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## Clinical paper

# Moving from physical survival to psychologic recovery: a qualitative study of survivor perspectives on long-term outcome after sudden cardiac arrest



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### Abstract

**Background:** Over 400,000 adults suffer out-of-hospital cardiac arrests (OHCA) each year in North America. Despite a very high mortality rate, even 10% survival means that a minimum of 3500 people return to their lives and their families. However, their experience of living and their health-related quality of life after such a life-changing event are quite variable, much more complex than just having lived or died, and should not be reduced to crude measures of neurological functioning.

**Methods:** We conducted 32 in-depth qualitative interviews with survivor/family member dyads at various stages of survival. The interviews focused on the recovery journey, long-term issues most important to them and how measuring such concepts could help. Interviews were audio-taped, transcribed verbatim and analyzed using constant comparative thematic analysis techniques.

**Results:** During in-depth interviews with more than 30 survivors and caregivers we have heard that despite being a relatively high functioning group, their lives have been deeply affected by their cardiac arrest experience. They speak about the importance of both psychologic and physical recovery, the impact of return to work or changes in work identity and the necessity of support from family members in the recovery process. Spouses/family members also mentioned differences in perspective on their loved one's recovery and how they manage the fear of recurrence.

**Conclusions:** This work purposively brings a unique lens to the concept of cardiac arrest outcomes by placing priority on what is important to survivors and their families and what we may be missing in standard outcomes measures. There is a clear need for a more patient-centred outcome set for this population and our work indicates that psychologic assessment, return to work status and family input are key domains to be considered.

**Keywords:** Cardiac arrest, Survivorship, Patient-Centred outcomes, Qualitative research

## Introduction

Over 400,000 adults suffer out-of-hospital cardiac arrests (OHCA) each year<sup>1</sup> in North America. Despite a very high mortality rate,<sup>2</sup> even 10% survival means that a minimum of 3500 people return to their lives and their families. The classic primary outcome measures of any

sudden cardiac arrest trial are 'survival to hospital discharge' and 'good neurologic outcome' as measured by compartmentalized clinical scales.<sup>3</sup> By choosing such outcomes, we make significant assumptions about what constitutes a "good" outcome following a cardiac arrest. The five-year survival rate for out of hospital cardiac arrest patients discharged from hospital alive is approximately 75%,<sup>4</sup> so there are thousands of people "living" after cardiac arrest. However,

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their experience of living and their health-related quality of life after such a life-changing event are quite variable,<sup>5–7</sup> much more complex than just having lived or died, and should not be reduced to crude measures of neurological functioning.

Within the health sciences, the term that focuses on the health and life of a person who has come through a critical illness, from post-treatment until the end of life, is survivorship.<sup>8</sup> Conceptually, survivorship encapsulates the physical, psychosocial, and economic impacts of critical illness for the period of time subsequent to the event or diagnosis and treatment phases. Survivorship is a fairly new area of study in the field of cardiac arrest research, although it has been recognized as important in other clinical areas such as cancer care for much longer. For example, it is well documented that many cancer survivors find it hard to make a transition to a new way of life after treatment; they struggle with issues such as the physical and emotional changes after discharge, coping with fear of recurrence, changes in relationships with loved ones who are now in a caregiver role, financial burdens, latent side effects, and changes in day-to-day functioning.<sup>9</sup> Similar challenges have been shown for survivors of OHCA,<sup>10,11</sup> but the paucity of survivorship research in this clinical area means that the experiences and post-discharge quality of life for SCA survivors are significantly less well understood.

While there is growing body of published work on survivors' experiences of cardiac arrest,<sup>10–13</sup> to date there has not been much empirical research focused on what actual outcomes are important to survivors and their families. Great strides have been made with recent guidance from important publications such as the American Heart Association Survivorship Statement,<sup>14</sup> and the International Liaison Committee on Resuscitation's Adult and Pediatric Core Outcome Sets for Cardiac Arrest.<sup>15,16</sup> We must continue to build the evidence base behind these documents in order to inform a more patient-oriented approach to health system improvements that could enhance survivorship for this population. Accordingly, we undertook an in-depth qualitative study to understand what "survivorship" means to survivors and their families, what outcomes are important from their perspective and how they may change over time.

