

Psychosocial Functioning of Adults with CHD

The comprehensive care of adults with congenital heart disease (CHD) includes paying attention to both medical and psychosocial needs. This is evident from European and American guidelines for the care of adults with CHD which advocate for resources targeting patients' psychological concerns. In this article, we first summarize research about the psychosocial experiences of adults with CHD. We then present a research study that asked whether patients themselves are interested in psychological services because it's important that the patient voice is heard. It's important to keep in mind that research summarizes groups of patients, but does not describe any one patient. Therefore, it's possible that a reader might personally relate to none, some, or all of the information here.

The Psychosocial Functioning of Adults with CHD: According to Researchers and Psychologists

It is important to know that at any one time, most adults with CHD do not experience clinical levels of psychological distress. The resiliency of this patient group is both impressive and inspiring. Research, however, does indicate that North American adults with CHD are at greater risk of psychological difficulties than healthy peers. A 25-year follow-up study of adults with CHD who received treatment in childhood revealed higher levels of psychological symptoms compared to their peers. Three separate studies that used clinical interviews found that approximately one in three patients with CHD meet diagnostic criteria for a psychiatric disorder, most commonly mood or anxiety disorders. This rate is higher than in the general population. Most importantly, only a minority of patients in these studies with clinical diagnoses receive mental health treatment. One interesting note is that there are differences between research findings in North American and the Netherlands. Despite the results of American studies that suggest largely negative outcomes, in multiple studies of Dutch adults, the psychological functioning of adults with CHD patients has been found to be similar or better than their healthy peers. There are no published studies of the psychological well-being of German or Swiss-German adults with CHD.

If we think that adults with CHD might have a higher rate of psychological concerns, the logical next step is to try to figure out why some people have difficulties and others do not. Risk factors related to psychological difficulties among adults with CHD have been studied, and there is some research that suggests that younger patients and females tend to have more psychological difficulties. But these findings are inconsistent. Results investigating the impact of medical variables are also not consistent. There are some studies that show that there are differences between individuals with different types of cardiac defects. However, other studies show that there is not a strong link between disease severity and psychological well-being or quality of life. It seems that functional status (which is related to cardiac symptoms and one's ability to do activities of daily living) are more strongly linked to psychosocial functioning than cardiac diagnoses.

A focus on the broader psychosocial experiences of adults with CHD, however, should not be limited to depression and anxiety. One of the most common themes of living with CHD is

‘coping with the presence of disease.’ In adult CHD programs that have psychologists, there are several reasons why patients might be referred to the psychologist. Some patients have “heart-focused anxiety,” meaning that their worry about their heart is interfering with their quality of life. Some patients also have concern about their long term health expectations, mortality, and end of life issues. Other patients are seeking help with making medical decisions, adjusting to an implanted cardiac device (a pacemaker or defibrillator) or preparing for cardiac surgeries or interventions. Some patients have concerns about becoming independent and/or the way that they interact with their parents or peers. Some patients might also struggle with keeping a healthy lifestyle (e.g., physical activity, healthy diet, no tobacco) or remembering to take medications. Here is a list of things that can sometimes be difficult for some adolescents and adults with CHD:

- Feeling different
- Looking different
- Problems keeping up with their friends
- Teasing or bullying
- Parents who sometimes seem too involved
- Moving from pediatric to adult care
- Focusing too much on their heart
- Having lots of doctor’s visits
- Remembering to take medications
- Dealing with medical information that wasn’t expected
- Getting ready for surgery or a procedure
- Worrying about future health

Although there can certainly be some extra psychosocial challenges due to living with CHD, it’s important to note that some patients talk some positive aspects of having CHD. Here is a list of some of those things:

- Learning how to focus on what they can do and like to do (instead of what they can’t do)
- Feeling strong because they have managed things that other people haven’t
- Knowing what is most important in life
- Being comfortable spending time alone
- Knowing who their real friends are

