

# Surviving Sudden Cardiac Arrest: A Pilot Qualitative Survey Study of Survivors

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Research describing survivors of sudden cardiac arrest (SCA) has centered on quantifying functional ability, perceived quality of life, and neurocognitive assessment. Many gaps remain, however, regarding survivors' psychosocial perceptions of life in the aftermath of cardiac arrest. An important influence upon those perceptions is the presence of support and its role in a survivor's life. An Internet-based pilot survey study was conducted to gather data from SCA survivors and friends and/or family members (FFMs) representing their support system. The survey was distributed to members of the Sudden Cardiac Arrest Foundation (SCAF) via the Internet by SCAF leadership. Questions included both discrete multiple-choice and open-ended formats. Inductive thematic analyses were completed by three independent researchers trained in qualitative research methodology to identify primary themes consistent among study participants until thematic saturation was achieved. No statistical inferences were made. A total of 205 surveys were returned over the 5-month study period (July to November 2013); nine were received blank, leaving 196 surveys available for review. Major themes identified for survivors ( $N = 157$ ) include the significance of and desire to share experiences with others; subculture identification (unique experience from those suffering a heart attack); and the need to seek a new normal, both personally and inter-personally. Major themes identified for FFMs ( $N = 39$ ) include recognition of loved one's memory loss; a lack of information at discharge, including expectations after discharge; and concern for the patient experiencing another cardiac arrest. This pilot, qualitative survey study suggests several common themes important to survivors, and FFMs, of cardiac arrest. These themes may serve as a basis for future patient-centered focus groups and the development of patient-centered guidelines for patients and support persons of those surviving cardiac arrest.

## Introduction

**S**URVIVING SUDDEN CARDIAC ARREST (SCA) is a variable phenomenon and often depends on the geographical or temporal circumstances surrounding the event (Nichol *et al.*, 2008). Efforts to improve survival after cardiac arrest have motivated significant research efforts focused on optimizing links in the Chain of Survival (Cummins *et al.*, 1991), including early recognition of cardiac arrest; reducing barriers to bystander chest compressions; increasing access to automated external defibrillators (Berg *et al.*, 2010); and comprehensive postarrest critical care, including targeted temperature management (Peberdy *et al.*, 2010). There are, however, relatively few guidelines available to assist the healthcare system to provide these survivors of cardiac arrest and their support system, namely friends and/or family members (FFMs), thorough

discharge-planning, rehabilitation services, and resources for adjusting to life following the index event.

Contemporary research describing survivors of cardiac arrest concentrates on quantifying functional ability and perceived quality of life. More recently, outcome studies have focused on complex cognitive or neuropsychiatric measures beyond discharge (Raina *et al.*, 2008; Beesems *et al.*, 2014; Balouris *et al.*, 2015). These studies have utilized varying questionnaires or tests to report often conflicting results, although all suffer from relatively small samples and dissimilar methodologies (Rittenberger *et al.*, 2011; Nichol *et al.*, 2015; Smith *et al.*, 2015).

Frequently following cardiac arrest, a procedure to place an implantable cardioverter defibrillator (ICD) is indicated. A significant body of literature describing the emotional and psychological challenges for patients with ICDs exists. Patients

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with ICDs commonly report anxiety and risk for maladjustment, necessitating multidisciplinary attention to psychosocial needs and proactive referrals to support groups (Sears *et al.*, 2011; Dunbar *et al.*, 2012; Hazelton *et al.*, 2013; Rosman *et al.*, 2015).

A recent systematic review identified high occurrence of reported psychological distress in patients surviving cardiac arrest (Wilder Schaaf *et al.*, 2013). However, little attention has been directed to addressing the gaps in knowledge of *how* survivors experience life after cardiac arrest. An experiential understanding of this phenomenon is the first step to organizing recommendations to meet the needs of survivors, their caregivers (Brown, 2008), and the larger support system. We therefore conducted a pilot, Internet-based needs assessment survey study to identify themes unique and important to cardiac arrest survivors and their FFMs.

## Materials and Methods

An Internet-based survey was sent via email to registered members of the Sudden Cardiac Arrest Foundation (SCAF) by SCAF membership coordinators. Membership to the organization is voluntary, free, and open to anyone, regardless of country of residence. Rarely, survey participation was extended to others, by direct inquiry only. Internet access was required for participation or any communication regarding the study.

