



Clinical paper

Modifiable provider-patient relationship factors and illness perceptions are associated with quality of life in survivors of cardiac arrest with good neurologic recovery



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ABSTRACT

Aim: To evaluate associations between provider-patient communication, readiness for discharge, and patients' illness perceptions with post-arrest quality of life (QoL).

Methods: We distributed an online survey to survivors of cardiac arrest who were members of the Sudden Cardiac Arrest Foundation. Survivors completed the Questionnaire for the Quality of Provider-Patient Interactions (QQPPI), Readiness for Hospital Discharge Scale (RHDS), and the Brief Illness Perception Questionnaire (B-IPQ). When completing the QQPPI and RHDS, survivors were asked to think back to their hospitalization and discharge. QoL domains (physical, psychological, social) were measured via the WHO-QOL BREF. Three multiple regression models examined associations between QQPPI, RHDS, and B-IPQ scores with QoL domains, adjusted for age, sex, months since arrest, self-reported understanding of cardiac arrest and potential post-arrest symptoms at discharge, self-reported memory at discharge, and functional status as defined by the Lawton Instrumental Activities of Daily Living scale.

Results: A total of 163 survivors (mean age: 50.1 years, 50.3% women, 95.5% white, mean time since arrest: 63.9 months) provided complete survey data. More threatening illness perceptions (β : -0.45, $p < 0.001$) and lower readiness for discharge (β : 0.21, $p = 0.01$) were associated with worse physical QoL. More threatening illness perceptions (β : -0.47, $p < 0.001$) was associated with worse psychological QoL. More threatening illness perceptions (β : -0.28, $p = 0.001$) and poor provider-patient communication (β : 0.35, $p < 0.001$) were associated with worse social QoL.

Conclusions: Modifiable provider-patient relationship factors and illness perceptions were associated with quality of life in survivors of cardiac arrest with good neurologic recovery.

Introduction

Cardiac arrest survivorship has been conceptualized as a chronic condition with neurological, functional, and psychological challenges,^{1,2} and recent attention has been directed to ensuring and supporting better quality of survivorship. As such, a recent American Heart Association (AHA) scientific statement has identified a need for more comprehensive assessment of post-cardiac arrest survival for clinical and research purposes.²

Quality of life (QoL) is a patient-centered construct defined by the WHO as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to

their goals, expectations, standards and concerns."³ To date, many studies in survivors of cardiac arrest have utilized a simplified measure of survival outcome, such as the Cerebral Performance Category Score. Others have attempted to approximate QoL by implementing various batteries of neuropsychological, emotional, and functional outcomes.⁴ However, there remains a paucity of studies utilizing a comprehensive QoL assessment, making it difficult to fully understand the nature and predictors of QoL after surviving cardiac arrest. Nevertheless, the high incidence of multi-domain impairment, and particularly psychological distress post-arrest, gives rise for the potential that survivors may experience poor QoL.

Modifiable provider-patient relationship factors, such as quality of

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provider-patient communication and patients' perceived readiness for discharge may have important implications for post-discharge QoL. Previous qualitative research has revealed that survivors with good neurologic recovery do not have a clear understanding of their arrest, nor are prepared to confront the multi-domain impairments they experience after their hospital discharge.⁵ Others have documented that survivors are unaware of the consequences of their hypoxic-ischemic encephalopathy, and that their providers fail to discuss these sequelae with them.⁶ Accordingly, a recent scientific statement by the AHA has reported that post-arrest survivors are poorly equipped to maximize their recovery due to the lack of coordinated post-discharge care, and survivors' lack of direction and lack of expectation of post-arrest symptoms.² Importantly, in other patient populations, high quality physician-patient communication has led to greater patient satisfaction, treatment adherence, and improved clinical outcomes.⁷⁻¹¹

Another potentially important, modifiable variable regarding QoL is survivors' illness perceptions, defined as the cognitive and emotional appraisal of one's illness and recovery.¹² Previous work has found that a threatening perception of one's illness (i.e. negative appraisal of one's illness status and potential for recovery) is implicated in less accountability in treatment, lower likelihood of attending cardiac rehabilitation, more psychological distress, higher rates of disability, and slower return to work times.¹³⁻¹⁵ In the context of cardiac arrest, survivors may develop a more threatening perception of their arrest and recovery due to the multi-domain symptoms they experience, and the lack of domain-specific support they have at their disposal.