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## Methods

### Study design

This qualitative study was informed by the foundations of phenomenology, an approach to inquiry focused on understanding the life-world of people from their perspective as "insiders" who experience, have perceptions of, and derive meaning from particular things and situations.<sup>17</sup> Phenomenology has been particularly acknowledged as a foundational starting point for health-related quality of life research<sup>18</sup> because it seeks to derive in-depth knowledge about what it is like to have particular experiences. This approach is geared towards illuminating the details and aspects of people's experiences that may seem trivial or even be taken for granted but ultimately serve to create the meaning in their everyday lives.<sup>19</sup> As such, it is a useful framework to help us generate an understanding of the most relevant long-term outcomes of SCA from people with lived experience of this life event. In keeping with the tenets of this methodology, we approached this study with open minds, non-judgemental attitudes, and embraced curiosity as we thought deeply and reflectively about how people construct meaning about "good" outcomes and described their experiences of SCA survivorship.

### Study population

The population for this study was English-speaking, adult survivors of sudden cardiac arrest and their spouses or family members/closest next of kin. The language was limited to English due to our available study resources and research team expertise. We did not limit the time since arrest as we were specifically looking at long term outcomes of survivorship and felt that increases in time since the arrest gave participants richer depths of experience to draw from.

### Participant recruitment

Participants for this study were selected purposively, that is to say we focused our recruitment efforts on people who would be most likely to have experience with and insights about important long-term outcomes of SCA survivorship.<sup>20</sup> Our team is significantly involved in the Canadian Resuscitation Outcomes Consortium (CanROC), a collaborative association of researchers, Emergency Medical Service agencies, and members of the public (including SCA survivors and families) who support a Public Engagement Committee. We contacted the members of the Public Engagement Committee and asked for their consent to be contacted for research purposes. We also used the CanROC investigator network to identify and connect with survivors from across Canada (who were not part of CanROC). Those who agreed were invited to participate in in-depth qualitative interviews. We also asked those who agreed to assist us with recruiting additional participants by sharing information about this study with their acquaintances and social contacts who had experience with SCA. This technique is called snowball sampling and is frequently used in research when the members of a target population may be difficult to locate, as was the case with this study.<sup>21</sup> We endeavoured to enroll survivors and family members/caregivers from across various points in the cardiac arrest survival trajectory (post-discharge, 6 months, 1 yr, 3 yrs, 10 yrs, etc). We also intentionally sought to include participants with a range of socio-demographic characteristics including age, gender, marital status, and geographic location. All participants who agreed to participate in this research were given an opportunity to review a letter of information and consent form, ask questions, and provide verbal consent prior to commencing the interviews. All of the survivors who were approached about the study agreed to participate.

### Data collection

We conducted in-depth qualitative interviews with SCA survivors and family members/caregivers between January 2018 and February 2019. The interviews were conducted in person or by telephone at a time and in a location that was convenient and comfortable for the participants, such as their homes, coffee shops, and public meeting places. All interviews were conducted by a PhD trained research coordinator with extensive experience in qualitative methods and supplemented with field notes to document dynamics, contextual factors, impressions of the interview process, and preliminary analytic insights.

The interviews were conducted in an open manner structured around the following domains: experience of the SCA and immediate aftermath, short term recovery and life changes, and longer-term health status and quality of life. Our research team developed a loose interview guide to address key topics of interest, including understanding of their current condition, functional status, other health concerns, social concerns, and impact on relationships (Appendix A).

However, the selection of follow-up questions, question order, and phrasing during the interviews was flexible based on how and what participant chose to share of their stories. This approach enabled the emergence of truly participant-led accounts, reflecting their varied histories, modes of expression, and particular foci of their SCA survivorship experience.<sup>22</sup> The interviews were digitally recorded, transcribed verbatim by an external transcription service, and all transcripts were uploaded into NVivo qualitative software for data management.

