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Getting better or getting by?: A qualitative study of in-hospital cardiac arrest survivors long-term recovery experiences

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Abstract

In the United States, approximately 292,000 adults (>18 years old) per year suffer an in-hospital cardiac arrest (IHCA). Survival rates have increased over the last decade and many survivors return to their communities. IHCA has been recognized as a unique disease entity because the arrest happens in a medical care setting and survivors often have more medical co-morbidities. Although more individuals are surviving IHCA, very little is known about their long-term recovery experiences. Semi-structured interviews with 19 IHCA survivors were conducted to better understand their recovery experiences and identify strategies of adaptation that they felt aided their recovery. Thematic analysis indicated that IHCA survivors experience ongoing challenges to recovery. Reconceptualization of independence was necessary for some participants to re-engage in social and physical activities and a few were able to engage in new activities. Our findings suggest that IHCA survivors often develop their own strategies for adaptation in order to continue participation in their social lives and that their recovery experiences are ongoing. Intervention programs and follow-up care should continuously ask survivors what is important to them and

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Ethical statement

This manuscript represents original research. MH drafted the manuscript. MH, LAK, KH, CS, PRK, MR, BMV acquired, analyzed, and interpreted data. BKN and TJI conceived and designed the work. All authors revised, approved and are accountable for the accuracy and integrity of this work. This manuscript is not under review at another journal.

Declaration of competing interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

identify resources that will support their goals. Questions should include physical, cognitive, psychological and social goals that extend beyond those specifically related to IHCA since our findings indicate that the effects of IHCA are long-lasting and encompass all aspects of survivors' lives.

Keywords

In-hospital cardiac arrest; Long-term recovery; Qualitative research; Semi-structured interviews; Thematic analysis

1. Background

In the United States (U.S.), approximately 292,000 adults (>18 years old) per year suffer an in-hospital cardiac arrest (IHCA) (Holmberg et al., 2019). While the number of IHCA has risen in the past two decades, the survival to hospital discharge rate has also increased from roughly 13%–25% (Benjamin et al., 2019; Girotra et al., 2012; Neagle & Wachsberg, 2010). When assessing the one-year survival rate, study estimates range from 13% to 59% (Chan et al., 2013; Feingold et al., 2016; Schluep et al., 2018). Although the vast range of survival rates may be attributed to differences in outcome measures (i.e., survival to discharge versus one-year survival post-IHCA), the numbers do provide important estimates of how many patients survive after discharge. These studies, however, lack description of the patient experience once they return to their lives and adjust to potentially new life circumstances.

Differences have been observed between patients who experience IHCA and those who have an out-of-hospital cardiac arrest. For example, Moskowitz et al. (2018) state that, “patients who experience IHCA tend to have more medical comorbidities, have a witnessed arrest, and [are] attended to by professional first responders,” (p. 151) and IHCA should therefore be considered a unique disease entity with its own guidelines and recovery care plans. Although there is recognition that the context and ongoing comorbidities of IHCA survivors may require distinct recovery plans, very little is known about their long-term experiences.

Studies focused exclusively on IHCA, especially long-term outcomes, are lacking (Bremer et al., 2019; Feingold et al., 2016; Sawyer et al., 2020; Schluep et al., 2018). Current literature is mainly focused on either out-of-hospital cardiac arrest or combines findings from survivors regardless of cardiac arrest (CA) location (Beesems et al., 2014; Elliott et al., 2011; Haydon, van der Riet, & Inder, 2017; Moulart et al., 2009). Many of these studies have focused on the quality of life (QoL) of CA survivors. The World Health Organization (1997) defines QoL as, “a broad concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment.” Utilization of quantitative measures to determine QoL have been researched and most of these studies have found that CA survivors report a generally good quality of life after discharge (Elliott et al., 2011; Haydon, van der Riet, & Maguire, 2017; Moulart et al., 2009).

Given that QoL studies indicate that CA survivors consider their functioning “generally acceptable”, some research has shifted to focus on possible factors that may help increase

and/or support QoL within this population. For example, studies have found that when survivors are able to participate in social activities, they report a higher level of life satisfaction regardless of their functional level (Moulaert et al., 2017; Wachelder et al., 2016).