The present inquiry seeks to evaluate the potential relationships between provider-patient communication, readiness for hospital discharge, and illness perceptions with the essential QoL domains (physical, psychological, social). We hypothesize that low quality provider-patient communication, lack of readiness for discharge, and more threatening illness perceptions will be associated with worse QoL in a sample of survivors of cardiac arrest with good neurologic recovery.

Methods

This study is part of a larger online survey study distributed between October and November 2019 to survivors of cardiac arrest who were registered as members of the Sudden Cardiac Arrest Foundation (SCAF). SCAF membership is free and open to all survivors of cardiac arrest. The surveys were conducted through REDCap, a secure data capture software.¹⁶ This study was approved by the local Institutional Review Board under expedited review.

Measures

Participant characteristics

The survey probed for demographic variables such as age at arrest, sex, and race, as well as participant characteristics such as months since initial cardiac arrest, comorbidities at the time of the arrest (which were then used to calculate the Charlson Comorbidity Index (CCI)¹⁷), provision of cooling therapy, arrest location, and functional independence (measured via the Lawton Instrumental Activities of Daily Living scale¹⁸). The Lawton is an 8-point scale measuring functional dependence; higher scores indicate higher autonomy. Additionally, survivors reported their level of recall at the time of their hospital discharge. They also responded to two 5-point Likert scale questions querying their level of understanding of cardiac arrest at the time of their hospital discharge and their level of awareness of potential post-arrest symptoms at the time of their hospital discharge. Finally, we collected zip code data which we used to characterize the geographic make-up of participants.

Quality of life

We measured three domains of QoL described in the WHO's definition for QoL³ (i.e. physical, psychological, and social QoL) through the WHO-QOL BREF.¹⁹ The physical QoL subscale examines perceived

independence in activities of daily living, utilization of medical treatments, pain, mobility, sleep quality, fatigue, and work capacity. The psychological QoL subscale assesses experience of positive and negative emotions, cognitive function, self-esteem, meaning making, and body image. The social QoL subscale examines quality and availability of social support and satisfaction with sex life. Individual items are rated on a 5-point scale, with higher scores indicating greater QoL. From these ratings, we calculated domain scores according to published scoring recommendations (range 4–20).²⁰

Provider-patient communication

To examine the quality of provider-patient communication, we utilized the 14-item Questionnaire on the Quality of Physician-Patient Interaction (QQPPI).²¹ Individual items are rated on a scale from 1 to 5 and summed to yield a total continuous score, with higher scores indicating greater quality of communication. Because survivors of cardiac arrest endure lengthy intensive care unit and step-down stays, they interact with many providers. Thus, in this study, the language of the scale was adapted to query about interactions with both physicians and nurses during hospitalization and can be found in the **Addendum**.

Table 1

Demographics, participant characteristics, and quality of life scales of analytic sample.

Demographics		Scale Range
Age at arrest, mean ± SD ^a	50.8 ± 11.5	
Gender—Female, % (n)	50.3 (90)	
Race, % (n)		
White	96.1 (171)	
Non-white	3.9 (7)	
Participant Characteristics		
Pre-arrest Charlson Comorbidity Index, median (IQR) ^b	1 (0–2)	
Out-of-hospital arrests, % (n)	85.4 (152)	
Therapeutic hypothermia, % (n)	42.1 (69)	
Months since arrest, mean (IQR)	63.9 (26–91)	
Consistent memory at discharge, % (n)	83.3 (135)	
Level of understanding of arrest at discharge ^c , mean ± SD	2.8 ± 1.1	1–5
Level of awareness of post-arrest symptoms at discharge ^d , mean ± SD	2.5 ± 1.2	1–5
Lawton IADLs ^e , mean ± SD	7.7 ± 0.7	0–8
QQPPI ^f mean, ± SD	46.8 ± 15.5	14–70
RHDS ^g mean, ± SD	51.7 ± 19.4	0–80
B-IPQ ^h mean, ± SD	36.8 ± 15.8	0–80
Geographic Region, % (n)		
United States East	17.9 (32)	
United States South	34.6 (62)	
United States Midwest	20.1 (36)	
United States West	20.1 (36)	
Non-United States	7.3 (13)	
WHOQOL-BREF Subscalesⁱ		
Physical QoL mean, ± SD	15.1 ± 3.1	4–20
Psychological QoL mean, ± SD	14.4 ± 3.2	4–20
Social QoL mean, ± SD	13.9 ± 3.7	4–20

