Caregiver strain among relatives of out-of-hospital cardiac arrest survivors; the DANCAS relative survey

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Clinical paper

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Abstract

Background: Knowledge about caregiver strain among relatives of out-of-hospital cardiac arrest (OHCA) survivors is limited. Thus, the objectives were to i) describe differences in self-reported mental well-being, mental health, and caregiver strain at different time points (1–5 years) post-OHCA and ii) investigate characteristics associated with caregiver strain.

Methods: A national cross-sectional survey (DANCAS) from October 2020 to March 2021 with OHCA survivors and their closest relatives. The relative survey included the WHO-5 Well-being Index (WHO-5), the Hospital Anxiety and Depression Scale (HADS) and the Modified Caregiver Strain Index (M−CSI). Differences in scores between time groups were explored using descriptive statistics. Associations between characteristics and caregiver strain were investigated with multivariable logistic regression models, presented as odds ratios (OR) with 95% confidence intervals (CI), adjusted for gender, age, education status, relative affiliation, and time after OHCA.

Results: Of 561 relatives, 24% (n = 137) experienced caregiver strain, with no significant differences in the relatives' mental well-being, mental health, or caregiver strain with time since OHCA. In the adjusted analyses, older age (OR 0.98 95% CI 0.96;0.99) and several self-reported outcomes, including reduced mental well-being (WHO-5 OR 7.27 95% CI 4.86;11.52), symptoms of anxiety (HADS-A OR 6.01 95% CI 3.89;9.29) and depression (HADS-D OR 15.03 95% CI 7.33;30.80) were significantly associated with worse caregiver strain.

Conclusion: Nearly one-quarter of relatives of OHCA survivors experience caregiver strain, with this proportion remaining unchanged with time. Several outcomes were associated with caregiver strain, emphasising the need to identify relatives at greater risk of burden following OHCA.

Keywords: Out-of-hospital cardiac arrest, Cardiac arrest, Relatives, Caregiver Strain, Caregiver burden, Cross-sectional study

Introduction

Following out-of-hospital cardiac arrest (OHCA), recent studies show how relatives experience emotional problems, including anxiety, depression and trauma-related stress.[1–3] Beyond this, relatives frequently encounter a sense of burden in everyday life following OHCA.[3–8] To address this, understanding the consequences of caregiving for OHCA survivors is needed, e.g., using the concept of caregiver burden. Caregiver burden is a multidimensional and complex strain due to physical, psychological, social, and financial consequences of caring for a family member.[9] This burden, known as caregiver strain, associated with social isolation, sleep disorders, poor quality of life and high levels of distress[10,11] can impede optimal support for the patient, leading to adverse patient outcomes.[1]

The incidence of caregiver strain among individuals caring for OHCA survivors fluctuates between 15–28% within the initial two years following the event.[1–3,12] While studies have shed light on the potential reduction in caregiver strain from the first months to years following OHCA,[1,2] knowledge on a longer perspective is lacking. However, based on our recently published data on survivors' outcomes, where we describe no changes in self-reported outcomes from 1-5 years after OHCA[13], we do not expect caregiver strain to improve with time either.

Causes of caregiver strain after OHCA are multifaceted, commonly related to changes in everyday life due to supporting the

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OHCA survivor and needing to adapt one's own life and needs.[6,8] However, caregiver strain might also be attributed to the secondary consequences of OHCA, e.g., cognitive impairment.[3] Bohm et al. have shown how caregiver strain and quality of life are worse among relatives of survivors with cognitive impairment compared to those without.[3] Furthermore, relatives who have directly witnessed the OHCA and actively participated in resuscitation efforts might be at greater risk of experiencing trauma-related stress.[1–3,12] To effectively support and identify relatives at risk of experiencing caregiver strain, a deeper understanding of the characteristics defining these relatives and the potential impact of strain on other outcomes is needed. Thus, the objectives of this study were to describe differences in mental well-being, mental health, and caregiver strain at different time points 1–5 years post-OHCA among relatives of OHCA survivors and to investigate characteristics associated with worse caregiver strain.

