Psychosocial Aspects of Adults with Congenital Heart Disease

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Contents

Abstract

During the last few decades, the survival rate of adults with congenital heart disease (ConHD) has increased considerably. The psychological characterization of adults with ConHD is very different from patients with acquired cardiac pathologies. Recent guidelines of cardiology associations indicate the necessity for specialized psychosocial support. The majority of the studies in the literature indicate the absence of a relationship between diagnosis, physical functionality, and the presence of residual symptoms and a worse psychological functioning in these patients. The variables which seem to be related to psychological well-being in these patients are the following; negative thoughts, solitude, social support, fear of negative evaluation, imposition of limits, perceived health status, somatic symptoms, perception of an economical difficulty, and restrictions linked to the surgical scar in females. Interestingly, studies, which utilized psychiatric interviews or similar methodologies, outlined that it was common for patients, who were diagnosed with a mood or anxiety disorder, not to have

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received any appropriate treatment and often they were assumed to be well psychologically. When it comes to the life experiences of adults with ConHD, it has been outlined how these patients feel different from their healthy peers. It has been seen that often there is a struggle to feel normal and also to be perceived by others as being normal. This could lead to denial of the conditions and also efforts to exceed their physical boundaries imposed by their condition. Three main domains in which clinical health psychologists can contribute in the handling of adults with ConHD were identified: provision of clinical services, multidisciplinary research, and professional education.

Keywords

Congenital heart disease • Psychology • Clinical psychology • Psychosocial • Life experiences • Anxiety • Depression

Introduction

The global prevalence of congenital heart disease (ConHD) is estimated to be 9.3 per 1,000 newborns making it the most common birth defect (van der Linde et al. 2011), even though interestingly this condition is not very well known in the general population. During the last few decades, the survival rate of adults with ConHD has increased considerably as almost 90 % of children with ConHD currently survive into adulthood (Marelli et al. 2007; Moons et al. 2010), and when considering the whole ConHD population, the percentage of adults has risen to 60 % (Marelli et al. 2014).

The term ConHD comprises many different conditions of varying severity, but many of these patients have a complex condition which requires lifelong medical assistance (Gatzoulis et al. 2005). In fact, about one-third of this population is born with a critical heart disease which entails having a malformation which is life threatening and which necessitates corrective or palliative surgery in the first years of their lives (Marino et al. 2001; Samanek 2000). For a more detailed description of congenital heart disease, please refer to Dr. Chessa's chapter "▶ Congenital Heart Diseases," in the manual.

The psychological characterization of adults with congenital heart disease is very different from patients with acquired cardiac pathologies. Becoming aware of having a cardiac condition during one's childhood has a very different impact from acquiring an illness, to which the general population is familiar to, at a much later stage in life.

When it comes to acquired cardiac illness, it is well known that a cardiac rehabilitation is of great benefit, even with it comes to overall psychosocial well-being (Mampuya 2012). It is very interesting to note that there are still no precise indications when it comes to cardiac rehabilitation with ConHD patients. When conducting a literature review regarding this, only a letter to an editor can be found (Holloway et al. 2011) where there is encouragement for the participation of these patients to cardiac rehabilitation programs. In this letter it is specified that historically ConHD patients have not participated in traditional cardiac rehabilitation programs.

Since it has been demonstrated that the capacity of physical exercise diminishes with the advancement of age in ConHD (Diller et al. 2005), it would be advisable that these patients participated in cardiac rehabilitation programs since they are effective at improving the capacity for physical exercise in chronic heart failure patients. This group of patients has many factors leading to low physical exercise which are in common with adults with ConHD (Giannakoulas and Dimopoulos 2010).

It is important to consider the fact that the education regarding physical exercise is not optimal in specialized clinics (Swan and Hillis 2000). In addition, the majority of adult patients with ConHD report having from a moderate to an extreme level of preoccupation regarding physical exercise (Harrison et al. 2011). Most of ConHD patients result as not satisfying the national recommendations when it comes to the participation in physical exercise (Swan and Hillis 2000), and as a group they have often expressed an interest in it and a desire to have formal advice on what physical exercise they can engage in (Harrison et al. 2011).

