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Clinical paper

Follow-up care after out-of-hospital cardiac arrest: A pilot study of survivors and families' experiences and recommendations



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Abstract

Background and objectives: Cognitive and physical difficulties are common in survivors of out-of-hospital cardiac arrest (OHCA); both survivors and close family members are also at risk of developing mood disorders. In the UK, dedicated follow-up pathways for OHCA survivors and their family are lacking. A cohort of survivors and family members were surveyed regarding their experience of post-discharge care and their recommended improvements.

Method: 123 OHCA survivors and 39 family members completed questionnaires during an educational event or later online. Questions addressed both the actual follow-up offered and the perceived requirements for optimal follow-up from the patient and family perspective, including consideration of timing, professionals involved, involvement of family members and areas they felt should be covered.

Results: Outpatient follow-up was commonly arranged after OHCA (77%). This was most often conducted by a cardiologist alone (80%) but survivors suggested that other professionals should also be involved (e.g. psychologist/counsellor, 64%). Topics recommended for consideration included cardiac arrest-related issues (heart disease; cause of arrest) mental fatigue/sleep disturbance, cognitive problems, emotional problems and daily activities. Most survivors advocated an early review (<1month; 61%). Most family members reported some psychological difficulties (95%); many of them (95%) advocated a dedicated follow-up appointment for family members of survivors.

Conclusions: The majority of OHCA survivors advocated an early follow-up following hospital discharge and a holistic, multidimensional assessment of arrest sequelae. These results suggest that current OHCA follow-up often fails to address patient-centred issues and to provide access to professionals deemed important by survivors and family members.

Keywords: Out-of-hospital heart arrest Assessment Patient outcome Patient involvement Psychosocial functioning Cognitive impairments

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Introduction

Every year approximately 30,000 individuals in England alone are treated by emergency services following an out-of-hospital cardiac arrest (OHCA); around 8% of them survive to hospital discharge, consistent with comparable data from other European countries.^{1,2}

There is mounting evidence of persistent long-term difficulties following OHCA, affecting different physical, cognitive and psychosocial domains. These include but are not limited to fatigue³, difficulties with memory and other cognitive abilities,^{4,5} difficulties in returning to work/driving/other activities of daily living,^{6,7} pain,⁸ and significant levels of anxiety, depression, and Post Traumatic Stress Disorder (PTSD).⁹ The reported incidence and prevalence of these difficulties vary in the scientific literature, possibly due in part to the variable timing of the follow-up, as some issues tend to manifest themselves in different ways at different points in time.¹⁰ A recent scientific statement from the American Heart Association highlighted these challenges and the knowledge gaps around survivorship care.¹¹

Specific cardiac arrest related follow-up after hospital discharge is recommended by current American Heart Association (AHA) and European Resuscitation Council (ERC) guidelines.¹² Both guidelines identify a need to complete a multidimensional assessment of survivors and caregivers/family members, covering physical (fatigue) and non-physical domains (anxiety, depression, posttraumatic stress, cognitive impairment) and providing information as appropriate. ERC guidelines also suggest this should be completed within three months of hospital discharge. These suggestions are similar to those provided in NICE guidelines on rehabilitation after critical illness in adults¹³; however, although most OHCA survivors (but notably not all) are also ICU survivors, AHA and ERC guidelines introduce recommendations that apply specifically to this cohort of patients (that is, emotional screening of relatives/family members).

Common standards for a dedicated follow-up pathway following an OHCA are currently lacking in the UK. Indeed, it is unclear how frequently these follow-up appointments are being offered, at what point post-discharge, which professionals are involved, what topics are discussed, and whether such approaches were designed with patient and family input. To the best of our knowledge, there has been no systematic survey of current follow-up practice in the UK. Evidence from a Swedish national web-based survey of health care staff, suggests only very minimal involvement of professionals other than cardiologists, cardiac nurses or physiotherapists.¹⁴

The aim of this study was therefore to investigate the problems encountered by survivors and their families after OHCA, their experience of follow-up care and what improvements they felt could be made to the follow-up appointment to make it more relevant and targeted.

