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Hope and Life-struggle

Patients' Experiences with Transcatheter Aortic Valve Implantation

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Akademisk avhandling

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Abstract
The overall aim of this thesis is to explore experiences and self-reported outcomes from Transcatheter Aortic Valve Implantation, TAVI, among people with severe aortic stenosis. The thesis includes four studies. Study I-II are based on interviews performed the day before TAVI and Qualitative Concept Analysis was used for analysis. Study III is based on interviews at six months' follow-up and Grounded Theory was used for analysis. Study IV is quantitative and based on questionnaires at baseline and at six months' follow-up. Nonparametric, descriptive statistics were used for the analysis.
Study I described the vulnerable situation for patients with severe aortic stenosis before TAVI. They were facing death and at the same time struggling to cope with their symptoms and to maintain independent. TAVI offered hope but also caused uncertainty about the new method.
Study II focused on the patients' decision-making process. Three patterns were identified; ambivalent, obedient, and reconciled. The ambivalent patient is unsure of the value of treatment and aware of the risks; the obedient patient is unsure of the value of one's own decision and wants to leave the decision to others; the reconciled patient has reached a point where there is no choice anymore and is always sure that the decision to undergo TAVI is right.
Study III offered a deeper understanding of the TAVI trajectory. A journey of balancing between hope and life-struggle was the core category of the analysis. Before TAVI patients felt threatened, but also experienced hope. The rehabilitation phase was described as demanding and depressing or surprisingly simple. At the six months' follow-up patients described being pleased to return to life, however, many were still struggling with limitations.
Study IV focused on quantifying the symptom burden, function and health related quality of life before and after TAVI. The results were reflected against that of patients treated with open surgery. Self-rated function and health related quality of life increased and symptoms were reduced at follow-up, but breathlessness and fatigue were still common.
Conclusively, TAVI patients are struggling with limitations, both because of their comorbidities and because of their valve disease which also poses a threat to their lives. TAVI gives an opportunity to survive, to stay independent and to increase quality of life. To feel and preserve hope is essential for patients' wellbeing, both before and during the recovery process.

Keywords
Aortic stenosis, transcatheter aortic valve implantation, experiences, coping, decision-making, health-related quality of life, symptoms, function

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