

ORIGINAL RESEARCH

# Conceptual Framework for Personal Recovery in Patients With Acute Myocardial Infarction

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**BACKGROUND:** Although there has been movement in cardiology to advance patient-centered approaches to postacute myocardial infarction (AMI) care, work remains to be done in aligning patient preferences with clinical care. Our objective was to characterize patients' experience of AMI and treatment to develop a new conceptual framework of patient-centered recovery in cardiology.

**METHODS AND RESULTS:** We conducted in-depth interviews with people who previously experienced an AMI (2016–2019). The interview focused on participants' experiences of their recovery, which were audio-recorded, transcribed verbatim, and analyzed using a phenomenological framework. The overarching theme described by the 42 participants was feeling like a "different person" after the AMI. This shift manifested itself in both losses and gains, each of which posed new challenges to everyday life. The experience appeared to be an active process requiring people to take responsibility for their health. In terms of loss, participants describe how the AMI threatened their sense of safety and security and led to social isolation, fragility, uncertainty about the future, and difficulty expressing emotions accompanied this new fear. A conceptual framework describing the relationship between AMI, identity change, and functioning was developed.

**CONCLUSIONS:** Participants experienced the AMI as an unexpected disruption in their lives that had far-reaching effects on their daily functioning, and were resolved in numerous ways. The conceptual framework may assist in providing a theoretical basis for future interventions in cardiology that not only engage and retain patients in care but also improve long-term adherence to secondary prevention and other aspects of self-care.

**Key Words:** acute myocardial infarction ■ patient care ■ personal recovery ■ qualitative research

There has been a call to action in cardiology to help advance the field's progression toward a patient-centered approach to cardiovascular care.<sup>1</sup> Such thinking represents a fundamental shift from the traditional disease-centered model of care to one that considers the whole person, including specifically issues that patients themselves identify as important. While cardiology has adopted patient-centered practices, such as shared decision making and development and/or implementation of patient-reported

outcomes,<sup>1–5</sup> the traditional disease-centered model persists, and obstacles remain to instituting effective patient-centered care in cardiology,<sup>1,6</sup> particularly in how this translates to recovery after acute myocardial infarction (AMI). These difficulties are likely because of the lack of a comprehensive patient-centered recovery framework to understand the wide range of complex challenges people face after an AMI.

Research has demonstrated that patients with AMI have poor adherence to cardiac rehabilitation

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## CLINICAL PERSPECTIVE

### What Is New?

- Individuals experience a major identity shift as a consequence of acute myocardial infarction, which manifests in terms of both losses and gains.
- A conceptual framework describing the relationship between acute myocardial infarction, identity change, and functioning was developed.

### What Are the Clinical Implications?

- The personal recovery framework can serve as a basis for future interventions in cardiology to help improve long-term care for patients with acute myocardial infarction.

(CR), and secondary prevention interventions have not shown lasting lifestyle changes.<sup>7,8</sup> Additionally, recovery is not as homogenous as once was thought, with certain subgroups (eg, women, people of color) not achieving the same degree of recovery as other groups.<sup>9,10</sup> Further, patients identify barriers such as anxiety, loss of safety, and physical and emotional fatigue.<sup>11</sup> Yet, such factors do not play a central role in the care of people post-AMI. Prior research has indicated that people negotiate significant, and often discordant, psychosocial changes following AMI that have long-lasting effects on their lives, similar to people with chronic illnesses, yet recovery from AMI is often clinically conceptualized as a discrete event.<sup>11</sup>

Psychiatry faced a similar challenge, but over the past decade has made a significant shift to person-centered care for people with mental illness through the development of a concept of “personal recovery” to serve as a complement to traditional clinical recovery.<sup>12</sup> This concept was developed to speak to patients’ efforts and ability to adapt to a new challenge of living with and beyond a chronic disease and refers to those processes and outcomes that matter most to patients themselves (eg, relationships, work, identity), in the process of learning and practicing self-care. This form of personal recovery is a multidimensional process<sup>13–15</sup>—“a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. A way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness.”<sup>16</sup> Clinical recovery, on the other hand, has been based on those outcomes traditionally important to clinicians, such as symptom reduction—much like the standard secondary prevention approach in cardiology for patients with AMI, which incorporates CR,<sup>17–20</sup> without ensuring that patients see the benefits of self-care in the areas that matter most to them over time.

Unlike mental health services, where personal recovery frameworks have been adopted for patients with mental illnesses and influence mental health policy,<sup>21</sup> personal recovery in AMI is under-researched. Specific knowledge gaps include the characteristics and processes of recovery, how recovery can be monitored, and barriers to supporting self-management. Subsequently, the implications of shifting to a recovery orientation in cardiac disease are currently unclear.

Our objective is to gain a deeper insight into personal recovery in patients with AMI and the relationship between personal recovery and clinical recovery. We will summarize the major tasks and challenges individuals face post AMI—some of which provide opportunities for improvement. Based on these qualitative findings, and a prior metasynthesis review of the available literature in cardiology,<sup>11</sup> we will present a personal recovery framework for patients with AMI. This framework may assist in providing the basis for future interventions in cardiology that can not only engage and retain patients in care but also improve long-term adherence to secondary prevention and other aspects of self-care.

## METHODS

All supporting data are available upon request from the corresponding author.

### Study Design

This exploratory qualitative study used a participatory action research (PAR), phenomenological approach.<sup>22</sup> We collaborated with 3 people with lived experience of AMI to analyze the data and present the findings (A.H., R.D., K.D.). The co-researchers received training in phenomenological qualitative methods based on the participatory work of the senior author. Incorporating people with lived experience of AMI, its treatment, and recovery was crucial to both elicit and understand personal recovery in people who have experienced an AMI. A phenomenological approach to interviewing and analysis was most appropriate to the research questions, as this personal recovery area has yet to be studied in cardiology.<sup>12,13</sup> Additionally, we were interested in both the ways people derived meaning from their experience of AMI as well as the meanings themselves, indicating a phenomenological approach.<sup>23,24</sup> In-depth interviews with patients were conducted to collect rich, detailed stories from which to generate possible understandings of recovery from the lived experience of patients post AMI, specifically in terms of understanding factors important to patients that have yet to be described in the literature and aspects of identity other than that of being a patient.