^a Standard Deviation.

^b Interquartile Range.

^c Likert scale 1–5 (5 = complete understanding).

^d Likert scale 1–5 (5 = complete awareness).

^e Lawton Instrumental Activities of Daily Living (scale range 0–8). Lower scores = more functional dependence.

^f Questionnaire for the Quality of Provider-Patient Interactions (scale range 14–70). Lower scores = lower quality communication.

^g Readiness for Hospital Discharge Scale (scale range 0–80). Lower scores = lower readiness for discharge.

^h Brief Illness Perception Questionnaire (scale range 0–80). Higher scores = more threatening illness perception.

ⁱ World Health Organization Quality of Life Scale – Brief (subscale ranges 4–20). Lower scores = lower QoL.

Readiness for discharge

To examine readiness for discharge, we used the Readiness for Hospital Discharge Short Form (RHDS),²² an 8-item scale measuring 4 domains of patients' perceived discharge readiness. Domains include: personal status (i.e. the patient's emotions on the day of discharge), knowledge (i.e. the patient's knowledge about how to care for themselves when they return home); perceived coping ability (i.e. the extent to which each patient believes they will be able to cope at home after discharge); expected support (i.e. the amount of help the patient will have if/when needed at home after discharge). Items are rated on a scale from 0 to 10; scale scores are calculating by adding the item scores and dividing by 8 (total number of items) which yields a mean score across item scores. Lower mean scores are indicative of lower readiness for hospital discharge. In this study, patients were prompted to recall back to the day of their discharge when responding to items.

Illness perceptions

We utilized an adapted version of the Brief Illness Perception Questionnaire (Brief-IPQ).²³ The Brief-IPQ is an 8-item inventory that measures aspects of patients' current illness perceptions (i.e. cognitive and emotional appraisals of their illness and recovery). The Brief IPQ has previously been adapted in different disease populations, with the language tailored to the specific disease being studied.²⁴⁻²⁹ In the present study, the language was tailored to the cardiac arrest event and recovery process. Survivors were asked to base their answers on their present perceptions. Specifically, the individual items were based on survivors' perceptions of the *consequences* of their cardiac arrest, the *timeline* of the disease and recovery process, their *personal control* over recovery, their *treatment's control* over recovery, their *identity* as a survivor of cardiac arrest, the *coherence* of their understanding of cardiac arrest, *concerns* about cardiac arrest, and their *emotional responses* to cardiac arrest. Individual items are summed to yield a total score; higher scores are indicative of a more threatening illness perception. An additional "cause" item was not included in the present analysis as it is a qualitative item that is not factored into the Brief-IPQ total score.

Statistical analysis

First, we calculated measures of central tendency to describe participant characteristics, QoL domains, QQPPI, RHDS, and B-IPQ. We then utilized t-tests, chi-square, or Fisher's Exact tests as appropriate to compare characteristics between participants who fully completed the survey from those who did not complete the survey. Next, we ran a bivariate correlation matrix between each QoL domain, QQPPI, RHDS, B-IPQ, and participant characteristics. We did not include race in this analysis, as 96% of the sample reported being white. Participant characteristics that were significantly associated with any of the QoL domains ($p < 0.10$; two-tailed) were then included in consequent multivariable regression models as covariates. We utilized an alpha of < 0.10 because it allows for greater inclusion of covariates that in turn could have synergistic confounding effects when included together in a multivariable model. Additionally, more traditional alpha levels, such as 0.05, can fail to identify important covariates.³⁰

Three multiple regression models examined associations between QQPPI, RHDS, and B-IPQ scores with each QoL domain, adjusted for significant covariates as indicated by the bi-variate correlation matrix. Additionally, we conducted omnibus tests for each model to capture the amount of variance explained by each model.

