Surviving Sudden Cardiac Arrest: A Pilot Survey

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“We were saved by CPR, an AED and someone like you!”
Surviving Sudden Cardiac Arrest: A Pilot Qualitative Survey Study of Survivors

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Introduction

• Rates of survival from out-of-hospital cardiac arrest vary and depend on:
  – Strength of links in Chain of Survival, including CPR and defibrillation
  – Geographical/ temporal circumstances
  – Comprehensive post-arrest critical care, including therapeutic hypothermia

• Few guidelines and resources to help survivors and friends and family members (FFMs) post-resuscitation
Contemporary Research

• Focus
  – Functional ability
  – Perceived quality of life
  – Cognitive or neuropsychiatric measures

• Study limitations
  – Small sample sizes
  – Different methodologies
  – Conflicting results

• Related literature explores emotional and psychological issues among patients with ICDs
Contemporary Research

• Literature review found high incidence of psychological distress in cardiac arrest survivors
  – Anxiety 13-61%
  – Depression 14-45%
  – PTSD 19-27%

• Recommendation
  – Psychological screening
  – Early intervention
  – Further research
Research Gaps

Understanding survivors’ psychosocial perceptions of life in the aftermath of cardiac arrest is the first step to development of interventions and resources that meet the needs of survivors... their loved ones... and the larger support system.
Objective of Our Study

- Identify themes unique and important to cardiac arrest survivors, family members and friends
- Results may serve as basis for future patient-centered focus groups and development of patient-centered interventions and resources
Methodology

• Internet-based survey of SCA FDN members conducted among survivors and friends/family members (FFM), July-November 2013
• Use of discrete multiple choice questions and open-ended questions
• Independent researchers conducted inductive thematic analyses using accepted qualitative research methods
• Data divided and reviewed independently to ensure inter-rater reliability
• Key story elements organized into global and major themes
• No statistical inferences made
Results

• 1,060 members contacted
• 30% opened e-mail; 15% clicked survey link
• 196 members (157 survivors and 39 FFMs) completed surveys (18.5% response rate)
Characteristics of Survivors
Age at Time of Study

- 81+ (1%)
- 61-80 (21%)
- 18-40 (18%)
- 41-60 (60%)
Characteristics of Survivors
Location of Arrest

- Public place: 57%
- Home: 33%
- Hospital: 10%
Characteristics of Survivors

Therapeutic Hypothermia Provided

- Yes: 35%
- No: 53%
- Don't know: 12%
Characteristics of Survivors
Received an ICD

- Yes: 69%
- No: 31%
Characteristics of Survivors
Discharge Location

- **Home**: 95%
- **Rehab**: 5%
Characteristics of Survivors
Back to Work/ School

- Yes, no limitations: 69%
- Yes, with limitations: 25%
- No: 14%
Characteristics of Survivors

Memory Issues

• Memory loss near time of arrest: 75%
• Remembered being in hospital: 58%
• Remembered discharge from hospital: 79%
• Daily problems with memory after discharge: 22%
Characteristics of Survivors
Discharge counseling

• Who provided counseling?
  – Doctor (65%)
  – Nurse (24%)
  – Other/ unknown (14%)
Characteristics of Survivors

Discharge counseling

• Advice
  – Expect possible emotional, psychological and memory difficulties at home. (5%)
  – “I don’t remember/don’t know.” (12%)
  – “I was told nothing.” (19%)
  – “Take it easy.” (54%)
Characteristics of Survivors
Biggest Challenges (%)

- Anxiety: 55%
- Memory: 41%
- Depression: 39%
- Driving: 36%
- Work/school: 33%
- Financial concerns: 29%
- Balance: 27%
- Safety: 14%
- None: 12%
- Ambulation: 11%
- Vision: 7%
- Other: 6%
Survivor Themes

Global Themes

• Significance of others
• “We are in this together.”
• Too many feelings
• Seeking a new normal

Major Themes

• Desire to locate and share with others with similar experiences
• Subculture identification (different from heart attack)
• Mental health: anxiety, depression, helplessness, loss of identity, existential concerns
• Financial concerns
• Lack of preparation for emotional/cognitive changes
• Changed relationships
I want to talk about it but no one wants to or understands why.

People act as if they knew what was best for me

Anxiety and depression don’t just go away because you’re happy you survived.

People treat me as if I would die at any minute.
The Most Neglected Survivors?

• Those deemed highly functioning after cardiac arrest are more likely to deceive providers and acquaintances because they “look and act” neurologically intact before hospital discharge.
• This subset may be most neglected with regard to resources provided at discharge.
Friends/ Family Member Themes

Global Themes
- Lack of information at discharge
- Lack of mental health resources
- What if it happens again?

Major Themes
- Memory loss around and after event
- No information on what to expect after discharge; follow-up appointments centered on cardiology
- Peer support would be helpful
- What to expect going forward
Family Member/Friend Quotes

- He is still experiencing memory loss.
- There was a lack of information at discharge.
- What if it happens again?
- I’m afraid of leaving him alone.
- I have to make sure this doesn’t happen again.
- I received no mental health resources.

“I wish I had known...”

It’s not the same as a heart attack.

How common is this?

What if it happens again?
Family Member/ Friend Quotes

“It would have been helpful to connect with someone who has gone through it, not just a doctor, nurse or social worker.”
Limitations

• Self-selected sample of respondents with Internet access and functional ability to complete survey
• May not be representative of population at large
• Relatively low response rate (18.5%)
• No statistical inferences made

However...

• Goal to identify themes for further qualitative research
• Larger studies with multiple survey methods may be warranted
Conclusions

• Research informs clinicians and researchers on complexity of survival and themes important to survivors and FFMs

• Use of open-ended questions and thematic analysis provided room for honesty about thoughts and feelings

• Themes should be used to explore survivors’ perceptions and needs and spur development of resources for survivors and FFMs.
Discussion

- This qualitative pilot study takes a necessary step in assessing how patients experience life after survival and also provides insights on experiences of FFMIs.
- There is a need for support networks and social media groups with expertise from people who are trained in supportive care of others.
Recommendations

• Develop a system for discharge counseling that includes:
  – Follow-up and expert re-evaluation
  – Reiteration of instructions, expectations and resources for survivors

• Provide resources for survivors and FFM including options for peer support
Sudden Cardiac Arrest Network

The Sudden Cardiac Arrest Network provides peer support, opportunities to participate in discussion groups, research, blogging, and more. Visit [www.sca-aware.org](http://www.sca-aware.org) for more information.

And visit us on [Facebook](http://Facebook) and [Twitter](http://Twitter).
Together We Can
Save More Lives