## Data Collection

Participants were interviewed once up to 24 months after their AMI event at each of the sites by 2 researchers trained in qualitative interview methods (R.P.D., A.J.P.). Interviews averaged about 45 minutes long and lasted anywhere from 10 to 60 minutes. A semistructured interview guide was developed with input from people with lived experience of AMI (A.H., R.D.) and researchers with experience in recovery-oriented psychiatric research (L.D., A.J.P.). The semistructured interviewer guide included open-ended questions (Table S1), and interviewers used techniques to follow patients' stories of what was most important to them in the post-AMI period. In addition, we collected baseline information from participants on sociodemographics and socioeconomic status.

## Participants

Between November 9, 2016 and July 16, 2019 we enrolled patients with a prior history of first-time AMI from 3 urban and suburban sites across Yale-New Haven Health: The Health Heart and Vascular Cardiac Rehabilitation Center, the Yale-New Haven Health TakeHeart Cardiovascular Health Center, and the Yale-New Haven Health Chest Pain Center. To be eligible, participants must have had a rise of cardiac biomarkers (preferably troponin) with at least 1 value above the 99th percentile of the upper reference limit within 24 hours of admission.<sup>25</sup> In addition, there must have been evidence of acute myocardial ischemia, including at least 1 of the following: symptoms of ischemia; ECG changes indicative of new ischemia in the ECG (new ST-T changes; new or presumably new left bundle branch block; or the development of pathological Q waves), or other evidence of myocardial necrosis by imaging. Exclusion criteria included (1) being <18 years of age, (2) inability to read or understand English, and (3) inability to provide informed consent. Institutional review board approval was obtained at each participating site, and patients provided informed consent for study participation, including baseline hospitalization information and interviews. There was no preexisting relationship between interviewers and participants in this study.

## Statistical Analysis

The interviews were audio recorded and transcribed verbatim. We did not invite participants to review their transcripts or the findings (ie, member checking). Our participatory action research approach was used to ensure credibility and trustworthiness.<sup>22</sup> By involving people with the lived experience of AMI and chronic conditions in the analysis, we were able to ensure that the perspectives of patients were central and did not get subsumed into traditional, clinical understandings. There were 6 people involved in the data analysis. The senior author, an expert in qualitative methods, oversaw the project and was

involved in generating themes. Narratives were created by 2 researchers and an individual with lived experience. Themes were generated via a consensual model by all 6 members of the team. A coding tree was used informally with our stakeholders in multiple sessions that facilitated the goals of participatory action research.<sup>22</sup> This allowed the creation and discussion of themes and subthemes that were revised over time to generate the main themes presented in the paper.

In the first stage of analysis, transcripts were condensed into narrative summaries written solely in the participants' own words in order to highlight the meaning participants made of events and experiences.<sup>26</sup> In the second stage, the researchers analyzed each narrative to identify patterns across participants. First, each researcher identified common themes of each narrative as well as across narratives. Second, the researchers went through each narrative to highlight commonalities and discrepancies between narratives. A common narrative that fit for all participants emerged that consisted of 3 major themes. Lastly, this common narrative was verified against each original transcript to ensure fidelity to participants experiences. Because of the nature of our analytic approach (creation of narratives), the use of software was not needed.

We used 4 main methods of triangulation to develop a comprehensive understanding of our data.<sup>27</sup> First, method triangulation included our qualitative interviews, observations, and field notes.<sup>28</sup> Second, we used investigator triangulation by using 2 or more researchers in our study, which provided multiple observations and conclusions.<sup>29</sup> Third, theory triangulation was used by our team to develop different theories or hypotheses that assisted in supporting or refuting our findings. Lastly, we used data source triangulation in the form of involving people with different lived experience of illness, including AMI, cancer, pain, and other chronic conditions to see if our results reflected their experience.<sup>27</sup> This allowed us to gain multiple perspectives and validation of our data. We were also guided by a prior paper we published that was a metasynthesis review of the field of post-AMI recovery.<sup>4</sup>

For quantitative data, baseline characteristics were examined for the overall population with categorical variables presented as numbers (%) and continuous variables presented as mean (SD) or medians (interquartile ranges). All analyses were performed in SAS version 9.2 (SAS Institute, Cary, NC).

## RESULTS

### Study Characteristics

This study included 42 participants who had experienced at least 1 AMI (54.7% women) in the previous 24 months (mean time since AMI: 7.0±6.7 months)

and aged between 38 to 84 years (mean age 61.0±11.6 years) (Table). Of the total population, 78.6% of participants completed 1 or more sessions of CR (with the average number of sessions completed being 21 out of a total of 36). Further, at the time of the interview 50% of these patients were currently enrolled in CR. The majority of participants were White, graduated from college and/or graduate school, married, and were not currently working. Of those not working, the main reason was disability (45%).

## Qualitative Findings

### "I'm a Different Person Now"

The overarching theme of the narrative spoke of participants feeling like a "different person" as a consequence of the AMI. This shift in one's sense of identity manifested itself in 2 major ways: loss and gain—both of which posed new challenges to everyday life, making

their experience of AMI a day-to-day active process that required them to take responsibility for their health. Participants described the experience of the AMI as discontinuous in that it disrupted their everyday ways of being in indelible ways. Participants also described the AMI as marking a distinct shift or phase of their lives that felt discontinuous with their self before the AMI. One participant made a comparison to how she had to mourn her self before the AMI, coming to terms with the fact that she will never feel the same again:

*"I feel like that was just a different person then, but she's gone. And I'm ok that she's gone. I don't want her back actually...I went through a mourning period for sure... but I don't want her back. I don't know if I could do what she used to do. I just don't have it in me."* (Woman)

