Abstract: 119

Younger patients’ experience of living with mechanical cardiac support

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Congestive heart failure is increasing in younger patients aged 18-44 years. Life-threatening heart failure may occur and a heart-transplantation can be needed. Treatment with mechanical circulatory support (MCS) may be necessary for the patient to survive until the transplantation. Previous research has briefly described how younger patients react with shock and difficulties in adapting to their pre-modified body and self-image, but some adapting to the changed life situation nevertheless occurs gradually. Perceived self-efficacy plays a crucial role in how to handles stress reactions. Knowledge about what treatment with MCS means for younger patients is limited.

Aim: To describe the younger patients’ experiences of living with MCS with focus on self-efficacy.

Method: An interview study with qualitative approach. A pilot study with three interviews was conducted to test the feasibility of the method. The informants had been treated with mechanical heart pump, Excor® and they had been transplanted several months earlier when the interview took place. The ages of the informants were between 21-36 years. The interview took place within one year after the heart transplantation. They were treated and lived with Excor® 6-9 months before being transplanted. Data was analyzed using qualitative content analysis.

Results: Three main themes and associated subthemes were identified: To suddenly find yourself in an altered reality’s describes an experience of a foreign body, a lost empowerment and the need to mourn their broken hearts. Finding the strength to fight for your life describes how informants were struggling to become confident with the technology and coping to suffer through, as well as how they felt hope and confidence. Needs for overcome loneliness and to regain control of the situation are also important. Getting strength from your surroundings describes the support from the environment and the importance to rest from the disease but also how informants suffered when they treated with incomprehension.

Conclusion: Caregivers should be aware of the different phases patients living with MCS undergo, so they can sensitively support patients’ to increase the probability of regain control over the situation. By strengthening patients’ self-efficacy, patients can experience their changed reality as manageable and controllable, with increased well-being as a result.