Surveys were administered using an Internet-based survey tool (SurveyMonkey, Inc., Palo Alto, CA). Survey questions were developed by study authors using both discrete multiple-choice and open-ended formats. The investigators agreed on face validity by consensus and limited pilot testing on professional colleagues. Questions were organized into two sections, intended for either (1) SCA survivors or (2) FFMs of survivors. Study participation consent was assumed by voluntary participation and survey completion. This study was approved by the Institutional Review Board under expedited review.

To increase the likelihood of participation, no identifying information was collected; therefore, missing or incomplete information could not be obtained after the survey was submitted. Data were downloaded from the Internet survey instrument into an Excel (Microsoft 2010) format. The

software JMP 12.1.0 (SAS, Cary, NC) was used to calculate descriptive statistics; no statistical inferences were made.

Inductive thematic analyses were completed according to accepted qualitative research methods discussed by Reissman (2008) and Burnard *et al.* (2008). Three independent researchers trained in qualitative research methodology conducted the thematic analyses to understand the lived experience of study participants. One researcher analyzed the open-ended responses provided by 39 FFMs, utilizing a process of constant comparison to identify patterns. These patterns were initially isolated, categorized, and condensed into themes. The lead researcher (F.B.) reviewed the major themes to ensure accurate representation of the data.

A similar process was followed by two additional researchers (R.C., C.D.), who reviewed the responses provided by SCAF survivors. This data set was split into two equal halves to promote inter-rater reliability. Each SCAF survivor's response was read through as a whole; major phrases or pivotal details were noted, including frequently occurring words, phrases, and experiences. Each researcher organized these notations and key story elements from the respective split sets into themes; quotes that supported thematic relevance were noted.

Finally, the researchers came together to compare the themes each identified among SCAF survivors. Results that were not common among both data sets were set aside and revisited to determine whether they should be discarded or collapsed into more encompassing themes. Themes that occurred in both data sets over multiple instances were organized as global themes; discarded themes generated discussion for future research. Given the study design, participants were not asked to provide feedback on the validity of the themes identified or the interpretation of their responses. Table 1 presents the open-ended questions given in the survey. The complete survey can be found in the Appendix.

## Results

SCAF membership at the time of this study included 1060 people. Three email invitations were sent over the study

TABLE 1. OPEN-ENDED SURVEY QUESTIONS

### Survivor questions

1. Describe your memories around the time of your cardiac arrest; at discharge and/or since discharge
2. Describe what you were told at discharge regarding your diagnosis; who communicated this to you?
3. Describe what you were told regarding what to expect after discharge; who communicated this to you?
4. After discharge, which appointments were scheduled or recommended for you?
5. After discharge, what were your biggest challenges; what challenges remain now?
6. What do you wish you had been told before going home from the hospital?
7. What do you wish your friends/family better understood about your cardiac arrest?
8. Describe how your personal relationships may or may not have changed since your cardiac arrest.
9. Describe whether you are back to school/work and whether you have any limitations now.

### Friend/family member questions

1. Describe whether s/he experienced any trouble with memory around the time of cardiac arrest.
2. Describe what you were told regarding what to expect after discharge; who communicated this to you?
3. After discharge, which appointments were scheduled or recommended for him/her?
4. After discharge, what were his/her biggest challenges; which remain now?
5. Describe your biggest challenges after s/he suffered cardiac arrest.
6. Were you offered counseling after s/he suffered cardiac arrest; would it have been helpful?
7. Describe what you would have liked to have been told after the cardiac arrest.
8. Describe what you think others should better understand about cardiac arrest.
9. Describe how your personal relationship with her/him has or has not changed since the cardiac arrest.
10. Describe whether s/he is back to school/work and whether s/he has any limitations now.

period of July 2013 to November 2013, with roughly 30% of recipients opening the email and ~15% of recipients clicking on the survey link. A total of 205 study surveys were attempted but 9 were blank entries. Thus 196 surveys were available for review.