**Table 1. Summary of Participants' Sociodemographic and Socioeconomic Status Data**

N (%)	Total AMI population (N=42)
Age, y, mean±SD	61.0±11.6
Female sex	23 (54.7%)
Cardiac rehabilitation participation	33 (78.6%)
Number of CR sessions attended	21.7±12.9
Currently in CR	21 (50.0%)
Time since AMI (mo), mean±SD	7.0±6.7
Race	
White	28 (66.7%)
Black	12 (28.6%)
Asian	2 (4.8%)
Other*	0 (0.0%)
Ethnicity	
Hispanic/Latinx	5 (11.9%)
Education	
Less than high school	5 (11.9%)
Graduated high school	10 (23.8%)
Completed some colleague	13 (30.9%)
Graduated college/graduate school	14 (33.3%)
Marital status	
Married	21 (50.0%)
Single/never married	7 (16.7%)
Widowed	3 (7.2%)
Divorced/separated	11 (26.2%)
Employment status	
Full-time work	13 (31.0%)
Part-time work	7 (16.7%)
Not working	22 (52.4%)

AMI indicates acute myocardial infarction; and CR, cardiac rehabilitation.

\*Other races (American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander).

Participants described the post-AMI period as a process that required them to be active in their recoveries. When describing this period, participants often used terms like "recovery process" or being "in recovery." One participant compared her AMI to being diagnosed with HIV and how she felt newly defined by her diagnosis of heart disease. There were many similarities of her experience with the AMI to her prior HIV diagnosis. However, the AMI felt distinct in the way it interrupts daily life:

*"There was this poster, an AIDS poster in 1992, that I remember stealing from somewhere. And it said, 'Life was interrupted by HIV.' When I first got diagnosed with HIV, I felt like my life had been interrupted by HIV. But then, I continued my life, you know? And now I feel like the heart disease has really interrupted my life again. But this one just seems to be harder to crawl out of the hole."*(Woman)

Participants often described this period as one of taking an active role in their recovery. They described both lifestyle changes, including eating healthier, exercising more, being aware of stress, and taking medications, and personal changes, such as accepting limitations, actively considering what they valued, and planning for the future.

### Loss

One aspect of feeling like a "different person" was that participants felt unprotected and unsafe—in a "world [that] is not a safe place anymore." Participants often described the pain and discomfort after an AMI in

complex ways. The following participant describes how the AMI blurs the line between physical and emotional pain—and how the AMI "diminishes you" and makes it hard to communicate emotions in words:

*"You hardly ever hear anyone describe the pain....it's such a weird pain. It's not like when you cut your finger. It's sucking you, no it's shrinking you...It's like physical pain and a sense of complete darkness...[I]t is such a lonely pain....It's a kind of pain that is just, so out of your control - and that I cannot ever describe in words, kind of like bubbles of gas bursting inside of you."  
(Woman)*

Some participants had minor things happen and felt fragile, such as the common pains after an AMI (eg, chest pain, shortness of breath). One participant expressed how she had daily reminders that she is now different, leaving her feeling confused, unsafe, and vulnerable:

*"[W]hen I learned how really serious it had been and that kind of really alerted me to, uh, life's fragile. Just a rude awakening. It's like I still don't know what to look for, like a heart flutter? I'm like I don't even know what that is. How could I recognize it? Sometimes it feels excited in there....I'll get a little pain here or there once in a while and I'm like [gasp] is that stent falling out? Stupid things."  
(Woman)*

Because participants felt different, they were in a sense rewriting their past in terms of their identity. People would often find things in their past and dwell on the negative aspects (thus the rewriting had a negative valence to it). In this way, participants would often blame themselves for the AMI. Feeling like they were at fault for the AMI contributed to the lack of safety in the present. One man describes how his past behaviors may have caused the AMI:

*"I had a heart attack in August and I think I brought a lot of it on myself. I would run around, do all the shopping, do all the chores...But I think I kinda just stepped over the line with some of the stuff I was doing too much of."  
(Man)*

Participants experienced fear in a variety of ways. Many were scared of being alone and had nighttime

fears of dying in their sleep. Often, the psychosocial barriers such as anxiety and depression were tougher to deal with than the physical component. Because of this, many sought help from a psychiatrist or other mental health specialists. The following quotation connects the physical feeling of weakness to feeling scared—and how anxiety connects to feeling vulnerable:

*"In the beginning, not only did I feel weak, but I would get scared. I felt like I was going to have like an anxiety attack...I think the anxiety may have been tougher than the physical aspect of it."  
(Man)*

Participants tended to respond by feeling overly cautious and worried that a misstep would result in a subsequent, fatal AMI that was solely their fault—for example, "if I do anything, I could kill myself." Some people described being worried about eating the wrong foods or physically exerting themselves too much—aspects of their lifestyle that were in line with medically suggested changes. However, participants also described aspects of their everyday life (eg, getting dressed) that they were also worried about:

*"You sit and think if your heart is pumping. And then you're like 'Oh my, God. Is that regular? Is that irregular?' It's just the thought process...I know my part, what I need to do but I'm always thinking. If I put a bra on and it's a little too tight, I'm thinking 'Oh my God. Is this stopping my heart?' I'm starting to get like teary eyed. Because it's like 4 freaking months....Because every heartbeat is a thought."  
(Woman)*

In the aftermath of the AMI, participants were also compelled to contend with their own mortality. At times, participants described a tenuous grasp of the future, along with fear that another AMI would kill them. There was often fear because of ongoing symptoms and not being able to see their heart healing. However, although participants felt a deep fear about killing themselves, they also described contending with these fears to continue living their lives.

