary, the present study demonstrated that the acute onset and chronic effects of CVD cause both positive and negative changes to the couples' relationship. The results highlight the need for more specialized couples-based interventions that aid both patients and their partners through the new reality of living with CVD. Changes within the relationship are inevitable after a cardiovascular event; therefore, it is essential to support couples as they cope with these changes in ways that strengthen their connections to peers and each other and improve their health.

## IMPLEMENTATIONS FOR PRACTICE

- Partners should be actively included in interventions aimed at improving recovery of patients with CVD. Practical resources, opportunities to share with peers, and couples-based interventions are required.

- Changes to patients' and partners' relationship quality should be assessed within cardiac rehabilitation programming and action taken to support patients and partners in strengthening their relationship.
- Future research should investigate whether couples-based programming is effective in reducing both partners' stress brought on by CVD and whether meaningful changes to relationship quality and clinical outcomes are observed as a result of participating in such couples-based programming.

**Contributors:** HT, PG designed the study. HT, PG, SJ, & ND collected the focus group data and HT, LM & MC conducted the analysis. HT, KB & LM wrote the manuscript with contributions from all authors.

**Competing interests:** None declared.

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**Disclosures:** None

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# Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No. Item | Guide questions/descriptions | Reported on Page # (tracked copy) |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| **1. Interviewer/facilitator:** | Which author/s conducted the interview or focus group? | Page 8 |
| **2. Credentials:** | What were the researcher's credentials? E.g. PhD, MD | Page 9 |
| **3. Occupation:** | What was their occupation at the time of the study? | Page 9 |
| **4. Gender:** | Was the researcher male or female? | Page 9 |
| **5. Experience and training:** | What experience or training did the researcher have? | Page 9 |
| *Relationship with participants* | | |
| **6. Relationship established:** | Was a relationship established prior to study commencement? | Page 9 |
| **7. Participant knowledge of the interviewer:** | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | Page 8-9 |
| **8. Interviewer characteristics:** | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Page 8-9 |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| **9. Methodological orientation and Theory:** | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Page 7,9 |
| *Participant selection* | | |
| **10. Sampling:** | How were participants selected? e.g. purposive, convenience, consecutive, snowball | Page 8 |
| **11. Method of approach:** | How were participants approached? e.g. face-to-face, telephone, mail, email | Page 8 |
| **12. Sample size:** | How many participants were in the study? | Page 10 |
| **13. Non-participation:** | How many people refused to participate or dropped out? Reasons? | Page 11 |

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| | | |
|---|---|---|
| *Setting* | | |
| **14. Setting of data collection:** | Where was the data collected? e.g. home, clinic, workplace | Page 8 |
| **15. Presence of non-participants:** | Was anyone else present besides the participants and researchers? | Page 8 |
| **16. Description of sample:** | What are the important characteristics of the sample? e.g. demographic data, date | Page 10-11 |
| *Data collection* | | |
| **17. Interview guide:** | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Page 8-9 |
| **18. Repeat interviews:** | Were repeat interviews carried out? If yes, how many? | Page 8 |
| **19. Audio/visual recording:** | Did the research use audio or visual recording to collect the data? | Page 9 |
| **20. Field notes:** | Were field notes made during and/or after the interview or focus group? | Page 9 |
| **21. Duration:** | What was the duration of the interviews or focus group? | Page 8 |
| **22. Data saturation:** | Was data saturation discussed? | Page 10 |
| **23. Transcripts returned:** | Were transcripts returned to participants for comment and/or correction? | Page 9 |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| **24. Number of data coders:** | How many data coders coded the data? | Page 10 |
| **25. Description of the coding tree:** | Did authors provide a description of the coding tree? | Page 10 |
| **26. Derivation of themes:** | Were themes identified in advance or derived from the data? | Page 9-10 |
| **28. Participant checking:** | Did participants provide feedback on the findings? | Page 9 |
| **27. Software** | What software, if applicable, was used to manage the data? | Page 9 |
| **29. Quotations presented:** | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number | Page 12-19 |

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| | | |
|---|---|---|
| **30. Data and findings consistent:** | Was there consistency between the data presented and the findings? | Page 12-19 |
| **31. Clarity of major themes:** | Were major themes clearly presented in the findings? | Page 11 |
| **32. Clarity of minor themes:** | Is there a description of diverse cases or discussion of minor themes? | Page 11 |

# Learning a new way of living together: A qualitative study exploring the relationship changes and intervention needs of patients with cardiovascular disease and their partners

| | |
|---|---|
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| Secondary Subject Heading: | Cardiovascular medicine, Qualitative research |
| Keywords: | cardiovascular disease, couples, relationship quality, cardiac rehabilitation, intervention |
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For peer review only

# Learning a new way of living together: A qualitative study exploring the relationship changes and intervention needs of patients with cardiovascular disease and their partners

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## ABSTRACT

**Objectives:** Cardiovascular disease (CVD) not only affects the patient, but has implications for the partner. Emerging evidence suggests that supportive couple relationships enhance CVD outcomes and reduce patient and partner distress. To date, however, little research has been done to address the couple relationship as a potentially important component of cardiac care. This article examines the impact of CVD on the couple relationship and assesses the perceived needs and desired intervention components of patients with CVD and their partners.

**Design:** Qualitative study using directed and conventional content analysis.

**Setting:** Single-centre, tertiary cardiac care hospital that serves a population of 1.4 million in the Champlain region of Ontario, Canada.