Material and methods

Study design

The study is based on data from a national cross-sectional survey, the DANCAS (DANish Cardiac Arrest Survivorship) survey.[14] The DANCAS survey is described in the published protocol.[14]

Participants, setting and data collection

Individuals $\geq$ 18 years old who suffered an OHCA between 1 January 2016 and December 2019 and alive after 30 days were identified through the Danish Out-of-Hospital Cardiac Arrest Registry (DHRCA). The survey was completed from October 2020 to March 2021, with Danish residents able to read and write in Danish being eligible.

The survivors were asked to choose a relative to respond to the relatives' survey. Relatives could be spouses/partners (living together), partners (not living together), siblings, parents, children or friends. The relatives had to be $\geq$ 18 years old and able to read and write in Danish. The relatives' survey was included in the invitation to the OHCA survivors. To enhance the representativeness of the study population, the OHCA survivors and their relatives were allowed to request a paper survey sent by postal mail with stamped envelopes. Hence, respondents were not constrained if they lacked access to a computer or not able to answer the questionnaire online. Reminders were sent via e-Boks and by post. Additionally, all respondents could contact a DANCAS survey phone if they had any questions regarding the study.[14] Before enrolment, feedback from a user panel led to a reduction in the number of questions and improved the clarity of the participation information sheet.[14]

The cohort was separated into different groups based on the number of years since the occurrence of the OHCA. This resulted in four distinct groups, each corresponding to relatives of OHCA survivors from the years 2016, 2017, 2018, and 2019.

Clinical and sociodemographic data

Clinical and sociodemographic data related to the OHCA survivors were obtained from DHRCA and included age, gender, date and location of OHCA, potential cardiopulmonary resuscitation (CPR) before ambulance arrival (yes/no), and potential defibrillation before ambulance arrival (yes/no).

For relatives, sociodemographic data and other self-reported information related to the OHCA were obtained as part of the survey and included age, gender, relative, witnessing of the OHCA (yes/no) and performing CPR (yes/no).

Self-reported health

The four distinct caregiver groups were compared using the following self-reported measures:

The World health organisation's five well-being index

The World Health Organisation's Five Well-being Index, WHO-5, is a measure of mental well-being, which includes five statements with six responses on a scale from "At no time" to "All of the time" (scoring 0–5).[15] The scores are summed and multiplied by 4, with 0 representing the worst imaginable well-being and 100 representing the best. A total cut-off score $\leq$ 50 represents a potential risk of depression or stress.[15,16] WHO-5 has been validated across various populations, including myocardial infarction,[16] but not among caregivers of OHCA survivors.

The hospital anxiety and depression scale

The Hospital Anxiety and Depression Scale, HADS, measures symptoms of anxiety and depression within one week of recall. The scale consists of 14 items, divided into two sub-scores: HADS-A and HADS-D with scores from 0 to 21 and a cut-off score $\geq$ 8 representing symptoms of anxiety (HADS-A $\geq$ 8) or depression (HADS-D $\geq$ 8).[17] The HADS has been validated among wide groups of populations, including cancer and stroke[18], but not caregivers of OHCA survivors.

The modified caregiver strain index

The Modified Caregiver Strain Index, M−CSI, measures possible caregiver strain,[19] based on 13 items with three response levels ("yes, on a regular basis", "yes, sometimes", and "no"). The M−CSI score ranges from 0 to 26, with higher scores indicating a higher level of caregiver strain and a total cut-off score $\geq$ 7 representing caregiver strain.[19] The M−CSI has been validated among caregivers of patients with e.g., chronic illnesses, disabilities, dementia and stroke[9,11,20] but not among caregivers of OHCA survivors. The M−CSI was chosen because, in addition to physical caregiving, it also captures several other aspects of caregiving, including sleep disturbances, emotional adjustments, changes in social plans and economic consequences of caring – areas that have all been found to be relevant among relatives of OHCA survivors.[8]