Results

A total of 179 cardiac arrest survivors initiated the survey; 163 survivors (mean age 50.8 years, 50.3% women, 95.5% white) provided complete survey data. There were no significant differences between those who initiated, but did not complete the survey, from those who did complete the survey. Descriptive statistics are presented in Table 1. The

Table 2
Bivariate correlations.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Physical QoL ^a	1															
2. Psychological QoL	0.71**	1														
3. Social QoL	0.43**	0.6**	1													
4. B-IPQ ^b	-0.61**	-0.6**	-0.42**	1												
5. QQPPI ^c	0.37**	0.42**	0.47**	-0.4**	1											
6. RHDS ^d	0.46**	0.46**	0.37**	-0.48**	0.62**	1										
7. Age at arrest	0.03	0.17*	0.9	-0.2**	0.12	0.13*	1									
8. Male	-0.26**	0.28**	0.11	-0.29**	0.16**	0.19**	0.23**	1								
9. Months since arrest	0.18**	0.18**	0.1	-0.21**	0.09	0.21**	-0.2**	0.02	1							
10. Charlson Comorbidity Index	0.02	0.2**	0.08	-0.14*	0.13*	0.13*	0.73**	-0.26*	0.25**	1						
11. Provision of therapeutic hypothermia	-0.02	-0.02	-0.02	0.13	-0.55	0.00	-0.02	-0.11	-0.09	-0.02	1					
12. Out-of-hospital arrest	0.11	0.09	0.11	-0.12	-0.02	0.17**	-0.12	0.22**	0.1	-0.09	0.27**	1				
13. Consistent memory at discharge	0.21**	0.17**	0.09	-0.13*	0.11	0.17**	0.15*	0.53	0.95	-0.15**	-0.15**	0.03	1			
14. Level of understanding of cardiac arrest at discharge	0.31**	0.34**	0.31**	-0.45**	0.56**	0.62**	0.24**	0.21**	0.05	0.24**	-0.03	0.11	0.17**	1		
15. Level of awareness of post-cardiac arrest symptoms at discharge	0.25**	0.33**	0.3**	-0.4**	0.38**	.51**	0.2**	0.33**	0.05	0.19**	0.03	0.18**	0.17**	0.63**	1	
16. Lawton IADLS ^e	0.34**	0.11	0.14*	-0.26**	-0.02	0.05	-0.07	0.05	0.1	-0.08	-0.01	0.05	0.03	0.01	-0.01	1

Note: * $p < 0.1$, ** $p < 0.05$.

^a QoL = Quality of Life.

^b B-IPQ = Brief Illness Perception Questionnaire.

^c QQPPI = Questionnaire for Quality of Physician-Patient Interactions.

^d RHDS = Readiness for Hospital Discharge Scale.

^e IADLS = Instrumental activities of daily living.

mean time since the cardiac arrest event was 63.9 months (interquartile range: 26–91). Survivors were extremely independent (mean Lawton 7.7). The majority of participants had experienced an out-of-hospital cardiac arrest (85.4%) and did not receive cooling therapy (42.1%). On average, participants reported low levels of understanding of cardiac arrest by hospital discharge (2.8) and low levels of post-arrest symptoms by hospital discharge (2.5). Overall, pre-morbid disease severity was low (CCI: 1). On average, participants reported moderate levels of quality of provider-patient communication (46.8), moderate levels of perceived readiness for discharge (51.7), and moderate-high levels of threatening illness perceptions (36.8). Finally, participants reported moderate levels of QoL in each subscale (13.9–15.1).

