PHuman™
Self-Management Series

WEBINAR: Intimacy and PAH – a conversation for the bedroom or the consultation room?

Episode 4 – Thursday 17 May 2018

DISCUSSION SUMMARY

Overview

On Thursday 17 May 2017, Actelion hosted a webinar entitled '*Intimacy and PAH – a conversation for the bedroom or the consultation room?'.* The webinar featured guest speaker Wendy Hill, a PAH nurse specialist at Cedar-Sinai Medical Group in California, US, who has been working in the field of PAH for 20 years. As a nurse practitioner, Wendy is at the forefront of patient conversations relating to PAH and intimacy, including discussions around pregnancy and contraception. She believes the topic is far too often ignored, leading to potentially life-threatening consequences for women living with PAH. Wendy is a strong advocate for re-prioritizing intimacy as a subject of importance for PAH patients and one that needs to be addressed in a clinical setting.

The primary objectives of the webinar were:

- To increase understanding of the impact of PAH on people's sex lives and emotional barriers to discussing intimacy with their healthcare teams
- To share and discuss best practice approaches to counselling patients on intimacy, contraception and pregnancy prevention, as a critical part of patient self-management
- To identify sources of quality patient information on intimacy and relationships

Discussion summary and key learnings

Survey results – what does this mean for clinical practice?

- Wendy and two colleagues at Cedar-Sinai Medical Group recently developed a survey to understand the issues surrounding intimacy, contraception and pregnancy prevention for PAH patients from a clinical perspective. The survey was aimed at healthcare professionals (HCPs) and received 116 responses from the Pulmonary Hypertension Professional Network (PHPN) and Pulmonary Hypertension Clinicians and Researchers (PHCR) group. Insights gathered showed that:
    - The number of women who become pregnant intentionally is surprisingly high
    - HCPs are not having conversations about sex often enough or in enough depth
    - HCPs state that the overwhelming barrier to having such conversations around intimacy is lack of time
- The survey results indicate that clinics and HCPs need to prioritize and consider best practice approaches to counselling patients on these important issues, as a critical part of patient management

Patient perspective: intimacy, pregnancy and contraception

Intimacy

- As the physical symptoms of PAH are often the focus, and time pressures are ever present, intimacy issues are too frequently ignored in clinic. With 75% of patients stating they have issues with intimacy, this is a hugely important topic that needs to be addressed from a clinical perspective
- Symptoms that indicate a patient may be experiencing intimacy issues include reports of low self-esteem and loss of libido – if this is mentioned during consultation this provides a platform for HCPs to start the conversation about PAH and intimacy

Pregnancy

- The mortality rate for women with PAH giving birth is upwards of 50% and therefore it is of the utmost importance that clinicians counsel women that pregnancy is contraindicated
- Despite receiving this advice, some women with PAH will still decide they want to fall pregnant. At this point clinical teams must consider the best course of action to take so the patient receives the best possible care throughout the pregnancy
- Understandably many women will find it difficult to be told pregnancy is contraindicated, with one describing it is as a “void” in her life. It is important that clinicians are compassionate when discussing this topic and do so sensitively. It may also be appropriate (at the right time) to discuss potentially encouraging options with patients such as surrogacy or adoption

Contraception

- Due to the dangers of pregnancy, it’s incredibly important that postpubescent women with PAH are counselled on contraception
- For example, it is recommended that two forms of contraception are used, one being a barrier method e.g. condom or diaphragm. If a single form of contraception is preferred by the patient, an intrauterine device (IUD), sterilization or implant are recommended options
- It’s important that contraception remains an ongoing point of conversation between HCPs and patients as contraception needs may change depending on a patient’s current lifestyle/life stage

Training needs

- Developing a program to help HCPs specifically address pregnancy prevention and intimacy on a regular basis is a great way to structure these all-important conversations:
    - Some clinics use checklists for patients, which include filling in contraceptive use and pregnancy questions. This helps prompt conversations and avoids missing the topic
- It is important for clinics to document their conversations relating to sexual health, such as a patients last menstrual cycle, contraceptive use and issues with intimacy, as a way of recognizing any symptom changes and increasing the frequency and regularity of the conversation

Practical considerations for counselling patients

- Clinics need to take the time to identify which team member is best placed to have conversations around intimacy. Anyone who is involved in the patient's care and is comfortable discussing the issue can open the conversation. For instance the staff member doing the medication reconciliation could ask when a patient's last menstrual cycle was or what contraception they are on. The vital issue is that someone in the practice is identified, and the conversation is started
- It is then the responsibility of the HCP to discuss the topic frequently. By bringing up the conversation regularly, feelings of embarrassment by either the HCP or patient are reduced. Patient groups can also help facilitate these conversations
- As lack of time is cited as the biggest barrier to having these conversations, not only should an individual staff member be identified as the facilitator of these conversations, but also referral should be seen as a good use of time. Referring to a counsellor, obstetrician or gynecologist, patient organization or non-PAH support groups uses time effectively and continues the conversation

Conclusion

- Pregnancy is contraindicated and is highly dangerous, and this should be clearly explained to women living with PAH as it is of huge importance. These conversations need to be approached in a highly compassionate and empathetic manner
- Patients need to be able to make well-informed decisions by being given the correct information
- Each clinic should identify a staff member who will open the conversation with each female patient living with PAH
- The goal of a clinic should be to increase awareness regarding the need for contraception counselling and to talk to patients on a regular basis on pregnancy prevention
- Clinics should highlight the fact that patients can still experience intimacy and have a good quality of life, emphasising that living with PAH does not mean you have to sacrifice such an important aspect of your personal life

For more information on PAH, intimacy and sexual health please refer to the following resources:

- *Survey link to be uploaded as soon as possible*
- *Understanding the impact of pulmonary arterial hypertension on patients' and carers' lives,* European Respiratory Review, http://err.ersjournals.com/content/22/130/535 (2013 22: 535-542) accessed 01 June 2018