**Participants:** Patients with CVD and their partners (N=32, 16 couples) participated in focus groups. Patients were mainly male (75%), white (87.5%), aged 63.4 years (range 31-81 years), with varied cardiac diagnoses (50% coronary artery disease; 18.75% valve disease; 18.75% heart failure; 12.5% arrhythmia).

**Results:** Five categories were generated from the data reflecting changes within the couple relationship as a result of CVD: 1) emotional and communication disconnection; 2) overprotection of the patient; 3) role changes; 4) adjustment to lifestyle changes; and, 5) positive relationship changes. Three categories were constructed regarding intervention needs and desired resources: 1) practical resources; 2) sharing with peers; and, 3) relationship enhancement.

**Conclusions:** Overall, the data suggest that there were profound changes in the couple relationship as a result of CVD, and that there is considerable need to better support the caregiving spouses and the couple as a unit. These results call for interventions designed to provide instrumental support, peer-sharing opportunities, and relationship quality enhancement to help couples cope with CVD. Future

studies should examine whether couples-based programming embedded into cardiac rehabilitation can be effective at improving relationship quality and reducing patient and partner stress in the aftermath of a cardiac event.

**Keywords:** cardiovascular disease, couples, relationship quality, intervention, cardiac rehabilitation

## ARTICLE SUMMARY

### Strengths and Limitations of this Study

- This study is the second, to our knowledge, to explore potential areas of intervention for couples in which one partner has cardiovascular disease.
- The ORBIT model for developing behavioural treatments for chronic diseases was employed.
- Generalizability is limited by recruitment at one site, mainly male patients, and heterosexual couples.
- The findings cannot reveal how couples' needs may change over time as the focus groups were conducted at one time point.
- The unique needs of specific CVD diagnostic groups were not analyzed due to limited sample size.

## INTRODUCTION

Cardiovascular disease (CVD) is a leading cause of mortality in most western nations. Multiple modifiable risk factors for CVD have been identified, including smoking, physical inactivity, hypertension, poor diet, metabolic syndrome, and stress. These factors are routinely targeted in primary and secondary prevention programs, which reduce morbidity and mortality, and improve mental health and quality of life outcomes among patients with CVD.[1] Interestingly, despite the well-established link between social relationships and the progression of CVD,[2,3] this component is rarely targeted in the prevention or management of CVD.[4]

Accumulating evidence indicates that positive social relationships are integral to health. To illustrate, a meta-analysis with over 300,000 participants revealed an increased survival rate of 50% for those in supportive relationships.[3] Socially isolated individuals or those in poor relationships, in contrast, experience increased morbidity and mortality. For example, a 29% increased risk of coronary artery disease was reported in a recent meta-analysis including over 35,000 participants.[2] Given the importance of intimate relationships for most adults, it is not surprising that partner support is the strongest determinant of wellbeing relative to other sources of support.[5] In fact, a recent systematic review revealed that simply being married is associated with fewer CVD risk factors and improved survival rates.[6] One cohort study with almost one million patients with acute coronary syndrome, for example, detected lower mortality rates for married (OR=0.86) and widowed patients (OR=0.96), whereas single patients had increased rates (OR=1.07).[7]

Other evidence indicates, however, that the quality of the relationship, not just its presence, may dictate the impact on heart health. High-quality relationships are characterized by high relationship satisfaction, warmth, support, and closeness, while distressed relationships exhibit high levels of conflict, hostility, distance, and dissatisfaction.[8, 9] The presence of strong patient-partner relationships, high in relationship quality, has been associated with improved physical and mental health outcomes. Marital discord, in contrast, has been related to elevated risk of CVD development and to the progression of established disease, even when other risk factors such as age, blood pressure, and BMI are controlled for in the analyses.[10-13] For example, one study found that the survival rates of patients who underwent coronary artery bypass surgery and reported satisfying relationships were 3 times higher than those in poor relationships.[14] Hypertension and increased heart rate is observed with marital conflict,[15, 16] whereas reductions in blood pressure are observed during supportive interactions.[17] Patients in well-adjusted relationships are more likely to adhere to medical prescriptions and to be more assiduous in their attendance at cardiac rehabilitation.[18, 19] There is evidence that high quality patient-partner relationships can also reduce caregiver burden, distress, and depressive symptoms.[20] Taken together, the evidence connecting poor patient-partner relationship quality to deleterious physical and mental health outcomes continues to mount, whereas high quality relationships appear to buffer the impact of CVD and to enhance physical and mental health.

Despite this evidence, few interventions for cardiac patients and their partner exist. To date, the focus, not surprisingly, has been on traditional CVD risk factors such as exercise, diet, and smoking behaviour. A systematic review of seven couples-based psychological interventions for patients with coronary artery disease reported modest improvements in patients' knowledge of disease and treatment, blood pressure, and quality of life with intervention participation, but no effect on morbidity or mortality.[4] Low quality methods were thought to explain the reduced efficacy. Methodological limitations of couples-based interventions include: outdated studies – many are over 20 years old and the medical care and related couple experience has changed substantially; interventions were not based in theory or were simply informational; small sample sizes; and data collection has been restricted to the patient and lacked measures of relationship quality.[4, 21-23] Further, to our knowledge, only one study in the CVD context has targeted the couple relationship as an intervention component to date.[24] Results of that study demonstrated improvements in exercise levels, but distressed couples did not maintain gains at intervention completion (18 weeks). A more targeted intervention aimed to improve relationship quality may be required to enhance couple-related, psychological, behavioural, and physical health outcomes.