Participants also felt a loss in terms of their roles in their families, communities, and occupations. One man detailed how "he is nothing like he used to be" in maintaining work and household tasks:

*"I can do some stuff now. But I'm nothing like I used to be. I used to work, sometimes*

*16 hours a day, at least 3 times out of a week. And the others might be 8 hours, 12 hours. I'd leave 5 o'clock in the morning, come home 9 o'clock at night...And now I can't do that anymore. I don't go to work anymore, you know. My sons, my daughter-in-law, everybody looks at me like...wow, we came way down. We were living a good life. When you can't do what you want to do to provide for your family, it's really hard." (Man)*

Participants often felt guilty that they no longer filled a previous social role. For example, 1 participant spoke about how she can now longer take care of her mother, for whom she was previously *her* caregiver. Her role as a caregiver was lost, her identity taken away:

*"[A]t the time my mom was dealing with breast cancer. And I'm the one supposed to be taking care of her. I think about that all the time. Like I'm supposed to take care of my mother. Here she is having to take care of me. And I don't like that...And, the fact that I was scared, I wasn't going to be there to help get my kids right." (Woman)*

After the AMI, participants felt abandoned in various ways. Some felt abandoned by their social networks. Although family and friends were supportive they often asked themselves "Who will I speak to?" and "Who will understand me?" One man described how although he is surrounded by family, he feels isolated and alone (as he appears "normal"):

*"I feel supported. I been doing most of the supporting though, from within. I got family members and everything, but I really don't talk to them about it. They just think I'm normal. Nobody will bring it up. They won't say nothin'." (Man)*

Appearing physically "better" often signified to others that participants were healed or returned to normal, yet this was often not the case. A challenge for many was that others could not "see their insides" and often compared the damage to their hearts to a having a broken arm—which is a clearly visible injury:

*"Once you survive the heart attack everybody thinks it's over. That's just the beginning of it, right?" (Woman)*

The invisibility of both the sequelae of the AMI and the personal changes they experienced led others to the misconception that "you're ok, you're living, you're fine," but many participants expressed how recovery was not experienced as a discrete event in this way. Further, many felt abandoned by the health care system and health care professionals in their long-term care post CR:

*"When you're in cardiac rehab, yes, you have a lot of support. But when you're not at rehab—and you're home, and you're [trying to] live your everyday life, it's different because you don't have that support. I really wish that there were more...different support things and stuff like that in the long-term, that were out there and were able to help women in my stage of transition. Just some kind of companionship for people like me...who are in my kind of situation." (Woman)*

In conjunction with the loss of social roles, participants felt persistently misunderstood and that their struggles remain unrecognized.

After the AMI, participants also mourned the loss of independence and often struggled with feelings of dependency on others:

*"I mean my family took care of me. I was emotional at times because I'm so used to doing things myself. So that got to me a little bit. My husband and my son, they did everything, took care of me, watched over me, sometimes too much." (Woman)*

Some even described feeling infantilized by their close social supports and as a result of the loss in independence, many felt being treated differently by others. One man said:

*"She [my wife] watches me very close. If I go out for an errand and should be back in 10 minutes and I'm 15, she's on the phone. Everything OK? That bothers me a bit because I don't want to be babied either...but it's nice to know people care." (Man)*

### **Gains**

In parallel with these losses, the AMI was often simultaneously experienced as bringing about a somewhat positive occurrence in participants' lives. This took different

forms. Some participants described feeling more emotionally present after the AMI, both with themselves and with family, friends, and colleagues. One Navy seal expresses how he was not an emotional individual before the AMI, but that after the AMI and "invasion in his body," he experiences his emotions more directly:

*"I will tell you one thing and I think it's absolutely true of anyone who's ever had anyone invade their body...is that you become very emotional. I was a Navy Seal, OK? For 30 years. I've got gunshot wounds across the belly. I have a radiation burn on my butt from a Russian nuclear device we stole...None of it ever affected me. But now I get very emotional. They say that when you have your body explored, you know, or when people touch you inside, particularly your heart, that somehow it does affect your emotions. I was not like that before." (Man)*

Although feeling "more emotional" was discussed positively, participants described how more painful emotions were difficult to tolerate, especially soon after the AMI.

Relationships were strengthened in different ways. Participants noted the AMI had facilitated a deeper level of connection with others. One man spoke of how his relationship with his children had changed:

*"You think you know your children, or, maybe you don't. I lived with my kids, [but] I didn't know my kids. And then when I went through the divorce and I got sole custody of my kids. So, now they're mine and I have to raise them and take care of them. And, I got to know them a little bit. But, with the heart attack, I've gotten to know all 3 of them even more...It's been great so I want to see that more." (Man)*

Participants often described a new sense of the importance of their relationships in their recoveries and lives.

Although participants described how they were able to return to prior activities, some approached them now in new ways. For example, 1 woman spoke of how her return to work was an important part of her recovery:

*"It was great...I just needed to get back to work...I felt healthy and that I was able to get back to work. I did ask the doctors was it okay. Of course, they said no, but you*

*know. I have to feed my children and I mean it was 5 days already in the hospital. You know, and it took a toll on my house, my household. I needed to get back to work. And I got [kids in] college and high school." (Woman)*

However, participants also described new ways of approaching prior activities. The following participant detailed how once he was back at work after the AMI he was able to navigate work stress differently than before—with more balance:

*"When I get to the office [now] and I feel a situation getting stressful, I leave." (Man)*

Participants found returning to previous activities, especially in new ways, to be empowering and motivating aspects of their recoveries.

Participants described being more active in deciding what was most important to them and acting in ways that helped them live in line with these values. Although they may have valued work, and success in the past, they often described giving more priority to relationships or previous personal dreams and goals after the AMI:

*"I'm focusing on my daughter in college... The other one is 25. I'm just getting my kids right. And the milestone of trying to live longer than my dad did. Fifty-six, he was young, man. I like to cook. I was a chef. I got a lot of hope. I want to jump out of an airplane...I want to travel again. Next year I'm going on a cruise. And I got a lot of things I got going on that I want to do. So, it's going to be good." (Woman)*

Many participants felt more present as a result of the AMI. One man said:

*"[The heart attack puts] you in this awareness thing... 'Okay time to pay attention.' Yeah time to pay attention all the time. Pay attention to how you're walking. Pay attention to how you're breathing. Pay attention to what you're eating." (Man)*

In feeling more present, participants felt grateful for a second chance and some described a sense of relief as the AMI allowed for such positive changes in their lives:

*“So, I think in a sense to me, that was my wake up call, ya know what I’m saying, because I could have died then, but I didn’t so there’s a reason. I don’t know. I’m just lucky to be alive. That day, I quit smoking, never another cigarette. Switched my diet. A lot was going through my mind. I was an emotional wreck, a wrecking ball. But then I kept thinking, everything happens for a reason and things could have been a lot worse.”*  
(Woman)

