

2022-03 TIMELY workshop report

A workshop was held together with the German Heart Foundation and two patient representatives as part of the TIMELY project. The primary aim was to include the patients' perspective on new, innovative care solutions such as the TIMELY platform and their requirements and wishes.

The focus was on psychocardiological aftercare, dealing with new technologies and the role of the patient himself and patient groups.

Unmet need for psychocardiological follow-up

Mental symptoms and cardiovascular diseases influence each other. Psychological problems can contribute to the development of cardiac disorders or have a negative impact on the course of the disease. Conversely, it is also possible that mental symptoms are triggered by cardiac diseases. In practice, patients still feel that the consideration of psychological factors in cardiovascular therapy is insufficient. "*We have to have at least the level of cancer aftercare*" (BRK).

Patients who suffer a heart attack and receive acute care in the hospital are confronted with a new reality after they are discharged from the hospital. In doing so, they first have to process the realization that they are actually suffering from a serious illness – a fact which, given the rapid sequence of events during and immediately after a heart attack, is often not consciously noticed or is quickly suppressed again. "*One of the patients from our support group said, 'I'm doing great. I only found out from the doctor and the documents how I actually jumped off the devil's shovel. I had to come to my senses first.'*" [...] *there were many who said: "First of all, I have to understand what happened to me."* (BRK) The severe heart event leads to stress and anxiety disorders and thus weighs on the psyche.

Fears and great uncertainty arise - newly occurring symptoms are perceived very precisely and it is often difficult to assess whether this is another cardiac event. "*I have one in the heart sports group who, I think, was in the emergency room five times after her first heart attack because she always thought there was something else and was always sent home: "No, you have nothing." At some point you have then also fear of not being taken seriously anymore. This feeling even after rehab: "Is something wrong? Oh, I'd better go." It's very difficult for laypeople to assess that.*" (KSA)

Patients who develop depression after a heart attack have a worse prognosis for the course of the cardiac disease than patients without depressive symptoms. Appropriate therapeutic support after a heart attack is all the more important.

Set low inhibition thresholds for the greatest possible acceptance of new technologies

Patient representatives agree that the advantages and opportunities of digital solutions clearly outweigh them and are also perceived as such by patients. The decisive factor here, however, is the correct introduction, especially of older patients, to the new technologies - it must not be too complex, it is much more important to emphasize the practical advantages for everyday life in conversation with the patients: "*If the older people don't see this thing as digitization [...] offers, but they are told: "This is your medication. In addition to the pill, you also need a smartphone or tablet and you will be introduced to it and get started. [...] Afterwards they notice: "Oh, that's much nicer, I can see my grandson too."*

"It's simply important that you try to pick everyone up in the best possible way and then simply make it as accessible as possible. "

While fears of the unknown predominate at the beginning, over time it is recognized that digital technologies open up new opportunities for communication and social participation. *"I have two 80-year-old women in my environment. I've shown them digital media and now they are happy that their fear was taken away."* (BRK)

Patient empowerment and self-help crucial for disease coping

In addition to a highly professionalized health system and family and everyday social support, organized self-help is the third recognized area in the health care system that significantly shapes and promotes the topic of patient orientation and empowerment.

Especially in the area of chronic cardiovascular diseases, the self-empowerment of the patient (patient empowerment), his active participation in the therapy and decision-making process is essential for a positive course of the disease: *"I don't know anyone who has had a heart condition and now no longer has to deal with it. Whether it's the medication, whether it's the care, whether it's the equipment - no matter how good the doctor is, the best is the one who has had it before. [...] No doctor or clinic will be able to "manage" that for you anymore. We as patients must become advocates for our own illness."* (BRK)

Patients are increasingly finding support in becoming their own expert from self-help groups, since doctors do not have time for continuous and comprehensive support of the patient: *"There is a very large number of us with heart disease who are not taken care of by the clinic and sports group. It has to be structured differently. [...] I think it boils down to the heart groups picking it up."* (BRK)

Some of the self-help groups could thus increasingly act as self-organized providers of services, such as advice, within the framework of the health care system and lead to new forms that lie between traditional self-help and professional offers.

Artificial intelligence and data protection

Artificial intelligence is perceived by patient representatives as an opportunity to improve the quality of care "I believe that artificial intelligence does not make these careless mistakes and does not show signs of fatigue" (KSA). However, it is important that artificial intelligence is only ever used as a support and that people continue to make the decisions. In addition, there should always be the option of being able to switch off the devices if the patient so wishes. The feeling must not arise that the technology and the machines are completely taking over control and that the patient has no creative freedom. "I think there is also a certainty. Maybe there should be a way for people to turn it off if they're really afraid of feeling monitored." (KSA)

The subject of data protection is viewed very pragmatically by those involved. The patient representatives do not regard the sharing of their own health data with the providers or the feeding of the data into the technical solution as critical - on the contrary, the data protection regulations in Germany are regarded as ineffective and inhibiting.

Summary

The patient representatives see great potential in new technologies in the healthcare sector to positively influence the way patients deal with their illness and to enable them to deal more intensively with the illness and to participate in the design of therapy. The prerequisite for this is the lowest possible inhibition threshold, i.e. easily accessible and understandable operating elements and functions.

Self-help groups represent a suitable support system whose resources need to be expanded in the future.