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Patient-reported outcomes in patients with heart failure

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Document Version

Publisher's PDF, also known as Version of record

Publication date:

2017

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Kraai, I. (2017). *Patient-reported outcomes in patients with heart failure*. Rijksuniversiteit Groningen.

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Summary

Patient-reported outcomes in patients with heart failure



Summary

The key challenges in heart failure care research is to explore new directions for optimizing care on an individual and population level. This thesis aimed to investigate the use of different patient-reported outcomes in patients with heart failure and the perception of these outcomes by the patients themselves.

Chapter 1

Preferences of heart failure patients in daily clinical practice: quality of life or longevity?

The preferences of 100 outpatients with heart failure were assessed in interviews using the time trade-off approach (TTO). Health-related quality of life was assessed with the EQ-5D and the Minnesota Living with Heart Failure Questionnaire (MLHFQ). Patients' own estimation of life expectancy was assessed with a visual analogue scale. The mean age of the included patients was 70 years and 71% were male. A total of 61% of the patients attach more weight to quality of life over longevity. Nine and 14% of the patients were willing to trade 6 and 12 months respectively for perfect health and thus attach more weight to quality of life. Patients willing to trade time for quality of life had a significantly higher level of NT-pro-BNP and reported significantly more dyspnea during exertion. Predictors of willingness to trade time were higher NT-pro-BNP and a lower EQ VAS score.

The conclusion of this study is that the majority of patients with heart failure attach more weight to quality of life over longevity. Disease severity and dyspnea during exertion were associated with the preference of quality of life over longevity. There was no difference in life expectancy, as estimated by the patients, between patients willing to trade time and patients not willing to trade time for quality of life. These insights enable open and personalized discussions of patients' preferences regarding treatment and care decisions and can guide the future development of more patient-centered care.

Chapter 2

“Not getting worse” a qualitative study of perception of treatment goals in patients with heart failure

This study had a qualitative design and included one focus group interview with 6 patients with heart failure. Data were analysed using qualitative content analysis. The participants were invited for the focus group based on their participation in a previous study on patient preferences (Chapter 1). The mean age of the participants was 70 years, and the duration of their heart failure ranged between 2 to 10 years. The participants described that their heart failure meant that they had to cope with numerous limitations and often had to make sacrifices, but that appropriate treatment could prevent their condition from deteriorating. The qualitative content analysis showed that not getting worse was the overall theme of this study. This theme was composed of 4 categories that described how the participants perceived the goal of treatment: to decrease symptoms, to improve physical functioning, to prevent readmission and to live a normal life. None of the participants mentioned improved survival or being cured of their heart failure as a treatment goal.

The main conclusion of this study is that “not getting worse” is perceived as the treatment goal that matters. This finding could be used to develop the composite endpoint further. More research is needed to develop endpoints that are consistent with the perception of patients, useful for clinical practice and measurable

Chapter 3

Perception of impairments by patients with heart failure.

The data for this study were collected during a larger study on the preferences of patients with heart failure (Chapter 1). The prevalence of impairments due to heart failure was assessed in 100 outpatients with heart failure using items of the MLHFQ. The degree of perceived harshness of impairments was assessed using a structured self-assessment tool. The prevalence of impairments ranged from 18 to 77%. The most prevalent impairments included tiredness and impairments in physical activity. Impairments that were frequently perceived as severely harsh included tiredness (67%), dyspnea (57%), and impairments in physical activity (55%). Corrected item-total correlation (range 0.10-0.59) showed that

tiredness ($r=0.54$) and impairments related to resting ($r=0.59$) and to participation in physical activities ($r=0.52$) and social activities ($r=0.55$) contributed highly to the sum-score of the MLHFQ.

This study concludes that highly prevalent impairments are not by definition perceived as severely harsh by patients with heart failure, with the exception of the impairments tiredness and having difficulty working around the house or yard. As a result highly prevalent impairments do not contribute relevantly to overall health-related quality of life. Therefore, it is important for healthcare providers to also discuss less prevalent impairments with their patients. Insights into the prevalence and perceived degree of harshness of impairments due to heart failure are important with respect to providing personalized care.

Chapter 4

Optimism and quality of life in patients with heart failure.

The data for this study were collected during a larger study on the preferences of patients with heart failure (Chapter 1). Dispositional optimism was assessed in 86 patients with heart failure. The mean age of the included patients was 70 years and 72% were male. Dispositional optimism was assessed with the Revised Life Orientation Test (LOT-R). The (mean \pm SD) total score on the LOT-R was 14.6 ± 2.9 (range 0-24), and the scores on the subscales optimism and pessimism were 8.1 ± 1.9 and 5.5 ± 2.5 , respectively. Higher age was related to more optimism ($r = 0.22$, $p < 0.05$), and optimism was associated with higher generic health-related quality of life ($B = 0.04$, $p < 0.05$).