In light of these gains, participants reported a new sense of purpose in their lives after the AMI—and many were able to move forward with a new sense of hope and optimism. People accepted their limitations but were still hopeful:

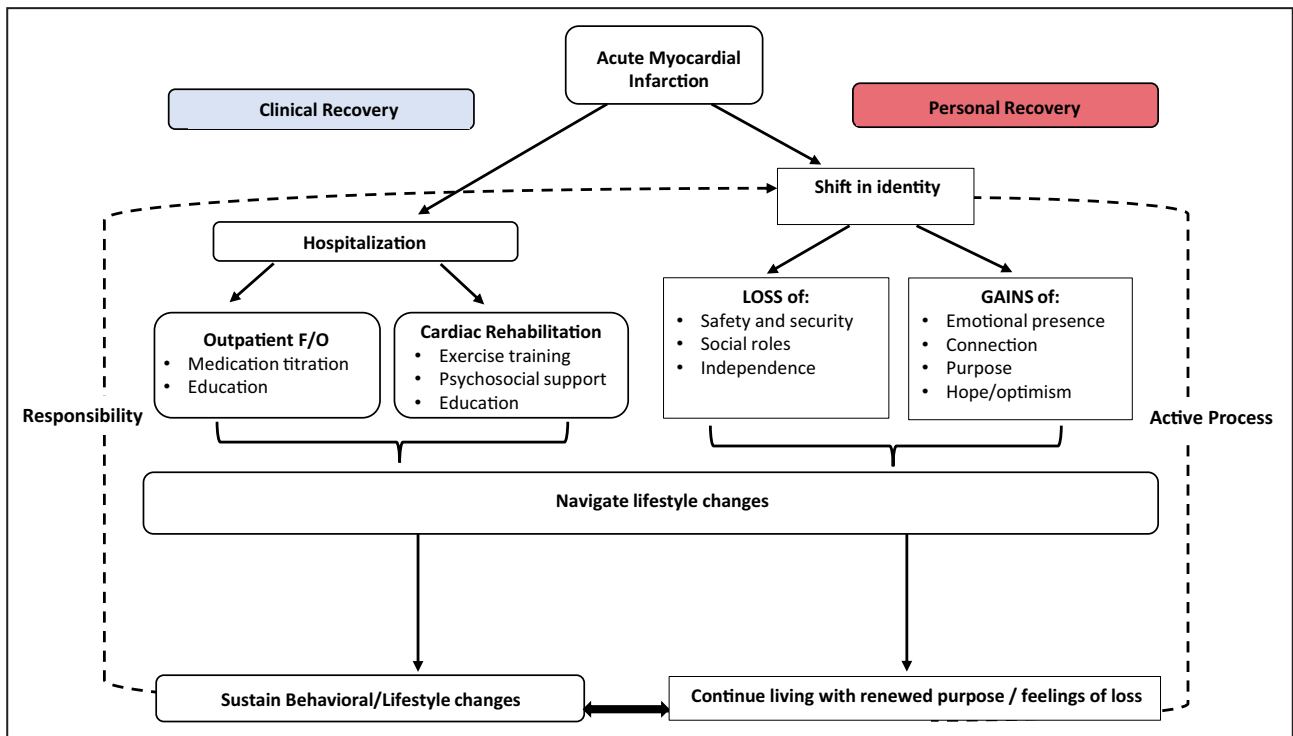
*“I feel like the second part of my life is in a sense going to be better than the first part of my life. I had had so much going on in regard to anxiety and the stresses of life that I definitely think were also contributors. But the last couple of years I’ve stabilized so I do have an optimistic outlook for the future.”*  
(Man)

### Conceptual Framework

The Figure outlines the framework of personal recovery based on our findings.<sup>11</sup> The left part of the figure outlines clinical recovery in cardiology (blue): the patient has an AMI and is hospitalized, receives discharge instructions, and is referred to CR. During the post-AMI period the patient needs to navigate important lifestyle changes in order to sustain behavioral/lifestyle changes long term. The right left part of the figure outlines personal recovery (red): the patient has an AMI and has a shift in identity while experiencing both losses and gains that need to be addressed in order to be able to both navigate and sustain behavioral/lifestyle changes and continue living with renewed purpose and feelings of loss. The post-AMI period is an active process and requires ongoing responsibility. Additional Quotes according to themes and subthemes are presented in Table S2.

### DISCUSSION

We have presented findings from a large qualitative study using a participatory, phenomenological approach that aimed to better understand patients’ experience of AMI and treatment, with the goal of articulating the distinction between personal and clinical recovery in cardiology. In doing so, we have conceptualized the characteristics and processes of personal



**Figure.** Framework of personal recovery in cardiology. (Blue) Clinical recovery in cardiology; (Red) Personal recovery in cardiology.

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recovery from AMI to inform future work. Our findings suggest that patients experience a major identity shift as a consequence of the AMI, which manifests in terms of both losses and gains. Both themes posed new challenges to everyday life, making their experience of recovery following AMI an active daily process that required people to take responsibility for their own self-care. This was necessary in order to both navigate and sustain the required behavioral and/or lifestyle changes after the AMI. These themes were amplified by age, sex, and race/ethnicity—as has been found in prior work,<sup>30–36</sup> yet the overall structure of people's experience remained consistent. Further research on this framework could begin to identify different ways some groups experience of each these themes. Furthermore, this study provides specificity to the trauma experienced by patients after an AMI. Although patients facing any life changing condition may experience the event as traumatic, the changes in meaning-making, particularly in terms of actively negotiating responsibility in new ways, are important when developing a personal recovery framework and may help clinicians talk to patients about their recoveries.

