

WEBINAR: Mental health in PAH: not our responsibility?
Episode 2 – Thursday 11 January 2018

DISCUSSION SUMMARY

Overview

On Thursday 11 January 2018, Actelion hosted a webinar episode entitled '*Mental health in PAH: not our responsibility?*'. David Gilbert, a former mental health service user and current Patient Director at the Sussex Musculoskeletal Partnership, presented his personal experiences of living with mental health issues, as well as his professional reflections on managing mental health within a clinical setting. Webinar attendees included PAH healthcare professionals (HCPs) and patient group representatives, who were invited to share their experiences and insights into the best practice management of mental health as part of PAH care.

The primary objectives of the webinar were:

- To increase understanding of the impact of mental distress on a person's ability to self-manage
- To share simple ways multidisciplinary team members can integrate mental health into their consultations
- To suggest ways that people living with PAH can access wider mental health support

Discussion summary and key learnings

David Gilbert's personal reflections: what can mental distress look like?

- It's important to recognize that mental health can manifest itself in different ways. For David, six years of "severe psychological distress" manifested itself predominately as anxiety and often suicidal depression
- Poor mental health often impacts physical health and motivation to self-care, including basic personal hygiene, therefore clinical or support group intervention is needed
- Mental health issues can "drown everything else out" – an understanding of this from a clinical perspective is important to allow for meaningful engagement and patient care

Considerations for managing mental distress as part of PAH: working through the 'fog of distress'

From 'what is the matter?' to 'what matters to you?'

- The 'fog of distress' describes a state in which a person finds it difficult to mentally engage with their surroundings and what's being communicated to them. It's important for HCPs to recognize, understand and navigate this within mental health and PAH to ensure meaningful interactions and successful two-way communication is achieved
 - Using considered language is incredibly important when interacting with patients in mental distress. For example, while terms such as 'clinical outcome', 'safety', and 'competence' hold meaning to clinicians, patients with mental distress may respond better to words like 'help', 'care' and phrases that recognize them as a person and not a patient
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- Using open questions is helpful to understand the broader needs of someone living with mental health issues. Changing the conversation from ‘what is the matter?’ to ‘what matters to you?’ opens up dialogue and allows HCPs to provide recommendations for holistic support. For example, a person may need something as simple as help walking their dog or cleaning their house to reduce their anxiety and give them the freedom to better self-manage their health

Pathologizing distress

- When faced with managing mental distress some HCPs may not feel adequately trained, there may be a culture of risk aversion or blame or the HCP may not feel they have enough time to approach the problem in hand; therefore referring patients to psychiatric care is common
- This can lead a patient who is experiencing mental health issues down a narrow psychiatric route, and ultimately increase the stigma that mental health patients experience by separating them from other patients e.g. PAH patients being treated for physical symptoms vs PAH patients who also experience mental distress
- Routinely discussing mental health in consultations helps avoid pathologizing and stigmatization, and normalizes it for people who are afraid to discuss such issues

Goal-setting

- Goal-setting is a recommended technique to bring mental health issues to the forefront of discussion and empower patients to better self-manage their illness in order to reach personalized targets (for example, ‘attending my cousin’s wedding abroad’)
- Importantly, goals have to be relevant and achievable for the individual and should be SMART (specific, measurable, achievable, realistic and time-bound) – HCP support may be required to help develop these

A multidisciplinary approach to mental health management: patient as leader

Multidisciplinary (MDT) approach

- Taking an MDT approach and involving relevant stakeholders at a decision-making level can lead to better health outcomes in mental health and in PAH
- Stakeholders to consider including in conversations may be clinical bodies, patient groups, social care networks, sports groups, members of the voluntary sector and friends and family
- Examples of successful health structures in the UK that aim to provide an MDT service include the mental health charity MIND, Diabetes UK and St. Giles Trust, who all employ patient/service user advocates in order to provide an MDT, peer-to-peer service

Patient as leader

- Involving the patient in decision-making and management of their own health is important and helps shift the mentality of ‘ill patient’ to ‘leader’ which ultimately encourages self-care
- Self-management and co-decision-making between an HCP and patient is the first step in patient empowerment and is achievable within the PAH sphere. Many PH patient groups have developed resources to help facilitate HCP-patient dialogue

How can HCPs use time effectively to manage mental health as part of PAH care?

- Time constraints are an ongoing challenge for many HCPs and consultations will understandably often focus on physical symptoms of PAH as opposed to discussion around the emotional impact of the disease

Resources

- Utilizing patient support resources is a useful way to increase efficient consultations. For example, HCPs can share a quality of life patient questionnaire to be filled out before appointments, which aims to understand the patients' priorities. This will save time during the consultation and also highlight if mental health is a concern
- Patient goal-setting also helps with the efficiency of consultations as appointment time can be used to focus on already established challenges and goals

Appropriate referrals

- Signposting and referring to other organizations can save time and improve holistic care for patients. An advice leaflet, patient organization contact, psychiatric referral or Facebook group may be the best support, therefore it's important for HCPs to know what resources are available and what is most useful for individual patients