Cognitive impairments, especially memory, are common among CA survivors and may affect QoL (Andersson et al., 2015; Buanes et al., 2015; Lim et al., 2014; Moulaert et al., 2009; Steinbusch et al., 2017). Sulzgruber et al. (2015), work further specified that, “memory function after cardiac arrest was found to be particularly impaired in resource demanding memory qualities such as delayed recall or working and prospective memory,” (p. 125) potentially impacting their activities of daily living (ADLs), including medication adherence and recovery care. Additionally, although memory loss affects survivors’ ability to recall the CA, the need to know what happened remains in order to feel some control over their lives. Family and friends are relied upon to fill in these gaps of understanding (Bremer et al., 2019; Haydon et al., 2017a, 2019; Sawyer et al., 2016). Issues with memory may also impact survivors’ ability to process information from health care providers immediately following CA thus impacting their recovery. These studies indicate that recovery continues after hospital discharge and that survivors rely on their social networks to support them in their healing process.

Studies that have sought to understand survivors’ perspectives and experiences of life post-CA, although fewer in number, provide important insights into CA survivors’ challenges and recovery. These studies have shown that CA greatly impacts survivors’ lives and, “is always in the background of living,” (Haydon et al., 2019, p. 460) indicating that recovery is an on-going process.

Although more patients are surviving to hospital discharge and the one-year survival rate has improved (Schluep et al., 2018), there is still a lack of research that focuses specifically on patients’ experiences of IHCA, recovery after hospital discharge and the adaptations they may have to make in order to reintegrate back into their lives. Understanding their long-term experiences is even more critical given that they are often dealing with multiple comorbidities and most survivors are discharged home (Mallikethi-Reddy et al., 2017; Steinbusch et al., 2017), sometimes without additional in-home health care support. Therefore, we sought to understand IHCA survivors’ long-term recovery experiences and identify strategies of adaptation that they felt aided their recovery.

2. Methods

2.1. Study design

An exploratory, qualitative study design was used to better understand IHCA survivors’ long-term recovery experiences and strategies they developed to resume their daily activities. This study was approved by the VA Ann Arbor Healthcare System institutional review board (IRB #2018–1086).

2.2. SAMPLING and RECRUITMENT

2.2.1. ResCU1 study—In 2014, the Veterans Health Administration (VHA) Health Services Research & Development funded the Recovery after In-hospital Cardiac Arrest: Late Outcomes and Utilization (ResCU1). The goal of ResCU1 was to understand patterns of long-term outcomes and healthcare utilization across VHA hospitals in the U.S. after IHCA and develop strategies to better support recovery. The ResCU1 study found, using ICD-9-CM codes (diagnosis and procedure codes associated with hospitalization in the U.S.), that 2554 IHCA occurred across VHA medical centers between October 2014–January 2016. The survival to discharge rate was 47% (N = 1188) at 8 weeks. A manual chart review, performed by trained Research Assistants, was then conducted and determined that 253 (21% of 1188) were not eligible for study recruitment for reasons such as CA did not occur in hospital or cognitive impairment. An additional 371 (31% of 1188) were deceased upon review. The chart review confirmed that 564 (48%) of the 1188 had an IHCA and were eligible for enrollment in the study. However, when enrollment began, 90 (16% of 564) were found to have died and 16 (3% of 564) were excluded for various reasons including cognitive impairment (unable to provide informed consent), and/or non-English speaking, leaving a final eligible cohort of 458. Of these, 325 (71% of 458) were located, contacted and provided informed consent to receive surveys focused on assessing their health status, cognition and ADLs at 3, 6, 9, and 12 months. The survey results identified individual recovery trajectories of Veterans who had reported a range from inability to function to excellent function in their ADLs (including independence in dressing, walking across a room, bathing, eating, getting in/out of bed, toileting, making a hot meal, making phone calls, taking medications, paying bills, shopping for groceries). This study provided the sampling pool for the current study, ResCU2.

2.2.2. ResCU2 sampling—Of the 325 Veterans who completed surveys for ResCU1, 237 were still enrolled in the study as of November 2017 and thus, eligible for participation in ResCU2. We then purposefully sampled from this pool to ensure representation of a range of post-IHCA recovery abilities. The range consisted of Veterans who had recovered full independence in at least 3 ADLs in the year following their IHCA to Veterans who reported little to no recovery or a decline in their ADLs. At the start of interviews for ResCU2 (February 2019), there were 44 eligible Veterans.

Eligible participants were mailed a research information letter explaining the study along with an opt-out letter to return if not interested. If the opt-out letter was not received within one week, a study team member called them to determine interest, answer any questions, and schedule an interview for a future date. At least three phone calls were made to an eligible Veteran before it was considered a passive decline and no further contact was attempted.