Of those who answered as an SCA survivor ( $n = 157$ ), 24 had suffered cardiac arrest within the last year and 40 had survived cardiac arrest for >5 years (range 5–33 years). Only two indicated they had assistance with survey completion, suggesting this study population is highly technologically functional. General characteristics of this group are presented

in Table 2. Of those who answered as an FFM ( $n = 39$ ), eight had FFMs who suffered a cardiac arrest within the last year and six had FFMs who survived cardiac arrest for >5 years (range 6–30 years).

Global and major themes identified from the data are listed in Table 3.

## Discussion

Our investigation identified a number of major themes for survivors and their support systems. Survivors often have an

TABLE 2. CHARACTERISTICS OF SURVIVORS

<i>Characteristic</i>	<i>Count (%)</i>
Age at the time of study	18–40 years old; 28 (18.1) 41–60 years old; 93 (60.0) 61–80 years old; 33 (21.3) 81+ years old; 1 (0.6)
Location of cardiac arrest	Home, 52 (33.5) Public place, 88 (56.8) In hospital, 16 (10.3)
Defibrillator implantation	Yes, 107 (68.6) No, 49 (31.4)
Therapeutic hypothermia treatment	Yes, 55 (35.5) No, 82 (52.9) I don't know, 18 (11.6)
Discharge location	Home, 135 (95.1) Rehabilitation, 8 (5.6)
Memory loss near time of arrest	Yes; 118 (75.2) No; 33 (21.0)
Memory of being in hospital	Yes; 91 (58.0) Vaguely, A little, Some; 46 (29.3) No; 7 (4.5)
Memory of discharge from hospital	Yes; 124 (79) Vaguely, Part of it, Barely; 12 (7.6) No; 8 (5.1)
Daily problems with memory after discharge	Yes; 35 (22.3) Some; 36 (22.9) No; 72 (45.9)
Discharge diagnosis counseling	Provided by nurse; 37 (23.6) Provided by doctor; 102 (65.0) Provided by other/unknown; 22 (14.0)
Counseling on expectations after discharge	I was told "nothing"; 29 (18.5) I "don't remember" or "don't know"; 19 (12.1) Cardiac/postprocedural/rehab or "take it easy" instructions only; 85 (54.1) Possible "emotions" or psychological/memory "difficulties" at home; 7 (4.5)
Biggest challenges postdischarge	Memory; 64 (40.8) Driving; 51 (32.5) Depression; 57 (36.3), anxiety; 86 (54.8) Re-establishing routine; 61 (38.9) Balance; 22 (14.0%), ambulation; 11 (7.0) Vision; 9 (5.7) Work/school; 46 (29.3) Financial concerns; 43 (27.4) Safety; 19 (12.1) None; 17 (10.8)
Back to work/school	Yes, no limitations; 92 (68.7) Yes, with limitations; 34 (25.4) No, not able to go back; 19 (14.2)

TABLE 3. GLOBAL AND MAJOR THEMES

SCA survivor global themes	Major themes and quotes
Significance of others	Desire to share experience, "...I want to talk about it but no one wants to or understands why"; reflections on first responders; benevolent character assumptions
"We are in this together"	Subculture identification, different from those who have had a heart attack; unique experience creates separation for some, "...that anxiety just doesn't go away, that depression doesn't go away just because you're happy you survived"
Too many feelings	Mental health issues most present, least addressed; anxiety/helplessness; depression/loss of identity; existential concerns
Seeking a <i>New Normal</i>	Financial concerns; lack of preparation for emotional/cognitive changes; changed relationships, "People treat[ing] me as if I would die at any moment...act[ing] as if they knew what was best for me"
Family member/friend (FFM) global themes	Major themes and quotes
"My FFM did/is still experiencing memory loss"	Memory loss around and after event; some on a daily basis
There was a lack of information at discharge	Majority reported no information on what to expect after discharge; follow-up appointments centered on cardiology
"I received no mental health resources"	Majority agreed it would have been helpful, "...especially from someone who has gone through it, not just doctor, nurse, or social worker..."
What if it happens again?	"[I have to] make sure it doesn't happen again..." "[I am afraid of] leaving him alone."
"I wish I had known..."	"What to expect..." "How common it is..." "It's not the same as a heart attack..."