A key contribution of qualitative research is exploring the range of opinions, thus the sample size for qualitative studies is often determined by thematic saturation.<sup>23</sup> This is the point at which researchers agree that most viewpoints are fully accounted for and successive interviews will provide no new insights into relevant themes. In keeping with the iterative process of qualitative methodology, we collected and analyzed the interview data concurrently in order to continuously monitor emerging themes and general areas for further exploration in subsequent interviews. Once we felt that there were no new insights coming out in subsequent interviews and we had sufficiently explored our preliminary understandings of the most relevant outcomes of SCA based on survivorship experiences, we conducted an additional two interviews

and then ended data collection feeling confident that we had reached saturation.<sup>24</sup>

### Data analysis

We performed a phenomenologically-informed, thematic analysis of the data.<sup>25</sup> The phenomenological orientation guided us to focus on each participants' subjective experiences of life after OHCA and the meanings they assigned to this while the thematic analysis approach enabled us to identify essential patterns of experience and meaning across the sample. Research team members MBS and KND independently reviewed the transcripts, identified sections that reflected the key domains of interest, and carried out the initial coding process before meeting to compare codes, analytic notes, and preliminary reflections about the data set. We used emergent codes to guide a de-novo analysis of the entire corpus for overarching subthemes, and NVivo to record which subthemes occurred in each interview, ensuring their accurate representation in the analysis. Subthemes that expressed similar experiential patterns were brought together to develop core themes.

We employed multiple coding because it is a useful way of developing reflexivity – that is to say, it is a tool through which we were

**Table 1 – Study participant characteristics.**

LOCAS study participant characteristics

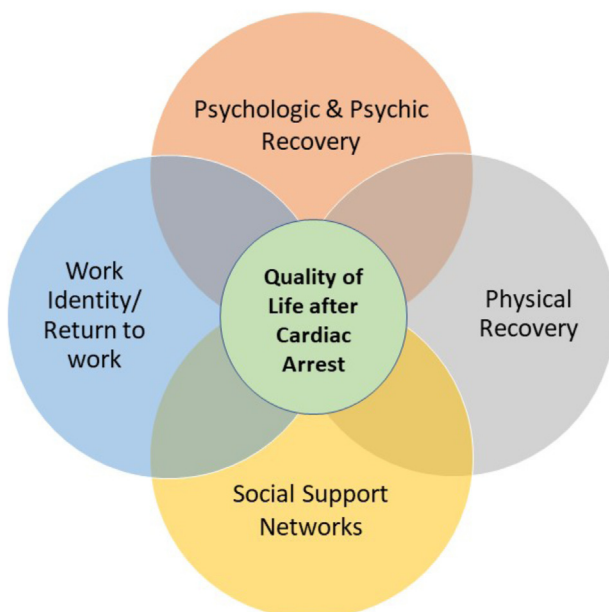
Study ID	Type (S=Survivor; FM=Family Member)	Dyad interview (Yes/No)	Gender (M/F)	Age range	Time since SCA	Perceived survivor outcome
P1	S	No	M	60+	2 yrs	Excellent
P2	S	No	M	30–40	10 + yrs	Excellent
P3	S	Yes - P3 & P4	M	50–60	3 yrs	Excellent
P4	FM	Yes - P3 & P4	F	50–60	3 yrs	Excellent
P5	S	Yes - P5 & P6	M	60+	8 yrs	Good
P6	FM	Yes - P5 & P6	F	60+	8 yrs	Good
P7	S	No	F	30–40	7.5 yrs	Affected
P8	FM	Yes - P8 & P11	F	40–50	3 yrs	Very Affected
P9	S	Yes - P9 & P10	F	60+	2 yrs	Affected
P10	FM	Yes - P9 & P10	M	60+	2 yrs	Affected
P11	S	Yes - P8 & P11	M	40–50	3 yrs	Excellent
P12	S	No	M	60+	4 yrs	Good
P13	S	Yes - P13 & P14	M	60+	< 1 yr	Very Affected
P14	FM	Yes - P13 & P14	F	60+	< 1 yr	Very Affected
P15	S	No	F	50–60	3 yrs	Very Affected
P16	S	No	F	40–50	4 yrs	Very Affected
P17	S	Yes - P17 & P18	M	50–60	5 yrs	Affected
P18	FM	Yes - P17 & P18	F	50–60	5 yrs	Good
P19	S	No	M	50–60	2 years	Good
P20	S	Yes - P20, P21, P22	M	20–30	3 years	Excellent
P21	FM	Yes - P20, P21, P22	M	50–60	3 years	Excellent
P22	FM	Yes - P20, P21, P22	F	50–60	3 years	Excellent
P23	FM	Yes - P23 & P24	F	60+	10 years	Excellent
P24	S	Yes - P23 & P24	M	50–60	10 years	Excellent
P25	FM	No	F	50–60	< 1 year	Good
P26	S	No	F	20–30	< 1 year	Affected
P27	S	Yes - P27 & P28	M	60+	< 1 year	Good
P28	FM	Yes - P27 & P28	F	60+	< 1 year	Good
P29	S	No	M	50–60	3 yrs	Good
P30	S	No	M	40–50	3 years	Good
P31	S	No	M	50–60	3 years	Affected
P32	S	No	M	30–40	2 years	Very Affected