The bivariate correlation matrix is presented in Table 2. Significant correlations with at least one QoL domain included: age at arrest, sex, months since arrest, CCI, Lawton, understanding of cardiac arrest at the time of hospital discharge, understanding of post-arrest symptoms at the time of hospital discharge, and presence of consistent memory at hospital discharge, ($r = 0.14$ – 0.33 , $p < 0.05$).

Full details on the multiple regression models are presented in Table 3. More threatening illness perceptions (β : -0.45 , $p < 0.001$) and lower readiness for discharge (β : 0.21 , $p = 0.014$) were associated with worse physical QoL. More threatening illness perceptions (β : -0.47 , $p < 0.001$) was associated with worse psychological QoL. More threatening illness perceptions (β : -0.28 , $p = 0.001$) and poor provider-patient communication (β : 0.35 , $p < 0.001$) were associated with worse social QoL. Our models explained 50%, 44%, and 30% of the variance in physical, psychological, and social QoL, respectively ($p < 0.001$).

Table 3

Associations between provider-patient communication, readiness for discharge, and illness perceptions with QoL domains.

Variable	Physical QoL	Psychological QoL	Social QoL
	β (p-value)	β (p-value)	β (p-value)
Provider-patient communication ^a	0.1 (0.18)	0.14 (0.08)	0.35 (< 0.01)**
Readiness for discharge ^b	0.21 (0.01)*	0.14 (0.12)	-0.01 (0.92)
Illness perceptions ^c	-0.45 (< 0.01)**	-0.47 (< 0.01)**	-0.28 (< 0.01)**
Age at arrest	-0.11 (0.24)	-0.07 (0.45)	-0.04 (0.69)
Male	0.13 (0.04)*	0.11 (0.11)	-0.06 (0.43)
Months since arrest	0.03 (0.7)	0.08 (0.22)	0.01 (0.93)
Consistent memory at discharge	0.14 (0.02)*	0.08 (0.19)	0.02 (0.77)
Level of understanding of cardiac arrest at discharge	-0.07 (0.41)	-0.13 (0.19)	-0.1 (0.34)
Level of awareness of post-cardiac arrest symptoms at discharge	-0.09 (0.27)	0.02 (0.82)	0.15 (0.11)
Pre-arrest Comorbidity Severity ^d	0.01 (0.91)	0.17 (0.07)	0.04 (0.71)
Functional Status ^e	0.2 (< 0.01)**	-0.02 (0.71)	0.08 (0.28)

Note: * = $p < 0.05$, ** = $p < 0.01$.

Quality of life subscales taken from the World Health Organization Quality of Life Scale – Brief.

^a Questionnaire for the Quality of Provider-Patient Interactions.

^b Readiness for Hospital Discharge Scale (scale range 0–80). Lower scores = lower readiness for discharge.

^c Brief Illness Perception Questionnaire.

^d Charlson Comorbidity Index.

^e Lawton Instrumental Activities of Daily Living (scale range 0–8). Lower scores = more functional dependence.

Discussion

To our knowledge, this was the first examination of the relationships between modifiable provider-patient relationship factors and illness perceptions with QoL in survivors of cardiac arrest. Our results indicate that poor provider-patient communication was associated with worse social QoL, lack of readiness for discharge was associated with worse physical QoL, and more threatening illness perceptions (i.e. negative appraisal of one's illness status and potential for recovery) was associated with worse physical, psychological, and social QoL.

Based on our findings, it appears that survivors of cardiac arrest with good neurologic recovery could benefit from a clear understanding of the cardiac arrest disease process and domain-specific (e.g. neurological, psychological, functional) prognosis. Previous research has found that survivors do not have an adequate understanding of the cardiac arrest disease process, are not aware of the consequent sequelae of hypoxic-ischemic encephalopathy, and are not prepared to confront these sequelae upon returning home.^{2,5,6,31} This lack of expectation of post-arrest challenges, as well as inconsistent post-discharge follow-up infrastructure, may lead to survivors being poorly equipped to confront post-arrest survivorship.