Finally, even though the participation to some kind of exercise regime is indicated in the guidelines (Baumgartner et al. 2010; Warnes et al. 2008a), these indications are based more on theoretical rather than scientific knowledge. A little pilot study was conducted which indicated that seven adults with ConHD completed a traditional cardiac rehabilitation program successfully, with an improvement in the capacity for physical exercise at the end of the program (Holloway et al. 2011).

Recent guidelines of cardiology associations (Warnes et al. 2008a; Report of the British Cardiac Society Working Party 2002) indicate the necessity for psychosocial support for adults with congenital heart disease. In the recommendations of the British Cardiac Society Working Party in 2002 (Report of the British Cardiac Society Working Party 2002), it was outlined that specialized consultancies were necessary in the following areas: relationships, contraception, pregnancy, career choice, insurance, psychosocial problems, and risky behaviors when it comes to health and free-time activities.

In 2008, in the guidelines of the American College of Cardiology/American Heart Association Task Force (Warnes et al. 2008b), it was specified how expert nurses, social workers, psychologists, and physician assistants should have a fundamental role in the care of these patients, especially when it comes to their evaluation and the provision of psychosocial assistance. This has been confirmed in other recommendations in which it was specified that it is necessary to offer the availability of specialized psychological support to these patients, which should be integrated in the medical team (Callus and Quadri 2010; Callus et al. 2010; Kovacs et al. 2006). Specific indications about psychosocial care will be given further on in this chapter. In the following paragraphs, the psychological characterization of adults with congenital heart disease will be described.

Psychological Characterization of Adults with Congenital Heart Disease

When it comes to studies assessing the psychological aspects of these patients, there is either a comparison with other healthy groups or an attempt to correlate psychological functioning with other variables, including the ones pertaining to the medical condition.

The majority of the studies in the literature indicate the absence of a relationship between diagnosis, physical functionality, and the presence of residual symptoms and a worse psychological functioning (Cox et al. 2002; Kovacs et al. 2008; Rietveld et al. 2002; Utens et al. 1994, 1998; van Rijen et al. 2003, 2005; Callus et al. 2014). There are only a few studies which suggest a weak link between physical functionality and psychological functioning (Popelova et al. 2001; van Rijen et al. 2004).

There are two literature reviews regarding the psychological aspects of these patients (Callus et al. 2013a; Kovacs et al. 2005). In the review by Kovacs and colleagues (2005), it is indicated that these patients often have to deal with psychosocial difficulties which can influence their emotional functioning, the perception of themselves and their relationships. There patients often have to pay particular attention to their lifestyle as there could be limits to their physical capacity and the possibility of proceeding with pregnancy when it comes to the females with ConHD.

In another more recent review (Callus et al. 2013a), the comparison between the population of these patients and healthy ones and which variables (both related to the cardiac condition and others) are linked to the psychological functioning of these patients is explored.

In some studies, in which a comparison was made between adults with ConHD and the healthy and other populations (Cox et al. 2002; Utens et al. 1994, 1998; van Rijen et al. 2003, 2005), no significant differences were found and in some cases a better psychological functioning was found in these patients. In a more recent study, the only difference found between these patients and the general population was on the subscale of somatic symptoms, which were linked to anxiety and depression symptoms (Eslami et al. 2013).

Some authors have indicated that the possible reasons for these results are linked to the fact that these patients could have a higher “sense of coherence” (Moons and Norekval 2006). Sense of coherence represents the generalized world view of an individual and expresses the extent to which he/she perceives: (1) stimuli as structured and predictable (i.e., comprehensibility), (2) the availability of resources to meet the demands posed by these stimuli (i.e., manageability), and (3) that these demands are challenges in which it is worth to make an investment (i.e., meaningfulness). This theory aims to try to give a description of the processes through which people remain healthy even though they are exposed to ubiquitous stressors. It is hypothesized that sense of coherence exerts its positive influence on health through adaptive health behaviors and coping behavior (Antonovsky 1987).