able to examine our own assumptions about the world and separate these from our understanding of participants' perspectives.<sup>26</sup> By comparing our respective and evolving understandings of the transcript data, each member of the coding team had an opportunity to check our own beliefs and ideas. Our reflexive practice was further supported by keeping reflective research journals throughout the analysis process to document and "bracket" our personal ideas, experiences, and scientific beliefs about SCA and survivorship. "Bracketing" enabled us to consciously separate our pre-existing ideas and knowledge from our developing understanding of survivor and family members' perspectives. We also kept an audit trail of decisions made, met regularly as a team to discuss our interpretations, and constantly returned to the transcripts to ensure we stayed close to the data.

## Results

We interviewed a total of 32 participants (21 survivors and 11 family members). The interviews were approximately 1 h in duration (range 25–90 mins). Most of the survivors and family members (20 participants in total) were interviewed individually, although 6 couples (12 participants in total) chose to conduct the interview together. The average age for the participants was approximately 50 years (range 27–75 years) and the average time since their arrest was approximately 4 years (range 6 months – 14 years). The majority of the survivors we interviewed were male (16 participants or 76%). More detailed participant demographics are included in Table 1.

Our analysis of how people construct meaning about "good" outcomes and describe their experiences of SCA survivorship produced findings situated around key themes of psychologic recovery, work identity, and social support and relationship needs. We have also created a figure to represent how these themes relate to each other and the wider concept of outcomes after cardiac arrest (Fig. 1).



**Fig. 1 – Visual representation of thematic findings.**

## *The Forgotten Outcome: Psychologic Impact*

Almost all of the participants spoke about the great care they received from healthcare providers for their physical person during and after their cardiac arrest. They were deeply appreciative of the diagnostic tests and procedures performed by specialists to determine and rectify the underlying cause of the cardiac arrest, and sincerely grateful for the support and education provided within the health care system for rehabilitation. However, they often lamented that little attention was paid to the psychologic impact of the arrest which remained for them following discharge. This included their struggle with existential issues such as questions about the meaning of life, "why did it happen to me/my family member", or "why did I/my family member survive", as well as their fear of a repeat event, feelings of loneliness or isolation, and mental health issues including depression and symptoms of post-traumatic stress. Some participants described "feeling more" or being "more emotional" after the arrest and many struggled to incorporate the enormity of what had happened into their concept of themselves, their place in the world, and general sense of how the world works and how life is supposed to unfold.

"This was more than just recovering from an illness. This was actually a substantive life changing event that was not only going to change my life, it was going to change my perspective on life . . ." [P3]

"I think also people that have a cardiac arrest don't know what the future might look like for them . . . the unknown and the apprehension of what's going to come now is quite stressful . . ." [P24]

Of note, few survivors and family members had been offered or were able to find support for their psychologic recovery outside of private therapists paid for through personal insurance plans, although several shared that they had taken up yoga, were studying Buddhism, or practicing mindfulness to help them cope. Some family members who witnessed or were lay responders to their loved one's cardiac arrest had been profoundly affected by the event and described experiencing nightmares, fear of recurrence, and reported that their mental health had suffered in the initial months and 1–3 years following the cardiac arrest. Although many eventually managed to recover enough to adjust to the "new normal" of their lives, we learned that this did not typically happen without significant adjustments to their lifestyle and social relationships, including moving homes (to get away from triggering memories of the location of the arrest), retiring early (to remain close to their loved one), obtaining an automatic external defibrillator for personal use when away from home, distancing themselves from personal relationships deemed stressful or non-supportive, and ceasing sexual relations within the marital relationship (feared to produce too much strain on the now fragile heart).