Methods

Design

A questionnaire was developed for this study (see [Supplementary material](#)) and delivered as a hybrid paper-and-pencil and on-line survey using a descriptive, cross-sectional mixed method study design. Family members/friends of survivors completed a separate survey to

explore their own experience of support after discharge of the OHCA survivor. The design was informed by the patient experience improvement framework adopted by the UK National Health Service¹⁵ with a particular focus on improving patient experience and engaging with groups of patients to inform delivery of a new model of care.

In accordance with the above objective, a questionnaire was co-designed by an expert multi-disciplinary group with specialist interest and expertise in the follow-up of cardiac arrest survivors to ensure content validity (this group included clinical psychology, occupational therapy, cardiac nursing and cardiology). Thirteen close-ended questions investigated survivors experience in hospital and after discharge, with a focus on most common difficulties as reported in the literature, actual follow-up received, referrals to support services and suggestions regarding an 'ideal' follow-up experience. Survivors were asked to provide basic demographic information (age, gender, date of cardiac arrest), and cause of arrest if known.

Five close-ended questions were also asked to family members, focussing on what support they received during and after hospital admission of the cardiac arrest survivor, what psychological difficulties they experienced after discharge, their ability access psychological support and whether a dedicated appointment for relatives of survivors was needed.

An additional open-ended question was added at the end of the questionnaires for both survivors and relatives to provide additional qualitative feedback.

The survey was first administered to a convenience sample of survivors and their relatives during an educational event ('Not Alone' - <https://www.suddencardiacarrestuk.org/not-alone-event/>) co-organized by the Essex Cardiothoracic Centre and Sudden Cardiac Arrest UK¹⁶ in September 2019. The same survey was later made available on the sudden cardiac arrest UK website in June 2020 for 17 days and promoted on the SCA UK Facebook main public page. The delay between the 'in-person' and 'online' survey was due to administrative delays and to the onset of the Covid-19 pandemic.

The study was registered by Mid and South Essex NHS Foundation Trust and was conducted as a service evaluation as defined by the UK NHS Health Research Authority (www.hra.nhs.uk) using anonymous data and therefore did not require review by the Research Ethics Committee.

Data analysis

Quantitative data were tabulated and analysed using standard software (Excel, Microsoft Corp, Redmond WA; Jamovi). Multiple response analysis was adopted to report frequencies and percentages by cases and responses. Qualitative data provided in the open-ended questions were subject to thematic content analysis¹⁷; two different coders (MM and EN) independently familiarized themselves with the dataset, and identified and coded data into broad categories. Categories were refined via repeated reading and familiarization with responses and comparison of codes in relation to the whole dataset, using a constant comparative method.; themes were then identified inductively to capture respondents' experiences. A consensus was reached for both survivors and family members and examples provided for each theme for illustration.

Results

A total of 123 people attended the Not Alone event. 82 completed this survey (66%) on the day, but only 75 questionnaires were analysed (49 survivors, 26 caregivers – 6 participants did not sign the informed consent page and 1 only provided demographic information without answering any question). The online survey was later completed by 87 participants (74 survivors; 13 caregivers). All available socio-demographic data is presented in Table 2 (supplemental material).

Chi-square tests of associations were completed for the variables considered in this study to investigate differences between online and in-person respondents; the null hypothesis was not rejected for any analysis, therefore all responses were merged and analysed as a single dataset.

All applicable items were completed in the submitted questionnaires with no missing data.

Cardiac arrest survivors

A total of 49 questionnaires were completed during the Not Alone educational event, with 74 more completed online at a later date (total N = 123). 100 survivors (81.5%) provided their demographic, with 68 of them (55.2% of total sample) also giving valid information about the cause of the cardiac arrest.