SCA, sudden cardiac arrest.

innate need to share feelings with others and talk about his/her "event." Many articulated a desire to locate and share with others who may have had a similar experience—identifying themselves as part of a subculture that had experienced something unique. Given the low survival rate in any one city, it appears this need may be best met by referral to support organizations specific to cardiac arrest. However, it is important to note that in the absence of such referrals, an organic evolution of social media groups, crossing demographics and time zones, has occurred to fill the same supportive void.

In contrast, another major theme emphasized the desire for others to understand the difference between a cardiac arrest and heart attack. This is an important distinction that the Institute of Medicine (IOM) emphasized in its recent report on cardiac arrest (IOM, 2015). Not all patients who suffer cardiac arrest have a coronary artery occlusion or require an ICD; some have a congenital anomaly or a heritable cardiac arrhythmia. Thus, each of these subsets may, in turn, have unique emotional concerns for themselves or their families and have difficulty identifying with each other.

The presence of mental health concerns, including anxiety and depression, was a major theme for survivors and has been previously described (Wilder Schaaf *et al.*, 2013; Rosman *et al.*, 2015). Respondents stated that these issues were typically not well addressed by medical providers, "...that anxiety just doesn't go away, that depression doesn't go away just because you're happy you survived." Finally, the need to seek a *new normal* was evident from survivors. While many did return to work or school in some capacity, they felt ill-prepared for emotional changes and relationship strains. Perhaps never being sick before, respondents admitted to stress over, "People treat[ing] me as if I would die at any

moment...act[ing] as if they knew what was best for me." Summary characteristics in Table 2 highlight that even though 95.1% of survivors were discharged directly to home, many of them do not remember the hospital stay or discharge process and many admit to trouble with short-term memory on a daily basis. Thus, developing a system for discharge counseling that includes close follow-up and expert re-evaluation may be necessary to reiterate instructions, expectations, and resources for survivorship.

Our qualitative survey study takes a necessary next step in assessing how patients experience life after survival of cardiac arrest. To a smaller degree, our study also provides insight into how FFMs of survivors experience living through such an event. Several recent quantitative studies suggest more patients are surviving cardiac arrest and the majority do so with "good" outcomes.<sup>8</sup> Unlike other disease processes, however, such as cancer, stroke, and diabetes, there are few patient-level data available for what resources cardiac arrest survivors and their FFMs need to improve and be successful with survival after discharge from the hospital. The development of support networks and social media groups for those touched by cardiac arrest has been slow and primarily spearheaded by survivors themselves, who are experts in the experience of the event but not necessarily trained in the supportive care of others.

For FFMs, some of whom were at bedside during recovery or even first to respond to their loved one, emotional and psychological themes surfaced. Respondents emphasized a worry over whether "it," referring to the cardiac arrest, would happen again. They agreed that there was a lack of information about what to expect after discharge. Many stated mental health resources would have been helpful for

them, "...especially from someone who has gone through it, not just doctor, nurse, or social worker..." Although grief counseling is often routinely offered for FFMs of someone who does not survive cardiac arrest, these results resound the need for caregiver support, even when their loved one is able to return to work or school like "normal."

### Limitations

Our study design inherently limits the subject population to a subset of survivors with the means to have Internet access and the functional capacity to complete the survey, even with assistance. While this limited subset may not be representative of the population at large, this cohort is of significant interest. Those deemed highly functioning after cardiac arrest are more likely to deceive providers and acquaintances because they "look and act" neurologically intact before discharge from the hospital. This subset may be most neglected with regard to resources provided at discharge.

This study was meant to identify themes for further qualitative study and thus no statistical inferences can be made from the results. Survey response was relatively low (18.5%) despite attempts to encourage participation by collecting nonidentifiable data and sending the survey out multiple times. We expected a higher response rate due to the nature of the questions and the population targeted; however, the lack of nonresponder information prevents further insight. The delivery method may have contributed to this low rate since email is impersonal and easy to delete in bulk.

