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Learning together: insights from the first Heart Failure Association patient forum

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We gathered patients with heart failure, their caregivers and health care professionals in the first Heart Failure Association (HFA) Patient Forum, with the overall aim of ‘learning together’. The workshop was held in Dubrovnik in October 2019. This HFA patient forum was intended as a pilot activity in which patients and professionals come to ‘learn with each other and from each other’. This approach signifies a shift from paternalistic ‘doctor–patient’ relationship to the acceptance of patients’ equity and rights in health care processes, as well as the importance of their voices and contributions.

The reason

The HFA of the European Society of Cardiology (ESC) previously has involved patients in several projects, such as discussing HFA activities, to the ESC Patient Forum, co-designing an informative website (heartfailurematters.org) and working with patients in recent position statements on palliative care and self-care.

We decided to take these activities one step further by organizing an HFA patient forum, an innovative international activity with the goal of bringing together health care professionals, patients and their carers. This perfectly fits with the plans of the ESC to encourage patient engagement, that in 2018 established the ESC Patient Forum bringing together 21 patients from 13 countries around Europe.

Supported by the HFA board, the HFA Patient Care Committee initiated the idea of the HFA patient forum with the goal of ‘learning together’, meaning that all participants would contribute to each other’s learning process. The initiative was endorsed by the ESC Patient Forum. To pilot this HFA patient forum, the activity was planned as a part of the 1-day Patient Care Workshop for 30 international professionals (cardiologists, nurses, general practitioners).

The setup

During the 3 h HFA patient forum, the participants (professionals, patients and caregivers) were mixed sitting at round tables to facilitate discussion. Two clinical cases were presented and discussed at each table with active engagement of participants. The first case was describing a female patient with heart failure and depressive symptoms and addressed the complex issue of physical activity. Participants discussed challenges and solutions related to physical and social activity, exercise and rehabilitation. After group conversations, there was a central discussion on the importance of physical activity, what is needed to be physically active (motivation, programmes, family support, etc.), how to practically do it and how to stay motivated. Professionals and patients jointly suggested practical recommendation to the patient in the case and provided personal experiences on what worked for them (e.g. involving social support) and what did not work (ignoring symptoms).

After a short break, the second case presentation addressed ‘adherence to medical treatment’, again firstly a discussion in small groups before a more central discussion. In this case, professionals shared the importance of optimal dosing according to guidelines, whereas patients shared experiences with side effects. The HFA patient forum was concluded with an open discussion with all attendees.

Who attended?

Besides the 30 international professionals (cardiologists, nurses, general practitioners) who attended the HFA Patient Care Workshop, 3 heart failure patients from the ESC Patient Forum, and 10 Croatian patients and family members attended. Patients were of different age, some of them had cardiac transplants, some had implanted left ventricular assist devices. They were expected to be able to contribute to a discussion that mainly would take place in

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English. Patients were invited to bring a caregiver for translation and support.

Lessons learned

Patients expressed that they liked the format of case discussion, since they heard a diversity of opinions and felt welcome to add their own opinions. The recommendation for future events from the patients was they could prepare and present the case themselves as well as suggest topics for sessions, instead of having this totally done by faculty. They suggested that in such kind of meetings professionals should aim to learn *from* patients, in contrast with traditional “doctor–patient relationship”, acknowledging that patients are “professional in their disease”. New subjects for similar meetings were proposed, such as improved patient–provider communication. Many patients also found that the time allocated for the forum was too short. Future meetings should also consider the language issues, since the limitation in English was a barrier for effective participation of some attendees.

Professionals evaluated the activity as useful, adding new viewpoints and finding it a powerful experience. Some suggested to introduce this format in more aspects of education and some professionals also wanted to apply this concept in their home country. Faculty members also reflected that including the discussion with patients in the cases added to the quality of the Patient Care Workshop.

The format of this HFA activity – discussion of the cases in small groups at a table, where all participants were invited to share what

they know from research and personal experience – fits well with the objectives of the forum. Active participation was key in the HFA patient forum and this was facilitated by the case discussions (rather than uni-directional presentations) and by the setup of the environment (round tables with a multi-professional/mixed group of discussants).

Value and future plans

In general, patients were enthusiastic in sharing their personal experiences, they had many suggestions for coping with the disease and motivating the peers based on their own stories, what definitely can enrich the recommendations from professionals. The unique feature of this first HFA event was its emotional touching atmosphere, which indicates the participation of patients as a necessary and fruitful partnership. The event is planned to be replicated taking this learning into consideration.

Summarizing, based on experiences for the HFA patient forum we recommend to:

- Include patients as educational partners in the future learning/educational activities of the HFA/ESC.
- Facilitate active participation by having a format that facilitates discussion (round table, case) and ease with language.
- Include patients as co-chairs of the programme in joint events.
- Consider implementing wider patient participation on an international and national level.