The informant questionnaire on cognitive decline in the elderly-cardiac arrest

The modified version of The Informant Questionnaire on Cognitive Decline in the Elderly-Cardiac Arrest, IQCODE-CA, was included as a proxy for possible cognitive decline.[21] The instrument is an observer-reported measure, where the informant is asked to evaluate the current cognitive function of the survivors compared to before the cardiac arrest. The instrument includes 26 items and is scored on a five-point scale, with total scores divided by 26. A higher score indicates greater observed cognitive decline. A cut-off of $\geq$ 3.04 has been suggested as possibly indicating cognitive decline among OHCA survivors.[21] The IQCODE-CA has been validated and found to be a reliable tool among OHCA survivors.[21]

The feeling of loneliness and experience of support

The survey included a question about loneliness derived from the Danish National Health Survey[22]: "*Does it ever happen that you*

are alone even though you would prefer to be with other people?" Similarly, three questions on post-OHCA support were included: *"Do you have someone to talk to if you have problems or need support?", "Have you sought support after your relative's cardiac arrest?"* and *"Have you lacked support from others in the process after your relative's cardiac arrest?".*[14]

Statistical analysis

Descriptive statistics were used to describe the study population, with categorical data presented as numbers and percentages and continuous data presented as mean and standard deviation (SD) or median and interquartile range (IQR), as appropriate. Normality was tested with the Shapiro-Wilks test and visualised with a Q-Q plot.

One-way ANOVA/Bonferroni correction or Kruskal-Wallis test, as appropriate, was used to investigate differences in scores of the self-reported instruments and time groups (years of the OHCA). The equal variance was tested with Bartlett's test. Similarly, differences in proportions of self-reported outcomes and time groups were tested using the Chi-squared (χ^2) test.

Unadjusted and adjusted logistic regression models were performed separately to investigate factors associated with worse caregiver strain (M−CSI ≥ 7) and adjusted for the following, based on evidence[1,2,23]: age, gender, education status, relative affiliation and year of the OHCA. Test for equality between the predicted and the observed value was tested with the Pearson goodness-of-fit test. The results were expressed as odds ratios (ORs) with 95% confidence intervals (CIs).

The level of statistical significance was p-value < 0.05. The analyses were performed with STATA® version 18 (StataCorp, College Station, TX, USA).

Ethics approval

The investigation conformed to the principles outlined in the Declaration of Helsinki. The Region of Southern Denmark Ethics Committee was notified about the study (20192000-19). The Danish Data Protection Agency in the Region of Southern Denmark approved the handling of data for the present project (journal no. 22/17759). All participants received written information.

Results

Study population

In total, 561 relatives of OHCA survivors responded (response rate 45%) (Fig. 1). Of the responding relatives, 492 (88%) were women, the median age was 64 years (IQR 55;70), and the majority (83%) were a spouse or partner living with the survivor (Table 1). Half of the OHCAs (50%) occurred in private residences, and 53% of the relatives had witnessed the OHCA, with 54% having performed CPR (Table 1). The relatives described having sought help from family and friends (63%), general practitioner (18%) and psychologist (21%), among others, while 23% stated that they lacked help (Table 1).

Mental well-being, mental health and caregiver strain

Mental well-being, mental health and caregiver strain across groups of years since the OHCA was compared. The overall median and mean scores of each instrument and differences among the groups are presented in Table 2.

Impaired mental well-being (scores ≤ 50 of WHO-5) was reported by 22% of relatives (n = 126), symptoms of anxiety (HADS-A) by 31% (n = 174), and symptoms of depression (HADS-D) by 10% (n = 54). Similarly, 24% (n = 137) reported caregiver strain (M−CSI ≥ 7) (Table 2). Descriptive analyses revealed no statistically significant differences in continuous scores for each instrument or the proportions of relatives reporting worse scores among the time groups (Table 2). Of the 24% relatives reporting caregiver strain (M−CSI ≥ 7), n = 111 (81%) also reported possible survivor cognitive decline (observer-reported IQCODE-CA cut-off ≥ 3.04, p < 0.001) (not shown in table).