The first major knowledge contribution of this study is confirming, using prospective qualitative data, that an AMI is experienced by people as something that exists over time, versus having a discrete end point—and thus should be treated as a chronic condition. For example, 1 participant in this study compared having an AMI to having HIV, yet the experience of AMI was discontinuous in that it disrupted her everyday ways of being beyond having HIV. These findings are consistent with a metasynthesis review of the available literature to compile qualitative accounts of patients' experiences after AMI.<sup>11</sup> These data suggest that conceptualizing recovery in the traditional sense, specifically as people returning to their prior lives, may not capture their full lived experience. Further, we have demonstrated that recovery as an active patient-based process is the significant paradigm shift between clinical and personal recovery in cardiology, which is similar to mental health. For example, the move from the basic challenge being to do things to the patient to the basic challenge being supporting the individual to do things for themselves. This approach of supporting goal-striving by the individual underpins interventions in mental health such as REFOCUS.<sup>37</sup> Additionally, existing chronic care frameworks, such as the Chronic Care Model, Improving Chronic Illness Care Model, and the Transitional Care Model may offer guidance in providing care for people post AMI. Based on our work, we propose a shift in regards to secondary prevention, in giving primacy to each patient's personal needs, preferences, and goals in addition to the diagnosis and in identifying the contributions of self-efficacy, social support, and

engagement in and adherence to care, self-care, and personal recovery.

Second, we have developed a novel personal recovery framework. Although current qualitative research on understanding recovery, particularly regarding psychosocial factors in the post-AMI period, is well discussed in the literature (ie, demonstrating key themes and/or stages of recovery),<sup>38–42</sup> this has been mainly subjective and lacks a broader overarching framework not only to understand identity change but also in terms of how people see themselves in the world after an AMI. Thus, our work builds on prior studies in understanding recovery post AMI in a more granular way to better understand what personal recovery means for patients with AMI. To address this, we worked closely with patient stakeholders using a participatory action research approach,<sup>22</sup> which ensured we captured patients' lived experiences in developing the interview guide and throughout the entire research process. This approach led to rich interviews regarding themes around meaning, social supports, identity, and what was most meaningful to patients. This personal recovery framework may assist in organizing current efforts and providing the basis for future interventions in cardiology that not only engage and retain patients in care but also improve long-term adherence to CR/secondary prevention and other aspects of self-care. For example, shared decision-making practices, particularly eliciting needs and providing tailored information to patients, could be expanded to include these findings, ensuring that clinicians are preparing patients for both clinical and personal recovery. To support patients, CR could help facilitate peer support on 2 levels. First, peer services can be integrated into CR, as have been done in mental health.<sup>43</sup> Hiring peer workers, or people with lived experience of AMI, its treatment, and recovery, can provide support for patients in ways that are currently unavailable in CR as they may serve as living examples of recovery. Second, CR can facilitate mutual support among patients through more formal measures, such as support groups or facilitating relationships among CR patients.

Our work maps on and builds on established personal recovery frameworks in mental health such as the Connectedness, Hope and Optimism about the Future, Identity, Meaning in Life, and Empowerment (CHIME) framework.<sup>12</sup> This new emphasis within the mental health and social care system on personal recovery has underpinned significant innovation, including 19 randomized controlled trials of peer support work,<sup>44</sup> 28 randomized controlled trials of the Individual Placement and Support approach to employment,<sup>45</sup> the development of education initiative called Recovery Colleges in 22 countries,<sup>46</sup> as well as the development of new academic disciplines such as survivor research<sup>47</sup> and Mad Studies.<sup>48</sup> The development of a

recovery orientation within cardiac services has similar potential as a source of innovation.

## Limitations

There are several limitations to this study. First, participants were enrolled from 1 hospital setting, therefore limiting extrapolation of our findings to other settings and international comparisons. Second, we interviewed participants within the 1 to 24 months after their AMI and thus recovery beyond this timepoint may differ from those enrolled in this study. Third, several interviews collected in the earlier part of this study lasted under 20 minutes, which is shorter than necessary for qualitative research, especially phenomenology. However, this was not the norm. As the topics in the interview guide (Table S1) were not those often discussed in traditional care, we noticed there were difficulties in these earlier interviews in that people's descriptions were not as thick as needed for qualitative research. This difficulty in verbalizing emotional experience is consistent with the alexithymia literature (ie, inability to recognize and verbalize emotions in words).<sup>49–51</sup> To overcome this challenge in the initial interviews, we met with our stakeholder team to discuss strategies to facilitate people elaborating on their experience. For example, we conducted interviews in the community versus the CR centers. This was in part the rationale for conducting more interviews. The subsequent interviews were more typical for qualitative research. Although brief, these shorter interviews were consistent with the themes found in the analysis and confirmed the findings. Lastly, 79% of participants in this study were in (or had completed) CR. Future work should focus on understanding personal recovery among those patients who were either referred and did not attend CR or were not referred at all. This is important as there are known differences in demographics and social determinants of health between these patients.<sup>52</sup> However, despite having a smaller proportion of patients not in CR (22%), we found that the overall structure of people's experience after an AMI remained consistent in terms of our main themes. We are thus confident we have captured some core commonalities to the experiences of persons with AMI.

## CONCLUSIONS

In conclusion, our findings highlight the major identity shift individuals experience as a consequence of the AMI, which manifests in terms of both losses and gains. The personal recovery framework provides an opportunity to shift to a personal recovery orientation in cardiology and has the potential to underpin innovation in knowledge (eg, lived experience), roles (eg, peer workers), and interventions (recovery colleges, individual placement/support).

## ARTICLE INFORMATION

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### Disclosures

None.

### Supplementary Material

Tables S1–S2

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# **SUPPLEMENTAL MATERIAL**

**Table S1. Patient interview guide demonstrating narrative qualitative questions.**

<b>Question</b>	<b>Prompt</b>
How have things been going for you since your heart attack?	What happened after you left the hospital?  What's it been like on a day-to-day basis?
What's been most important to you since your heart attack?	
Have you felt life has been different lately to how things were before your heart attack?	What has made things difficult for you after you heart attack?  What has made things easier for you after your heart attack?  Has anything hindered, or gotten in the way of, your recovery after your heart attack?
Do you feel like you have recovered from your heart attack at this point?	How could you tell you were recovering?
How important has been the support of others since your heart attack? (I.e. family, friends).	
Have you been in contact with other heart attack survivors?	What was that like? Did you find this interaction helpful? If so, what was helpful about it?
Where do you think things are going from here?	What are your hopes for your future?
Is there anything else you would like to tell me about your experience after your heart attack that I didn't think to ask?	

