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CONGENITAL HEART DISEASE (RA KRASUSKI, SECTION EDITOR)

Anxiety and Depression in Adults with Congenital Heart Disease: When to Suspect and How to Refer

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Abstract

Purpose of Review Adults with congenital heart disease face many potential psychosocial challenges. This review focuses on their experiences of clinically significant anxiety and depression and provides recommendations for appropriately timed referrals to mental health professionals.

Recent Findings Adults with congenital heart disease have a higher probability of experiencing symptoms consistent with mood and anxiety disorders, yet risk factors are not well understood. Although patients as a group are often interested in psychological treatment, there is currently under-recognition and under-treatment of mental health concerns.

Summary As provider and patient awareness of the biopsychosocial implications of living with congenital heart disease continues to grow, the focus of comprehensive care is broadening to include attention to psychosocial well-being. Care teams are encouraged to create a culture that fosters open and ongoing dialog about emotional well-being, including depression and anxiety, and includes reliable processes for mental health referrals.

Keywords Congenital heart disease · Depression · Anxiety

Introduction

There are nearly 1.5 million adults living with congenital heart disease (CHD) in the USA [1]. With increased awareness of the biopsychosocial implications of CHD, there is growing emphasis on understanding and managing patients' mental health care needs [2, 3]. Adults with CHD face a variety of psychosocial challenges that fall into two general categories: intrapersonal (e.g., self-esteem, body image concerns, and uncertainty regarding the future) and interpersonal (e.g., difficulties with social interaction and feeling different from others) [4]. Although CHD may affect multiple domains of emotional and social well-being, this review will focus primarily on depression and anxiety, as research has demonstrated that approximately one in three North American adults with CHD who participate in structured psychiatric interviews meet diagnostic criteria for a mood or anxiety disorder [5–7]. Persistent and untreated emotional distress negatively impacts quality of life and may have detrimental effects on cardiovascular outcomes [2, 8••]. As depression and anxiety are often used in colloquial terms, we begin with an overview of psychiatric diagnostic criteria. We next summarize data regarding the prevalence and predictors of depression and anxiety in adults with CHD. We conclude with clinical suggestions for adult CHD (ACHD) providers, namely when to suspect mood or anxiety disorders and a process for referring patients to mental health professionals.

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What do we Mean by "Depression" and "Anxiety"?

Depression

The range of human emotions includes sadness and sometimes feeling down or blue. Individuals with and without CHD often report feeling "depressed," yet it is important to differentiate transient low mood from symptoms consistent with a mood disorder. Psychiatric diagnoses entail

consideration of the number, frequency/duration, and impact of symptoms. In this review, we present diagnostic criteria as outlined in the American Psychiatric Association's fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* [9]. It should be noted that despite its widespread use, the DSM-5 is not without criticism, including that its framework prioritizes diagnoses over individual differences and treatment [10]. Nonetheless, we present *DSM-5* criteria here because many readers are likely familiar with the diagnostic structure. As per the *DSM-5,* a major depressive episode requires the presence of at least five of the following nine symptoms (typically most of the day and/or nearly every day) for a period of at least 2 weeks: depressed mood, decreased interest or pleasure in most activities, significant change in weight or appetite, insomnia or hypersomnia, psychomotor agitation or retardation, fatigue or loss of energy, sense of worthlessness or excessive/inappropriate guilt, difficulty with concentration or decision-making, and recurrent thoughts of death or suicidal ideation; at least one of the symptoms must be depressed mood or loss of interest [9]. A *DSM-5* diagnosis of major depressive disorder requires one or more major depressive episodes in the absence of manic or hypomanic episodes. Major depressive disorder may be coded as mild, moderate, or severe, and may include qualifiers such as anxious distress. Persistent depressive disorder is a distinct mood disorder that shares many symptoms with major depressive disorder (although fewer are required for diagnosis); it is a chronic condition in which depressed mood is present most days, for most of the day for ≥ 2 years [9]. To be diagnosed with a major depressive episode or persistent depressive disorder, symptoms must result in significant distress and/or functional impairment (e.g., negative impact on social and/or occupational roles) [9].