Association between different characteristics and the risk of experiencing caregiver strain

In the adjusted regression models, higher age was significantly associated with a reduction in caregiver strain (OR 0.98 95% CI 0.96;0.99) (Table 3). No other sociodemographic variables were associated with caregiver strain.

Mental well-being (OR 7.27 CI 95% 4.86;11.52), symptoms of anxiety (OR 6.01 CI 95% 3.89;9.29) and symptoms of depression (OR 15.03 CI 95% 7.33;30.80) among the relative, and (observer-reported) cognitive decline of the OHCA survivor (OR 6.65 95% CI 4.06;10.88) were significantly associated with caregiver strain in the adjusted analyses (Table 3). Lack of support after OHCA was significantly associated with caregiver strain, as well as loneliness, lack of having someone to talk to and having sought support from a general practitioner, psychologist, social worker or others (e.g. a priest, peers, The Danish Heart Foundation or Center for Brain Injury) (Table 3).

Discussion

In this cross-sectional study, we aimed to describe mental well-being, mental health and caregiver strain among relatives of OHCA survivors, and potential differences in these outcomes at four distinct time points, 1–5 years after the OHCA. In addition, we investigated characteristics associated with caregiver strain. We found that 24% of the relatives experienced caregiver strain with higher age being associated with a reduction in caregiver strain. Worse scores of mental health and well-being were associated with higher levels of caregiver strain. Contrary to previous studies,[1,2] our findings revealed no differences in caregivers' reporting of mental well-being, mental health, and caregiver strain when comparing the four distinct groups. Although being investigated in a cross-sectional study, this suggests that relatives' mental well-being, mental health, or caregiver strain remains at the same levels across time. One-quarter of the relatives experienced impaired mental well-being and caregiver strain, with nearly one-third reporting significant symptoms of anxiety consistent across the four distinct years. This indicates a prolonged negative impact of OHCA. While our findings contrast with some longitudinal studies,[1,2] they align with studies showing increased care burden when facing survivor issues or witnessing the event.[3,24] To add to the high proportion of relatives experiencing symptoms of anxiety, we highlight how this proportion is seemingly higher than the proportion of survivors. Although not performed as paired analyses, 31% of the relatives reported symptoms of anxiety compared to nearly 20% of the OHCA survivors also completing the DANCAS survey.[13] The explanation for this high proportion among relatives is likely complex. Still, it might be related to trauma from the OHCA, fear of
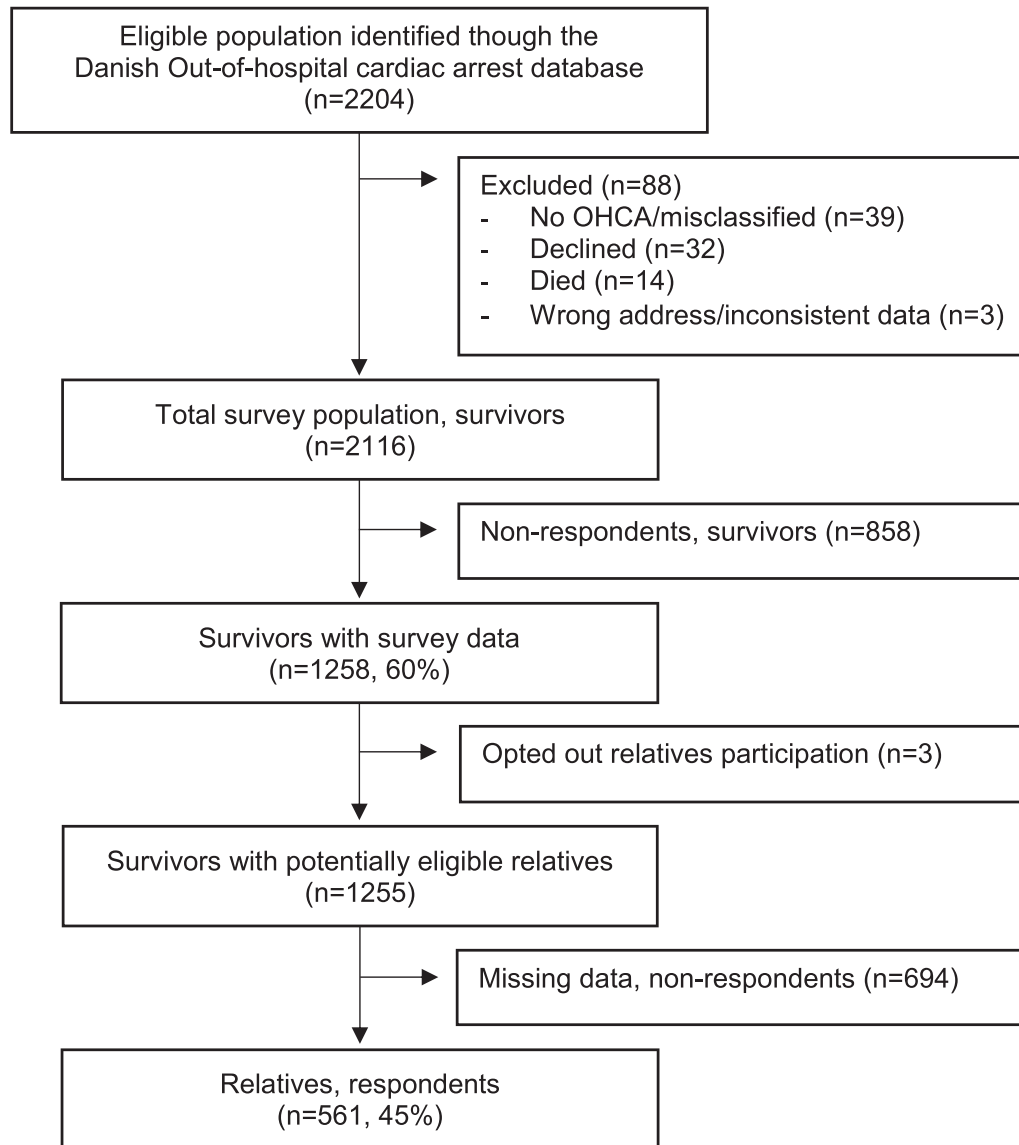
Fig. 1 – Study flowchart. Study flowchart illustrating the population from eligible survivors to responding relatives.