**Table S2. Additional Quotes according to themes and sub-themes.**

Overall themes	Themes	Subthemes	Quotes
Shift in identity	-	-	<p><i>“Since the heart attack, not good. I’m not the same person anymore. I feel like I’m a lot older than I am. I’m a very concerned individual. I worry a lot. And I never had the worries or stressors and concerns before. I get a lot of discomfort. Aches and pains that I never felt before in my chest. And it’s stressing me out and making me worry thinking, you know, something is wrong. I check my blood pressure five, ten times a day. Some days way up, some days way down and...call my doctor, and well, double up on this, take an extra one of these, and it was just a very, very rocky road for a long time until finally, they put me on the right blood pressure pill. And every day I’ve been pretty steady.” (Male)</i></p> <p><i>“I would say that I'm a different person [since the heart attack]. I feel a whole lot physically better. One thing that definitely concerned me is that I definitely felt a lot more in touch with my own [mortality]. And I was like oh my God. I want to get healthy and strong. I don't want to live a sickly life. Because I feel like I haven't done all the things I want to do yet. Without being healthy, you know, it's very hard to do the things that you want to do and take hold of the reins in life.” (Male)</i></p> <p><i>“All I’m doing is just taking the baby steps. You know, trying not to get ahead of myself, but you know there’s that part of me that remembers who I used to be. Not the same anymore ... maybe I’m better than I was because I quit smoking.” (Male)</i></p>

			<p><i>“I think I'm in recovery. I think I'm going to consider myself to be in recovery for a long time. Taking care of myself as much as possible. Because before I did it for health and fitness and longevity. But now I'm doing for survival. This is not something I can be playing around with. I'm preparing my food a lot which has been very satisfying. I feel like it's important for me to prepare my food because I need to know what's in it.” (Male)</i></p>
Loss	<ul style="list-style-type: none"> <li>• Loss of safety/security</li> </ul>	<ul style="list-style-type: none"> <li>○ Reminders about the pain</li> </ul>	<p><i>“I think what scares me is that I'm running out of fuel. I'm very resilient but shit.... It's getting harder and harder. Before it was like ok I can climb this mountain but now it's like I could try to climb the mountain but I wonder when I will get to the point where I'm like, yeah no. Not interested. Enough is enough. I'm happy to stay in the valley but enough. I'm not there yet but I know it's coming.” (Female)</i></p> <p><i>“I do believe I've recovered from the heart attack. I know my heart has, emotionally. Somebody told me, he said a heart attack may save you from [another one], but you always have the curse. And I didn't realize what that meant until I had my heart attack. What that means is, every little gas pain, every little heart burn, every little thing, you just stop and it makes you think for a second, "Am I having a heart attack?" And, so to forget you ever had a heart attack will never happen.” (Male)</i></p>
		<ul style="list-style-type: none"> <li>○ Self-blame</li> </ul>	<p><i>“Sometimes it's like a dream and it didn't really happen. But then the reality is, you know, I've always lived with controlled high blood pressure. I've lived knowing both my parents had heart disease. I was going to a</i></p>

			<p>cardiologist regularly five years ago but when everything came out great I made a mistake and I just stopped going. So I regret that.” (Female)</p> <p>“Glad that I’m here. Most of the time [laugh] I feel that way. I’m just reading labels constantly. And trying to do with the low sodium and the low carbs because I was a junk food junkie. The exercise is difficult because I am hurting all the time. I’ve always loved exercise before all this happened and then I just got lazy and depressed and just stopped everything. I’ve lost 15 pounds since this happened so I’ve got quite a bit more to go.” (Female)</p>
		<ul style="list-style-type: none"> <li>○ Fear</li> </ul>	<p>“When I went home, I stopped really eating and I think I did more harm than good. I think I was afraid to eat. Should I eat this piece of meat? Should I have the egg whites? Should I have the whole egg?” (Female)</p> <p>“When I got home and I got in my own bed. That helped but then I didn’t have access to things I needed. I pretty much stayed home quite a bit because I was kind of scared to go out to places. How much of it is the actual disease or how much of it is the psychological part of it?” (Male)</p> <p>“After I came home, living on the third floor, I was really paranoid about having another heart attack, and I have a dog. Going out, walking the dog and walking back up the stairs. I was thinking, what if another piece of the clot flies away? So, that was a little disconcerting to me.” (Female)</p> <p>“And then I went home and I was scared to death, all the time. Still I’m a little scared. Scared to move, I mean</p>



			<p><i>from my living room to my bedroom. I was like, scared that something would happen to me walking in there. And they say you need to walk back and forth in the house. And I was a wreck all the time I was doing it. I have to finish up here [Rehab] and just watch it. I'm still scared, afraid that if I overdo it, in the sense that I'm going to drop dead or something like that. I try not to overdo it and I'm pretty good about making sure I'm not in a stressful situation.” (Female)</i></p>
	<ul style="list-style-type: none"> <li>• Loss of social roles</li> </ul>	<ul style="list-style-type: none"> <li>○ Roles</li> </ul>	<p><i>“Fortunately, my wife is relatively active, although she’s losing her sight. I have become the caregiver in our house because she is legally blind, though she can maneuver enough to get around the house. So I’m driving the car, which is a big thing now. And that took me about four weeks before I decided to venture into driving a car.” (Male)</i></p> <p><i>“The only difficult thing is knowing that there’s been a change, because I was an athlete. Well, this is the second half of your life, you know? And you have to kind of deal with that.” (Male)</i></p>
		<ul style="list-style-type: none"> <li>○ Feeling abandoned</li> </ul>	<p><i>“[One of the things that was difficult for me after the heart attack was that I wasn’t ready to leave rehab]. I would like if it was like some kind of discount gym. Do you pay \$30 a month for a gym? Or do you get gas in your car? Those are the kind of choices that I had to make. Because I would imagine that there are several people who have Medicaid. And so what happens to those people including myself afterwards? We can't afford to go to a gym. It was like your time is finished...” (Female)</i></p>

