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PSYCHOLOGICAL ASPECTS OF CARDIOVASCULAR DISEASES (A STEPTOE, SECTION EDITOR)

Shock to the Heart: Psychosocial Implications and Applications of Sudden Cardiac Death in the Young

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Abstract

Purpose of Review Although rare, sudden cardiac death (SCD) in the young is a tragic event, having a dramatic impact upon all involved. The psychosocial burden associated with SCD can leave friends, families, and entire communities bereft. With only limited evidence to describe the volatile emotional reactions associated with a young SCD, there is an urgent need for care providers to better understand the psychological complexities and impacts faced by both at-risk individuals and those directly affected by these tragic events.

Recent Findings Current knowledge of the psychosocial implications associated with SCD in the young has recently generated interest in the cardiovascular community, with the goal of addressing prevention strategies (screening), family bereavement, and the psychological impact of at-risk or surviving individuals. With the emergence of novel strategies aimed at reducing the public health impact of SCD in the young, further discussion regarding the psychosocial impact of SCD, encompassing prevention, survivorship, and the downstream communal effects of a young death is required. Support systems and intervention could assist in the management of the associated psychosocial burden, yet there is a lack of clinical guidelines to direct this form of care.

Summary There is an important need for multidisciplinary collaboration across subspecialties to provide support to grieving individuals and manage patient well-being throughout the screening process for SCD. This collaborative approach requires the integration of cardiovascular and psychological expertise where relevant.

Keywords Sudden cardiac death · Sudden cardiac arrest · Psychosocial · Psychological adaptation · Athletes · Multidisciplinary care

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Introduction

The occurrence of sudden cardiac death (SCD) in a young person is devastating, having profound impacts on both the victim's family and an entire community. The reported incidence of SCD among those < 35 years of age in the USA from 1999 to 2015 was 1.32 per 100,000 individuals [1], although there is great variation in these estimates noted across the globe for specific age groups [2]. Evidence has shown that the incidence of a young SCD increased with age from 0.49 (1–10 years of age) to 2.76 per 100,000 individuals (26–34 years of age) [1]. In comparison, for infants < 1 years of age, sudden infant death syndrome is the most common cause of death [3]. Among youth, inherited heart diseases are the major cause of SCD, including both arrhythmia syndromes and cardiomyopathies [1, 2].

Given the rarity of SCD in the young, tragedy lies in the dramatic loss of life-years for a young individual, and the loss of this individual's contribution to society. With the unexpected nature of such an event, it is difficult to apply social productivity metrics to quantify the impact of shock, sense of injustice, and fear of these events upon the victim's network. To reduce the public health impact of young SCD, recent efforts aim to identify at-risk patients through screening initiatives and risk stratification [4]. Additionally, the development of preventative education focused on the provision of high-quality resuscitation and defibrillation, particularly among children and young adults, has emerged as a potential tool to improve bystander emergency care and survival [5].

Although recent advancements in preventative and onsite emergency protocols have been made, little is known of the psychological impact faced by at-risk patients and those directly impacted by a young SCD. The profound psychosocial burden that affects those close to a young victim of SCD throughout the stages of bereavement is often overlooked by the clinical cardiovascular community, particularly during immediate management and post-mortem familial screening processes. Yet, with early therapy and support, the psychological implications of SCD can oftentimes be improved, reducing the effects of anxiety, distress, and depression on those most impacted. Further discussion regarding the psychosocial impact of SCD, encompassing prevention, survivorship, and the downstream communal effects of a young death, is required. In particular, the development of clinical recommendations for psychological support in the familial screening, management, and post-mortem grievance processes following SCD in a young relative is warranted.

Psychological Implications of Prevention

The unanticipated tragedy of a SCD is often perpetuated by the victim's apparent health, typically not exhibiting any history of symptoms or disease prior to death. Given evidence that almost 50% of all sudden unexpected deaths under the age of 18 occur due to a potential inherited cardiac disease [6], the importance of screening and prevention cannot be overemphasized. The introduction of community-wide screening programs has been proposed for young, at-risk populations, such as athletes [2]. However, concerns regarding the accuracy of screening, impact of positive findings (whether they be false or true positives), and cost implications are major obstacles for uptake of such initiatives [2, 7]. Despite widespread interest in screening from the scientific community, non-profit organizations, and advocacy groups, the psychological consequences of the screening process among young individuals remain a pivotal concern.