In order to design more effective couples-based interventions, an in-depth understanding of the experience and needs of patients and partners in the context of CVD is required. Daltag and colleagues systematically reviewed qualitative and quantitative research investigating the impact of cardiac disease on the partner relationship.[25] Results indicated that the impact is extensive and distressing on multiple levels, including adjustment to illness and role changes, sexual concerns, and communication and overprotection. Unfortunately, the studies included in the review are now a decade old and, like the intervention research described above, they preclude a contemporary impression of the dyad's experience in the current medical environment. Since this review,[25] to our knowledge, six additional studies in the cardiac context were published. [26-31] Findings highlighted difficulties living with the uncertainty of the disease and managing lifestyle changes, feelings of worry and vigilance, and caregiver burden and support. Patients and partners also reported that caring involvement brought the couple closer together or, the opposite, a feeling of loss of the partner relationship and role changes. These studies, however, included select cardiac populations (i.e., patients with atrial fibrillation or heart failure), spouses only or family members other than spouses, or focused on dyadic coping regarding lifestyle changes only. Further, only one [32] of the previously reviewed[25] or newer studies inquired about potential areas of support for the patient-partner dyad. With approximately 30% of couples with CVD reporting marital discord[33] and the potential physiological detriment on patients' cardiovascular health, more research on the experience and intervention needs of patients with CVD and their partners is required. This information may then be used to enhance intervention development and efficacy.

Employing a systematic framework, such as the ORBIT model for developing behavioural treatments for chronic diseases,[34] has been shown to produce stronger behavioural treatments and to avoid costly trials of those that have not been optimized. Phase I (design and define) aims to identify the essential features of a treatment. Qualitative research is often employed to engage the community of participants and reveal details of the clinical problem and potential treatment components. Practical aspects of the intervention are also investigated, including, for example, the preferred mode of delivery, setting, and frequency and duration of contact. With this information, an intervention that is acceptable to the target population and has promise for clinically significant benefit can be created. This phase is followed by preliminary testing such as proof of concept trials (Phase II) and, if positive results are detected, an RCT pilot study is then justified. Efficacy testing in the form of larger randomized controlled trials (Phase III) and effectiveness research (Phase IV) complete the process.

The present study describes Phase I for the development of a couples-based intervention for patients with CVD and their partners. The specific aims were: 1) to further understand the impact of CVD on the nature of the couple relationship and 2) to assess the intervention needs and desires of patients with CVD and their partners, including an exploration of their interest in a couples-based intervention in cardiac rehabilitation. The ultimate goal was to inform the development of relevant cardiac interventions that involve the couple as a unit.

## METHODS

### Design and setting

This study used an exploratory and qualitative design. The study was carried out at the University of Ottawa Heart Institute in Ottawa (UOHI), a quaternary care cardiac hospital that serves a population of 1.4 million in the Champlain region of Ontario, Canada.

### Participant recruitment

All participants were past or current participants of the UOHI cardiac rehabilitation program; no restrictions were placed on cardiac diagnosis. Patients were recruited using purposive sampling from UOHI cardiac rehabilitation classes by one of the researchers (HT). Announcements were made stating, "we recognize that dealing with a heart condition can be difficult for patients and their significant others. We are recruiting patients and their partners to participate in a focus group meeting so that we might better understand your experiences, concerns, and needs with heart disease. Our goal is to improve the services we offer to the patients and their spouses." Interested patients approached the researcher who then screened them for eligibility and, if eligible, scheduled them for a focus group session. Participants were included if they had directly or indirectly (i.e., through a spouse) experienced a cardiovascular event, were in a couple relationship (married, common-law, or in a committed relationship for ≥ 2 years), were 18 years of age and older, and were able to speak English. There were no exclusion criteria for this study.

## Focus group interviews

Patients were invited to attend a 1.5 hour focus group with their partner. Focus groups were particularly suited for this study as it allowed for interactive and intensive discussions amongst both patients and partners. Furthermore, focus groups position participants as experts of their social worlds and can help to reduce unequal power relations amongst the researchers and participants that can manifest in individual interviews.[35] All focus groups took place in meeting rooms at the UOHI; only the participants and the interviewers were present. A semi-structured interview guide was used throughout the focus groups. Question development was guided by the clinical expertise of the investigators, analyses of transcripts of couple therapy sessions with heart patients, and previous research on couples and CVD.[36, 37, 25] Table 1 provides a sample list of questions that were asked in the focus group interviews. The interview guide was not piloted tested and there were no follow-up interviews. Four interviewers (3 women, 1 man; authors HT, SJ, ND, PG) were involved throughout the study with two interviewers present at each focus group. All interviewers were licensed clinical psychologists with over 10 years experience working with couples and/or patients with cardiovascular disease. As the patient participants were former or current patients of the UOHI, a clinician-patient relationship was established prior to the data collection period for some participants (n=4; none of the partners were known). The focus of these relationships was individual care as part of cardiac rehabilitation. All participants were aware that the aim of the research was to ascertain patients' and partners' perspectives of intervention approaches that would be relevant to their needs. Although the interviewers have experience providing individual and couples-based interventions, the purpose of the research was to learn whether this would be of interest to the participants and what intervention components might be included.

| **Table 1 Focus Group Sample Questions** |
|---|
| 1. Sometimes people say that heart disease brings them closer together. Other times they say that it just seems to create more problems and stresses on top of the ones they already have. How has your experience been?<br>2. A lot of times patients and partners see heart disease differently. How similar or different would you say your perspectives on having heart disease are?<br>4. What has been the most difficult part of having heart disease (or having a partner with heart disease)?<br>5. How could the Heart Institute help you and your significant other cope better together? What have you found most helpful so far?<br>6. Would you be interested in a couples-based intervention as part of cardiac rehabilitation? If so, what would it look like? |