2.3. Data collection

Between February–May 2019, 19/44 eligible participants completed a semi-structured telephone interview (Fig. 1) (Range 16–62 min/Mean 41 min). Open-ended questions focused on better understanding their recovery experiences both within and after discharge from the hospital. Verbal consent was obtained prior to starting the interview. Each interview

was conducted by one primary interviewer and one to two additional study team members who took detailed notes and asked follow-up or clarifying questions. Interviews were audio-recorded and transcribed for analysis. Participants who completed the interview received a \$10 gift card provided by funds from the awarded grant.

2.4. Data analysis

Thematic analysis was performed by inductively coding transcripts to identify patterns and themes (Braun & Clarke, 2012). To begin, each team member (MH, LK, KH, PK, MR, CS) read and independently coded the same transcript. We then met to discuss our coded transcript, reviewing, line-by-line, the text and corresponding code. Agreed upon codes were documented in a codebook along with the definition and example text. We continued to code 2 more transcripts as a team in this manner to expand and refine codes and definitions. Remaining transcripts were then divided amongst the team with two team members assigned to each transcript. The two team members individually coded the transcript and then met to discuss their codes and resolve any differences. This consensus process ensured that codes were being applied appropriately and consistently. If new codes emerged or established codes were refined during the coding process, they were added to the codebook and all team members were made aware of the changes. Previously coded transcripts were then reviewed to apply new codes if necessary. Agreed upon coded transcripts were then entered into NVivo 12 (QSR International Pty Ltd, 2018) for data management. Code reports, where data is aggregated under the same code, were generated for review. Each code report was read and grouped with other similar code reports based on content. Themes were developed by re-analyzing the grouped code reports to identify patterns and create theme definitions. Rigor was ensured through the involvement of a multi-disciplinary team and multiple members analyzing, comparing and interpreting the data.

3. Findings

Nineteen Veteran IHCA survivors participated in the interviews. At the time of the interviews, 4–5 years had passed since the participants' IHCA consistent with our desire to focus on long-term recovery. Among the participants, the mean age at the time of their IHCA was 62. Additional participant demographics are listed in Table 1.

Three predominant themes about participants' long-term recovery experiences emerged including: 1) Ongoing challenges to recovery-while participants talked about their IHCA, they also spoke about their continuing struggles. Additionally, their co-morbidities also hampered recovery. 2) Reconceptualizing independence-independence, both cognitive and physical, was important. Participants felt they had to make adaptations to how they lived in order to maintain some independence. 3) New engagements-a few of the participants found it helpful to engage in new activities. For each theme, participant-identified strategies or resources they felt helped them in their recovery were also identified. Table 2 provides an overview of the themes with supporting data.

3.1. Ongoing challenges to recovery

When asked about their current cardiac care, three participants stated they were not currently experiencing or being treated for ongoing cardiac issues and one questioned their IHCA diagnosis, stating they could not remember their arrest. Although participants did not specifically focus on their current cardiac issues, all did emphasize the lasting effects they felt their IHCA event had on their overall health, functioning (cognitive, physical and emotional) and self-perception. Only two participants stated that they felt their lives were the same as before their IHCA. Others (N = 17) felt they had not returned to their “prior self” and therefore, had to make adaptations to their lives.

I’m the kind that was always helping the neighbors move the couches and that kind of stuff and I can’t do any of that kind of stuff no more, even stairs, I can’t walk stairs without having a railing.

(ID# 2447)

Additionally concerning to participants was memory loss and how it continued to affect their daily lives. Fourteen participants stated they had or were still experiencing memory issues. Some remained hopeful that it would improve while others expressed disappointment at not being able to cognitively function at their pre-IHCA level.

I lost a lot of memory while I was in and I’m still searching for some of what I lost.

(ID# 2909)

The most common strategy participants used to deal with memory loss was to rely on their informal caregivers (e.g. spouse, sibling, children) to remember for them. They not only relied on informal caregivers to remember day-to-day tasks like taking medication and attending appointments but also to retell the story of how their IHCA happened. Although participants appreciated caregiver support, some struggled to accept the need for help and the feeling that they were now vulnerable.

... quite frankly my life is, I live in two worlds, the world of “You’re okay,” and the world that you could drop dead today from this affliction ... I need your help, I want your help, but I don’t want your help and, it’s weird.

(ID# 3955)

Inability to recall the actual IHCA event was common across all participants. Memory issues seemed to affect their ability to recall any IHCA information they may have received while in the hospital. Three participants stated that they did not receive a lot of information from their health care providers about the trajectory of their recovery even in their follow-up care. Others could not recall what they were told, if anything. This lack of information and recall left many participants to figure out for themselves what would help them overcome their challenges. As one participant stated, “I’ll try to figure out something that will help me help myself,” (ID# 3558). This participant described themselves as being independent and approaching life with this attitude.