Genetic Testing and Familial Screening

As the yield of screening tests are markedly increased by limiting testing to family relatives of disease probands [8], cascade screening has been suggested as an alternative to mass screening measures. The role of genetic testing and familial screening in SCD is threefold: (1) to determine potential disease expression in close relatives, (2) to clarify genetic risk to current or potential offspring, and (3) to identify the cause of death [9]. This approach is particularly useful for families with inherited cardiac conditions, such as hypertrophic cardiomyopathy (HCM), long QT syndrome (LQTS), and arrhythmogenic right ventricular cardiomyopathy (ARVC) [10]. As majority of cardiogenetic conditions, including those previously listed, are inherited in an autosomal dominant pattern, it is expected that on average, each first-degree family member of an affected individual has a 50% risk of inheriting the mutation [11].

Among the young population, identification of a potentially inherited heart condition is of paramount importance for risk stratification, management, and treatment. Early diagnosis has specific relevance for guiding lifestyle modifications, most notably exercise and physical activity. Although the health benefits of physical activity are well-known for acquired cardiovascular diseases or risk factors [12, 13], for patients with congenital or inherited conditions, it is unclear whether exercise training may offer physiological benefits, or could be detrimental [14].

In general, recommendations discourage young individuals with genetic heart conditions from participating in high-intensity and vigorous activities due to the fear of potential cardiovascular events or SCD [15, 16]. These recommendations are based upon evidence suggesting a positive relationship between high-intensity exercise and adverse cardiac events, due to the underlying arrhythmogenic nature of these conditions. For example, endurance exercise and frequent physical activity has been shown to increase the risk of ventricular arrhythmias, heart failure, and ARVC diagnosis in

desmosomal mutation carriers [17]. In comparison, for other populations, such as HCM patients, preliminary evidence has proposed that high-intensity exercise and sports participation are safe and efficacious for selected patient groups, although further prospective research is required to inform exercise recommendations [18].

Despite the controversy among lifestyle modifications for inherited heart disease patients, targeted post-mortem genetic testing following an unexpected death—based on current international guidelines—is routinely recommended [19, 20]. These molecular autopsy tests have relevant implications for both disease diagnosis in the victim and clinical investigations of surviving relatives [4]. However, despite the utility of post-mortem screening, recent evidence highlights important psychological concerns. According to a study of first-degree relatives of young SCD victims who attended a cardiac genetic clinic, over one-third (36%) of participants reported poor psychological adaptation to genetic findings. These individuals were also more likely to report post-traumatic stress symptoms ($p < 0.01$), depression ($p = 0.01$), and lower perceived social support ($p < 0.01$) than those who reported good adaption to genetic information. Overall, this group held a negative view of the molecular autopsy process [21•]. As well, despite the motivation to seek closure for an unexpected death and unveil certainties regarding a diagnosis [22], failure to receive an explanation for the loss of a young individual during the genetic testing process may lead to further grievance. The main reason for forgoing screening in relatives of young SCD decedents is feelings of worry and guilt. Indeed, confronting the possibility of having the disease or becoming aware of their responsibility for passing on the inherited condition or mutation that caused the death is a difficult process [9]. Interestingly, other research involving family members that pursued cardiogenetic evaluation found that majority of participants felt well cared for and not in need of psychological support during the screening process [23].

The integration of psychosocial support and genetic counseling within the cardiac screening process has been suggested as an important solution to manage the complicated social situations that arise from a potential genetic diagnosis, with unique implications for both adult [24] and pediatric populations [25]. Further work into the benefit and impact of cardiogenetic evaluation must not omit evaluation of the differing psychological factors that contribute to the decision of screening healthy, yet potentially at-risk individuals. There is a crucial need for national recommendations to guide the psychosocial care process among those affected by a young SCD.

The Cardiovascular Screening of Young Athletes

The majority of the data on SCD in young individuals has been informed from studies of young competitive athletes. Although these events in the athletic community are rare, they are often widely publicized and gain significant visibility. Among the young athlete population, the incidence of SCD is estimated to be 1–3 cases per 100,000 person-years, although it is hypothesized that this may be an underestimation [26]. Based on a comprehensive review of numerous studies, a reasonable incidence estimate of 1:50,000 was suggested for SCD in young athletes [27]. As several factors associated with sports activity have been shown to increase the risk of SCD among athletes with underlying cardiovascular abnormalities [26], a commonly used approach to SCD prevention is cardiovascular pre-participation screening (PPS). Numerous national organizations have put forward recommendations for PPS [7, 28, 29], although financial implications, resource availability, and the potential for negative psychological impact have limited uptake [2].