## Data analysis

Audio recordings of the focus groups were transcribed verbatim and subjected to directed and conventional content analysis,[38] using a combination of deductive and inductive processes. Field notes were not taken. The transcribed focus groups were not returned to patients for comment or correction due to concerns regarding the sensitivity of the data (e.g., medical history, relationship concerns) and previous research indicating that their corrections result in minimally higher data quality.[39] All coding of the transcripts was conducted using N-Vivo Software.[40] The focus group transcripts were subject to line-by-line coding and then similar codes were grouped into categories representing similar phenomena. General categories were defined by current research on patient-partner relationship quality, and newly emerging categories were added accordingly. Responses were coded by two independent researchers (MC & LM). Through discussing the categories with the first author (HT), the coders drew further analytic conclusions from the data; any discrepant items were discussed and resolved by consensus.

## ETHICS

As this study was a quality assurance and improvement project, the Ottawa Health Science Network Research Ethics Board exempted it from full review, but approved the publication of these data.

## PATIENT AND PUBLIC INVOLVEMENT

Although patients or the public were not directly involved in the development of the research, the authors devised the interview questions based on their clinical experience working with patients with CVD and their partners. Conducting these focus groups was the first step toward creating a couple-oriented intervention to ensure patient engagement from the outset. Further, the results from the study were incorporated into a "caregiver guide" that is provided to partners of patients at the UOHI upon patient discharge from the hospital. The guide was developed in close consultation with executive members of the Patient Alumni Association at the UOHI, a patient group that represents over 12,000 active members.

## RESULTS

All patients that approached the researcher regarding participation met the eligibility criteria. The study included 16 cardiac patients and their partners (N=32). Data saturation was reached with this sample size.[41, 42] Patients were mainly older (M=64.4 years, range 31-81 years), White (87.5%), and well-educated (M=14.86 years). Twelve (75%) of the patients with CVD were male, 3 were female, and 1 couple both had a history of CVD. The cardiac diagnoses were varied: 50% had been diagnosed with coronary artery disease; 18.75% had valve disease; 18.75% had heart failure; and 12.5% had arrhythmia. All couples were heterosexual. One couple dropped out of the study (patient was too distressed to speak about her heart condition).

Three focus groups were conducted, each with a maximum of 6 couples. The following categories that were generated from the analysis describe the nature of changes to the relationship that resulted from CVD: 1) emotional and communication disconnection; 2) overprotection of the patient; 3) role changes; 4) adjustment to lifestyle changes; and, 5) positive relationship changes. Three categories emerged regarding the need for intervention and resources: 1) practical resources; 2) sharing with peers; and, 3) relationship enhancement. These categories describe the participants' perceptions of what is required to adequately support couples managing CVD. Please see Table 2 for the outcome categories and example quotes.

| **Table 2: Outcomes of Content Analysis** | |
|---|---|
| **Category** | **Example Quote** |
| **Changes to the Relationship** | |
| 1) Emotional and Communication Disconnection | *Partner 04:We have to slow down our conversations because we don't hear as fast as we used to, and I say something and he only listened to the first half and the second half is the most important. Then, he might get mad at me because I didn't do what he thought I said, I had said something else. We used to get along. Our daughter used to say that we do everything in short hand, and now we have to go back to long hand…I want to go back to what I had before.* |
| 2) Overprotection of the Patient | *Patient 10: I try to get independence…'I want to do this…' and she says 'well, you shouldn't do that' and I couldn't stay up at the cottage alone because it takes the paramedics too long, so I felt that my summer was a little hijacked. After the angioplasty, you tread on eggshells and that's the way it's gonna be now…I feel like a puppet on a string sometimes.* His spouse replied: *And, I feel like the ogre. I had to be the one who would say, 'you can't do that, or I can't let you do that.' I was some scared. It takes a long time getting over being scared to that degree.* |
| 3) Role Changes | *Partner 02:For me it's been a 6 month full-time job, and that's my problem…something I've struggled with is doctors and nurses and support people saying "take care of yourself…" that is the most difficult thing in the world because there is no time to take care of yourself because you are looking after yourself and somebody else and life goes on… And for me, I managed fine for 3 months and after 3 months I all of a sudden realized I wasn't even breathing, so how can you rebalance, so what happens is, I get short tempered, intense and stressed.* |
| 4) Adjustment to Lifestyle Changes | *Patient 04: One of the things that we enjoy a whole lot together is ballroom dancing, and we got up to a fairly reasonably advanced level and, then all of a sudden with this heart issue, I didn't have the energy to stay upright for very much time at all. I would sit in one of the chairs on the side and [partner] would find herself busy dancing with an instructor, so at least she isn't sitting on the side as well, but it's so frustrating to not be able to do the things you used to be able to do before.* |
| 5) Positive Relationship Changes | *Patient 09: What [the cardiac event] has done actually, it has brought us closer together. I feel our relationship is stronger. From a selfish point of view, I am the one being taken care of. I have a 24-hour nurse. I feel it would be completely different if that even hadn't happened, who knows, we might have gone in different directions…now we do stuff together all the time…we try to see the positive side of things* |
| **Intervention Needs and Resources** | |
| 1) Practical Resources | *Patient 12: I think some media to take home. Some pamphlets or DVDs or something. You could have like workshops for different things for couples.* |
| 2) Sharing with Peers | *Partner 06: It's been a roller coaster, up and down, we tried to pick up the good moments and continue doing the right things…but it's tough. I'd like to learn more about other people and experiences and be able to share.* |
| 3) Relationship Enhancement | *Partner 13: Sometimes people are secretive, and with [patient], he doesn't talk much. I've actually been to some of his rehab visits so that we have everything laid out and we are able to understand each other. I think communication is key* |