Other factors which could be influencing these results could be denial and “high-achievement motivation” which could lead to these patients indicating that they are feeling better than they really are in self-report questionnaires (Utens et al. 1994; van Rijen et al. 2003).

Interestingly, in a study in which psychiatric interviews were utilized (Kovacs et al. 2008), it was outlined how an elevated percentage (39 %) of patients who were diagnosed with a mood or anxiety disorder had not received any type of psychological treatment. This was confirmed in two other studies in which similar assessment methodologies were utilized (Bromberg et al. 2003; Horner et al. 2000), where a significant portion of the patients, who were thought being well psychologically, were diagnosed with mood or anxiety disorders (9/29 and 8/22, respectively).

When it comes to the exploration of which variables impact on the psychological functioning of adults with ConHD, the pertinent literature indicates the absence of a relationship between diagnosis, physical functionality, and the presence of residual symptoms and psychopathology (Utens et al. 1998; van Rijen et al. 2005); hostility, neurosis, and a low self-esteem (Utens et al. 1994; van Rijen et al. 2003); anxiety and depression (Cox et al. 2002; Kovacs et al. 2008; Eslami et al. 2013; Bromberg et al. 2003; Horner et al. 2000); and psychological well-being (Callus et al. 2014). Only a few studies suggest a weak link between physical functionality and psychological functioning (Popelova et al. 2001; van Rijen et al. 2004).

A study which does not confirm this trend is the one by Brandhagen (Brandhagen et al. 1991), in which it is specified that adults with congenital heart disease have lower scores when compared to the healthy population. Interestingly, another study on adult patients with ConHD who had to implant an ICD showed high levels of anxiety, and this was also connected to a lower sexual functioning both in males and females (Cook et al. 2013). It was also reported that patients with a high level of trait anxiety were more vulnerable to overperceive symptoms which are connected to the heart (Karsdorp et al. 2009).

In other studies there was an exploration of the variables which are connected to psychological well-being (intended as less anxiety and depression, minor symptoms of psychopathology, and more psychological well-being, on the basis of the different instruments utilized in the various studies) (Kovacs et al. 2008; Rietveld et al. 2002; Callus et al. 2013a, 2014; van Rijen et al. 2004; Eslami et al. 2013), and these resulted as being the following:

- Negative thoughts (Rietveld et al. 2002)
- Solitude (Kovacs et al. 2008)
- Social support (Eslami et al. 2013)
- The fear of negative evaluation (Kovacs et al. 2008)
- The imposition of limits (van Rijen et al. 2004)
- Perceived health status (Kovacs et al. 2008; Callus and Quadri 2008)
- Somatic symptoms (Eslami et al. 2013)
- The perception of an economical difficulty (Eslami et al. 2013)
- Restrictions linked to the surgical scar in females (van Rijen et al. 2004)

As specified previously, being born with a congenital cardiac condition has very different implications when compared to patients who acquire an illness at a much later stage in their life. Complex congenital heart conditions can be assimilated to chronic conditions because of the long-term nature of the condition, the uncertainty of its course and prognosis, the signs and symptoms of the condition, and also the restriction on their everyday lives (Moons et al. 2002).

It is important to take into consideration qualitative studies exploring the life experiences of these patients, so as to improve the medical care provided to them and in order to improve medical adherence.

In the literature it is indicated that adolescents with ConHD struggle with physical limitations and face social exclusion (McMurray et al. 2001; Tong et al. 1998). The severity of the condition influenced the type of the limitations the patients felt. As many as one-fourth of adults with ConHD report their parents as being overprotective during their childhoods and adolescence (Brandhagen et al. 1991; McMurray et al. 2001; Arnett 2000). The tendency for these patients to live longer with their parents could be linked to them being overprotective, and it could be that this also creates difficulty for the patients to become more autonomous (Gersony et al. 1993; Kokkonen and Paavilainen 1992).