One of the most common strategies for promulgating PPS is encouraging uptake from the academic institutions of young SCD victims, although this approach has limited success due to the rarity of these events, which has led to a call for national and international standardization of PPS practices. Some organizations and health systems, such as the English Football Association [30] and the Italian National Health System [31], have implemented long-standing PPS programs for athletes, encouraging health administrators worldwide to consider the value of mass-screening programs. Other initiatives developed by charitable organizations, such as the *Testmyheart* (Cardiac Risk in the Young, UK) and *SafeBeat* (Screen Across America, United States) programs, have established local and regional preventative cardiac screening for youth in an attempt to reduce the risk of SCD. Although improving access to screening for young individuals is at the forefront of these organizations, controversy surrounding the value of cardiovascular PPS, and whether these programs should include electrocardiogram (ECG) screening (in addition to the recommended history questionnaire and physical examination), prevails [32].

Among the various concerns of PPS is the potential for false positive findings due to the use of non-invasive ECG screening. It is thought that such screening results may contribute to a psychological burden because of unnecessary follow-up evaluations and the possibility of disqualification without merit [7, 28]. However, previous research into the psychological impact of screening noted that ECG screening did not cause excessive anxiety in young athletes, including those with false positive findings [33]. Specifically, this study noted that among athletes undergoing ECG screening, only athletes with a true cardiac disorder described heightened anxiety during and after screening, whereas those with false positive findings did not. Furthermore, athletes who received an ECG were more likely to be satisfied with the process ($p < 0.001$), felt safer participating in sport ($p < 0.01$), and stated positive impacts of the ECG to their training ($p < 0.001$), in comparison to the no ECG group. Such

findings suggest that psychological distress should not be used as a rationale to forgo screening. Conversely, other work has demonstrated that young athletes with false positive results do express undue anxiety, mainly attributed to the concern for potential sport disqualification and the development of a future cardiac condition [34]. The highest psychological burdens are noted among those diagnosed with conditions that result in permanent disqualification, such as HCM and LQTS [35], highlighting the importance of sport in the mental well-being and identity of young athletes [36]. Despite the reduction of false positive ECG screens to only 3% as a result of refined international ECG criteria [37], reservations exist around the potential for false restriction and the creation of unnecessary life implications, with emotional, financial, and medical burdens for young athletes, their families, and the broader community.

In addition to the inclusion of the ECG in PPS, the potential role of multi-modality imaging, including echocardiography and stress testing, has also been explored to identify asymptomatic young athletes at risk of SCD [38, 39]. While their utility for the downstream evaluation of athletes who screen positive is well established, they are generally not included in initial screening algorithms due to concerns over cost and a paucity of the required expertise, which would result in unacceptably high false positive and false negative rates. The use of imaging tools with uncertain or imperfect accuracy may parallel the increased psychosocial stress resulting from further testing and unnecessary restriction observed with ECG screening. Imaging alone, without the inclusion of an ECG, is not advisable as many conditions associated with SCD, such as the channelopathies, would be missed. While some advocate for the inclusion of a limited transthoracic echo or point of care ultrasound [40], the diagnostic accuracy and impact on outcomes of this approach has yet to be proven [39].

Dorian et al. (2020) describe some of the potential considerations that need to be emphasized when screening young athletes for cardiac conditions associated with risk of SCD, noting the potential for unnecessary sports restriction and immediate or long-term psychosocial impact as major drawbacks [41]. Given the importance of PPS, providing high-quality psychosocial support and counseling to limit worry pertaining to potential disqualification and false positive testing would be of significant value, rather than opting to forgo testing all together. These considerations are particularly relevant during the midst of the COVID-19 pandemic, where heightened anxiety and stress levels have already been noted among student populations [42, 43] and competitive athletes [44–46].

With no current recommendations to guide the psychological care of at-risk athletes or those diagnosed with life-altering cardiac conditions, the use of shared decision-making (SDM) to enhance participation or restriction decisions has emerged as valuable clinical tool [47, 48]. The open communication engendered by the SDM process has been shown to reduce the anxiety associated with screening, management, and treatment within athletic settings [49]. Overall, ongoing communication with the athlete and a multidisciplinary support team should be emphasized for proper monitoring of psychological burden, both before and following a cardiovascular risk assessment, particularly if a cardiac condition is diagnosed.