The term ‘psychosocial’ rather than ‘psychological’ is best used to describe challenges faced by adults with CHD for two main reasons. First, among adults with CHD, social functioning is more strongly associated with psychological functioning than defect severity or demographic factors. Second, three of the most important domains impacting the quality of life of adults with CHD are the following social factors: family, education/career, and friends. Compared to their peers, adults with CHD face higher rates of unemployment, regardless of defect complexity. They are also less likely to receive career counseling, despite the fact that having received career advice is associated with a greater likelihood of employment compared to patients who do not receive advice. Many patients face difficulties obtaining health and/or life insurance. With regard to peer interactions, many adults with CHD recall isolation, embarrassment, teasing, or bullying during their earlier years. Approximately one-quarter of Adults with CHD describe parental over-protection in childhood and adolescence. Qualitative research indicates that ‘feeling different’ and body image concerns are common for many

adolescents and young adults living with CHD. For these reasons, psychologists working with adults with CHD often focus on social adjustment. There are things that people can learn to do to better manage social interactions with family or friends.

The Psychosocial Functioning of Adults with CHD: Are Patients Interested in Psychological Services?

As mentioned, previous studies have documented that approximately one-third of adults with CHD have mood or anxiety disorders. Research suggests, however, that a minority of adults with CHD with psychiatric diagnoses actually receive mental health treatment. Until recently, however, we didn't know whether adults with CHD were interested in psychological services. A team of researchers from Toronto conducted a study of 155 adults with CHD to learn about this. Forty per cent of the patients in their study reported a history of treatment from at least one identified mental health professional (such as a psychologist, psychiatrist or counselor). On a scale from 0 – 10, patients indicated how interested they were in psychological services focused on certain topics. Half of the patients reported a high interest in at least one of seven areas of psychological treatment. Patients reported the most interest in stress management and learning how to cope with heart disease. When asked about preferences for future mental health treatment, patients generally preferred psychotherapy (talk therapy) over taking medications (like anti-depressant or anti-anxiety medication). Patients were also asked whether they were interested in peer support. One-third of the patients were interested in receiving peer support and one-half were interested in providing peer support. This suggests that many adults with CHD are really looking to connect with other adults with CHD. This probably comes as no surprise to anyone who is involved with CHD patient organizations. In summary, this study highlighted the fact that it's not just researchers and psychologists who think that it's important to address the psychosocial challenges of adults with CHD; psychological services are also important to many adults with CHD.

Recommendations for Patients

Some people say that having CHD has not affected them at all. Other people say their lives have been turned upside down. And most people are somewhere in the middle. Everyone, with or without CHD, has times when they feel unhappy, sad, worried, frustrated, or angry. But when a person has problems with mood or anxiety that don't seem to go away, it's important that they think about getting proper treatment. A person with CHD should talk to their family doctor or cardiologist if they think they might have a mood or anxiety problem or any other psychosocial concern. Then, they and their doctor can decide whether they should see a mental health professional. There are many different types of mental health professionals. Psychologists are trained to provide talk therapy to help people cope. Psychiatrists can prescribe medications and also use talk therapy. There are also other kinds of professions who help people cope with psychosocial concerns. This list includes counselors, family doctors, social workers, religious counselors, and nurses.

Conclusions

In summary, adults with CHD face some extra challenges in their lives that come with living with a chronic medical condition. They are more likely to have problems with depression or anxiety as well as other psychosocial difficulties. But this does not mean that every adult with CHD has psychosocial problems. What it does mean is that if a patient is having psychosocial difficulties, they should know that they're not alone. And that they should seek appropriate treatment. In fact, the results of one research study show that patients themselves are quite interested in psychological services, particularly with a focus on stress management or coping with heart disease. Although most Adult CHD programs do not have a psychologist or psychiatrist as part of their team, patients who have psychosocial concerns should definitely speak with their family doctors or cardiologists about referrals to mental health professionals.

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