

ACHA Q and A: Quality of Life in Congenital Heart Disease

Does having congenital heart disease (CHD) doom you to a miserable life?

There has been a lot of interest in what kind of quality of life (QOL) people with chronic illnesses like CHD have. As more children and adults with CHD live longer, doctors and researchers want to know how they manage in daily life. In early studies, it looked like adults with CHD had a lower QOL. But more recent studies have shown that people with CHD can often have a higher QOL than their peers. This should be very encouraging for anyone with CHD or for parents/relatives of someone with CHD. As we begin to understand and define QOL, we can come up with ways to increase it.

What is quality of life?

QOL is a tricky subject. Not everyone agrees on what it means. There have been a number of studies of QOL in people with CHD. Most of these studies do not define exactly what they mean by QOL. In many studies, QOL is used to mean functional status. But in more recent studies, researchers have said that the quality of a person's life is related to how satisfied they are with their life overall. That satisfaction might be influenced by changes, for better or worse, in the parts of their lives that are important to them. Some of these important parts of life may be related to health, while others are not. It will vary from person to person.

What is functional status?

Functional status has to do with a person's ability to do normal daily activities and perform their roles in life. Functional status is often measured by asking questions like "Can you walk three blocks without shortness of breath?" or "Can you walk up two flights of stairs at a brisk pace?"

How is quality of life different from functional status?

QOL is hard to measure objectively. It is the way you look at your life and how satisfied you are with it. Functional status is more concrete and only focuses on health and ability. QOL takes many other things into consideration. QOL in recent studies was measured using two scales. One, called a linear

analog scale, is a vertical line from 1 to 100 where people can choose a number that they believe represents their QOL. The other tool used to measure QOL is a questionnaire called the Satisfaction with Life Survey. This questionnaire asks people to agree or disagree with five statements, using a scale of 1 ("strongly disagree") to 7 ("strongly agree"). These tools show us how a person views their own QOL, which might be very different from the results of a functional status survey.

Recent studies have shown that people with congenital heart disease can often have a higher quality of life than their peers

Don't people with CHD have a lower quality of life?

Not necessarily. In fact, some recent studies in Belgium and Germany showed that the QOL for people with CHD was actually better than the QOL for people in good health. It all depends on how you define QOL. If we use QOL to mean the same thing as functional status, then a person with CHD will probably have a QOL equal to or lower than that of a healthy person. But if QOL means how satisfied a person is with their life, then CHD patients will often have a better QOL than healthy people. The reason that most past studies have shown a lower QOL in patients with CHD is because of the way that researchers defined QOL.

Why do people with CHD often have a higher quality of life?

People with physical limitations or disabilities, such as some kinds of CHD, often have a higher QOL than healthy people. Although this may seem strange, researchers offer three possible explanations – the Disability Paradox, response shift, and sense of coherence.

What is the Disability Paradox?

The Disability Paradox is a theory that helps explain why some people with even major limitations are still able to have a good QOL. Researchers found that

certain things play a part in having a good QOL while other things play a part in having a poor QOL. They noticed this was true whether a person has any physical or mental disabilities or not. Things that contribute to a good QOL include:

- The ability to admit your disability or impairment
- Having control over your body, mind, and life
- The ability to perform expected roles
- Feeling satisfied when you compare yourself and your abilities with other people in similar situations

In other words, it is likely that you can have good QOL if you can say to yourself, “OK, here are my limitations. But I can still perform my expected roles. I still have control over many parts of my life. I know that there are other people who may be worse off than I am.”

On the other hand, you may have a poor QOL if you:

- Have constant or near-constant pain
- Feel tired most or all of the time
- Have lost much or all control over your body, mind, and life

What is a response shift?

A response shift is a change in what we see as important in life as a result of a change in what’s going on in our lives. For example, let’s say it’s very important to you to go for a run every morning. Then one day, you are hit by a car and seriously injured. Now, recovering becomes more important to you than your morning run as a result of that accident. Your priorities have changed. Your goal of running a marathon is less important than your goal of walking without crutches. In the same way, people with CHD have often faced life-threatening situations. Many times they develop different values than “healthy” people as a result of growing up with CHD. As a result, many will say, “We know what life’s worth, we don’t let the little things bother us.” People without CHD may not have had to face such serious issues in life, which may make it harder to deal with setbacks.

What is a sense of coherence?

Sense of coherence has to do with your view of the world and whether you feel your life is understandable, manageable, and meaningful. Are you able to understand what is going on around you? Do you feel able to cope with life? Can you find meaning in your experiences? If you answered yes to those questions, you have a high sense of coherence. Many people with CHD have a high sense of coherence because they understand their defect(s) and they have learned

how to manage their disease. After coming through surgery or other major events, they often feel their lives have a great sense of meaning and purpose. Research has shown a strong connection between a high sense of coherence and a positive QOL.

What can people with CHD do to improve their quality of life?

QOL depends a great deal on a person’s way of viewing the world and the changes that occur in their life. While some people may naturally be more optimistic, there are some things you can do to increase QOL. One way is to look at the things you can do, rather than the things you can’t, and remember there is always someone worse off than you. Keep the important things in life foremost in your mind and don’t sweat the small stuff. Since there is a strong connection between sense of coherence and a high QOL, see if you can improve your sense of coherence. Learning more about your CHD to raise your understanding and finding ways to manage or cope with your disease may help. It may also be helpful to find or make meaning out of your life experiences.

Tips to Improve Quality of Life

- Focus on what you can do, rather than what you can’t
- Remember, there is always someone worse off than you
- Focus on the things that are truly important in life – family, friends, etc.
- Don’t sweat the small stuff!
- Learn more about your CHD
- Develop ways to manage or cope with your CHD
- Find ways to derive meaning from your life experiences

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