For three of the participants that did receive recovery information from their health care providers, they were dismayed by the discrepancy between their own expectations for recovery, their own reality and what their health care provider told them.

They should say, “You’re going to get adequate if you do the right things.”

(ID# 3955).

This dismay did not, however, reflect their opinions regarding the care they received while in the hospital. Almost all the participants were positive about their hospital care and attributed their survival to receiving excellent care. They often praised the hospital staff, especially nurses, but still expressed a need for more information about recovery and services that may benefit them.

In addition to reliance on caregivers, other activities participants felt helped them stay active and improve their memory were reading, listening to audio books, doing puzzles, and writing things down. One participant stated that he took a class while still in the hospital that taught him how to improve short-term memory loss, which he found helpful. And still another participant was able to reframe his memory loss into a positive, stating,

Actually, it’s a good issue because I get to forget about all the bad things, it doesn’t bother me now.

(ID# 3955)

More concerning for many of the participants were current illnesses that took precedence over their IHCA recovery. Twelve participants reported that their co-morbidities (e.g., spinal cord injury, post-traumatic stress disorder, cancer, neuropathy, diabetes, kidney disease) hindered and at times exacerbated their recovery efforts. For example, one participant stated that he has kidney disease and found that treatment for both his kidney disease and congestive heart failure were at odds with each other.

I’m on a cardiac diet and I’m on a kidney diet and they don’t really, they don’t agree with each other ... the nephrologist wants me drinking all kinds of water and I have congestive heart failure, the cardiologist is saying “Absolutely not, 62 ounces a day, period.”

(ID# 536)

This participant had to self-coordinate his care by connecting his nephrologist and cardiologist so they could co-develop a plan that he could manage. Managing multiple illnesses was common among the participants.

After discharge from the hospital, ten participants had formal caregivers (e.g., in-home health care nurses, home assistants) to help with ADLs and stated that they valued this support. Informal caregivers (e.g., spouse, children, friends, etc.) also featured prominently in ongoing recovery. Participants spoke of the various ways they relied on their informal caregivers for physical, cognitive, social and emotional support. Not only did participants have to learn to adjust to their limitations but their informal caregivers often had to learn new skills.

I’m not supposed to eat dairy. My wife has learned to cook without dairy. And I just realized there’s some things I cannot have in my diet ... it would be impossible to make it without her.

(ID# 536)

3.2. Reconceptualizing independence

Fifteen participants acknowledged that they were not as independent in their lives as they were pre-IHCA. This resulted in a few of them having to make life decisions that they may not have been thinking about prior to their IHCA. For example, one participant stated that he had to stop working while another stated he was considering retirement because of the physical exhaustion he was experiencing.

We also found that, for six Veterans, their physical challenges often impacted their ability to participate in social activities. They could no longer engage in moderate physical activities which resulted in a decrease in their social interactions with friends and an increased reliance on family.

Well, it's changed, I've got to admit, I'm not doing a lot of things with the adults, I don't golf anymore. I tried to golf for a while but it got to where, there's an easy par 3 that's near my house and I would go like twice a week with one of my friends here at work and it got to where I couldn't get past the 7th hole without saying, "I've got to walk off the course, you're going to have to finish by yourself," and last year I didn't golf at all ...

(ID 2447)

However, others were able to reconceptualize what independence meant to them and made adaptations in order to maintain it in some aspects of their lives. Seven participants described not being able to fully participate in hobbies and activities but did state that they made adaptations so that they could continue to be active. Many of these adaptations were the result of being unable to regain their physical functioning. For example, one participant made furniture prior to his IHCA but was unable to lift heavy objects after, and therefore, had to modify his hobby.

I can't make furniture anymore like I used to as a hobby, but now I just make bird feeders.

(ID# 1246)

Staying socially active was important to ten participants, who often found ways to continue to be engaged. One participant stated that prior to his IHCA, he would hike with his friends. But, because he no longer had the physical strength to hike, he modified his participation in order to continue to be with his friends.

I drove two friends into [City], they went hiking up in Mount [Name] part way, and I sat and read a book. There's no way I was going up that mountain. They do hiking, I do driving and reading and we're all ex-Navy buddies and just hang together.