For the initial few months and years after the cardiac arrest, many of the survivors and family members we interviewed also discussed feeling compelled to "think positively", "practice gratitude", "not sweat the small stuff", and "make the most of every day." Adopting a positive attitude was seen as both a helpful and necessary response to the cardiac arrest experience – something that promoted physical, psychological, and psychic recovery in terms of dealing with their health and life post-arrest, as well as helping them to make peace with what had happened. This was largely self-motivated rather than a response to external social pressure. Participants told us they felt they

“should” have this perspective given their new understanding of the fragility and uncertainty of life. In the longer term, however, this compulsion to “think positively” and “embrace the moment” seemed to evolve or fade. Survivors with minimal physical and neurological impairment told us that it was hard to sustain this state of gratitude and appreciation for the miracle of life while experiencing the everyday stressors of “normal” life, such as frustration with slow-moving traffic or minor interpersonal disagreements. Survivors with more physical limitations and neurological impairment were eventually distracted by the significant stressors of their “new normal”, including fatigue, financial pressures, and fear of future age-related deterioration.

“I really didn’t care how hard it was financially and how hard it was physically and how hard it was emotionally and psychologically and all that. I didn’t even really care because I was just so grateful to be alive. But you can only be that way for so long. Then, when you’re facing real life, like bills and things stress related, then you start thinking again about how much it sucks and how much you wish your life was different and better.” [P16]

This finding draws attention to the need for including cardiac arrest outcome measures which consider more psychologic or mental health-oriented domains as well as different support needs at different time points in order to assess more holistic survival outcomes.

### **Return to work and work identity**

Because the average age of cardiac arrest victims is approximately 63 years,<sup>27</sup> a large proportion of survivors are actively working at the time of their arrest. For this cohort, surviving cardiac arrest produces additional anxieties and distress, particularly if their outcome involves any level of neurologic impairment which prevents them from returning to their job in their full capacity.

“I wondered when I could go back to work because it was going to impact a lot of people financially if I didn’t go back . . . but I didn’t feel ready so it was a struggle . . .” [P23]

The ability to return to work seemed to be a crucial marker of “recovery” for many of the participants in this study. While fully acknowledging that things had changed and life would never be quite the same, perceiving that the survivor was physically and psychologically ready to return to work appeared to function as a necessary condition for the research participants to begin the process of “moving on with life. Family members in particular seemed to regard the ability to return to work as indication that life was returning to an acceptable state of “normal” or “new normal”, while survivors appreciated being able to reconnect to valued aspects of their pre-arrest identity. It was a milestone embraced by those who could return to work and mourned by those participants who were not able to do so. We heard that not being able to return to their pre-arrest jobs, even if in a different position or lesser capacity, was profoundly destabilizing for survivors and their families. It tended to confound psychologic recovery and increase the effort required to cultivate and maintain the necessary positive attitude towards life.

Several survivors felt inspired or compelled to change careers or withdrew from the paid workforce altogether (by retiring or accepting long-term disability benefits). Interestingly, many of the participants we spoke to in this circumstance described having found a new life purpose that seemed to function as a “job” around which they

constructed their new identity. For example, a few survivors had taken on the emotional and practical “work” of educating others about cardiac arrest risk factors and treatment as a way of making their experience meaningful. They were involved in volunteer associations, participated in research, gave public presentations, trained others on how to perform CPR, and actively sought out opportunities to share knowledge about what they had experienced and inspire others by their new perspective on life. Others told us they were consciously and deliberately redirecting their time and energy to focus on connecting with loved ones and investing in those relationships as the most important thing in their lives, as one long-term survivor explained:

“I feel like my life should have ended at 17, so everything else is just bonus, and I guess that’s why I just appreciate being with family and being with friends and trying to create more opportunities for others to experience the same.” [P2]

Given the importance of return to work and work identity within our data, this also should be considered in more robust measures of long-term outcome for survivors.