The Spectrum of Psychological Impact

The SCD of a young individual is a critical public health concern, representing a devastating event for numerous parties, including families, friends, healthcare providers, and communities. The life of a child or young adult that is cut short due to SCD has dramatic implications, considering their productive years of life lost to provide meaningful societal and economic contributions in the future. In the event a young individual survives a sudden cardiac arrest (SCA), the emotional burden associated with survival, as well as various lifestyle and family modifications, are imminent. The spectrum of psychological impact due to SCD in the young, and the burden associated with SCA survival, is described in Fig. 1.

Psychological Burdens of SCD Prevention and Survival

The diagnosis of a potentially life-threatening cardiomyopathy or channelopathy has a profound impact on the quality of life (QOL), self-perception, and exercise behavior of affected individuals. In one study of children with LQTS, Pediatric Cardiac Quality of Life Inventory scores were comparable to those with Tetralogy of Fallot despite the significant differences in morbidity and prognosis [50]. Using two standardized mental health assessments, this study noted that significantly more children with LQTS reported elevated scores than those expected for the general population on the Internalizing Problems scale, which is intended to measure anxiety, depression, and somatic complaints among participants [50]. Moreover, individuals with HCM report less time engaged in vigorous-intensity exercise (2.2 vs. 3.8 h/week, $p < 0.01$), with over half indicating that exercise restrictions negatively affected their emotional well-being [51]. Comparable findings are reported in many other such disease states including ARVC, where younger women appear to be most at risk [52].

Primary prevention with an implantable cardioverter-defibrillator (ICD) generally has the effect of relieving physician and family anxiety but, for the patient, can serve as a constant reminder of the disease. Further, whereas a psychological benefit of having the device exists, compared to the general population, anxiety levels remain higher in individuals with ICDs across the age spectrum [53]. A consistently identified risk factor for increased anxiety is experiencing an ICD shock. Younger individuals are more likely to experience

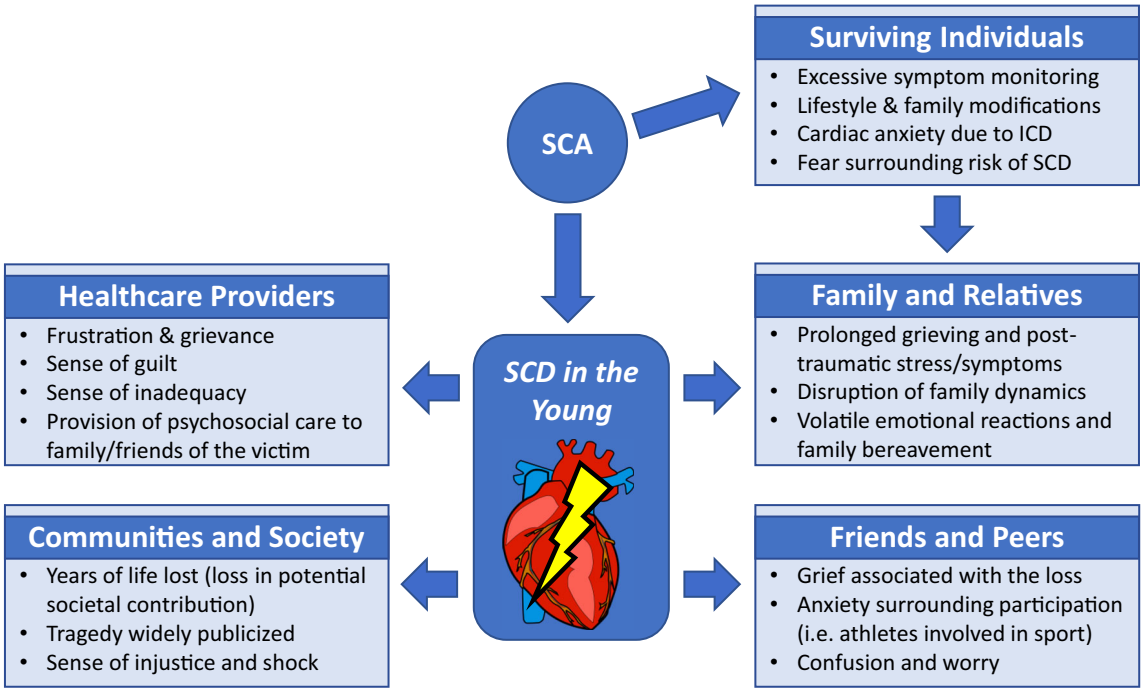

Fig. 1 The spectrum of psychosocial impact in the SCD of a young individual. Multiple complex psychological interactions surrounding the SCD of a young person exist. These unexpected deaths carry profound psychological and emotional effects through families, friends/peers, healthcare providers, society, and especially individuals who survive a cardiac arrest. ICD: implantable cardioverter-defibrillator; SCA: sudden cardiac arrest; SCD: sudden cardiac death