*to have people understand what's going on in your life, and sometimes you need that third party to get that communication going.*

## Relationship Changes

### *Emotional and communication disconnection*

The most prominent category that arose in the focus-group discussions was a feeling of being disconnected emotionally and in communication patterns. The presence of CVD created added stress to the relationship, causing the patient and or the partner to become more irritable, increasing their propensity for conflict. A common cause for conflict was a newfound disconnection in communication, typically manifested by withdrawal or being "shut down" emotionally. This often led to frustration, particularly among partners.

> *Partner 13:* Totally frustrating, I'll say 'are you upset with me?' because I will talk or, or I will be talking about something and pouring my heart out, and he'll say 'did you see that truck over there?…' and I'll be like, he didn't even hear one word I said…it's kind of like he's in a bubble. So, sometimes I get very upset. I can get downright hostile about it, and sometimes I want to throw my hands up and say, that's it, I'm out of here. You need to be able to communicate, and meet each other where you are at, be honest about your relationship and be honest about how you feel, and if you are afraid, say something, not try to hide if from the other person.
>
> *Patient 07:* I've become much more sensitive, like in terms of things that normally wouldn't bother me start to bother me now. I'm much more emotional a lot faster, and I think he struggles with that. We were used to a certain set of signals and now he doesn't know if it is coming or going. Her spouse added: One minute she can be really nice, and the other real nasty.
>
> *Partner01:* You think you are coping…with a new way to cook or control portions and ensuring everyday physical activity, but then you forget to talk to each other.

### *Overprotection of the patient*

As partners attempted to deal with the fear of potentially losing their loved one and an associated desire to keep them healthy to prevent another cardiac event, they became protective, often overprotective, leading to relationship conflict.

> *Patient 13*: Even now, she said 'I'm not going to let you do anything.' Even in the truck she would stand on the ramp and say no….it is really a lot of reminding me what I can and can't do.
>
> *Partner 01*: From the spouse point of view, we haven't lived in your position so we don't know, but we are there to help you, and sometimes it looks bad, or we're nagging, it's just we want what is best for you.
>
> *Patient 15*: Sometimes it's nice to have an alarm [spouse] in your ear saying 'you shouldn't do that,' and you say thank you for the alarm, but in my mind this is the biggest emotional toll that there is.
>
> *Partner 07*: She likes to dive in, and she gets so far into it she doesn't realize how far she's gotten in. I try to yell warning signs, but try to get her to listen…she's too headstrong, she'll do whatever she wants to do and it makes it difficult to warn her and it causes problems [between us] because of it.

*Role changes and related stress*

The onset of CVD led to changes in the roles each member assumed within the relationship on a day-to-day basis. One aspect of this was an increased caregiver burden and stress, where the increased responsibility of caring for the patient became a "full-time job" for the partners.

> *Partner 10:* Our children live [elsewhere], so it is basically just us, and when it comes down to it, it's basically just me…I continue to get stronger, but it has been heavy going, very stressful and very anxiety-making, and borderline situational depression or something like that, really just a different me inside, and it's coming back, but it's a piece of work.
>
> *Partner 16*: I'm the one who maintains the menu, and the food buying and I feel very responsible about that…we've maintained a healthy diet, and that's good for both of us. I don't resent that, but I feel very responsible.

In contrast, patients with a cardiac condition tended to perceive a loss of their previous roles. Male patients especially felt that they were judged by those around them for not being able fulfill expected masculine social roles. One patient said that he felt 'worthless' and 'unimportant' as a result of not being able to 'perform' as a man. Patients expressed guilt for being an added burden to their partner and for having a decreased ability to support them.

> *Patient 05:* There is definitely guilt involved. You put this on the other person. It's my heart problem, but now it's her problem…so, guilt is a big thing and you can hear the other person say 'It's ok, and its good and I love you and I support you,' but it's still guilt.

> *Patient 06:* I don't think it's only the role of the man, you're expected to be working together…we went to Costco after the surgery and I couldn't move my arms, and you know, I was there with arms crossed, which is the most comfortable position, and my mother and wife were putting stuff on the cart and the cashier got so upset, and got up and went there and helped them and gave me the look.

### *Adjusting to lifestyle changes*

It was apparent that the patient-partner relationship was impacted by the many lifestyle changes that were required following the onset of CVD. Many of the couples found that they needed to become accustomed to a 'new normal,' a loss of previous activity, and the presence of new restrictions to various aspects of their lives. Some couples lamented that they were not able to pursue personal or vocational activities they used to enjoy or joint activities that they did together:

> *Partner 04:* Many of our little habits that we do together, well, we can't do the same thing anymore… everything has to slow down and be much more directed, and we have to check with the other person much more than we ever did before… And it takes time, what I want is what I had before but I can't have that so now I have to get something different.

> *Patient 07:* I am struggling with taking pills everyday, that's not what I do. And, I know it sounds silly, but it difficult for me to know and admit that I have a problem, and that this is what I have to look forward to. Really, I'm very fortunate, but I'm struggling with some of that…the medication forces limitations on us, it's about the way we feel, and without it, what would our quality of life be, but it does change who we are and what we can do.

> *Partner 09*: We were very active people, sports wise, and…culturally being members of the [arts venue], so with the bypass surgery we are not able to do all the activities that we had before. So our life has changed significantly.