### **Crucial support networks**

The key role that spouses and family members played in survivors’ ongoing recovery came up repeatedly in the interviews and took different forms. In the absence of external professional support to assist with psychologic recovery, the emotional support provided by spouses and family members was of particular help to survivors in coming to terms with the trauma of their cardiac arrest experience and doing the “work” of maintaining a positive, grateful attitude towards life.

“The energy that came out of [my family support] - I believe in that. It’s helped me to bounce back. The connection, having people that genuinely care for you. I felt so lucky.” [P1]

“There were things I could help [survivor] with. I could help him realize that the important things are moments. It’s not about the goal, it’s not about getting there. It’s about all the things that happen along the way, and you have to make those count.” [P21]

Spouses and family members also helped survivors resume meaningful activities post-arrest. When we asked participants to share their perspectives on what makes for a “good” life after cardiac arrest, most of the survivors highlighted the importance of being able to engage in the physical, social, and leisure activities that had previously given their lives meaning and enjoyment. Examples of these highly valued activities include playing sports, running, cycling, playing musical instruments, gardening, caring for young grandchildren, dining out with friends and family members, going camping, and traveling. Interestingly, we learned from those who were able to engage in these types of activities post-arrest that they frequently did so with some new level of involvement from their spouse or family members. In some cases, the newly assumed role of the spouse or family was overt and supportive in nature, for example directly participating in hobbies with the survivor or making the necessary arrangements for travel. In other cases, the new role was to facilitate the survivor and family members’ psychological comfort in having the survivor engage in these activities “independently”. This often took the form of monitoring or observing the activity from a distance, for example tracking the survivor’s long runs with a smart phone application, maintaining visual contact while the survivor swam



across a lake, and watching from in the home while the survivor performed physically demanding yard work outside.

In some cases, the important role of social support in helping the survivor to live a “good” life after cardiac arrest was more subconscious for the survivor, but very necessary from the perspective of the family member. We heard from most of the spouses and family members that they had assumed responsibility for the “little things” on behalf of the survivor, proving encouragement, reminders, and accompaniment to survivors to make their daily lives a bit easier. One spouse explained:

“I copy her activities into my day timer. And I try to help her, like just gently say, well, remember this or that. . . . to supplement her memory, so she doesn’t forget anything.” [P18]

These types of support, both overt and covert underscore the importance of ensuring survivors have a support network, something that should be addressed as part of routine discussions at discharge. It also draws attention to the significance of perspective in the assessment of outcome; a survivor’s impressions of their own recovery can be skewed for many reasons, particular in relation to their desire for “normality”. This speaks to the potential importance of family or care-giver oriented measures as part of a fulsome outcome assessment.

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## Discussion

During in-depth interviews with more than 30 survivors and family members we have heard that despite appearing as a relatively high functioning group, the lives of survivors from sudden cardiac arrest have been deeply affected by their cardiac arrest experience. For them, true outcome assessment must consider both psychologic and physical recovery, the impact of return or lack thereof to work and the influence of support and perspective from loved ones.

The nature of our findings in this study signal the need to move from the language of survival to a discourse of recovery and embracing the measurement of outcomes associated with good psycho-social recovery over the long-term along with physical recovery. While the growing number of survivors is a testament to the many successes that have been achieved in the chain of survival for cardiac arrest, it also represents a clear challenge to clinicians and researchers to look beyond physical survival to address the needs of and provide hope for a valued future to those living beyond hospital discharge.<sup>28</sup>

The reality is that victims of sudden cardiac arrest actually die for a short period of time; in other words, SCA survivors have faced what psychologists would call a near death experience or NDE. The sequelae of NDE has been recognized as a discrete syndrome since 1892 but was not formally labeled as such until 1975.<sup>29</sup> This body of research has since demonstrated that those who have a near death experience (NDE) show a marked change in their attitude, not only toward their own life but toward the lives of others as well. They tend to be more open, caring, and loving; but they may also re-examine their existing approach to life, and relationships, often ending things that are now not compatible with their new beliefs and attitudes. The experiencer and family members are often confused by this “new person” and adjustment problems do arise. Families can have a difficult time adjusting to the new normal. These types of effects are reflected in the findings of our study and further support the need to attend to the psychology of survival. By acknowledging the potential for pervasive and durable changes in

beliefs, attitudes, and values we will be able to develop more holistic long-term recovery support for survivors and their families.