arrhythmic events and, therefore, shock-related anxiety is suspected to be particularly common and debilitating [53]. Notably, experiencing even a single shock is associated with reduction in mental well-being and physical functioning [54]. Indeed, Ingles et al. (2013) reported an incidence of post-traumatic stress in 31% of young people who had experienced an ICD shock [55]. Conclusions from qualitative work has also described longitudinal attitude and activity changes among HCM patients with ICDs, noting adaptivity to necessary lifestyle changes (including leisure activities and professional life) and a reduction in perceived stigmatization [56].

Risk factors which influence QOL in patients with ICDs are age, ICD shock experience, premorbid anxiety and depression, lack of social support, and poor understanding of the device [53, 57]. Early recognition of these important post-procedural risks should be the focus of psychological interventions and must not be omitted during the decision-making process towards implantation. At the very least, it is incumbent upon cardiologists to ensure some level of psychosocial support is available post device implantation.

Survival from a SCA is often met with relief by loved ones and medical personnel. However, this event can profoundly impact perceptions of safety for the individual involved. The psychosocial sequelae may include cardiac anxiety with excessive symptom monitoring and accessing of medical services, avoidance behavior with reduction in physical activity, and distress with worse perceived health outcomes [58, 59]. In a study of 188 survivors of SCA, significantly higher levels of heart-focused attention, greater fear, and avoidance behaviors were noted when compared to LQTS [59].

For patients at risk of SCD, those with an ICD, and for survivors of SCA, current medical care focuses on clinical outcomes despite much of the morbidity relating to potentially modifiable psychological sequelae. Interventions such as education, cognitive behavioral therapy, exercise prescription, and rehabilitation are effective in reducing emotional burden, as well as improving exercise tolerance and QOL. Medical professionals should not provide cardiovascular care related to SCD intervention in a vacuum, devoid of the psychosocial harms a patient may face.

The Impact of Young SCD on Family and Friends

Regardless of the outcome in SCA, resulting psychological distress experienced by close individuals is commonly disregarded in medical practice. The SCD of a young person devastates immediate social networks and leaves a lasting impact on all involved. Given the profound impact associated with a young death from any cause, the silent pathology of most SCD events amplifies the stages of grief and loss for close relatives and friends. Family bereavement experiences following SCD highlights the unplanned and unwanted change that is forced on the family system. The loss of a family member leads to volatile emotional reactions, disrupts

family dynamics, and causes bereaving members to relearn the social world through addressing important questions surrounding the young death [60]. For instance, approximately 1 in 2 family members report significant psychological difficulties, such as prolonged grief, anxiety, and post-traumatic stress symptoms [9, 61]. This is of particular concern for those who witness the death [61] and mothers of the deceased [9]. It is reasonable to assume that psychological challenges may also be present in the siblings of young SCD victims, leading to heightened anxiety and a constant sense of fear surrounding the same risk of death as their sibling.

To better understand the grieving process, Wisten and Zingmark (2007) interviewed bereaving parents following the SCD of a young child and synthesized responses into four unique needs: (1) evidence to grasp the situation, (2) reconstruction of the event, (3) explanation of the cause of death, and (4) sensitivity from supportive parties [62]. Further research on the family bereavement process is sorely required to understand the dynamic management approaches undertaken by families. To this end, recent evidence has suggested the important psychosocial support needs of bereaving families impacted by the SCD of a young individual, highlighting the benefits associated with access to community and peer-to-peer support [63••]. These support networks have been shown to provide a sense of safety and comfort for affected families during times of greatest distress. Specifically, they facilitate the processing of the unexpected event, as well as offer meaningful ways to maintain a continuing bond with the deceased (i.e., fundraising for young SCD-related community organizations) [63••]. Additionally, recent evidence describing the multifactorial needs of parents following a young SCD noted that psychosocial needs were the most unmet; more than half (54%) of their parent sample reported psychosocial information and support needs as unfulfilled by the clinical team [64]. As previously shown, proper psychological management may help facilitate post-traumatic growth experiences following the death of a loved one, improving personal strength, resilience, and empathy [60]. Providing post-loss assistance to families through grief counseling and psychosocial support programs requires further development in clinical practice. The sensitive communication of medical explanations surrounding a SCD, as well as the integration of patient representative groups and peer support into clinical pathways, has been suggested as potential implications for practice [63••].