reoccurrence – or change in social or economic circumstances.[5,6,8] This suggests more research is needed with a focus on the relatives and the survivors' mental health during clinical follow-up.

Nearly one in four relatives experienced caregiver strain following OHCA, impacting family dynamics and roles.[5,6,20] Relatives who experience caregiver strain often feel compelled to adjust their lives to the survivor's needs, affecting social life and personal time.[6,8] This might explain why we find high proportions of relatives with caregiver strain and symptoms of anxiety. Also, cognitive impairments of the survivor can influence family life, including changes in roles and family dynamics.[3,5,6] Our study echoes findings from Bohm et al.'s[3] where relatives of survivors with cognitive impairment are twice as likely to experience caregiver strain, aligning with our results where 81% of strained relatives reported a possible cognitive decline in the survivor. High proportions of caregivers with strain pose challenges in supporting the survivor, and neglecting caregiver needs can be economically costly – with the United States spending $61 billion in 2015 on informal care for cardiovascular patients, a figure estimated to rise significantly.[25]

In line with previous studies[1,3], our research indicates that mental well-being, anxiety, and depression are significantly associated with caregiver strain. One explanation might be that caring for someone else influences your overall well-being, indicating how being burdened impacts quality of life.[23] Further testing of the measurement properties of these outcome measures is needed including relative's perspectives of the constructs being measured. A better understanding of the quality of the measures is important to ensure trustworthy research findings. Furthermore, seeking support from healthcare professionals was linked to a higher caregiver burden, emphasising the strain relatives face without adequate support.[5,6] Thus, evidence-based support during follow-up for OHCA survivors and their relatives is urgently needed, which is also supported by recent European guidelines on post-resuscitation care.[26]

Older relatives were less likely to experience caregiver strain, possibly because they have fewer roles to fulfil, e.g, due to retirement and an "empty nest" situation, where children are no longer residents at home.[9] In contrast, younger relatives with children at home may face higher burden due to caregiving expectations alongside

Table 1 – Characteristics of the OHCA survivors and their relatives.