> *Patient 01*: People come up to you and say, 'oh, you look really good,' but yeah, you look good physically, but mentally you are still a jumble of all kinds of stuff. And, you are thinking between you and your partner, she should have a normal life, but now I've created an obstacle for her to carry on. And, when I go to work, I get tired and I sit down and everyone else is working and now you feel that you are not yourself anymore because you would be helping them before and now you're not because you are physically exhausted.

### *Positive changes within the relationship*

In contrast, some couples expressed that the event brought them closer together and made their relationship even stronger, despite the changes that occurred in their lives as a result of the CVD. By working through the challenges of adjusting to their illness, they found new ways of showing affection and care for one another. Example statements include the following:

> *Partner 11*: The [cardiac event] made us realize, even though we don't admit it to each other, how much we really do need each other. And it goes both ways.
>
> *Patient 09*: Whatever you've had, that's an incident that opens the door that the relationship all of sudden has new facets, there are new things you find out about each other, strengths that you never realized about each other. You find out things that you probably wouldn't have told each other about your past. I think the incident is unique and it's a tool that can be used to strengthen a weak relationship or to reinforce one that is already fairly strong.

## **Perceived Needs and Desired Interventions**

Throughout the discussions, couples highlighted multiple needs and areas of potential intervention. Three themes emerged including: 1) practical resources and information; 2) the opportunity to share with peers; and, 3) help with relationship enhancement. Further, all couples reported an interest in couples-based interventions. One participant noted that, after dealing with three other major medical conditions, this was the first time anyone had asked about the needs of the patient *and* the partner. Patients and partners specifically requested that partners be involved in the care; one spouse pleaded "include us in that training" when speaking about teachings for lifestyle and medication management. One patient felt that it was "unfair" that spouses were not offered the program he was in, especially because he had a positive experience "connecting with the people in the rehab program."

### *Practical information and resources*

Participants requested practical information to help them cope with CVD management such as workshops on stress management, medication management, healthy eating, and generally what to expect when discharged from hospital. A recurrent theme was the importance of having information given to patients and partners about support they could be receiving. Spouses spoke about the need to repeat this information as they tended to be “numb” after first learning of the cardiac event. Participants noted the need for intervention at various times, including while in hospital, at the time of hospital discharge, and in the months post-discharge.

> *Partner 04*: First, there is the shock, oh, it was a heart attack, and then in the hospital there is so much information, but I didn’t get a lot of it because there is only so much I could take in my brain, because I had all this other stuff like ‘what…it really was?’
>
> *Patient 02*: We need information sessions and information on the [hospital] website.
>
> *Partner 02*: Something I’ve struggled with is doctors and nurses and support people saying, ‘take care of yourself’…but nobody says, ‘this is a helpful way to take care of yourself…if you could do a, b, c…’ for example, techniques for stress. A group to help learn new ways of doing something, even how to help yourself as your spouse recovers.

*Opportunity for sharing with peers*

The second area for intervention suggested by participants was the opportunity to meet and share experiences with other patients and partners coping with heart disease. This sharing was viewed as part of the healing process that could assist in normalizing feelings, as well as provide an opportunity to learn from others’ experiences and successes.

> *Patient 13*: I think a support group would be good…sometimes you hear others and it kind of sparks something in you, you have a common ground you can talk about. I went to a support group after I left here to meet with people who had similar difficulties and I found that very helpful to meet with people who were having the same issues. Even a doctor who had never experienced it would probably not have the same input as patient to patient, because you really don’t understand how a person feels until you’ve been there.
>
> *Partner 02*: We have really sick spouses at some point who are very critical, and we get a lot of information about them, but it seems to me that the spouses themselves are also critical in this area..it would be wonderful to actually have some support groups for us because most often we don’t know anybody else in the same critical situation and we flounder.
>
> *Partner 15*: This kind of thing [group discussion] would have been really helpful in the beginning, to see what we are going through is normal and other people are too and it is normal.

### *Relationship enhancement*

Lastly, participants spoke about a desire for assistance to enhance their relationship. As noted above, they were keenly aware of the changes in their relationship in light of the new stressor and wished to rebuild connections. They reported an interest in learning ways to communicate, reassure, and help each other, in order to strengthen the relationship. In fact, one spouse recommended offering a phone line for couples to obtain counseling, noting that what they are dealing with is 'not just a health thing.'

> *Partner 12*: I think it would have helped to know what I could do more to help, instead of fighting back or pushing him away.
>
> *Patient 09*: I think the incident [cardiac event] is unique and it's a tool that can be used to strengthen a weak relationship, or reinforce one that is already fairly strong. If you were going to use a group, you might want to concentrate on that aspect rather than just the incident, we've all been through the painful part. More on how to rebuild and keep building or strengthen what you have. His spouse added: And, how to cope with the sensitivity of the other, and that he is not the same human being any more. The challenge is to stay close to this person that is so special to you as they change, and of course, as they change, so do you. His life has changed, but mine too.
>
> *Partner 04*: We have this long relationship together. He contributes to my stuff and I contribute to his stuff…Finding out what is not so good is important as well as what's good so that we can capitalize on the good and try as much as possible to eliminate things that are not very good…so that is what we need to work on.