(ID# 2376)

Continuing to drive was essential for most participants and signified their need for independence. Nine stated that they were still driving, five were no longer driving and the remaining five did not discuss their ability to drive. Of the nine participants that were still driving, five stated that they had to negotiate, often with their informal caregivers, in order to continue driving. Some of the adaptations they made included always having someone

with them in case they could no longer drive, taking slower routes to avoid expressways and limiting the distance they drove.

I can still drive, although they [family] won't let me drive very far. I mean my daughter-in-law will take me to my appointments to the hospital. I can drive around the block to the store.

(ID# 3008)

For those who could no longer drive (N = 5), they had to rely on others for rides. If their caregiver was a family member such as a spouse, having a ride was easier to arrange. However, for participants whose caregiver was a non-family member, they often had to coordinate and negotiate for rides, which often took time and money. Some participants stated that public transportation was not always available in their area, especially in more rural areas, and if it was, it was difficult to navigate. For example, one participant stated that because he uses a cane, it was too hard for him to take the bus to the grocery store to buy food because he could not carry his bags and walk with his cane. Therefore, he had to arrange rides with friends or acquaintances, often having to pay them for their time. For two of the participants, the inability to pay for transportation meant that they were also limited in their ability to participate in social activities and for both, they often missed their medical appointments.

I live 64 miles round trip where I go to my doctor, it's 64 miles round trip and I have to ride that hot bus and I, like I say, I don't have the finances to do that.

(ID# 655)

Having to now pay for activities that participants once performed illustrates the "hidden costs" of chronic illness. Although the VHA covered the participants' medical care expenses and IHCA post-care, the extra costs of living presented, for some, a financial burden. For example, four participants talked about having to pay for services that they had previously done for themselves. This seemed to not only affect their financial situation but also their sense of self.

Yeah, it's kind of disheartening where you can't even mow the grass, I have [to pay to have] my grass cut now.

(ID# 1246)

3.3. New engagements

Although adaptations or strategies to continue established activities was the most common adjustment to life after IHCA, six participants did engage in new activities. They felt that these activities helped with their recovery and provided some type of therapy, either physical or emotional. Three participants were using acupuncture to help with their physical illnesses and one participant started aqua therapy in order to move more and lose weight. Another began gardening and felt that this helped him recover from his IHCA.

I'm active out here just about every day. I grow vegetables and it seems to be the thing that really pulled me through is, I guess, for some reason afterwards, I wanted to grow vegetables, so that's what I do now.

(ID# 3008)

Two participants began volunteering in their communities. One became a county historical commissioner while another participant took pride in being able to volunteer for different research studies at his VA. He even tells other Veterans that volunteering is a good way to be involved and help other Veterans. Volunteering seemed to provide him with a sense of purpose.

... that's another thing I tell the Veterans, I volunteer to be in that flu shot program. They give you a higher dose of the flu vaccine...so I participate in that. That was really nice, anything to help improve your physical stuff, but I tell the Veterans to volunteer for projects like that.

(ID# 1246)

Another participant stated that he and his wife purchased a recreational vehicle (RV) for travel and had it outfitted should he ever need to go on dialysis for his kidney disease.

We went out and bought an RV, we bought one large enough that if I have to go on dialysis, it'll be peritoneal and there's room in the RV for the and it's all set up if I ever have to go on it. So we'll continue to travel, even on dialysis.

(ID 536)

4. Discussion

The impact IHCA had on participants' lives varied, however, the majority felt it had significantly affected their lives. Most participants in this study stated that their memory was affected by their IHCA and, although several years had passed, they continued to struggle. Memory issues have been extensively noted in the literature (Green et al., 2015; Košir et al., 2021; Moulaert et al., 2009, 2017; Steinbusch et al., 2017; Sulzgruber et al., 2015; Wagner et al., 2021) and throughout the interviews, participants talked about how it affected different aspects of their lives. Due to the lack of interventions or resources to help aid participants with their memory loss, many engaged in self-identified activities, such as reading and doing puzzles, that they could do solitarily that they felt would improve or at least, help maintain their memory (Hauschildt et al., 2021). Solitary activities may also reflect their hesitancy to participate in social activities outside their home that require physical ability which many could no longer participate in.

Difficulty with memory affected participants' ability to retain information. Similar to Cartledge et al. (2018) finding that patients experience a lack of information while in the hospital, the participants in this study also stated that they either did not receive information, could not remember what they were told, or the information did not match their expectations. This left them often having to seek out information for themselves or go without. Information both during hospitalization and after discharge may be crucial given that information has a, "direct influence on the level of control [patients feel]," and has the potential to decrease negative emotions (Cartledge et al., 2018, p. 1163). Additionally, as Klint et al. (2019) found, information needs to be given in stages and repeated throughout the course of recovery including after discharge. Although several years

had passed, participants still expressed a need for information confirming that repeated and ongoing education is important in the recovery process. However, participants wanted this information to be based on realistic expectations for recovery. This sentiment reflects Turnbull et al. (2020) assertion that, “we should try talking to survivors about what their lives are likely to be like after discharge,” (p. 409).