Characteristics	OHCA survivor n = 561	Relatives n = 561
Women, n (%)	87 (16)	492 (88)
Age, year, median (IQR)	67 (59;75)	64 (55;70)
Relative affiliation, n (%)		
Spouse/partner, living together	–	462 (83)
Partner (not living together)	–	10 (2)
Sibling (sister/brother)	–	11 (2)
Parent	–	18 (3)
Friend	–	3 (1)
Child	–	55 (10)
Year of the OHCA, n (%)		
2016	119 (21)	–
2017	130 (23)	–
2018	137 (24)	–
2019	175 (31)	–
Localisation of OHCA, private, n (%)	280 (50)	–
Cardiopulmonary resuscitation before ambulance arrival, n (%)	430 (77)	–
Use of defibrillation before arrival of ambulance, n (%)	137 (24)	–
Potential witnessing of the OHCA, n (%)	–	294 (53)
Performing of cardiopulmonary resuscitation, n (%)	–	165 (54)

Table 2 – Self-reported mental well-being, mental health, caregiver strain and experience of support among relatives at different years of the OHCA.

| Characteristics of the relatives | Year of the OHCA | | | | | |
	All (n = 561)	2016 (n = 119)	2017 (n = 130)	2018 (n = 137)	2019 (n = 175)	p-value
Well-being, WHO-5						
Total score, median (IQR)	72 (52;80)	72 (48;80)	72 (52;80)	72 (56;80)	72 (52;80)	0.898
Total score, mean (SD)	65.9 (22.5)	63.9 (24.6)	67.2 (21.5)	65.9 (21.8)	66.2 (22.5)	–
WHO-5 $\leq$ 50, n (%)	126 (22)	31 (26)	24 (18)	31 (23)	40 (23)	0.553
Mental health, HADS						
HADS-A, median (IQR)	5 (2;8)	5 (2;8)	5 (2;8)	5 (3;9)	5 (2;8)	0.941
HADS-A, mean (SD)	5.6 (4.2)	5.6 (4.4)	5.7 (4.1)	5.8 (4.1)	5.5 (4.2)	–
HADS-A $\geq$ 8, n (%)	174 (31)	37 (31)	40 (31)	47 (34)	50 (29)	0.756
HADS-D, median (IQR)	1 (0;4)	1 (0;5)	1 (0;4)	1 (0;4)	1 (0;4)	0.878
HADS-D, mean (SD)	2.6 (3.4)	2.9 (3.8)	2.6 (3.6)	2.3 (2.9)	2.5 (3.5)	–
HADS-D $\geq$ 8, n (%)	54 (10)	17 (14)	9 (7)	9 (7)	19 (11)	0.120
Caregiver strain, M−CSI						
Total score, median (IQR)	2 (0;6)	3 (1;8)	2 (0;6)	3 (0;6)	2 (0;6)	0.319
Total score, mean (SD)	4.2 (4.9)	4.9 (5.5)	4.2 (5.4)	4.0 (4.4)	3.7 (4.5)	–
M−CSI $\geq$ 7, n (%)	137 (24)	35 (29)	31 (24)	34 (25)	37 (21)	0.447
Experience of support, n (%)						
Does it ever happen that you are alone even though you would prefer to be with other people? (*Yes*)	259 (47)	54 (46)	62 (48)	64 (47)	79 (46)	0.983
Do you have someone to talk to if you have problems or need support? (*No*)	50 (9)	13 (11)	14 (11)	11 (8)	12 (9)	0.538
Whom have you sought support from the following after the survivors' cardiac arrest?						
Friends/family	354 (63)	72 (61)	75 (58)	99 (72)	108 (62)	0.070
General practitioner	102 (18)	22 (18)	20 (15)	31 (23)	29 (17)	0.421
Psychologist	116 (21)	29 (24)	15 (12)	30 (22)	42 (24)	0.030
Social worker	9 (2)	<5	<5	<5	6 (3)	0.091
Others	41 (7)	8 (7)	6 (5)	18 (13)	9 (5)	0.023
None	105 (19)	28 (24)	29 (22)	18 (13)	30 (17)	0.112
Have you lacked support from others? (*Yes*)	127 (23)	31 (26)	33 (26)	26 (19)	37 (21)	0.448

Kruskal-Wallis test was used to investigate differences in scores of the self-reported instruments and time groups. Differences in proportions of self-reported outcomes and time groups were tested using the Chi-squared (χ^2) test.