Larger studies with multiple survey methods (focus groups, long form interview, traditional mail, etc.) are needed to assess generalizability of these results to other survivors of cardiac arrest, including less-functional survivors. Furthermore, thematic analysis is inherently limited by the assumption that "...everyone in a thematic cluster means the same thing by what they say (or write), obscuring particularities of meaning-in-context" (Reissman, 2008). In this study this limitation was mitigated by the researchers' purposeful *noninterpretation* of the data provided by the participants, instead focusing exclusively on *what* the participants wrote in their open-ended responses as the basis of identified themes.

### Conclusion

The results of our pilot study serve to inform clinicians and researchers on the complexity of cardiac arrest survival, and the themes important to both survivors of cardiac arrest and FFMs of survivors. Unlike recent studies, aimed at quantifying neurologic outcome or quality of life based on scales, the use of open-ended questions and thematic analysis provide room for honesty to describe the breadth and depth of important thoughts and feelings of having survived a cardiac arrest. The themes identified in this study should be used to explore survivors' perceptions and needs following the index cardiac arrest event and spur development of resources for survivors and FFMs.

### Author Disclosure Statement

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## Appendix

### Survivor Variation Survey

1. Are you a survivor of a cardiac arrest or a family/friend of a patient who suffered cardiac arrest?
  - a. Survivor (go to SECTION A)
  - b. Family member / Friend of a cardiac arrest survivor (go to SECTION B)

## SECTION A

2. How long ago was your cardiac arrest?
  - a. <6 mo ago
  - b. 6 mo–1 year ago
  - c. 1–2 years ago
  - d. 2–4 years ago
  - e. 4–5 years ago
  - f. Other \_\_\_\_\_
3. Are you completing this survey on your own or is someone helping you?
  - a. Self
  - b. Other, what is your relationship? \_\_\_\_\_
4. How old are you now?
  - a. <18 years old
  - b. 18–30 years old
  - c. 31–40 years old
  - d. 41–50 years old
  - e. 51–60 years old
  - f. 61–70 years old
  - g. 71–80 years old
  - h. >80 years old
5. Where did your cardiac arrest occur?
  - a. Home
  - b. Public place
  - c. In the hospital
6. Did you have an internal defibrillator (ICD or AICD) placed after your cardiac arrest?
  - a. Yes
  - b. No
  - c. I don't know
7. Did you receive therapeutic hypothermia or “cooling” therapy while in the hospital?
  - a. Yes
  - b. No
  - c. I don't know
8. Did you experience memory loss around the time of your cardiac arrest?
  - a. Yes.
  - b. No.
9. When were your last memories before the event?
  - a. Are your last memories minutes prior?
  - b. Are your last memories hours prior?
  - c. Are your last memories days prior?

10. What are your memories about the event?
11. Your memories since the event:
  - a. Do you remember being in the hospital?
  - b. Do you remember when you were discharged?
  - c. When did you start having consistent memory?
  - d. Do you have trouble with memory on a daily basis now?
12. Your memories:
  - a. Describe your memories immediately before your cardiac arrest.
  - b. Describe your initial memories after your cardiac arrest.
13. When you were discharged from the hospital, where did you go?
  - a. Home
  - b. Rehabilitation
  - c. Skilled Nursing Facility
  - d. I don't know
14. When you were discharged from the hospital, what were you told regarding your diagnosis and reasons why you were in the hospital?
  - a. Who communicated this information to you?
    - i. Nurse
    - ii. Physician
    - iii. Therapist
    - iv. I don't know
    - v. Other
15. When you were discharged, what were you told regarding what to expect after getting home?
  - a. Who communicated this information to you?
    - i. Nurse
    - ii. Physician
    - iii. Therapist
    - iv. I don't know
    - v. Other
16. After discharge from the hospital, what appointments were scheduled for you? or who were you told to follow-up with after discharge (Check all that apply: family physician, cardiologist, electrophysiologist (EP), neurologist, speech therapy, psychologist, brain injury specialist, other-please specify)?
17. What were your biggest challenges after going home from the hospital? (check all that apply)
  - a. Memory
  - b. Driving
  - c. Depression
  - d. Reestablishing a routine
  - e. Balance
  - f. Vision
  - g. Ability to ambulate
  - h. Working or school
  - i. Anxiety
  - j. Financial concerns
  - k. Safety
  - l. None
  - m. Other
18. What challenges, if any, remain now?
19. What do you wish you had been told before going home?
20. What do you wish your friends / family better understood about your cardiac arrest?
21. Do you have new challenges with your friends, family, or other inter-personal relationships since your cardiac arrest?
  - a. Yes. How so?
  - b. No but they treat me differently now.
  - c. No. Back to normal.
  - d. No. Better relationships now.
  - e. other
22. Are you back to work/school as usual?
  - a. Yes, no limitations
  - b. Yes, with limitations. What limitations?
  - c. No, not able to work/go to school. What limitations?
23. How did you find out about the Sudden Cardiac Arrest Foundation?
24. What kinds of information and/or support would you like to see the Foundation provide?
25. What could the medical community do better for patients/family/friends after cardiac arrest?