Anxiety

Anxiety is an umbrella term that includes many diagnoses including social anxiety disorder, separation anxiety disorder, and specific phobia. Two diagnoses that ACHD providers are perhaps most likely to encounter in patients are generalized anxiety disorder and panic disorder. The core symptom of generalized anxiety disorder is excessive worry about several events or activities that is difficult to control and occurs most days for at least 6 months [9]. A diagnosis requires ≥ 3 of the following additional six symptoms: restlessness, fatigue, concentration difficulty, irritability, muscle tension, and sleep disturbance. As with the aforementioned mood disorder diagnoses, to be diagnosed with generalized anxiety disorder, the symptoms are associated with significant distress and/or functional impairment [9].

Whereas generalized anxiety disorder is experienced on a daily basis, a panic attack is an intense, discrete episode of a specified cluster of symptoms. It is not uncommon for individuals to label significant anxiety as "having a panic attack," thus thorough assessment is required to properly characterize this experience. The *DSM-5* describes a panic attack as the rapid onset of intense fear or discomfort that reaches peak intensity within a few minutes, and includes ≥4 of the following symptoms: palpitations, chest pain, shortness of breath, dizziness/lightheadedness, sweating, trembling/shaking, choking sensation, nausea/abdominal distress, sensation of chills or heat, numbing/tingling, feelings of unreality/being detached from oneself, fear of losing control, and fear of dying [9]. To meet diagnostic criteria for panic disorder, an individual experiences repeated unexpected panic attacks as well as ≥ 1 month of persistent worry about recurrent panic attacks and/or related maladaptive behavior changes [9]. It is important to note that patients can have anxiety symptoms that do not meet diagnostic threshold, yet might still benefit from mental health treatment.

Depression and Anxiety in Adults with Congenital Heart Disease

Prevalence of Depression and Anxiety

Based upon research studies in which adults with CHD participated in structured interviews, it is estimated that one-third of North American adults with CHD experience symptoms consistent with mood or anxiety disorders; lifetime prevalence risks are even higher [5–7, 11]. An interview study from Germany has also demonstrated elevated prevalence of mood and anxiety disorders compared with the general population [8••]. It should be noted, however, that interview-based research from the Netherlands indicates more positive psychological adaptation among adults with CHD [12]. Although clinical interviews are considered the gold standard to determine whether psychiatric diagnostic criteria are met, most research studies investigating CHD outcomes have relied upon self-report symptom surveys [2]. Questionnaires typically allow for statistical analysis of continuous data (e.g., total symptom scores) and/or categorical data (e.g., whether total scores meet a specified threshold indicative of elevated distress) rather than determination of the presence/absence of formal psychiatric diagnoses. Although results are not unequivocal, it appears that many adults with CHD experience elevated symptoms of emotional distress [2]. In a recent American survey of 130 adults with CHD, 42% reported clinically elevated symptoms of anxiety and 12% endorsed elevated depression symptoms; all but one patient who reported elevated depression symptoms also had elevated anxiety symptoms [13•]. Perhaps the most worrisome aspect of this collective body of research is that a minority of adults with CHD who meet diagnostic criteria for a mood or anxiety disorder and/or report clinically elevated symptoms of emotional

distress have a history of mental health treatment [5–7, 8••, 13•].

Although not a *DSM-5* anxiety disorder, heart-focused anxiety, described as "the fear of cardiac-related stimuli and sensations based upon their perceived negative consequences," [14] merits mention here. A validated measure of cardiac anxiety includes three domains: fear/worry about heart sensations and functioning, avoidance of certain activities out of fear of eliciting cardiac symptoms, and attention/monitoring of cardiac activity (e.g., heart rate) [14]. Heart-/health-related anxiety was the second most frequent psychological concern (71%) identified by patients included in a retrospective review of 100 adults with CHD referred for psychological treatment [15]. Therefore, CHD providers are encouraged to be mindful of the possibility that patients might not report "traditional" psychiatric concerns (e.g., generalized anxiety or depressed mood), yet still endorse cardiac anxiety or coping difficulty that would benefit from mental health treatment.

