

WEBINAR: Rehabilitation and mental health in PH -

Where do I go for support?

Episode 10 - Thursday 12 December 2019

DISCUSSION SUMMARY

Overview

On Thursday 12 December 2019, Actelion hosted a webinar entitled 'Rehabilitation and mental health in PH – Where do I go for support?' Aldo Aguirre-Camacho, Assistant Professor of Psychology at the European University of Madrid and a member of the Spanish National Association of PH, was the guest speaker. Aldo discussed how pulmonary hypertension (PH) can impact mental health and provided strategies for talking about mental health with family, friends and healthcare professionals (HCPs). He also spoke about the importance of holistic care, including why HCPs should be involved in discussions about psychological support as well as physical health.

The primary objectives of the webinar were:

- To discuss the impact of PH on mental health and how this can affect physical symptoms and a person's overall wellbeing
- To share and discuss best practice approaches to help support conversations with HCPs about mental health and psychological support
- To identify sources of information to support mental health needs for those living with PH

Discussion summary and key learnings

The impact of PH on mental health

- Mental health has a huge impact on a person's quality of life, so it is important to recognize signs and symptoms of difficulties with mental health
- Mental health conditions are quite common in people living with PH. One reason for this is that PH can exert a strong impact on many domains of a person's life including physical, psychological, functional and social wellbeing
- These life domains are often interrelated, here are a few examples:
 - The physical burden of PH such as an unclear prognosis and awaiting for medical appointments can be stressful and in some instances can trigger anxiety or depression (psychological)
 - A PH diagnosis can have a functional impact, for example having PH may mean you have to alter your career path. Losing or changing a job and/or loss of financial independence can be hard and affect your mental state
 - People living with PH can have feelings of social isolation which can impact their emotional wellbeing
 - Mental health problems such as stress and anxiety can exacerbate the physical impact of PH
- Understanding that life domains are connected can be hugely helpful, as making changes to one domain could also transfer benefits to another. For example, if you seek psychological support, it could also improve your physical and social wellbeing



The importance of talking about mental health

- Mental health problems are also common amongst the general public and are often a normal response to greatly altered circumstances. Despite this, there is still a stigma associated to them
- To reduce the stigma, it is important to talk about mental health and remember that there should be no shame attached to it
- The goal is for mental health problems to be treated with the same respect as physical problems

Talking to family, friends and work colleagues

- The symptoms of PH are not always visible to others and this can make it difficult for those around you to understand what you are going through. This can lead to feelings of isolation. It is important to try and communicate with your family and friends to help them understand your needs and enable you to feel more understood
 - If you are employed, consider speaking to your work colleagues to educate them about your PH so that they can support you at work
- Try to remember you are not alone. Many people living with PH have experienced mental health problems. Furthermore, your family and friends will also have experienced high and low moods over the course of their lifetime. There are plenty of people who can empathize with your feelings and who will want to offer support

Talking to HCPs

- It is important to speak to your HCP if you are experiencing symptoms of anxiety, depression, a sense of a lack of control or feelings of isolation, even if they are mild. Early management and prevention is key as it can provide you with coping strategies to prevent your emotional state from worsening
- If you are nervous about speaking to your HCP about mental health, try to remember that they have likely treated other patients with similar problems in the past and will be more than happy to discuss both your physical and emotional needs
- It can be helpful to keep a record of your symptoms including when they started and their duration before your appointment. One way to do this precisely is to write them down in a diary
- During the appointment, it is important to ask questions if there is something that you do not understand and to mention things that have and have not worked for you in the past. This will help your HCP provide the best possible support which could include talking therapy, medication and psychotherapy

Supporting mental health needs

- **Ask your Patient Association for support.** If you have been newly diagnosed with PH, it is normal to feel quite stressed and overwhelmed, it can be helpful to contact a local patient organization for support during this challenging time. For example, the Spanish National Association of PH will call new members to ask them how they are feeling and provide information and support if needed. A simple phone call can go a long way to support someone in their time of need
- **Find a peer support system.** This is another way to connect with other people who are going through similar experiences.
- **Try activities that can help improve your mood.** A low mood and anxiety can result in a pessimistic outlook and low energy levels, which can interfere with health routines, social activities and relationships. Try to do things to increase your mood to help lift energy levels and benefit your health e.g. read a book, paint
- **Focus on the present.** Many of us spend time worrying about the future or dwelling on the past, when in fact we should try to stay in the present. It can be calming to remember that 'all that can be done at one time is to act in the present'

Conclusion

- Remember that conditions such as PH commonly impact on mental health and it is important to recognize this, as early management can help to prevent a negative spiral
 - Seeking support to improve one life domain e.g., psychological wellbeing, can have a positive impact on other domains too e.g., physical health and social wellbeing
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- It is important to talk to others about how PH is affecting you to help reduce feelings of isolation and enable others to support you most effectively. This includes friends and family, colleagues, HCPs and patient support groups

Appendix

For more information about coping with PH visit: <https://phassociation.org/patients/living-with-ph/coping-with-ph/>

And for specific information about depression with PH visit: <https://phassociation.org/caregivers/coping-as-a-caregiver/identifying-depression/>

If you are concerned about your or another person's mental health, please seek advice from your HCP