## SECTION B

26. How are you related to the patient?
  - a. I am the patient's spouse
  - b. I am the patient's parent
  - c. I am the patient's child
  - d. I am the patient's sibling
  - e. I am a friend of the patient
  - f. Other
27. How old are you?
  - a. <18 years old
  - b. 18–30 years old
  - c. 31–40 years old
  - d. 41–50 years old
  - e. 51–60 years old
  - f. 61–70 years old
  - g. 71–80 years old
  - h. >80 years old
28. How long ago was your family member/friend's cardiac arrest?
  - a. <6 mo ago
  - b. 6 mo – 1 year ago
  - c. 1–2 years ago
  - d. 2–4 years ago
  - e. 4–5 years ago
  - f. other
29. To the best of your knowledge, did your friend/family member experience memory loss around the time of the cardiac arrest?
  - a. Yes
  - b. No
  - c. I don't know
30. During what time period? Check all that apply.
  - a. Trouble with memories before cardiac arrest
  - b. Trouble with memories about how/where/when the arrest happened
  - c. Trouble with memories after cardiac arrest
31. Trouble with memory since the event
  - a. Did s/he remember being in the hospital?
  - b. Did s/he remember being discharged?
  - c. Does s/he have trouble with memory on a daily basis now?
32. **What information** were you given regarding what to expect after your family member/friend went home?
33. Who communicated this information to you?
  - a. Nurse
  - b. Physician
  - c. Therapist
  - d. I don't know
  - e. Other
34. After discharge from the hospital, what appointments were scheduled for your family member/friend? or who were you told to follow up with after discharge (Check all that apply: family physician, cardiologist, electrophysiologist (EP), neurologist, speech therapy, psychologist, brain injury specialist, other-please specify)?
35. What do you think were the biggest challenges for your family member/friend after he/she went home from the hospital? (check all that apply)
  - a. Memory
  - b. Driving
  - c. Depression
  - d. Reestablishing a routine
  - e. Vision
  - f. Balance
  - g. Ability to ambulate
  - h. Working or school
  - i. Anxiety
  - j. Financial concerns
  - k. Safety
  - l. None
  - m. Other



36. What challenges remain for him or her now, if any?
37. What were your biggest challenges as the friend/family member after the cardiac arrest?
  - a. Depression
  - b. Reestablishing a routine
  - c. Working or school
  - d. Anxiety
  - e. Financial concerns
  - f. Safety
  - g. None
  - h. Other
38. What challenges remain now, for you?
39. **Were you** (as the caregiver or friend) offered information or counseling after your friend/family member's cardiac arrest? Yes or no
  - a. If yes: Was this helpful? Why or why not?
  - b. If not, do you think that would have been helpful?
40. What **would you have like to have been told** after the cardiac arrest?
41. What do **you think** your friends/family should better understand about cardiac arrest?
42. Do you have new challenges with the relationship with your friend/family member since the cardiac arrest?
  - a. Yes. How so?
  - b. No but I am afraid it could happen again.
  - c. No. Back to normal.
  - d. No. Better relationships now.
  - e. Other
43. Is your friend/family member back to work/school as usual?
  - a. Yes, no limitations
  - b. Yes, with limitations. What limitations?
  - c. No, not able to work/go to school. What limitations?
44. How did you find out about the Sudden Cardiac Arrest Foundation?
45. What kinds of information and/or support would you like to see the Foundation provide?
46. What could the medical community do better for patients/family/friends after cardiac arrest?