Risk Factors for Depression and Anxiety

Given the elevated prevalence of significant psychological distress among adults with CHD, the goal of identifying risk factors is understandable. The heterogeneity of the CHD experience, however, seems to correspond with inconsistent outcomes regarding risk factors. In general, the impact of CHD severity (simple, moderate or complex) appears to have less impact on emotional outcomes than functional status [16•, 17]. Similarly, poorer self-reported health status and subjectively rated CHD disease severity have been shown to be more relevant to understanding psychological outcomes than medically documented disease severity [6, 18]. Therefore, providers are discouraged from making assumptions about patients' psychological well-being based upon their original CHD diagnoses.

With regard to sociodemographic factors, here too one observes heterogeneity in outcomes. Results are generally inconclusive with regard to sex, age, marital status, educational attainment, and employment status [19]. Once again, the temptation to make generalizations about psychological well-being based upon sociodemographic background should be avoided.

The "psychosocial" adjective clearly denotes the bidirectional relationship between emotional and social factors and certainly applies to CHD outcomes. Qualitative research highlighted the interpersonal challenges faced by many adults with CHD [4]. In addition, in a cross-sectional study of 280 adults with CHD, social factors (namely loneliness and fear of negative evaluation) emerged as significant predictors of depression and anxiety symptoms in linear regression analyses, whereas cardiac defect complexity did not [6]. Within a subsample of this same cohort, patient recall of parental overprotection in childhood and adolescence was associated with heart-focused anxiety in adulthood [20]. In another study that surveyed 272 Canadian adults with CHD, structural equation modeling revealed that poorer perceived social support was directly related to elevated symptoms of depression and anxiety [21]. Emerging international evidence suggests that patient-reported outcomes are generally poorer among adults with CHD who are unemployed and have never been married [17, 22]. Given apparent relationships between social and emotional functioning, providers are encouraged to inquire about the psychological well-being of patients who self-disclose significant social challenges or poor social support.

Clinical Suggestions for Adult CHD Providers

Recognition of Depression and Anxiety in the Clinical Setting

Providers are challenged with the recognition of significant emotional distress during routine clinic visits as demonstrated by a study that found that 8/22 (36%) of patients identified as "well-adjusted" by their providers indeed met diagnostic criteria for a major depressive episode or generalized anxiety disorder [5]. Some adults with CHD may be reluctant to express psychological health concerns to health providers. Another challenge for providers is the overlap between symptoms of both psychiatric disorders and heart disease (e.g., fatigue, sleep disturbance, palpitations, and chest pain) [2]. The question thus becomes how ACHD programs and providers can better identify patients who might benefit from mental health treatment.

Psychosocial screening has been recommended for adults with coronary heart disease as well as CHD [23–25] and this might seem an obvious clinical pathway. However, we are currently without strong and consistent evidence that supports routine depression screening (i.e., through self-reported questionnaires) in pediatric or adult care settings [26, 27]. Furthermore, there are concerns associated with routine depression screening, including the impact of false-negative screens and antidepressant medications being prescribed to patients with false-positive screens as well as the allocation of limited mental health resources away from appropriate intervention [28]. It is unlikely that many ACHD programs will have sufficient resources for administering psychological symptom surveys to all patients, scoring the surveys, interpreting and discussing scores with patients, following up with interviews to understand ambiguous scores, and, finally, making appropriate referrals. We thus advocate for fostering an environment, in both outpatient and inpatient settings, whereby patients feel more comfortable disclosing psychosocial challenges and providers have greater opportunity and ability to inquire about and recognize significant psychological distress.