In addition, for a distinct subgroup of survivors, cardiac arrest is a disabling event which prevents them from returning to their previous vocation. A recent study by Garland et al. used over 19,000 cases in the Canadian Hospitalization and Taxation Database to show that acute MI, cardiac arrest and stroke all resulted in substantial loss in employment and earnings that persisted for at least 3 years after the events<sup>30</sup> Similar studies conducted in Australia and Sweden found that those employed in labour-intensive occupations such as tradespersons, production or transport and the sales and service industry experience the greatest number of barriers in returning to work after cardiac arrest, mainly due to the impact of fatigue, depression and restricted mobility.<sup>31,32</sup> Regardless of the job or career, work gives a sense of belonging, of being a contributor; an important part of an organisation and in turn a valued part of society.<sup>33</sup> An inability to return to work or to find new activities which provide these kinds of fulfillments may be very detrimental to psychologic recovery for cardiac arrest survivors. Our findings indicate that this is a major factor in defining outcome from cardiac arrest, however we are unaware of any qualitative studies that further explore the burden of return or lack of return to work or trials of interventions to improve cardiac arrest survivors’ ability to remain in or return to the workforce post-treatment. In particular interventions that enable survivors to better manage fatigue, cope with their “disrupted normality,”<sup>34</sup> and reduce symptoms of anxiety and depression would be expected to enhance survivor’s ability to return to work more readily.

For more than 20 years, the oncology community has recognized the challenges of recovery and survivorship and made substantial progress toward preventing or ameliorating them. But we need to be clear: cancer survivorship has improved not just because of heroic efforts by cancer survivors and their physicians, nor as an inevitable result of new cytotoxic therapies. The lives of cancer survivors have gotten better because improving long-term cancer survivorship has been institutionally supported as a goal of research and care.<sup>35</sup> The field of resuscitation science has very recently begun to make significant statements about the importance of survivorship, recovery and patient-centred outcomes. In 2018, an international group of investigators from the International Liaison Committee on Resuscitation worked to develop a consensus core outcome set for adult cardiac arrest (COSCA) advisory statement. Consensus emerged that a core outcome set for reporting on effectiveness studies of cardiac arrest in adults should include survival, neurological function, and health-related quality of life.<sup>15</sup> Similar work has now been done for Pediatric cardiac arrest as well and includes recommendations for assessment of survival, brain function, cognitive function, physical function, and basic daily life skills.<sup>16</sup> Most recently (2020), the American Heart Association Survivorship Statement was published and systematically reviews existing post-cardiac arrest literature and identifies the current gaps in care for cardiac arrest survivors using a holistic lens on the healthcare system. This statement draws attention to the far-reaching effects that a cardiac arrest event has on individuals, their care providers, and their community and seeks to empower patients and caregivers to address their current and future needs with providers across the healthcare system.<sup>14</sup> Where cardiac arrest survival, understood as discharged alive from hospital, has historically been the measure of success,<sup>36</sup> our results align with these recent statements which call attention to the need for measurement of outcome from cardiac arrest to extend beyond the critical illness episode for survivors to recover and thrive in their lives post-discharge.<sup>37–39</sup> By focusing this work on discussions of longer-term

outcomes and the associated support systems that are needed, we have gained important insight that we hope to use to contribute to the design of survivor-centred outcome measures for prospective use both clinical practice and in cardiac arrest research. Having such data more systematically collected and available to post-arrest care teams (ie. part of the clinical chart) would support the move from a focus on clinical/physical recovery to a more holistic approach to survival.

## Conclusions

There is more to survival from sudden cardiac arrest than physical healing. Psychologic recovery is an ongoing, long-term and dynamic process. This work purposively brings a unique lens to the concept of cardiac arrest outcomes by placing priority on what is important to survivors and their families and what we may be missing in standard outcomes measures. There is a clear need for a more patient-centred outcome set for this population and our work indicates that psychologic assessment, return to work status and family input are key domains to be considered.

## Author credit statement

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## Authorship declarations

All of the authors were involved in the conceptualization of the project, data analysis and interpretations and drafting of the manuscript. All have approved the final version for submission.

## Disclosures

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## Declaration of 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.

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## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.resplu.2020.100055>.

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