			<p><i>“You know, I think a lot of my friends like try to avoid talking about it, you know. My sister, you know, she will call the doctor in a minute. People just disappear when you get sick. But there are ones that are really there for you through what happened. In the recovery process, talking to friends and family is very important.”</i></p> <p><i>(Female)</i></p>
	<ul style="list-style-type: none"> <li>• Loss of independence</li> </ul>	-	<p><i>“When I came home, I just took my time and I didn’t do anything. I had no choice, but I was gonna carry my laundry basket upstairs, but I didn’t carry it. I put it on the stairs. My granddaughter: “Grandma!” “What?” I says, “I’m not carrying it.” Oh, no, they watched me. Full two weeks. Yeah. Because they know me. They know I would do what I’m not supposed to do. Well, I’m too old to be doing anything anyway, so I just sit back and relax.”</i> <i>(Female)</i></p> <p><i>“I have four kids. They have been supportive but they can be in a position of being overly supportive. By that I mean, they now treat me as a child and they’ve sort of taken over as if they were the parents. I’ve had to kind of low them down a bit about that.”</i> <i>(Male)</i></p>
Gains	<ul style="list-style-type: none"> <li>• Feeling ‘softer’ (emotional presence)</li> </ul>	-	<p><i>‘I feel like I am living in some sort of alternative reality. It’s so strange. It’s like I know I’m alive, I’m here, I didn’t die. But I feel like I’m stuck in limbo between ‘I could have died’ but I lived. And I’m not really sure how to deal with that. I think I’ve become softer a little bit.’</i></p> <p><i>(Female)</i></p>
	<ul style="list-style-type: none"> <li>• Connection</li> </ul>	<ul style="list-style-type: none"> <li>○ Strengthening relationships</li> </ul>	<p><i>“People don’t usually think about [staying alive] every day but, you know, life is what happens when you were</i></p>

			<p><i>making other plans, so the importance of family and your friends has risen considerably. I'm starting to get back in touch with cousins I haven't seen in quite a while. We've started trying to put together a family reunion so our kids would get to meet the other kids."</i> (Male)</p> <p><i>"I think my wife and I are closer than we were. I mean we were close but I think now we're closer."</i> (Male)</p> <p><i>"Well, that's [social support] been a big factor I think you know. I think if I was alone, it would be much harder. Or if I had to depend on a stranger to ... if I had to pay somebody to pay attention or to take care of me. I think that would be much harder."</i> (Male)</p>
		<ul style="list-style-type: none"> <li>○ <i>Return to prior activities</i></li> </ul>	<p><i>"I noticed one day I woke up, somewhat recently, and I'm doing things on my own. I'm not even thinking about the anxiety. So I do think that that I've been extremely blessed. And I definitely think that living a healthy lifestyle prior to the heart attack has done a lot to help me with my recovery. I'm ready to actually get back to the gym and start weight training again. I'm hoping to do that as quick as possible."</i> (Male)</p> <p><i>"Well, a week later I went back to my full time job. Yeah. And I'm executive director of a non-profit organization so I went back and I live around the corner from my office and so I felt it's important to keep my mind engaged. And I feel passionate. I love my work. And I, knowing circumstances of people working way longer than 69 today. I felt very capable and it kinda got my mind off this. My company didn't even know."</i> (Female)</p>

	<ul style="list-style-type: none"> <li>• Purpose</li> </ul>	<ul style="list-style-type: none"> <li>○ <i>Re-thinking values</i></li> </ul>	<p><i>“I’ve got too much I want to do in my life yet, that I didn’t want to die right then. So something must have been in me. I’m just so happy that it worked out. So, every day you want to see tomorrow. I have to see my grandson graduate. I want to see him hopefully get married. I would like to see great grandchildren. I mean, there’s things I want to do in my life. I don’t want to rush it, but you never know, right?” (Female)</i></p>
		<ul style="list-style-type: none"> <li>○ <i>More present</i></li> </ul>	<p><i>“Living life fully, definitely [is the most important thing since the heart attack]. (Female)</i></p>
		<ul style="list-style-type: none"> <li>○ <i>‘I’m alive’/feeling grateful</i></li> </ul>	<p><i>“Yes, definitely [my life is better]. I’m more active than what I was. Before I would just sit in the truck and not do anything. Just, you know. Now I get up. I walk. I’ll do, you know, some of the work that my workers do, just to keep myself more motivated, more active more mobile.” (Female)</i></p> <p><i>“Yes. I [have recovered], absolutely. Yeah, the routine that I had before, prior ... I’m there, and probably even a little bit better. Honestly, because, you know, whatever he did, the stent, I mean, I feel stronger. You know, I feel better, uh, and of course the medication is helping, you know. The blood thinners or whatever they have me on, but, honestly, I feel much better even up to having the heart attack from where I am now.” (Male)</i></p> <p><i>“[The most important thing since the heart attack has been] looking at my kids. Looking at life, just living life. Appreciating every freaking thing that you see or do. I’m here for a reason. If I didn’t have faith then I’d be dead. Really. You’ve got to have faith and you have to believe</i></p>

			<i>that God is in you and thank God every day. There's something bigger that he has planned for me and I need to see it, so that's why [laughter] I'm still here. When you're sitting in the ICU with a tube down your throat and you can't do nothing about it I have to have faith. I have to, so that's what it is.” (Male)</i>
	• Hope/Optimism	-	<i>“I’m taking advantage of every day now. Take nothing for granted. Seeing my grandchildren, my family, and realizing that in a heartbeat, literally, that could have all been gone and through the Grace of God it’s not, so take advantage of it and just move on. Move forward.” (Female)</i>
	• Relief	-	<i>“It’s like something went and it’s...all clean. Everything’s starting all over again. And that’s how it feels. So, I don’t want to...mess it up.” (Male)</i>