The "4 As" have been suggested as a strategy to identify and manage psychosocial issues in the ACHD setting: ask,

advise, assist, and arrange referral [29]. With regard to *asking*, newly published American ACHD guidelines recommend including point-of-care assessment with "simple questions" about mental health during the provider's symptom review [30]. Our examples of open-ended questions to begin the dialog that extends beyond cardiovascular symptoms include the following: (i) How are things (e.g., school, work, free time) going for you these days? (ii) How is your overall quality of life? (iii) How are you doing from an emotional standpoint? (iv) Do you have a hard time managing low mood or anxiety? Such questions can help to facilitate ongoing conversation and create a culture in which patients feel comfortable raising psychological concerns as they arise. It is through such dialog that providers will often be able to *advise* patients about how to cope with common foreseeable challenges (e.g., preparing for a major re-operation). Providers may be able to *assist* patients with current concerns through education and brief problem-solving (e.g., addressing patients' specific concerns during surgical recovery). Finally, as clinically indicated, ACHD providers ideally *arrange* referral to mental health professionals for patients with significant psychological distress. Figure 1 presents a pathway for ACHD providers to engage patients throughout this process during regular clinical encounters. Note that this pathway does not focus on patients at risk for suicide, as these individuals should be referred for urgent psychiatric assessment.

Referring Patients to Mental Health Professionals

Referrals to mental health professionals can be initiated by patients themselves or any member of the ACHD care team. Adults with CHD, as a group, have expressed interest in

