

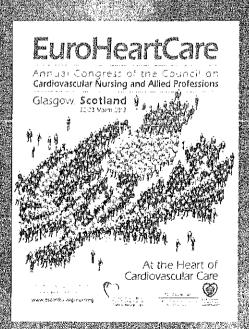
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and increased over time (P < 0.01) and so did burden related to environment (P < 0.01). The indexes related to isolation and disappointment did not change over time. The emotional index decreased significantly after 24 months (P < 0.001). Predictors of caregiver burden were higher number of co-morbidities in the patient, poorer mental health, more symptoms of depression and a lower level of perceived control over the heart disease in the partner. These variables explained 64% of the variance.

Conclusion and implications: This study is the first longterm follow up of caregiver burden in partners to patients with HF describing an increase in several aspects of this burden over time. To identify caregivers that experience high caregiver burden and target those with support and interventions can lead to a significant improvement in caregiver well-being.

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The impact of an individualized patient health passport on disease-related knowledge in adolescents with congenital heart disease

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Purpose: Several task forces recommend the use of a health passport as an education tool for patients with congenital heart defect (CHD). Such a passport outlines key information on the medical and surgical history, medication regimen, healthy lifestyle issues and follow-up plan. To date, the impact of the use of an individualized passport on the optimization of the level of knowledge in these patients is unknown. Our study evaluated if an individualized passport improved the level of disease-related knowledge in adolescents with CHD.

Methods: As part of a 4-wave longitudinal study, the overall level of knowledge was assessed in 429 adolescents (median age = 16.3 y [Q1 = 15.3y; Q3 = 17.3y]; 53% boys) using the 27-item Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD). An individualized health passport was developed and provided to 29 patients with Atrial Septal Defect (ASD 2), 29 patients with coarctation of the aorta (CoA), and 18 patients with a Transposition of the Great Arteries (TGA), corresponding to a simple, moderate or complex heart defect, respectively. Two-hundred ninety patients who did not receive a passport served as a control group. A total knowledge score (0-100) was calculated as the proportion of correct answers. This is

the total number of correct answers divided by the number of questions that should be answered by that respondent. Hierarchical multivariable regression analysis was used to determine whether the passport explained the change in knowledge level over time, adjusting for potential confounders.

Results: The mean knowledge score improved significantly from 47 ± 14 at baseline to 53 ± 17 after receiving the individualized passport (Z = -3.73, p < .001). The mean knowledge scores in the control group were 44 ± 16 and 47 ± 15 (Z = 13.95, p = 0.04, n = 287), respectively. Regression analysis demonstrated that the passport (Bèta = 0.135, p = 0.014) independently determined improvements in the level of knowledge, adjusting for disease complexit (Bèta = 0.044, p = 0.426) and patient's educational level (Bèta = -0.001, p = 0.990). Although the passport was a significant contributor of improved knowledge levels, only 1.8% of the variance in knowledge levels could be accounted for by this model.

Conclusions: Several education programs and tools to inform and instruct patients with CHD have been developed in the past. The success of such programs and tools was limited. The provision of an individualized health passport was found to be a promising method to improve the knowledge of adolescents with CHD. Further research should evaluate whether this health passport can result in long-term improvements.

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The relationship between self-care and quality of life in heart failure patients and spousal caregivers: a dyadic analysis

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Purpose: Many studies have emphasized the strong interdependence between patients and their spousal caregivers in chronic illness but few studies have investigated the dynamics influencing self-care and quality of life (QOL) in couples where one person suffers from heart failure (HF). The purpose of this study was to investigate the relationship between self-care and QOL in couples using the Actor-Partner Interdependence Model (APIM).

Methods: A cross-sectional design was used to study a sample of 138 HF patients and their spousal caregivers enrolled from cardiovascular centers across Italy. Patients completed the Self-Care of Heart Failure Index v.6.2 and caregivers completed the Caregiver Contribution to

Self-Care of Heart Failure Index. Both instruments comprise three separate scales: the self-care maintenance, management and confidence. Also, patients and caregivers completed a sociodemographic questionnaire and the SF-12 to measure QOL.

Results: Patients were 73.6 years old (SD, 9.6) and mostly male (67.4%) while caregivers were 70.4 years old (SD, 9.4) and mostly female (67.4%). Patients and caregivers reported similar levels of self-care and contributions to self-care respectively (p = ns), but patients had a worse physical and mental QOL that caregivers (p = 0.001). In the APIM analysis, several actor effects were found: in patients, poorer self-care maintenance and management were associated with better physical QOL (p = 0.009 and 0.034, respectively); in caregivers, worse contribution to patient's self-care maintenance was associated with better physical QOL (p = .024), and better confidence in their abilities to contribute to patient's self-care was associated with better mental QOL (p = 0.02). Only two partner effects were seen; better self-care maintenance in patients was associated with better mental QOL in caregivers (p = 0.031) and higher caregiver confidence in contributing to patient's self-care was associated with poorer physical QOL in patients (p = 0.002).

Conclusion: The major clinical implication is a renewed appreciation of the importance of confidence in the performance of self-care. In caregivers, confidence in the ability to support patients in the performance of self-care improved caregivers' mental QOL and improved patients' physical QOL. Interventions the build caregivers' confidence are needed.

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How to get information about sexual concerns: views from heart failure patients

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Background: It is known that patients with heart failure may experience problems with sexual activity as a result of their disease, medications or anxiety. They worry about resuming sexual activity and are in need of education and counseling. However, these issues are seldom discussed with health care providers in daily practice. The aim of this study was to identify how and when patients want to receive information and discuss sexual concerns and which role nurses could play.

Method: We used a qualitative design with a focus-group interview in Germany. Ten patients and one spouse participated in the focus group interview. Qualitative content analysis was used to analyze the transcripts.

Results: Focus groups revealed specific information on the wish to discuss sexual concerns. Patients reported that they want to receive information about sexual activity and that they are dissatisfied with the fact that no one does actively approach them to discuss this topic with them. If they do not ask, they will not receive any information. "We always have to be active, why couldn't someone help us regarding this issue?" Participants reported that written materials in the hospital could help them to get an overview and realize that this is a topic they are allowed to talk about. Information's about sexuality and heart failure should be part of rehabilitation, and at the same time general practitioners should invite discussions on this topic with heart failure patients and their spouses. It is important, that health care providers find a sensitive way to raise this topic. Nurses could also discuss this topic with patients, but they should be educated and trained to do this. In our focus group, patients did not feel that nurses were competent in this regard.

Conclusion: Heart failure patients wish to receive information about sexual concerns and they want to discuss it without making the first step. According to patients, first information should be delivered in the hospital, but the individual situation could best be discussed with the general practitioner. This implies that nurses and physicians express an interest in in and provide information and instructions related to sexual activity. Additional training for professionals might beneficial, especially with respect to but not exhaustive to communication skill sets.

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Patients undergoing primary percutaneous coronary intervention (PPCI) as a treatment for acute myocardial infarction (AMI) perceive their illness as an acute avent over which they have little control

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Purpose: Treatment approaches for AMI patients differ according to presentation, and there is uncertainty in the literature as to whether this impacts on patients' understanding of the diagnosis. This study is designed to compare three groups of AMI patients receiving different treatment modalities; ST Elevation Myocardial Infarction (STEMI) treated by PPCI, STEMI treated by thrombolytic therapy, and Non ST Elevation Myocardial Infarction (NSTEMI) treated by medication and/or PCI as appropriate. We aim to determine if treatment modality impacts on illness perception at hospital admission and six months later.