When it comes to the life experiences of adults with ConHD, it must be considered that this population is a highly heterogeneous one and this entails very different life experiences; however, some common patterns of experience and perspective seem to have been found in this broad diversity (Verstappen et al. 2006). In fact, in the qualitative studies which have been carried out on this population, it has been outlined how these patients feel different from their healthy peers (Verstappen et al. 2006; Berghammer et al. 2006; Claessens et al. 2005; Gantt 1992, 2002; Callus et al. 2013b). It has been seen for often there is a struggle to feel normal and also to be perceived by others as being normal. This could lead to denial of the conditions and also efforts to exceed their physical boundaries imposed by their condition (Berghammer et al. 2006).

Particular issues which could be present in the female population are concerns regarding fertility, contraception, pregnancy, and their surgical scar. It seems that scarring and cyanosis could bear a more negative influence in females and that for men the difficulties related to their body image are more present during adolescence, probably due to the involvement in sports activities (Claessens et al. 2005; Gantt 1992; Callus et al. 2013b).

Since many of the patients have to spend a lot of time in hospital, these experiences are often referred to in the qualitative studies. In one particular study, it was observed how different expectations about the management of the patients' conditions from the patients, their families, and the nurses were associated with interpersonal conflict, distrust, anxiety, and dissatisfaction with the healthcare provided (Kools et al. 2002), outlining the importance of a transparent communication in these settings.

In a very interesting article (Verstappen et al. 2006), quotations from patients are reported from the Adult Congenital Heart Association in an attempt to address the patients' perspectives in order to outline the implications for care.

There was often an ambiguity regarding their condition and their prognosis, also because of language-based misperception in understanding if the condition is completely cured or not. Many patients reported difficulties when having to go to the "regular" medical system, where the sanitary personnel is not specialized in ConHD. They also reported that the people who are close to them sometimes had difficulties to understand the entity of their restrictions. Other patients have described that information about their condition was withheld from them and they got to know about their real condition at the onset of new problems, causing psychological distress and trust issues.

Interestingly, having this condition does not only have negative consequences, but it can also be linked to having some benefits. Some patients report receiving special attention, gaining an increased resilience and maturity, and also gaining a clearer sense about the meaning of life. There can be an increased appreciation of life, more clarity of purpose, and better decision-making when one has to deal with an ongoing awareness of one's mortality due to specific health conditions (Mathieu 2005).

The Role of Psychologists in the Care for Adults with Congenital Heart Disease

Three main domains in which clinical health psychologists can contribute in the handling of adults with ConHD were identified. Kovacs and colleagues (Kovacs et al. 2006) identified: provision of clinical services, multidisciplinary research, and professional education.

Provision of Clinical Services

It is possible that ConHD patients tend to be more sensitive to heart-focused anxiety and bodily sensations due to their condition (Utens et al. 1998; Eifert et al. 2000; Rietveld et al. 2004). Psychologists can help in the reduction of excessive self-monitoring and reduction of cardiac anxiety by utilizing psychoeducation and behavioral strategies. Patients can also be helped to deal with family and peer concerns through social skills training and guidance in communication strategies (Kovacs et al. 2006).

Clinical strategies in order to maximize psychosocial care in ConHD patients have been previously identified in the literature (Kovacs et al. 2005). In particular, the necessity to demonstrate increased psychosocial awareness in settings which work with these populations was outlined. It was also suggested to initiate proactive discussions as trying to avoid important topics will harm the patient in the long run, and initiating discussions allows them to feel they can ask questions and that what they are going through is common. Finally, when it comes to screening, the following four A's have been suggested to detect and manage psychosocial issues:

(a) Ask the patient about specific challenges.
(b) Advise the patient on common challenges and how to manage them.
(c) Assist the patient through psychological interventions such as support and brief problem solving.
(d) Arrange referral when the patient is evaluated as needing a mental health specialist.