## DISCUSSION

Utilizing focus groups, this study explored relationship changes among patients with CVD and their partners. The data demonstrated that both patients and partners grappled with many adjustments to their relationship after the cardiac event, and were challenged to adapt to a 'new normal.' Similar to previous studies [25, 36] our findings call attention to the emotional and communication disconnection between partners, and distress related to role changes, lifestyle adjustments and overprotective behaviours. Like other studies,[25, 36] we also observed a silver lining to the CVD cloud - the strengthening of the couple bond. Possibly the most novel aspect of our study, however, was the exploration of needs and desired areas of intervention proposed by participants. To our knowledge, only one other study engaged patients with CVD (i.e., heart failure) and their partners on this topic, particularly regarding information and education support.[28] While our participants noted value in instrumental support and practical resources, they clearly communicated the importance of assistance in building connections with their peers and partners to help them cope. Our results underscore the need for interventions that target both members of the dyad, instead of the current status quo which, for the most part, includes only the patient in care.

A systematic review by Dalteg and colleagues found that the themes of overprotection, communication deficiency, sexual concerns, changes in domestic roles, and adjustment to illness were the most common themes across 20 different studies. [25] These themes, except sexual concerns, were major topics that arose in the focus groups conducted in this study. Similar to findings from a study of couples managing atrial fibrillation,[26] we also observed that some couples would collaborate and agree upon adjustments in lifestyle as a way to cope with uncertainty. Developing shared appraisals of a stressor and (i.e., viewing a problem as "ours" versus "yours") and then engaging in collaborative problem solving has been described as a process of communal coping.[43] Burgeoning evidence indicates that these shared appraisals may facilitate better adjustment to chronic illness and improve health behaviours.[44]

In contrast, many of the patient participants described distancing themselves from their partners in an attempt to protect their partner from distress or worry. Further, our findings indicated that a cardiac event changed the communication and emotional aspects within the relationship as well as the logistical aspects of everyday habits, activities, and roles. Any change in circumstance in any of these aspects for one partner would inevitably affect similar aspects of the other partner, as well as the identity of the couple. Each member of the couple needed to relearn aspects of each other in order to reduce conflict and sustain the relationship.

Evidence continues to link poor spousal relationships to worsened cardiovascular health and negative behaviours affecting CVD outcomes;[45] as such, screening and monitoring changes in patient-partner relationship quality may be an important task for clinicians. Table 3 provides some suggested questions that clinicians and other healthcare professionals may use to inquire about changes to the patient-partner relationship. Further, when couples spoke about what they would find useful in a couples-based intervention, several individuals mentioned the benefit of meeting other couples with similar experiences and learning strategies to improve their relationship in order to help the other person cope with CVD management.

| Table 3: Potential questions for clinicians & healthcare professionals to ask patients and partners |
|---|
| 1. It is common for your relationship to change after experiencing a heart event. Have you noticed any changes to your relationship with your spouse?<br>2. Have changes to your relationship with your spouse made it more difficult for you to cope with the challenges of heart disease?<br>3. What do you and your partner do to help promote a positive relationship with each other?<br>4. What would you and your partner require to help you cope better together? |

Some patients seemed to have an ambivalent attitude toward their partners who have taken more of a policing and caregiver role. It was clear that, although they appreciated the support they received, it was a cause of stress and guilt for patients as well. Uchino, Smith, and Berg[46] found that members of couples who felt ambivalently towards their spouse were less likely to seek or benefit from the support of their relationship; this ambivalence was related to increased CVD risk-factors. Clinically, this suggests that the presence of discord in the relationships of cardiac patients, as was found in the present study, may increase their risk of recurrent disease and result in poorer quality of life for this population.

It is apparent that partners have been neglected and deprived of care to date, despite their clear contribution to our health care system.[47, 48] This fact is disturbing considering the mounting evidence to suggest that partners of patients with CVD are also vulnerable to developing poorer health outcomes, such as increased distress and depressive symptoms, higher blood pressure, weight gain, and disordered sleep.[49,50] In fact, research shows up to 25% of partners of CVD patients experience symptoms of post-traumatic stress.[51] In our focus groups, it was evident that many of the partners provided care without the adequate resources to do so and were more isolated than the patient in facing the uncertainty of the CVD they were helping to manage. Despite the psychological benefits of cardiac rehabilitation,[1] partners of patients with CVD are often excluded from this important intervention. The present study shows the vital role of partners in the care of cardiac patients; thus, it is important to recognize that providing support to partners is critical for both partners' psychosocial and medical health outcomes.[30]

## LIMITATIONS

This study is not without limitations. First, although the sex distribution is similar to that of the cardiac rehabilitation population, the majority of the patient participants were heterosexual males, potentially biasing the data by sex and preventing meaningful analyses between the sexes. Second, the data were collected from one cardiac centre in Canada; an exploration of needs and desires of this population in other centres would strengthen our findings. It is important to note, however, that the systematic review of 20 studies from various countries identified similar categories.[25] Third, a clinician-patient relationship existed with four of the patient participants, but not their partners. Although conventional content analysis assumes that there are multiple perspectives of the data and that the researchers' positionality (i.e., their thoughts and feelings towards the data, subject matter, and participants) necessarily influences the data analysis,[38] one must be mindful of how their relationship to the participant the topic may ultimately shape their interpretation of the data. Fourth, we did not record the range of years that participants were in their couple relationship. Future research would do well to collect this information and investigate whether this variable influences the themes reported. Fifth, since the interviews were conducted at one time point only, the findings cannot reveal how intimate relationships and participants' needs may change over time. As the effects on martial satisfaction may be different depending on the cardiac illness timeline,[52] future studies employing a longitudinal design may be beneficial. Sixth, although our inclusion of CVD patients of any diagnostic group builds on previous research with select CVD populations and provides a starting point for the general understanding of couples' needs, it precludes an evaluation of the unique needs specific to one diagnostic group. Future research with a larger number of dyads from many diagnostic groups may uncover different needs highlighted by each group. Lastly, focus groups were used to facilitate interaction and discussion among participants, however, this format may inhibit sharing of some intimate information. As such, we recommend that focus groups be augmented with individual interviews in future studies. Despite these limitations, this is the first study that explored, in-depth, the desired intervention components of patients and their partners to help them better manage CVD. Findings allowed for the elucidation of strengths and weaknesses in cardiac rehabilitation programming and better determine the needs of this patient population and their partners.