Of the 100 survivors who provided valid demographic information (58 male; 42 female), the median age at time of OHCA was 51 years (IQR 13.25; range 18–71). In this cohort there was a significant difference in the median age at time of OHCA according to gender, with women being younger (46 vs 53 years, Mann-Whitney U = 828.5, $p = 0.00656$). Time from cardiac arrest to completion of the survey ranged from 19 days to 25 years, with a median time post-arrest of two years (IQR = 4). Seventy-two survivors (72%) experienced their cardiac arrest within the preceding five years.

The reported cause of arrest was myocardial infarction in 19 participants (26%), cardiomyopathy in 9 (12%) and idiopathic in 32 (43%). Eight survivors (11%) reported other causes.

Follow-up experience of care

Following discharge, 95 survivors (77%) were offered a follow-up appointment in relation to their cardiac arrest. Of these 95 survivors, 80% ($n = 76$) reported seeing a cardiologist; a nurse was also present in nearly a third of appointments (31% $n = 29$), whereas the presence of other therapists was much less frequent (see Fig. 1).

Survivors were asked to rate the quality of care both in hospital, prior to discharge, and if applicable at follow-up, on a 5-point Likert scale (Fig. 2). Although in both cases the experience was predominantly positive, more instances of poor experience of care ('mostly negative' and 'very negative' responses) were reported at follow-up (12.6% vs 0.8%).

Of the 95 survivors who were offered a follow-up, 55 (58%) reported that a family member was also specifically invited, 31 (33%) that this was not mentioned and 9 (9%) were not sure.

Most common concerns post-cardiac arrest

Survivors reported a wide range of difficulties following OHCA, with fatigue, issues with memory/thinking and anxiety being the most frequently reported, making up together more than half of the total responses (53%). Other commonly reported problems included loss of confidence, low mood and ongoing physical limitations (Fig. 3). Issue reported in the 'other' section included migraines, ICD related pain, loss of confidence when driving, pins and needles and general physical deconditioning.

Expectations and suggestions regarding an ideal follow-up

Survivors were asked to suggest what professional(s) should be involved in follow-up. Fig. 1 presents the percentage of survivors who indicated, for each professional role, whether they should be involved in a follow-up.

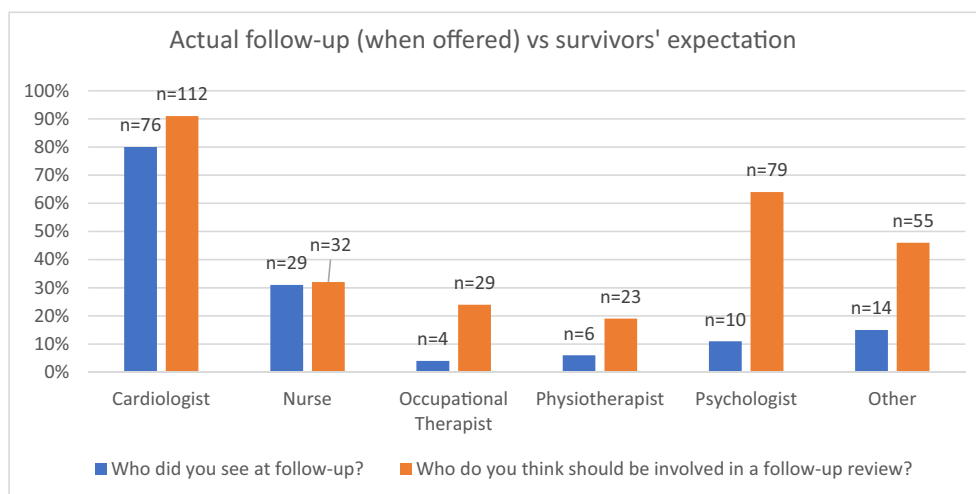


Fig. 1 – Number of respondents who reported having been followed up by cardiologist (n = 76; 80%), nurse (n = 29; 31%), occupational therapist (n = 4; 4%), physiotherapist (n = 6; 6%), psychologist (n = 10; 11%) and other doctor/allied health professional (n = 14; 15%) vs respondents' expectations around who should follow them up instead (cardiologist – n = 112, 90%; nurse – n = 32, 32%; occupational therapist – n = 29; 24%; physiotherapist – n = 23; 19%, psychologist – n = 79; 64%; other doctor/allied health professional n = 55; 46%).