Table 3 – Characteristics associated with caregiver strain, unadjusted and adjusted logistic regression models.

Characteristics	Caregiver strain (M−CSI ≥ 7)	
	Unadjusted (crude)	Adjusted
	OR (95% CI)	OR (95% CI)[*]
Women vs men	1.75 (0.89;3.45)	1.71 (0.85;3.43)
Age, years, per one year increase	**0.98 (0.97;0.99)**	**0.98 (0.96;0.99)**
Relative affiliation		
Spouse/Partner, living together	1.00 (ref)	1.00 (ref)
Partner, not living together	0.75 (0.16;3.60)	0.70 (0.14;3.42)
Sibling (sister/brother)	0.30 (0.04;2.38)	0.24 (0.03;1.94)
Parent	1.51 (0.55;4.11)	1.17 (0.39;3.49)
Friend	1.51 (0.14;16.79)	1.50 (0.13;17.55)
Child	0.84 (0.43;1.65)	0.56 (0.26;1.21)
Year of the OHCA		
2016	1.00 (ref)	1.00 (ref)
2017	0.75 (0.43;1.32)	0.77 (0.43;1.38)
2018	0.79 (0.46;1.38)	0.75 (0.43;1.32)
2019	0.64 (0.38;1.10)	0.66 (0.38;1.14)
Potential witnessing of the OHCA		
Witnessing vs not witnessing	1.19 (0.83;1.69)	1.20 (0.82;1.76)
Performing of cardiopulmonary resuscitation		
Not performed vs performed	1.23 (0.72;2.09)	1.45 (0.81;2.60)
Well-being (WHO-5)		
WHO-5 ≤ 50 vs WHO-5 > 50	**6.53 (4.22;10.10)**	**7.27 (4.86;11.52)**
WHO-5, continuous	**0.96 (0.95;0.97)**	**0.96 (0.95;0.97)**
Mental health (HADS)		
HADS-A ≥ 8 vs < 8	**7.75 (5.06;11.87)**	**6.01 (3.89;9.29)**
HADS-A, continuous	**1.34 (1.26;1.42)**	**1.33 (1.25;1.41)**
HADS-D ≥ 8 vs < 8	**13.50 (6.96;26.18)**	**15.03 (7.33;30.80)**
HADS-D, continuous	**1.43 (1.33;1.53)**	**1.44 (1.34;1.56)**
Observer-reported cognitive decline (IQCODE-CA)		
IQCODE-CA ≥ 3.04 vs < 3.04 (cognitive decline)	**7.26 (4.47;11.77)**	**6.65 (4.06;10.88)**
Does it ever happen that you are alone, even though you most want to be with others?		
Yes vs no	**4.20 (2.75;6.41)**	**4.12 (2.67;6.38)**
Do you have someone to talk to if you have problems or need support?		
No vs yes	**2.23 (1.22;4.07)**	**2.25 (1.21;4.19)**
Support from the following after your relative's cardiac arrest?[**]		
Friends/family vs no	0.90 (0.61;1.34)	0.72 (0.47;1.10)
General practitioner vs no	**2.41 (1.53;3.80)**	**2.18 (1.37;3.49)**
Psychologist vs no	**2.56 (1.65;3.96)**	**2.31 (1.45;3.70)**
Social worker vs no	**6.43 (1.59;26.06)**	**5.86 (1.37;25.17)**
Others[***] vs no	**2.64 (1.38;5.05)**	**2.59 (1.32;5.09)**
I have *not* sought the support of anyone vs yes	0.73 (0.43;1.24)	0.78 (0.45;1.34)
Have you lacked support from others?		
Yes vs no	**4.97 (3.23;7.63)**	**4.85 (3.11;7.60)**

Note. OR = odds ratio; CI = confidence interval.