Future Directions and Gaps in the Psychosocial Management of SCD

To bridge the gap between prevention initiatives, awareness/education, and psychological management in SCD, novel strategies have been established to reduce the burden associated with SCD in the young.

Community-Based SCD Awareness and Training

The goal of community-based prevention and education programs for children and adolescents is to reduce the public burden of SCD. Many of these programs have been initiated within school systems and boards, targeting young students. With limited basic life support training among staff and students, exacerbated by poor automated external defibrillator (AED) positioning within schools [65], significant interest in school-based SCD prevention programs has emerged. The rationale for introducing cardiopulmonary resuscitation (CPR) and AED training in primary and secondary schools is aimed at the knowledge dissemination within larger communities, adding students as potential resuscitators.

Studies have demonstrated preliminary evidence for the efficacy of training programs in educational domains. In Japan, the implementation of a multiple AED system (installing AEDs at assumed accident sites) across schools resulted in significantly shorter AED retrieval times [66]. As well, a recent systematic review demonstrated that CPR and associated skills, such as AED use and standard first aid, could be successfully delivered to children through short training interventions [5]. School-based CPR education has been shown to increase CPR knowledge and practical skill, and, most importantly, strengthen self-confidence in performing such maneuvers on SCA patients [67, 68]. These findings have important psychological implications, as an individual's motivation to initiate behaviors, such as CPR, is strongly dependent on levels of self-efficacy [69]. This phenomenon can be translated into improvements in bystander-initiated interventions—youth laymen with improved self-confidence of basic life support maneuvers perceive themselves as willing and able to commence CPR or defibrillation in the event of a SCA [70].

Novel teaching methods, such as the incorporation of a blended media-/manikin-based training model [71], student-designed and student-led CPR/AED methods [72], and app-based basic life support training for school children [73], have shown high levels of knowledge application and skill retention. Despite these promising safety initiatives, barriers to implementation, such as lack of funds, instructor competency, and scheduling difficulties [74], remain as major training obstacles. As a result, legislative and funding mandates have been recognized as the frontline requirements to systematically initiate school-based training [5]. Promising initiatives, such as the "KIDS SAVE LIVES" program, which has been endorsed by the World Health Organization [75], have led the charge in training schoolchildren in CPR, encouraging mandatory worldwide training as a means to improve the provision of bystander CPR [76–78]. Although before such mandates can be established, further outcomes-based research on the impact of CPR/AED training in young individuals is required.

Heart-Safe Exercise Promotion in Children and Young Adults

Physical activity and exercise are well-known preventive strategies for SCD among all age groups. Canadian physical activity guidelines suggest that all children 5–18 years of age should participate in at least 60 min of moderate- to vigorous-intensity physical activity per day [79]. Although SCD in the pediatric population is uncommon, the PPS of young individuals prior to entering organized sport or physical activity is gaining recognition, considering the unnecessary anxiety or psychological distress it may cause [33–35, 80]. Nevertheless, children and adults who are diagnosed with congenital or acquired cardiac diseases are still encouraged to maintain some level or physical activity or formalized rehabilitation [81]. Not only does this deliver direct cardiovascular health benefits, but the positive psychological effects of exercise on academic performance, self-esteem, and emotions have also been noted [82]. Since the psychological benefits of exercise are immediately experienced, the promotion of physical activity among children and adolescents through the lens of academic and emotional reward may be a better alternative to the long-term effects of cardiovascular disease prevention [82, 83]. Making involvement safer, through effective screening and SCD prevention therapies (such as AED and CPR education), could help mitigate the barriers and fears of engaging in exercise within the younger population.