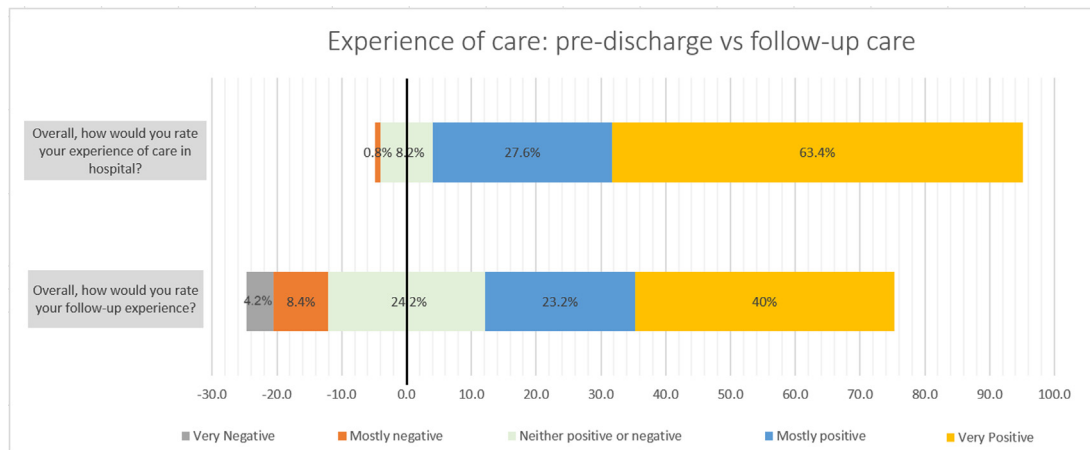


Fig. 2 – Percentage of respondents indicating quality of care before discharge from hospital (Very Negative = 0%; Mostly negative = 0.8%; Neither positive or negative = 8.2%; Mostly positive = 27.6%; Very positive = 63.4%) and after discharge from hospital (Very Negative = 4.2%; Mostly negative = 8.4%; Neither positive or negative = 24.2%; Mostly positive = 23.2%; Very positive = 40%).

Cardiologists and nurses were indicated as necessary during a follow-up by respectively 91% and 32% of the survivors. This cohort felt that occupational therapists, physiotherapists and psychologists should be more frequently involved than they currently are (respectively 24% vs 4%; 19% vs 6%; 64% vs 11%). They also indicated that other professionals should be involved, as appropriate, depending on the needs of the patient – e.g. other consultants (neurologist, intensivist, respiratory medicine), and rehabilitation staff.

Survivors were also asked to suggest the best time to offer a follow-up, and what topics should be covered. Their responses are summarised in Figs. 4 and 5. Nearly all subjects felt that a follow-up was advisable (99%). More than half (61%) reported that it should be offered within the first month, with only a quarter (24%) suggesting that this should happen between 3- and 6-months post discharge.

With regard to the topics that should be covered, most survivors indicated a wide range, with cause of cardiac arrest, heart disease, screening for emotional problems and discuss mental fatigue and sleep as the most common (Fig. 5).

Family members of cardiac arrest survivors

A total of 26 questionnaires were completed during the Not Alone educational event, with 13 more completed online later (N = 39). 33 participants provided demographic information in this group, with most responses provided by females (6 Male; 27 Females). Median age of this group was 52 years (IQR 15; range 15–73).

In this cohort, 24 (62%) witnessed the cardiac arrest, with 17 (44%) attempting CPR. The majority (95%) reported lingering psychological difficulties after the survivor was discharged from hospital; anxiety was the most commonly reported symptom (33% of responses), followed by poor sleep and 'flashbacks' (respectively 25% and 22%). Additional difficulties reported in the 'other' category included 'guilt'; 'mental breakdown'; 'hyper-vigilance'.