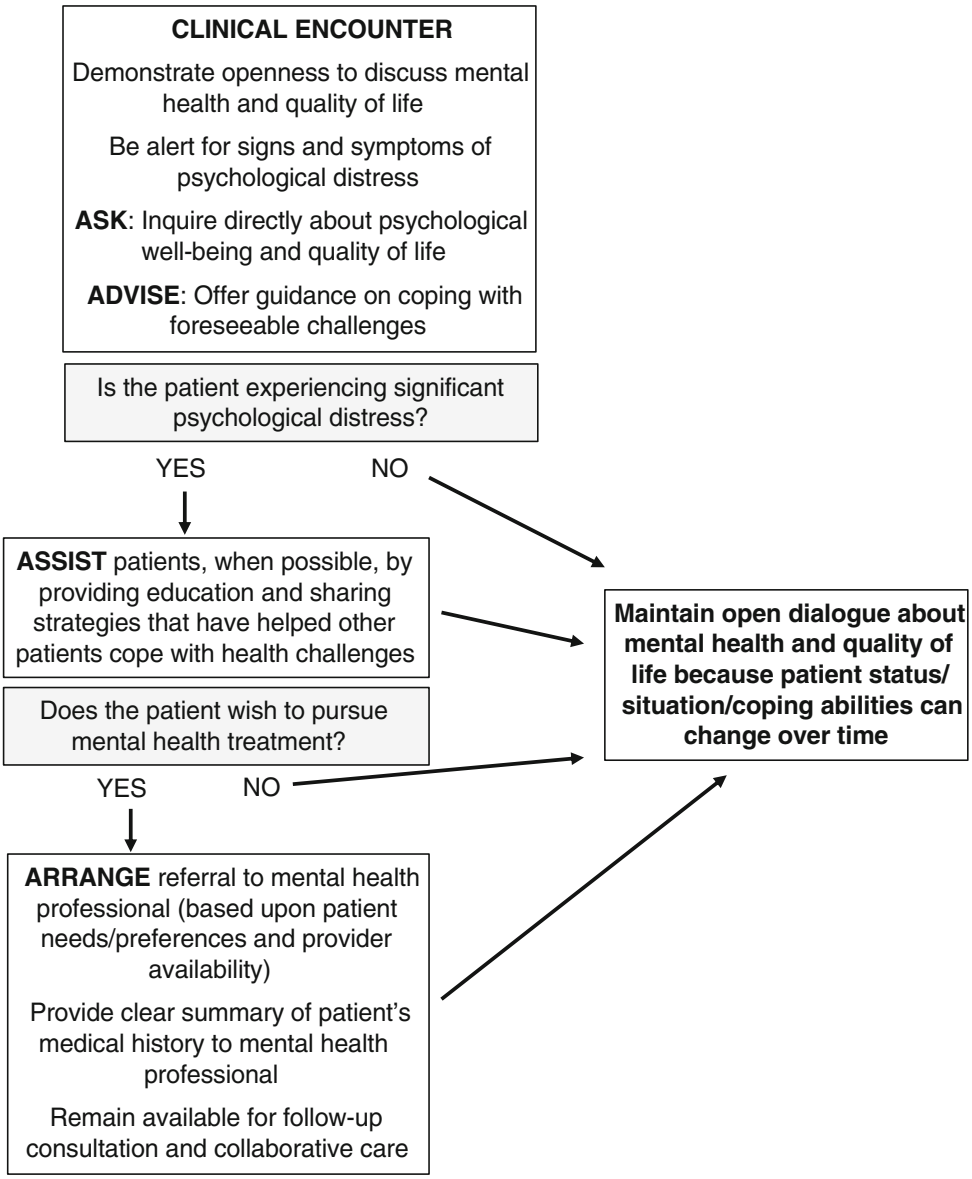

Fig. 1 Psychological distress in adults with CHD. Pathway for recognition and referral in the clinical setting

mental health treatment; among 155 surveyed adults with CHD, 51% reported significant interest in at least one area of psychological treatment, most commonly stress management and coping with a chronic illness [31]. Qualitative research has revealed that patients are interested in individual and/or group therapy and opportunities to interact with other adults with CHD [4]. Providers need not confirm a *DSM-5* diagnosis prior to making referrals; a thorough clinical assessment is the responsibility of mental health professionals. When providers initiate referrals, however, the first step is to ensure that patients themselves want these referrals to be made. Some patients will respond very favorably to the opportunity for mental health treatment whereas others may decline this for a variety of reasons (e.g., perceived stigma, preference to address psychosocial challenges without professional help, financial barriers, etc.).

For patients motivated and able to pursue mental health services, it can often be challenging to identify a mental health professional to whom to make referrals. Ideally, this would be a mental health professional integrated within the ACHD program or with whom the ACHD team has cultivated a strong relationship [31]. A referral list based on providers within the geographic catchment area is also advised [2]. Such a referral list would most appropriately include a variety of mental health professionals, including those with an ability to oversee pharmacotherapy (e.g., psychiatrists and psychiatric nurse practitioners) and those that provide psychotherapy (e.g., psychologists, licensed clinical social workers, and licensed counselors). Psychotherapeutic interventions include psychoeducation, cognitive-behavior therapy, mindfulness training, stress management training, and peer-to-peer support [32]. Although one study observed that adults with CHD tended to prefer psychotherapy over pharmacotherapy [31], individual preferences and matters related to insurance coverage should be explored.

Referral to a mental health professional should be considered the first step in a collaborative approach to coordinated interdisciplinary care. When making the referral, ACHD providers are urged to provide details about the psychological factors/symptoms that prompted the referral, as well as the patient's CHD diagnostic and treatment history. Clear, easy-to-understand information regarding the patient's medical history is especially important when referring to mental health professionals with limited knowledge of CHD or experience working with adults with heart disease. Any additional details regarding the specific impact of CHD on patients' psychosocial well-being may also be appreciated. Given the known overlap between many cardiac and psychological symptoms, referring ACHD providers should also remain available for follow-up consultation with mental health professionals as needed. Mental health professionals, in turn, might be able to offer suggestions to members of the ACHD team to enhance the psychosocial well-being of patients.

Conclusions

As the population of adults with CHD continues to grow, so does the demand for resources and programs targeting the specific psychosocial needs of this patient group. Many patients will experience symptoms consistent with mood and anxiety disorders as well as health-specific anxiety or coping difficulty that warrant consideration for mental health treatment. ACHD teams have the opportunity to impact psychosocial outcomes by creating environments that foster open and ongoing dialog about emotional well-being and establishing reliable processes for mental health referrals. Closer collaboration between traditional members of the ACHD care team (e.g., physicians and nurses) and mental health professionals (e.g., psychologists and psychiatrists) is strongly advocated.

Compliance with Ethical Standards

Conflict of Interest Alexandra Roseman and Adrienne H. Kovacs declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent All reported studies/experiments with human or animal subjects performed by the authors have been previously published and complied with all applicable ethical standards (including the Helsinki declaration and its amendments, institutional/national research committee standards, and international/national/institutional guidelines).

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