The Multidisciplinary Cardiac Genetic Team

Given the potential psychosocial effects of family management and screening following a SCD, the key role of a specialized cardiovascular genetics team is imminent. Recent recommendations have advocated for the importance of integrating multiple subspecialties in the management of SCD in attempt to address specific procedural, ethical, legal, and practical challenges for post-mortem genetic testing [84]. Importantly, the proper provision of care is deeply rooted in the ability of a team to effectively manage grieving individuals, particularly the family of the deceased. In addition to the clinical expertise provided by the cardiologist, the multidisciplinary cardiac genetic team aims to integrate key links with genetic counselors, nurses, geneticists, pathologists, psychologists, cardiologists, primary care partners, and patient-advocacy groups to provide complete physical and psychosocial care to those impacted [4]. Past work advocates for the involvement of such teams within the cardiogenetic evaluation of SCD families [23]. Involvement of clinical psychologists for the provision of direct psychological support and genetic specialists to communicate accurate information on the evaluation process are critical. The roles of members within the multidisciplinary cardiac genetic team during the screening of families with a young SCD are described in Table 1. Overall, improvements for the management of families following SCD have been centered on strengthening the

Table 1 Roles of members within the multidisciplinary cardiac genetic team

Member	Role description
Cardiologist	• Provide directive referral approach to initiate cardiac genetic investigation. • Provide initial cardiac assessment of family members at risk for inherited heart condition.
Genetic counselor	• Oversee and coordinate the genetic screening process. • Assist the family in understanding the risks, benefits, interpretation of results, and potential lifestyle modifications or treatment options following the genetic screening process.
Geneticist	• Perform genetic testing procedure on family members and interpret results. • Organize management and treatment strategies along with other team members.
Nurse	• Act as an intermediary between cardiology, pathology, and genetic specialists. • Serve as a health care contact for the family, providing clinical information, care, and ongoing support.
Pathologist	• Examine biological materials to assist in the diagnosis of a cardiac genetic condition. • Perform post-mortem examination of SCD victim to help guide genetic screening process.
Patient-advocacy Groups	• Provide support services for families suffering from a young SCD. • Allow families an outlet to advocate for personal and community-wide initiatives (i.e. pre-participation screening, cardiovascular safety and prevention measures).
Primary care partner/physician	• Provide directive referral approach to initiate cardiac genetic investigation. • Provide family with educational material surrounding the genetic screening process and answer preliminary questions/concerns.
Psychologist	• Provide ongoing mental health support, therapy, and communication with the family to address concerns throughout the screening process and/or emotional distress after the SCD of a young individual.

SCD sudden cardiac death

information and decision-making process in genetic evaluations, which requires the involvement of a multifaceted team. This may be achieved partly through the constant availability of accurate and relevant information on the evaluation process by the genetic team [23].

Clinical Application: Managing Young At-Risk Athletes and SCD Families

Among the younger population, the role of psychosocial care is of upmost importance for young athletes, of which unexpected cardiac risk or conditions may be unveiled during the PPS process. During the screening process, the clinical application of psychosocial care should intersect along several points of a young athlete's journey. It begins with provision of an informed SDM model, where the athlete (usually in discussion with parents/guardians) may choose to participate in a PPS process, aware of the consequences of participating, further diagnostic evaluation, and potential need for restriction.

Following initial screening, the young athlete and their family must be continuously supported, especially if cardiovascular concerns arise that have not yet led to restriction, but could still impact mental health, anxiety, and performance. Restriction from exercise or sport may have a profound impact upon self-identity, career, and feelings of well-being [85]. Currently, there are no formal recommendations for follow-up in such cases. Existing guidelines may provide detailed algorithmic approaches to screening and testing that would disqualify an athlete, but then omit to consider the impact of such a decision on the overall mental well-being of an athlete. The existing body of literature also fails to recognize the impact of a SCD on teammates, coaches, and parents. The main message from patient advocacy and charitable groups across the globe, such as the Sudden Cardiac Arrest Foundation (USA), Jordan Boyd Foundation (Canada), and Cardiac Risk in the Young (UK), is that the true cost of SCD is not accounted for in the calculus of deciding whether screening approaches are of benefit. A lack of bereavement resources and formal follow-up recommendations demonstrates a critical gap in athletic cardiovascular health. Figure 2 outlines the clinically relevant psychosocial impacts during the life stages of a young athlete, considering important prevention strategies, psychological health, and grievance support (in the case of the SCA/SCD of a young individual).