As noted by Moskowitz et al. (2018), IHCA survivors may have more medical comorbidities potentially complicating their recovery. Participants in this study were experiencing multiple comorbidities therefore, disentangling the effects of IHCA from their other illnesses and conditions was difficult. Several were dealing with other illnesses/diseases (e.g., diabetes, kidney disease) and had to figure out how to manage their comorbidities, often on their own. Interventions targeting IHCA survival should include an understanding of the multiple illnesses’ patients may be trying to manage in order to coordinate care and treatment plans.

Maintaining independence and the ability to engage in activities was important for participants. This required some of them to reconceptualize what independence meant to them and to adapt their activities to remain active. The ability to participate in activities may be especially important for recovery given that studies have found that involvement may provide a sense of meaning or purpose. For example, Wachelder et al. (2016) found that, “a higher level of social and leisure activities, a lower level of fatigue and a higher level of a sense of meaning and peace,” (p. 83) was associated with a higher level of life satisfaction. Although participants could not fully engage in their pre-IHCA activities, they were able to find ways to adapt their activities to make them conducive to their current abilities. This is similar to Moulaert et al. (2017) finding that although patient-reported functional level may be low, this does not prevent them from participating in activities.

In a study by Smith et al. (2015) they found that, “most patients retain their independence after their cardiac arrest,” (p. 179). Their assessment was based on patients being discharged home and being able to care for themselves. We found that although participants may have considered themselves “independent”, they still had to modify how they engaged in their activities to maintain their independence. Remaining active was important and again, by making small changes to their participation they were able to do so. However, the need to have someone always present for fear of another CA could discourage survivors from participating in activities where immediate help is not available.

Participants in this study preferred to drive, demonstrating their independence, but, at the same time, recognized that their physical and cognitive challenges did not always make it feasible. Instead, they modified their behavior by, for example, having someone with them or driving short distances, so they could continue to drive in what they determined to be a safe manner. Like Uren and Galdas (2015) found, not being able to drive challenges survivors’ sense of independence, and for those who could no longer drive, it presented an additional burden, especially financially, if they had to pay for rides.

Although less common, a few of the participants were able to engage in new activities that they thought helped their recovery. Acupuncture and aqua therapy were being used to help with their physical functioning and gardening provided one participant both physical and

mental benefits. Volunteering was also valued as a way of being engaged and being able to give back and feel useful.

Our findings suggest that IHCA survivors are having to, for the most part, develop their own strategies for adaptation in order to continue participation in their lives. As IHCA survivors continue to recover and re-engage in their activities, new challenges may arise requiring additional resources not identified early in the recovery process. Therefore, as other studies have suggested, intervention programs and follow-up care should continuously ask survivors what is important for them to be able to do and then identify resources that will support their goals (Dainty et al., 2021; Ketilsdottir et al., 2014). Additionally, offering opportunities for survivors to share their experiences with one another may provide the social support that many participants lack after their IHCA (Košir et al., 2021; Wagner et al., 2021).

In 2020, the American Heart Association (AHA) published a statement highlighting the lack of “existing protocols for systematically assessing [CA] survivor rehabilitation needs,” (Sawyer et al. p. e656). This statement presents a comprehensive summary of the potential impact CA has on survivors’ physical, cognitive, psychological, emotional and social abilities and the recovery paths and need for resources they may experience long after the actual event. Additionally, it recognizes the role and need for support that caregivers and families have in recovery. It calls for a standardization of assessment to help guide and coordinate multidisciplinary care, including community and outpatient care, needed for optimal recovery. However, standardization should be equated with individualization and recovery interventions should be developed with flexibility in mind so they can be tailored to individual needs.

Although the AHA statement presents a one-year roadmap to help guide multidisciplinary providers in supporting CA survivors, our findings indicate that the lasting effects of CA may extend far beyond this timeframe. Additionally, barriers to resources, such as inability to access transportation or financial constraints, may hinder survivors’ ability to participate. Providing online patient and family resources, often a strategy to reduce barriers, may only reach a small percentage of survivors. Also, because many survivors are coping with the cognitive and physical effects of CA arrest, it may be difficult for them comprehend the online information provided. Therefore, just making sure the information is available may not be enough. All of the multidisciplinary providers involved in a CA arrest survivor’s care should be aware of the resources available and educated on how to identify which resources are most accessible and likely to provide the most benefits to individual survivors. Thus, recovery is not static but a process with evolving needs that should include patient-centered information focused on what their goals for recovery are and how to identify resources and strategies that will help them obtain those goals.