The main conclusion of this study is that there is an association between optimism and health-related quality of life in outpatients with heart failure. The literature suggests that optimism is a modifiable trait; therefore, improving optimism may be a promising way to improve the health-related quality of life in patients with heart failure.

Chapter 5

Health-related quality of life and anemia in hospitalized patients with heart failure.

Baseline data from the COACH study (Coordinating study evaluating Outcomes of Advising and Counseling in Heart Failure) were used in this study. Health-related quality of life was assessed with two generic questionnaires (RAND 36-item Health Survey 1.0 and Cantril's Ladder of Life) and one disease specific questionnaire (the MLHFQ). Patients were included in this sub-study if baseline levels of hemoglobin were available; as a result, 1013 patients were included. The mean age of the included hospitalized patients was 71 years and 62% were male. Seventy percent of the patients had no anemia, 14% had mild anemia, and 16% had moderate-to-severe anemia. Independent associations were found between anemia and physical functioning ($p=0.019$), anemia and role limitations due to physical functioning ($p=0.002$), anemia and general health ($p=0.024$) and anemia and global well-being ($p=0.003$).

The conclusion of this study is that health-related quality of life is independently associated with anemia in hospitalized patients with heart failure in terms of global well-being, general health, physical functioning, and limitations due to physical functioning. Furthermore, in addition to the burden of the heart failure itself, anemia is an important factor influencing the health-related quality of life in hospitalized patients with heart failure. This effect was most pronounced in the domain related to physical functioning and general health. The association found in this study may serve as a mechanism for improving health-related quality of life in anemic patients with heart failure.

Chapter 6

Heart failure patients monitored with telemedicine: patient satisfaction, a review of the literature.

A comprehensive search was conducted through the Pubmed, Embase, Cinahl and Cochrane databases of medical literature using a customized search strategy for each database. Articles published up to November 2010 were retrieved. Heart failure, satisfaction and telemedicine related search terms were used. The literature search identified 193 publications, which were reviewed by 2 independent reviewers. Fourteen articles were included in the review. None of the articles described a clear definition or concept of patient satisfaction with telemedicine.

Patient satisfaction with telemedicine was measured with self-developed questionnaires or face-to-face or telephonic interviews. None of the articles used the same questionnaire or telephonic survey to measure patient satisfaction. Only one questionnaire was assessed for validity and reliability. In general patients seemed to be either satisfied or very satisfied with the use of telemedicine.

This study concludes that patient satisfaction is still underexposed in non-invasive telemedicine research, despite the recommendation by the FDA and the fact that patient satisfaction is considered to be an important indicator of quality of care. The few studies that did research patient satisfaction used poorly constructed questionnaires.

Chapter 7

The value of telemonitoring and ICT-guided disease management in heart failure - results from the IN TOUCH study.

A multicenter randomized controlled trial was performed testing the effects of INnovative ICT-guided-DMS combined with Telemonitoring in OUtpatient clinics for Chronic HF patients (IN TOUCH). A total of 179 patients were included in the study. Mean age was 69 years. 72% were male and 77% of the patients were in New York Heart Association Classification III–IV, with a mean left ventricular ejection fraction of 28%. Patients were randomized to either the ICT-guided-DMS arm or to the ICT-guided-DMS-with-telemonitoring arm. The follow-up period was 9 months. The composite endpoint included mortality, the first heart failure readmission, and changes in health-related quality of life. Health-related quality of life was measured with the MLHFQ. In total, 177 patients were eligible for analyses. The mean score of the primary composite endpoint was -0.63 in the ICT-guided-DMS group versus -0.73 in the ICT-guided-DMS with telemonitoring group (mean difference 0.1 , 95%CI: -0.67 $+0.82$, $p = 0.39$). All-cause mortality in the ICT-guided-DMS group was 12% versus 15% in the ICT-guided-DMS-with-telemonitoring group ($p = 0.27$); heart failure readmission was 28% versus 27% ($p = 0.87$), respectively; and all-cause readmission was 49% versus 51% ($p = 0.78$), respectively. Health-related quality of life improved in most patients during the study and did not differ between both groups. Incremental costs were €1360 in favor of the ICT-guided-DMS group. The ICT-guided-DMS-with-telemonitoring group had significantly fewer heart failure related outpatient clinic visits ($p < 0.01$).

The conclusion of this study is that ICT-guided disease management in combination with telemonitoring, as used in the IN TOUCH study, neither affected the primary (composite) endpoints of mortality, heart failure readmission, and health-related quality of life, nor the separate individual outcomes of this composite endpoint. The IN TOUCH study has demonstrated, however that the use of telemonitoring is safe and can reduce heart failure related visits to the outpatient clinic.