## CONCLUSION

In summary, the present study demonstrated that the acute onset and chronic effects of CVD cause both positive and negative changes to the couples' relationship. The results highlight the need for more specialized couples-based interventions that aid both patients and their partners through the new reality of living with CVD. Changes within the relationship are inevitable after a cardiovascular event; therefore, it is essential to support couples as they cope with these changes in ways that strengthen their connections to peers and each other and improve their health.

## IMPLEMENTATIONS FOR PRACTICE

- Partners should be actively included in interventions aimed at improving recovery of patients with CVD. Practical resources, opportunities to share with peers, and couples-based interventions are required.

- Changes to patients' and partners' relationship quality should be assessed within cardiac rehabilitation programming and action taken to support patients and partners in strengthening their relationship.
- Future research should investigate whether couples-based programming is effective in reducing both partners' stress brought on by CVD and whether meaningful changes to relationship quality and clinical outcomes are observed as a result of participating in such couples-based programming.

**Contributors:** HT, PG designed the study. HT, PG, SJ, & ND collected the focus group data and HT, LM & MC conducted the analysis. HT, KB & LM wrote the manuscript with contributions from all authors.

**Competing interests:** None declared.

**Ethics approval:** The Ottawa Health Science Network Research Ethics Board (OHSN-REB) deemed this study as a quality assurance/improvement project; therefore, full ethics review was not required, but approval was granted to publish these data.

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**Disclosures:** None

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# Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No. Item | Guide questions/descriptions | Reported on Page # (tracked copy) |
|---|---|---|
| **Domain 1: Research team and reflexivity** | | |
| *Personal Characteristics* | | |
| **1. Interviewer/facilitator:** | Which author/s conducted the interview or focus group? | Page 8 |
| **2. Credentials:** | What were the researcher's credentials? E.g. PhD, MD | Page 9 |
| **3. Occupation:** | What was their occupation at the time of the study? | Page 9 |
| **4. Gender:** | Was the researcher male or female? | Page 9 |
| **5. Experience and training:** | What experience or training did the researcher have? | Page 9 |
| *Relationship with participants* | | |
| **6. Relationship established:** | Was a relationship established prior to study commencement? | Page 9 |
| **7. Participant knowledge of the interviewer:** | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | Page 8-9 |
| **8. Interviewer characteristics:** | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Page 8-9 |
| **Domain 2: study design** | | |
| *Theoretical framework* | | |
| **9. Methodological orientation and Theory:** | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | Page 7,9 |
| *Participant selection* | | |
| **10. Sampling:** | How were participants selected? e.g. purposive, convenience, consecutive, snowball | Page 8 |
| **11. Method of approach:** | How were participants approached? e.g. face-to-face, telephone, mail, email | Page 8 |
| **12. Sample size:** | How many participants were in the study? | Page 10 |
| **13. Non-participation:** | How many people refused to participate or dropped out? Reasons? | Page 11 |

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| | | |
|---|---|---|
| *Setting* | | |
| **14. Setting of data collection:** | Where was the data collected? e.g. home, clinic, workplace | Page 8 |
| **15. Presence of non-participants:** | Was anyone else present besides the participants and researchers? | Page 8 |
| **16. Description of sample:** | What are the important characteristics of the sample? e.g. demographic data, date | Page 10-11 |
| *Data collection* | | |
| **17. Interview guide:** | Were questions, prompts, guides provided by the authors? Was it pilot tested? | Page 8-9 |
| **18. Repeat interviews:** | Were repeat interviews carried out? If yes, how many? | Page 8 |
| **19. Audio/visual recording:** | Did the research use audio or visual recording to collect the data? | Page 9 |
| **20. Field notes:** | Were field notes made during and/or after the interview or focus group? | Page 9 |
| **21. Duration:** | What was the duration of the interviews or focus group? | Page 8 |
| **22. Data saturation:** | Was data saturation discussed? | Page 10 |
| **23. Transcripts returned:** | Were transcripts returned to participants for comment and/or correction? | Page 9 |
| **Domain 3: analysis and findings** | | |
| *Data analysis* | | |
| **24. Number of data coders:** | How many data coders coded the data? | Page 10 |
| **25. Description of the coding tree:** | Did authors provide a description of the coding tree? | Page 10 |
| **26. Derivation of themes:** | Were themes identified in advance or derived from the data? | Page 9-10 |
| **28. Participant checking:** | Did participants provide feedback on the findings? | Page 9 |
| **27. Software** | What software, if applicable, was used to manage the data? | Page 9 |
| **29. Quotations presented:** | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number | Page 12-19 |

**Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist**

| | | |
|---|---|---|
| **30. Data and findings consistent:** | Was there consistency between the data presented and the findings? | Page 12-19 |
| **31. Clarity of major themes:** | Were major themes clearly presented in the findings? | Page 11 |
| **32. Clarity of minor themes:** | Is there a description of diverse cases or discussion of minor themes? | Page 11 |