4.1. Limitations

This study has limitations. First, several years had passed since their IHCA and participants ability to recall specific events may have been affected especially since they indicated issues with memory. But our goal was to examine long-term effects and whether their challenges were specifically related to their IHCA may be of less importance considering that they felt their lives were significantly altered and required adaptations. Second, most participants

were dealing with comorbidities and therefore, illnesses may have been conflated. However, since many older adults are coping with multiple illnesses, it is important to understand how they prioritize their health goals regardless of diagnosis. And finally, Veterans' experiences may not be generalizable to the larger population of IHCA survivors. Although most participants stated that they had in-home health care support after discharge, non-Veteran patients may not have access to such care. However, even with this support, Veteran participants still reported on-going challenges and the need for adaptations to continue engagement in their day-to-day activities.

5. Conclusion

Survivors of IHCA experience challenges several years after their IHCA. They are aware of their limitations and have created adaptations that help them maintain some of their independence and engage in activities that are important to them. However, far too many have to give up activities because of lack of support and/or resources. Intervention programs and follow-up care should provide long-term support so that as survivors attempt to reengage in their activities, resources are available. But, perhaps more importantly, an emphasis on systems of care that focus on coordinating care and communication across multidisciplinary providers involved in recovery is needed. CA survivors have stated that long-term interventions are needed and it is now time for healthcare systems to identify and provide those resources.

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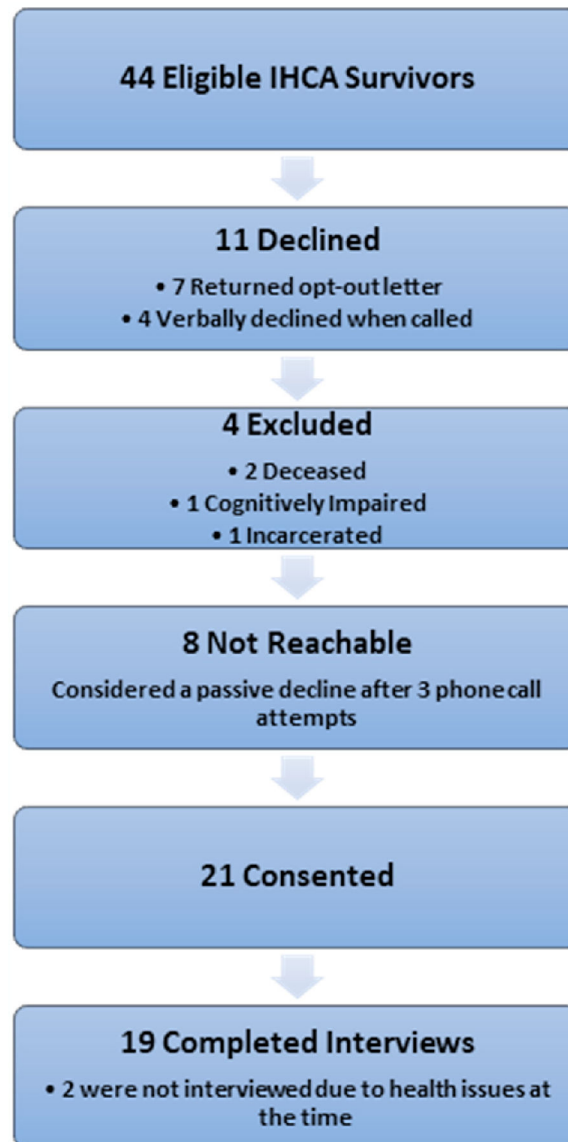


Fig. 1.
Sampling process and eligible participants.

Table 1

Patient demographics.