Of the 37 responders who reported ongoing psychological difficulties, only 11 were able to access support. Most family members (37 out of 39; 95%) reported that a specific follow-up appointment should be offered to relatives of survivors.

A summary of the suggestions provided by survivors and relatives is presented in Table 1.

Content analysis of qualitative data

Survivors

The following three superordinate themes were identified from the analysis of OHCA survivors' responses: "gratitude for survival/support received"; "poor/disjointed follow-up experience"; and "need for specific OHCA follow-up pathway".

Qualitative data suggested that survivors' experience of care before discharge was largely very good: 'The hospital care was faultless'; 'hospital experience was excellent'; 'survived thanks to the NHS'

However, many survivors experienced some difficulties in the transition from hospital to home, and limited clarity around who should provide support after discharge:

'I feel that it would have helped to have some kind of step down care'; 'Not sure who is "responsible" for treating with any post-discharge issues'

Several respondents also highlighted a lack of a specific offering tailored to OHCA survivors:

'The problems I was encountering post SCA [sudden cardiac arrest] were not what the others in my rehabilitation group had as they were post stents, post pacemakers'; 'it is important to be able to meet or interact with others who have suffered an SCA or professionals that understand the challenges',

For some survivors this impacted negatively on their mental health:

'Once out of hospital I was left to flounder and my mental health went backwards as the months progressed.'; '[I] felt confused and anxious and on my own to just get on with it.

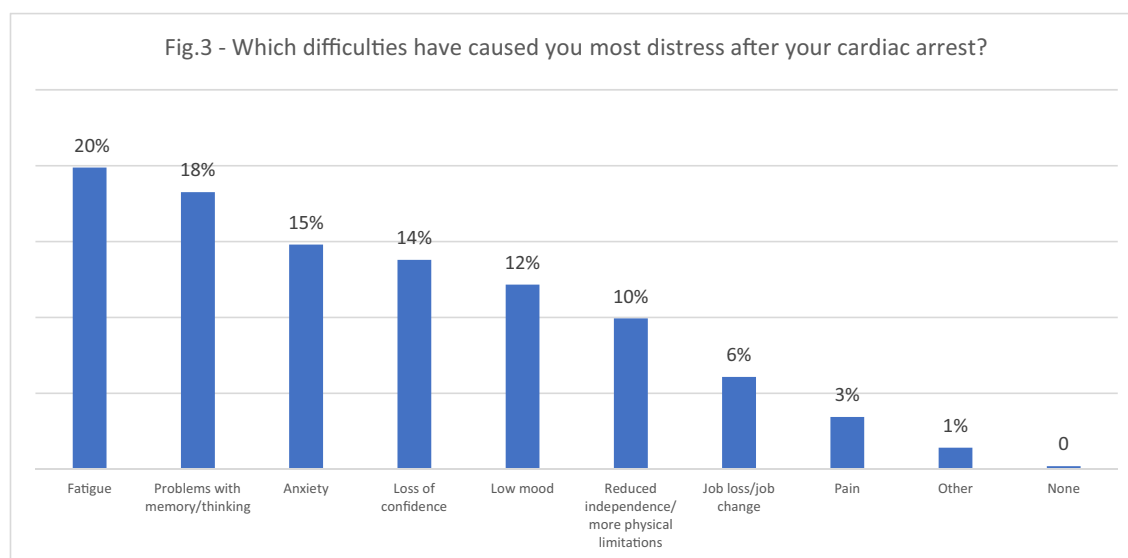


Fig. 3 – Most frequently self-reported difficulties following sudden cardiac arrest (percentage of total responses and, in brackets, number of survivors selecting each option): Fatigue = 20% (n = 98); Problems with memory/thinking = 18% (n = 90); Anxiety = 15% (N = 73); Loss of confidence = 14% (n = 68); Low mood = 12% (n = 60); Reduced independence/more physical limitations = 10% (n = 49); Job loss/job change = 6% (n = 30); Pain = 3% (n = 17); Other = 1% (n = 7); None = 0% (n = 1).