Patients going through different phases of the illness could benefit from psychological support, in particular:

- **When coping with becoming aware of the condition or changes in cardiac status**: Adults with ConHD often require lifelong medical follow-up (Warnes 2005) and they might have to manage situations where they suddenly get worse after many years of relative stability (Horner et al. 2000). Some patients also learn about their condition in adulthood and could have a hard time adjusting to this (Kovacs et al. 2006).
- **The transition from pediatric to adult care** results to be very difficult for many of these patients, and it has been reported that there is a significant number of adolescents who do not manage to successfully transition to adult care (Reid et al. 2004). Psychologists can provide support and individual consultation to those patients experiencing a difficult transition through strategies such as empowerment (Kovacs et al. 2006).
- **Adjustment to cardiac devices and surgical preparation**: As specified previously, it is possible that some patients have difficulty with the implantation of cardiac devices such as the ICD (Cook et al. 2013), especially if they are young (Sears et al. 1999), and cognitive behavioral strategies have been shown to be useful to enhance the confidence and QoL of ICD recipients (Sears et al. 2004). Psychologists can provide preparation techniques which improve the reduction of anxiety in cardiac patients which have to undergo a surgical procedure (Seskevich et al. 2004).
- **Maximization of adherence and behavioral modification**: It is especially important for cardiac disease patients to take care of their diet, to exercise appropriately, and not to indulge in risky health behaviors which can compromise their health. As indicated previously, physical exercise is especially important also in this population. Psychoeducation seems to be helpful when it comes to lifestyle behaviors in patients with coronary heart disease (Dusseldorp et al. 1999) although there are no specific studies regarding this in ConHD patients.
- **Dealing with anticipatory grief and mortality**: It is also possible that the patients of this population have an increased awareness of mortality and a psychologist could help by providing support, dealing with anticipatory grief, and working on strategies to communicate effectively with relatives and sanitary personnel.

Referral for psychosocial care can be initiated in a variety of ways and by different professional figures depending on the situation. However, it is important that psychological and psychiatric referrals are made with the patient's knowledge; otherwise the opposite effect could be obtained. Teams caring for these patients should have clear referral indications, which should be established with collaborating psychologists (Kovacs et al. 2006). In particular cases, referral to other specialists such as psychiatrists (Bassett et al. 2005) and experts in substance abuse (especially since it has been linked to unsuccessful transitioning from pediatric to adult care (Reid et al. 2004)) could be necessary.

Multidisciplinary Research

Psychologists can contribute in the conduction of multidisciplinary research in ACHD patients, especially in the following areas (Kovacs et al. 2006):

- **Development of specific measures**: there is a need for the creation of specific psychosocial measures developed for this population as there have been many studies using different instruments in this population (Deanfield et al. 2003). Some attempts in this direction have already been made (Kamphuis et al. 2004), although it would be advisable to develop additional measures in order to address the unique concerns of this population, as the psychosocial measures developed for acquired cardiac disease do not fully capture this population's experience (Kovacs et al. 2006).
- **Longitudinal psychosocial assessment**: there are few of these studies present in the literature and more are required to understand how the population deals with the various issues through time.
- **Evaluation of psychosocial interventions**: no trials yet exist when it comes to psychological interventions for adults with ConHD (Lip et al. 2003), and since there are few specialized centers, it is also feasible to think about how to provide long-distance support and how to evaluate it.
- **Evaluation of medical interventions and the relationship between mental and physical health**: psychologists can provide insights on the effectiveness of medical interventions by exploring how the patients feel before and after, especially in the domains of quality of life and psychological functioning. It is also important to assess how psychological factors could possibly influence physical functioning in this population.

Professional Education: Increasing Psychosocial Awareness

The guidelines mentioned previously specify that in order to be defined as a competent specialist for adults with ConHD, it would be advisable for the professional to be knowledgeable about the psychosocial aspects of adolescence, the transition to adulthood, and experience with lifestyle counseling and advocacy

(Deanfield et al. 2003). A psychologist could be a very useful figure to provide insight and resources when it comes to these areas.

Conclusion

As outlined in this chapter, the psychological implications of ConHD are quite specific to this population. More research on the psychological characteristics of these patients is required, particularly in the area of psychological interventions. It would also be interesting to compare the populations of acquired and congenital heart disease when it comes to psychological variables. Finally, it is important for psychological professionals to be adequately trained on the specificity of this population.

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