Participant Identification Number	Admitting Diagnosis	Age at Cardiac arrest	Year of Cardiac Arrest	Geographic Region in U.S.	Placement after discharge
2193	Abdominal Aneurysm	65	2015	Northeast	Home
2909	Unspecified Septicemia	71	2015	Northeast	Home
2719	No HIPPA signed	60	2015	South	Home
1075	Acute Myocardial Infarction	67	2015	South	Home
1246	Ventricular Fibrillation	57	2015	South	Home
4018	Other Chronic Osteomyelitis	45	2015	Midwest	Rehabilitation Center
2376	Cerebral Artery Occlusion	67	2015	West	Home
1072	Atherosclerosis	64	2015	South	Home
536	Unspecified Septicemia	66	2014	West	Home
3583	Chronic Parametritis	61	2015	West	Home
2267	Post-Operative Shock	64	2015	West	Home
3955	Dilated Cardiomyopathy	52	2015	West	Home
3558	Quadriplegia	62	2015	South	Home
3585	Acute on chronic diastolic (congestive) heart failure	60	2015	Midwest	Home
112	No HIPPA signed	66	2014	South	Home
3008	Osteoarthritis	64	2015	South	Home
2447	Acute Myocardial Infarction	62	2015	West	Home
665	Atrial Fibrillation	66	2014	South	VHA Nursing Facility
2402	Coronary Atherosclerosis	68	2015	South	Home

Table 2

Summary of themes.

Theme/Sub-theme	Definition	Example Quote
Current Challenges		
Not the Same as Before	Participant expresses sentiment that they are not the same as before their IHCA. Includes physical, cognitive, social, emotional, etc. changes they have experienced.	Yeah, emotionally I couldn't allow myself to get into a relationship with women, you know I couldn't do that, because that'd be kind of hard to explain to them you know why I get up in the middle of the night and have to take nitroglycerin, you know it's hard to form relationships with people ... because I didn't want to be a burden to anybody. (ID# 1246)
Memory Loss	Any statements about memory loss, difficulty thinking and/or remembering.	You know they fixed my body, but I'm still wondering about my mind. (ID# 2447)
Lack of Information	While in the hospital, did not receive or could not remember receiving information regarding recovery. Includes not being told or remembering being told they had IHCA.	I don't know that I had one (IHCA) myself. They said I did. I was in the hospital when it happened [I: Yeah] and I mean after it happened, I don't know anything about it. (ID# 112)
Current Illness/Co-morbidities	Co-morbidities mentioned that made recovery difficult.	Yeah, I do a hand, I do a hand therapy ... for a stroke that I had since I had the um, still since I had that heart attack. (ID# 2402)
Caregiver Support	Formal or informal support given after IHCA (at home or in a recovery facility).	Well, great help, my wife and my daughter-in-law ... they helped me put a shirt on or you know I didn't, tie my shoes, but just they were there, they were just as good as the, my intensive care nurse, you know, so no, I didn't need care management. (ID# 3008)
Strategies	Strategies or resources used to overcome current challenges to recovery (includes caregiving).	Just talked to my pastor, talked to my uh, did some self-talk basically to myself, realized it's not, you know that I could go to sleep and again it's God that would make the decision, not me, not anybody else. (ID# 536)
Reconceptualizing Independence		
Staying Socially Active (Or Not)	(In)ability to participate in social activities and/or maintain social relationships.	Geez, I don't think I really have much of a social life. I don't go out very much. Everybody works, so you know, I'm here at the house mostly by myself some of the time, unless a couple of friends drop in and no, I really don't go out much anymore. (ID# 3008)
Modifying Activities/Strategies to Maintain Independence	Reengaging in pre-IHCA activities but with modifications.	Well you know I don't do as much shoveling snow or mowing grass ... I got a riding snowblower and riding lawnmower ... all that good stuff you know, riding tractor. So I cut grass with that you know what I'm saying? (ID# 2193)
Driving	Ability to continue to drive or not. Includes having made modifications to continue driving.	I may not go far [driving] but I do go down to the newsstand and buy my lottery tickets. (ID# 2909)

Theme/Sub-theme	Definition	Example Quote
Pay for Services	Having to pay for services participants once did for themselves. Includes having to pay for transportation.	Like he [doctor] recommended I get you know more therapy and stuff like that but like I say, I don't have no way to get there, I live 64 miles round trip where I go to my doctor, it's 64 miles round trip and I have to ride that hot bus and I, like I say, I don't have the finances to do that. (ID# 665)
Caregiver Support	Role caregiver had in helping participant maintain their independence.	I can drive. I just, I just don't, my wife does most of the driving. My wife is the primary driver in the house. (ID# 112)
New Engagements		
New activities	Any new activities participant has engaged in since IHCA	I'm now actually a county historical commissioner for [city], so I do a lot of, how do you call it, brain work, traveling around in the county dealing with things like that. In fact, tomorrow I have to go sit in a local historical society meeting and act like a docent for a couple of hours. (ID# 2376)