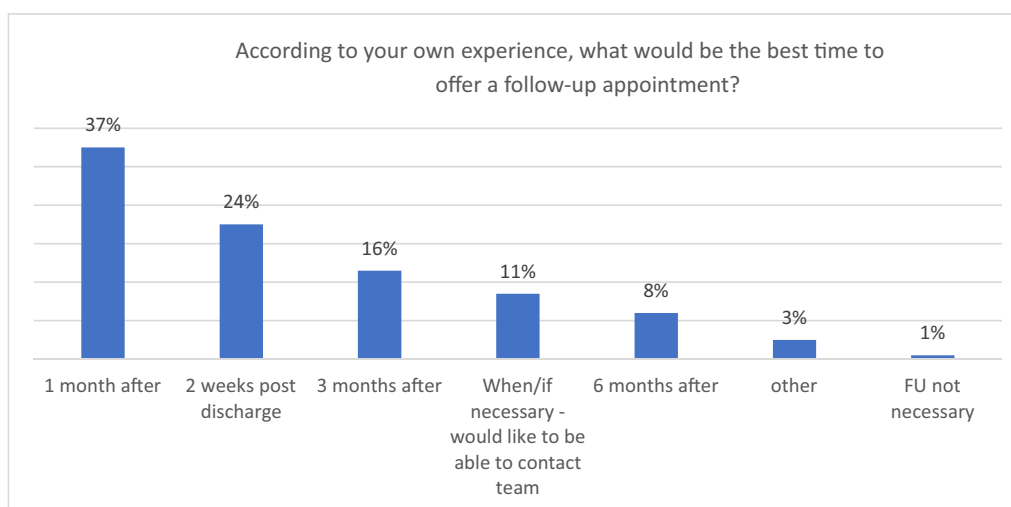


Fig. 4 – Optimal time for follow-up review according to OHCA survivor – percentage of total responses. 1-month post discharge = 37%; 2 weeks post discharge = 24%; 3 months post-discharge = 16%; When/if necessary – would like to be able to contact team = 11; 6 months post discharge = 8%; Other = 3%; Follow-up not necessary = 1%.

Some responses also indicated a need for a more structured follow-up pathway, with routine offering of some level of psychological assessment and therapy, aimed at preventing deterioration in mental health:

'A more bespoke review to include mental [health] and effect on family [is needed]'; '[post discharge care] has to be better than this with more psychological support than is currently available'

Family members

Qualitative data provided by family member allowed identification of the following two superordinate themes: a) *assessment of family members' emotional needs crucial to avoid long-term mental health issues*; b) *education needs for family members on how to help OHCA survivors post-discharge*.

Many family members reflected on the fact that this event affects the whole family, and as such some emotional screening should be offered to close family members too:

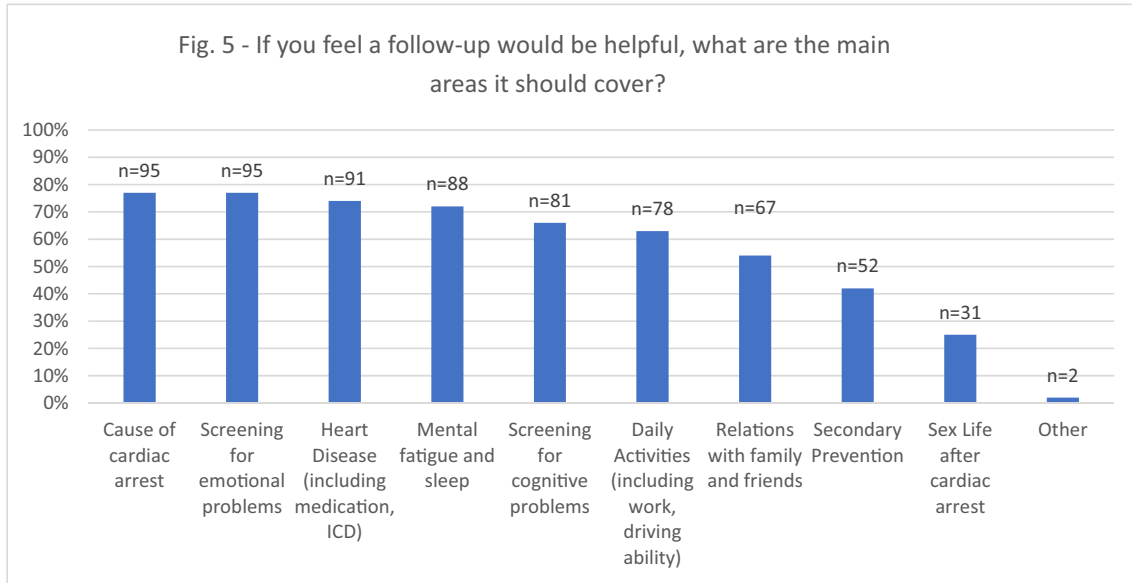


Fig. 5 – Number of respondents choosing each option: Cause of cardiac arrest (n = 95; 77%), Screening for emotional problems (n = 95; 77%), Heart Disease (n = 95; 74%), Mental fatigue and sleep (n = 88, 72%), Screening for cognitive problems (n = 81; 66%), Daily activities (n = 78, 63%), Relations with family and friends (n = 67, 54%), Secondary prevention (n = 52, 42%), Sex life after cardiac arrest (n = 31, 25%), Other (n = 2, 2%).

Table 1 – Follow-up recommendations based on survey data.

TIMING OF FOLLOW-UP	FAMILY INVITED?	PROFESSIONALS INVOLVED	TOPICS TO DISCUSS	AFTER FOLLOW-UP
Within a month of discharge	Yes	Cardiologist (specialist) Nurse ± Psychologist ± Occupational Therapist ± Physiotherapist ± Another medical consultant as appropriate	Cause of cardiac arrest; Heart disease; Screening for emotional and cognitive difficulties; Fatigue; Daily activities (including driving, return to work) Secondary prevention	Access to appropriate support as identified at follow-up

'Not everyone needs help, but I think it's important to recognise the whole family after the experience of arrest'; 'I needed advice on how to cope with our new existence, none was offered'

In addition, they report an unmet educational need around 'how best to help'

'Any advice on coping and helping the rehabilitation of the survivor would have been invaluable'.

Discussion

In this survey we aimed to investigate the actual experience of care after discharge of cardiac arrest survivors and their family members, focussing on specific difficulties experienced and their own perception of what follow-up care should look like.

A majority of survivors reported having been seen at follow-up by a cardiologist and/or a nurse. Although this appears in line with their expectations of who should complete the review (Fig. 1), a sizeable percentage (>40%) also stressed the importance of seeing other professionals such as psychologists/counsellors and other medical consultants, with around 20% also indicating they would have wanted a physiotherapist/occupational therapist at follow-up. This is possibly a reflection of the type of post-discharge difficulties experienced by this group of survivors; unsurprisingly, screening for emotional and cognitive problems, discussions around return to work and driving, management of fatigue, secondary prevention and identifying problems in daily activities are all areas that this group of survivors would like to see covered at follow-up (Fig. 3). We note that many of these areas – most notably, anxiety, memory, re-establishing a routine, depression and driving – were recently identified as the biggest challenges to overcome to achieve a 'new normal',¹⁸ and difficulties in transitioning to a 'new normal' were also described using semi-structured interviews in a small cohort of survivors,¹⁹ with emotional,

Table 2 – Socio-demographic data available for the cohort of respondents (survivors and family members).