The outcome of SCD is particularly tragic among young competitive and recreational athletes, oftentimes gaining widespread media attention and pleas from the community

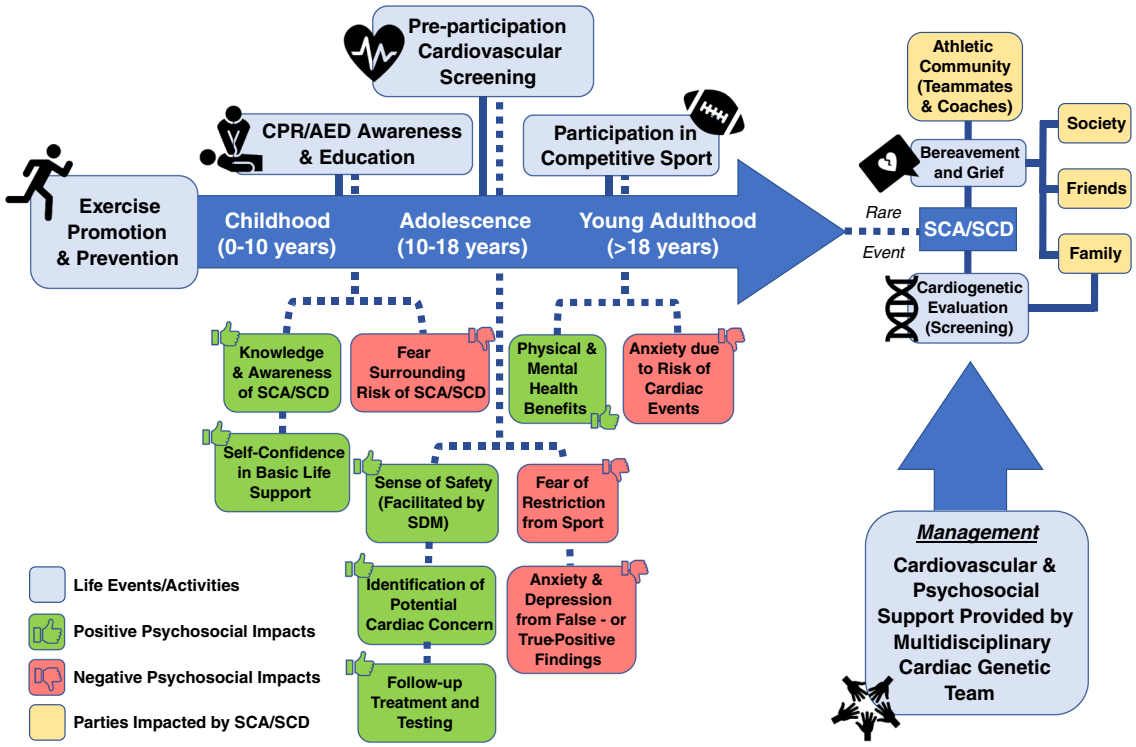

Fig. 2 Considerations and social impacts of cardiovascular care during the life stages of a young athlete. Throughout a young athlete's life, numerous life events and activities intersect the relationship between cardiovascular and psychosocial health, each with clinically relevant positive and negative impacts. In the rare event a young athlete suffers a SCA or SCD, various parties (including family, friends, athletic communities, and society) are affected, both psychologically and emotionally. The multidisciplinary cardiac genetic team should consider each of these important intersections and provide psychosocial support to both the at-risk athlete and grieving individuals. AED: automated external defibrillator; CPR: cardiopulmonary resuscitation; SDM: shared decision-making; SCA: sudden cardiac arrest; SCD: sudden cardiac death

for scientists, physicians, and funding agencies to "do more." These events have an outsized and unexpected psychosocial impact that cannot be compared with death following an illness. On a more local/regional level, strategies to help reduce the burden of SCD in sport and recreational environments are urgently required; these strategies must promote safe exercise while incorporating novel cardiovascular care, prevention, and safety initiatives into the fabric of communities and their environment. For instance, the Community and Athletic Cardiovascular Health (CATCH) Network recently held a national level meeting to discuss the implementation of a community-based action plan to address the burden of SCA/SCD in the physically active population of provincial regions across Canada. Critically, the intersection between cardiovascular and psychosocial care is a crucial consideration when creating, refining, and disseminating these response plans, adapted to local needs, resources, and environments.

Conclusions

The impact of SCD in the young is devastating, resulting in important psychosocial impacts among the victim's social network and beyond. Research should aim to further investigate the process of bereavement and develop strategies to minimize the psychological burden that accompanies the loss of a child or adolescent to SCD. Further collaboration among cardiologists, primary care physicians, geneticists, psychologists, and mental health professionals are required to develop approaches that complement the psychosocial management of SCD prevention strategies, as well as deal with the aftermath of such events.

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Compliance with Ethical Standards

Conflict of Interest The authors report no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain studies with human or animal subjects performed by any of the authors.

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