



Heart Failure and Cardiomyopathies

ACUTE DECOMPENSATED HEART FAILURE: THE JOURNEY FROM PATIENTS' PERSPECTIVE

Poster Contributions
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Background: Although innumerable therapy and outcome studies have been done on acute decompensated heart failure (ADHF), few have addressed patient reported outcomes. Gaining insights into patients' perspective of their ADHF journey can help to design effective patient centered care.

Methods: We used three different commercial patient panels to conduct 48-item online survey of ADHF patients in May-July 2014. Inclusion criteria consisted of patient age ≥ 50 , hospitalization for ADHF within 4-months of survey, and persistent heart failure (HF) symptoms.

Results: [Demographics] Of 14,390 respondents, 331 met the inclusion criteria. 52% of respondents were men, 46% women, and 2% did not answer. Women were more socio-economically disadvantaged (living alone: men 9%, women 21%, $p=0.01$; household income $> \$35,000/\text{year}$: men 63%, women 49%, $p=0.05$). [PRO] 79% of patients expressed confidence in knowing when ADHF is occurring. 79% of patients sought help within 12-hours upon experiencing decompensation symptoms. Most frequently ($>50\%$) reported symptoms include shortness of breath (81%), fatigue & weakness (71%), edema (68%), and rapid-irregular heart beat (57%). Top-3 locations when first noticing symptoms are sitting at home (26%), in bed at home (16%), and working at home (13%). Respondents reported low performance of self-care actions that did not improve with HF duration (<1 year vs. >5 years: tracking daily weight 52% vs. 53%, seek help for fluid weight gain 49% vs. 44%). Ranking from the most to the least likely, the top-4 self-care actions that correlated with discharge instructions are: taking daily blood pressure measurements, tracking daily sodium, taking diuretics as prescribed, and tracking daily weight with $p < 0.000001$ for each action.

Conclusions: Results suggest that high patient awareness of decompensation currently does not translate into of self-care actions. With respondents showing willingness to follow instructions, a well-designed regimen that teaches patients to translate self-monitoring to self-care actions can provide effective patient centered care for HF.