	Online	In-person	Age	Time from cardiac arrest	Cause of cardiac arrest (as reported)
Survivors taking part to the survey	Male N = 43	Female N = 31	-	-	-
Family members taking part to the survey	Male N = 0	Female N = 13	-	-	-
Survivors with available socio-demographic background data	Male N = 42	Female N = 30	Male (At time of OHCA) Range: 17–70 Median 53 Interquartile range 11.75	Female (At time of OHCA) Range: 18–71 Median 46 Interquartile range 13.25	MI = 19 Cardiomyopathy = 9 Idiopathic = 32 Other = 8
Family members with available socio-demographic data	Male N = 0	Female N = 13	Male (at time of survey) Range: 33–69 Median 54 Interquartile range 17.75	Female (at time of survey) Range: 15–73 Median 52 Interquartile range 15	-

physical and psychosocial factors all playing a role. The focus on these areas is strongly in line with AHA and ERC recommendations around timely assessment of cognitive, emotional, and physical domains.^{11,12}

The partial mismatch between actual and expected follow-up experience suggests that appropriate skill sets may not be currently available in OHCA follow-up teams. In the absence of a national survey around current standards of care for this cohort of patients, it is reasonable to assume that the results from a Swedish survey – that is, a paucity of health professionals other than cardiologists and nurses involved in the follow up – might also apply to the UK. There is currently no consensus around which health professionals should be part of the follow-up team, however our survey suggests access to psychologists, occupational therapists, physiotherapists and other specialist doctors could be beneficial to survivors and their relatives. Some OHCA follow-up clinics are already offering a similar pathway.^{20–22}

In our survey, a majority of survivors felt that a follow-up should be offered within a month of discharge, if possible [Fig. 4]; this is largely in keeping with ERC recommendations (complete a review in the first three months). Involvement of family members was advocated by most relatives, with a focus on their own recovery (as recommended by AHA guidelines). This is in keeping with a growing body of evidence suggesting that relatives undergo their own process of recovery; from the shock of witnessing the cardiac arrest,²³ to having to cope with the ‘abrupt disappearance of the system’ in the transition from hospital to home,²⁴ to experiencing persistent symptoms of post-traumatic stress disorder and anxiety.^{25–27} There is also growing awareness that relatives have a need for tools/instructions on how to help support the survivors after discharge²³; this was also reported by the group of relatives we surveyed, with some wishing they had received some indication on how to best support the survivor.

Limitations

This study has several methodological limitations. First, the questionnaire used in this survey, although informed by recent guidelines and co-designed by a multi-disciplinary group, did not include substantial input from survivors and their families in the choice of content and wording of questions. Also, the questionnaire would have benefitted from being piloted with a small sub-set of survivors/family members to investigate face validity and readability across different ages and socio-demographical backgrounds.

A further limitation is the extent to which the reported comments and suggestions can be generalised to all OHCA survivors: the opinions reported are from a self-selected group of relatively young cardiac arrest survivors (median age 52 years) with a high prevalence of idiopathic cardiac arrest, largely recruited via an internet-based support group aimed at providing information and support following OHCA. Arguably, this group is more likely to include survivors and family members who have experienced significant difficulties and lack of support post-discharge, introducing a significant sampling bias. Including open-ended questions in our survey allowed a trade-off between volume of responses and richness of data collected; however, participants’ comments do not provide the same depth of understanding obtainable using focused interviews, hence these results should be viewed as exploratory and requiring further investigation.

In addition, considering additional patient experience frameworks (such as the Warwick patient experience framework²⁸) in the creation of this questionnaire could have allowed a more nuanced exploration of patients' experience.

Survivors taking part in this survey were all members of Sudden Cardiac Arrest UK (UK residents and expats) and individually assessed by a member of our team (PS), who asked for confirmation that they had suffered a cardiac arrest and their individual motivations for joining the group (with those seeking bereavement support being signposted elsewhere). Survivors' self-reported medical details have not been verified and we cannot exclude the possibility that some of them reported incorrect information regarding their cardiac arrest.

Conclusions

Despite the above limitations, our work provides much needed preliminary data on the actual follow-up experience and expected standards of post-discharge care of a group of OHCA survivors and their relatives. Based on this data, future studies should work collaboratively with OHCA survivors to refine the specific survey questions, and to investigate the experience/expectations of a more diverse and representative sample.

CRedit authorship contribution statement

Marco Mion: Conceptualization.

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.

Appendix A. Supplementary material

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.resplu.2021.100154>.

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