[*] Adjusted for gender, age, relative affiliation, educational level, year since the cardiac arrest.

[**] As the responders could "tick" several options of support, these variables were tested individually and not grouped.

[***] Others included a priest, alternative treatment, relative peers, The Danish Heart Foundation, Center for Brain Injury and the municipality.

employment needs. As a result, the potential consequences of an OHCA involve restructuring family structures – influencing daily life.[5,6] Supporting "younger" OHCA families warrants increased attention from clinicians and future research.

Notably, gender was not a significant risk factor for experiencing caregiver burden either. In our study, the relatives were predominantly female spouses/partners. While previous studies have shown women often assume caregiving roles,[9] the unequal gender distribution among OHCA survivors might have influenced this result. Our findings demonstrate how the understanding of caregiver strain following OHCA can be complex, and thus, it can be challenging to identify relatives at risk of experiencing strain. With younger age as the only sociodemographic characteristic associated with strain, healthcare professionals should acknowledge this group of relatives needing specialised support. However, given that nearly one in four are grappling with caregiver strain, there is a pressing need to enhance support—be it through family assistance, early follow-up, or other tailored initiatives aimed at relatives.

Strengths and limitations

The main strength of this study is the large sample size compared to other studies about relatives of OHCA survivors, as well as the long-term follow-up.[1–3,24,27] Despite 88% of the relative respondents being women, the population is considered to be representative with a significant majority of men experiencing OHCA.[13] Still, the study has some limitations. First, the study is cross-sectional; therefore, the temporal link and potential causation between the outcome and the exposure cannot be determined. Second, although reporting the long-term consequences of OHCA on relatives is a strength of the study, this might also lead to a risk of recall- and selection bias. With a response rate of 45%, relatives of survivors with more comorbidities, lower mental health and cognitive decline might be reluctant/less likely to respond. Thus, there is a risk of relatives with the highest caregiver strain not being represented in the survey, and therefore, our results might be underestimated. Third, WHO-5, HADS, and M−CSI have yet to be validated among relatives of OHCA survivors. Still, due to their use among the general population, their performance is expected to be reasonable. Finally, limitations of the M−CSI include the limited response options (from "yes, on a regular basis" to "yes, sometimes" and "no") and showing examples on each item that can be irrelevant for the current group of caregivers (e.g. sleep disturbances due to worrying about the survivor contrary to the example on the M−CSI with sleep disturbances due to the person being cared for wandering in and out of bed).

Conclusion

Nearly one-quarter of relatives experience caregiver strain up to five years after OHCA. There were no variations across time groups in the proportion of relatives facing caregiver strain, diminished mental well-being and symptoms of anxiety and depression. Younger relatives faced a higher risk of caregiver strain, and various self-reported outcomes, e.g., survivor cognitive decline, lack of support and the feeling of loneliness, were significantly associated with caregiver strain. This knowledge underscores the need to address relatives at significant risk of experiencing strain following OHCA.

CRediT authorship contribution statement

Anne Sofie Hermansen: Writing – review & editing, Writing – original draft, Formal analysis, Data curation. **Vicky L. Joshi:** Writing – review & editing, Project administration, Methodology. **Mette Kirstine Wagner:** Writing – review & editing. **Karin B. Dieperink:** Writing – review & editing. **Ann-Dorthe Zwisler:** Writing – review & editing, Methodology, Conceptualization. **Britt Borregaard:** Writing – review & editing, Supervision, Methodology, Formal analysis, Data curation, Conceptualization.

Data availability statement

Due to the nature of this research, participants did not agree for their data to be shared publicly, so supporting data are unavailable.

Declaration of competing interest

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.

Acknowledgements

Appendix A. Supplementary data

The lay summary of the article can be found online at https://doi.org/10.1016/j.resuscitation.2024.110298.

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