In this study, more threatening illness perceptions was slightly/moderately associated with poor QoL in all three domains (physical, psychological, and social). In other diseases, threatening illness perceptions has been linked to lower likelihood of attending cardiac rehabilitation, greater psychological distress, higher rates of disability, and slower return to work times.^{13–15} Importantly, in post-myocardial infarction patients, controlled trials have targeted inaccurate illness perceptions and have demonstrated improvement in both functional and psychological outcomes.^{28,32} Other interventions aimed at addressing threatening or inaccurate illness perceptions have led to less psychological symptoms in survivors of esophageal cancer, reduced pain in a cohort of survivors of various cancers, greater physical activity in patients with chronic pain, greater treatment adherence to asthma prophylactic medication, and less physical and psychological symptoms in chronic fatigue,^{33–36} all of which can contribute to QoL. In the absence of quality patient-provider communication and domain-specific discharge care coordination, survivors may likely develop threatening illness perceptions about their cardiac arrest and recovery process. Taken together, in-hospital interventions focused on the provision of clear information about the disease and recovery process, educating patients regarding available post-discharge resources (e.g. cardiac and cognitive rehabilitation, psychiatry and psychotherapy, neuropsychology), and addressing threatening illness perceptions could lead to downstream improvements in QoL.

A previous cohort study found that cardiac arrest patients who survived to hospital discharge went on to have varied and dynamic recovery patterns by 1 year.³⁷ A recent review of the literature has indicated that, at a minimum, survivors of cardiac arrest are in need of both cardiac and cognitive rehab to potentiate optimal recovery.³⁸ Indeed, novel, multi-disciplinary European centers have recently begun following-up with survivors after discharge, with the intention of providing cognitive, cardiac, and psychological support, which in turn could yield improvement in patient-centered outcomes such as QoL.^{39,40} One Dutch intervention, which focused on both detecting cognitive and emotional problems and providing clear information for patient self-management (including consequences of hypoxic-ischemic brain injury), yielded improved QoL and anxiety symptoms at 1 year.⁴¹ Additionally, at 3-months, significantly more survivors in the intervention group had returned to work.⁴⁰ In short, clarity about the recovery process and the protective role of cardiac and cognitive rehabilitation attendance may be particularly beneficial for these survivors.

Limitations

Our study is not without limitations. First, it is prone to recall bias, as

participants retrospectively reported the quality of their provider interactions, as well as their readiness for discharge. The mean time since the initial arrest was 63.9 months (interquartile range: 26–91) indicating a wide variation in survey completers. Despite this, however, previous qualitative research has found these two notions (communication and readiness for discharge) to be overwhelmingly salient in survivors of cardiac arrest.⁵ To statistically control for recall bias, we adjusted for participant reported presence of consistent memory at hospital discharge.

Next, our analytic sample was prone to selection bias, as the survey participants were high functioning survivors able to independently complete an online survey. Further, our participant pool is not representative of survivors with severe neurological deficits, nor racially diverse survivors (96.1% white). As such, our results can only be generalizable to a select group of survivors. Nevertheless, the poor ratings of QoL indicated by these participants should be worrisome, given that these were survivors with good neurologic recovery.

Finally, as our models explained a low-moderate amount of the variance in each QoL domain, there is a significant amount of unexplained variance by potential unmeasured predictors, such as functional status and psychological symptoms at hospital discharge. While these variables were captured in the survey, they were assessed with regard to participants' current status and were not retrospectively assessed, as this would incorporate further potential for recall bias confounding. With that said, our findings indicate that potential modifiable factors within the patient-provider relationship explain a low-moderate amount of variance in QoL post-arrest.

Conclusion

Important, modifiable factors such as provider-patient communication, readiness for discharge, and illness perceptions are associated with quality of life in high functioning survivors of cardiac arrest. Transparency about the disease and recovery process, as well as the post-discharge resources available to survivors may need to be communicated so as to promote self-management. Further qualitative research may illuminate specific gaps in provider-patient interactions and subsequent QoL.

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Disclosures

All study authors have no disclosures to report.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.resplu.2020.100008>.

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